These 12 issues of "Exceptional Parent" present a variety of articles and other information relevant to parents of children with disabilities. The January issue provides an annual directory of national organizations, associations, products, and services. Other monthly issues each have several articles relating to a particular theme, including: (1) early intervention, (2) mobility, (3) summer activities, (4) recreational activities and services, (5) telecommunications, (6) teenagers and young adults, (7) health, (8) education, (9) toys, (10) technology, and (11) religion. Additional monthly features include columns providing parent-to-parent suggestions, suggested resources, personal narratives of parents, a directory of advertisers, a calendar of activities, and reviews of new products and books. (DB)
THE EXCEPTIONAL PARENT 1994 RESOURCE GUIDE

DIRECTORIES OF NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS & SERVICES

0096************* 5-DIGIT 22091
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COUNCIL FOR EXCEPT/CEC INFO
1920 ASSOCIATION DR
RESTON VA 22091-1589
Ford Mobility Motoring Makes Life More Rewarding!

Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created to make adapting your new Ford or Lincoln-Mercury product easier and more rewarding!

**A Smoother Road to Travel**

Mobility Motoring starts with a toll-free call. You'll know you've arrived when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in ... and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone and Roadside Assistance for the duration of the bumper-to-bumper limited warranty.

**Information You Need ... For Informed Decisions**

The Ford Mobility Motoring Program also provides:

- friendly toll-free and special "TDD" ... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance in addition to the amount you receive from the Mobility Motoring Program.

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

**Free Mobility Motoring Video**

This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

**Program Period**

October 1, 1993 — September 30, 1994

Customer is responsible for a 121-day minimum extension on the Ford Cellular System. Some local individual carrier may require a longer agreement as well as other mindless service and usage charges, so acceptance is denied. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of purchase or lease. *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance plan. Vehicles covered by the Lincoln Commitment, F Series Preferred Care or Red Carpet Lease plans have additional benefits.

**A New Car, Van or Light Truck ... Adaptive Equipment ... and On-the-Spot Cash!**
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When he’s at school with everyone else, the last thing he needs to worry about is where to write and put his books. With the MYDESC™ FlipTop Storage Desk, he has his own portable desk and a place to put things too!

Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it’s time for transfers, the entire desktop swings down to the side and out of the way.

It’s simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

1-800-4-MYDESC
Happy New Year and welcome to our first monthly issue of 1994—a special Resource Directory that will be useful all year. While some of these directories have appeared in previous issues of Exceptional Parent, most have been greatly expanded and enhanced since last published. In addition, we have made an unprecedented effort to verify addresses and phone numbers and to add “800” numbers, TDD and fax lines, and even computer bulletin board addresses when available.

National Resources

In an effort to organize our listings of national organizations and resources, we have created two distinct directories: National Information and Advocacy Resources and National Resources for Specific Disabilities and Conditions.

The Information and Advocacy directory lists groups focusing on issues of concern to many families of children with disabilities—regardless of their children’s specific diagnosis. This is the place to find answers to questions about education, employment, health care, independent living and more.

The Specific Disabilities directory—the most extensive we have published—lists more than 300 sources of support and information on specific conditions. For the first time, we have provided cross-references between disability categories to enable readers to find all relevant resources for a particular disability. We hope that this new approach will alleviate confusion over terminology differences while helping parents obtain information on related conditions that may be useful in understanding an individual child.

The federal government can also serve as a valuable national information resource. Accordingly, this issue lists two directories of federally-funded resources for parents and professionals: Federal Agencies and Federal Health Information Centers and Clearinghouses.

Resources Close to Home

Exceptional Parent magazine was founded because all parents of children with disabilities have similar needs for information and support. The federal government established Parent Training and Information Centers (PTIs) for much the same reason—to reach out to parents of children with disabilities and special health care needs in local communities, and to work to improve opportunities for all children. Readers who need information about available programs and services, or who just want to network with other parents, can contact the nearest PTI from among more than 70 listed in this issue’s directory.

Parent to Parent Programs have evolved in local communities as a way to provide one-to-one emotional and informational support to parents of newly diagnosed children with special needs. With the help of the Beach Center on Families and Disabilities at the University of Kansas, we are pleased to provide a state-by-state listing of local Parent to Parent groups.

Assistive technology has enabled many children with disabilities to interact with the world in new and exciting ways. In recognition of the importance of technology in the lives of many of our readers, this issue offers two state-by-state listings of assistive technology resources: State Assistive Technology Programs and Alliance for Technology Access Centers.

Products and Services

Parents and professionals constantly tell us about finding solutions to challenging problems through a product or service advertised in Exceptional Parent. For this special issue of the magazine, we have compiled a Products and Services Directory in which many companies and organizations have purchased listings. This directory can be used as a guide to the many specialized products and services available. In addition, a Free Product & Service Information card is available to parents and professionals who would like to obtain more detailed information from participating advertisers.

More resources

This issue also includes a complete topical index of all articles published in 1993.

Beginning with this issue, we are pleased to present another resource for parents and professionals—the Exceptional Parent Library. This service offers books on a variety of useful and interesting topics. We welcome suggestions about additional books we should include as this book service continues to expand.
National Information & Advocacy Resources

GENERAL
Access/Abilities
P.O. Box 458
Mill Valley, CA 94942
(415) 388-3250
(415) 383-8718 (FAX)

Alliance of Genetic Support Groups
35 Wisconsin Cir, Ste 440
Chevy Chase, MD 20815-7015
(800) 336-4363
(301) 652-5553
(301) 654-0171 (FAX)

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton St, Ste 410
Silver Spring, MD 20910
(301) 588-8252
(301) 588-2842 (FAX)

Any Baby Can
5410 Fredericksburg Rd, Ste 104
San Antonio, TX 78229
(210) 377-0222
(210) 377-0497 (FAX)

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(202) 628-8787
(202) 662-3520 (FAX)

Council for Exceptional Children
1920 Association Dr
Reston, VA 22091-1589
(703) 620-3660 (Voice/TDD)
(703) 264-9494 (FAX)

National Center for Youth with Disabilities
University of Minnesota
Box 721—UMHC
420 Delaware St SE
Minneapolis, MN 55455
(612) 626-2825
(612) 626-2134 (FAX)

National Easter Seals Society
230 W Monroe
Chicago, IL 60606
(800) 221-6827
(312) 726-6200
(312) 726-4258 (TDD)
(312) 726-1494 (FAX)

National Information Center for Children and Youth with Disabilities (NICHCY)
PO Box 1492
Washington, DC 20013
(202) 416-0300
(202) 416-0318 (TDD)
(202) 416-0312 (FAX)

National Organization on Disability
910 16th St NW, Ste 600
Washington, DC 20006
(800) 248-2253
(202) 293-5980
(202) 293-5988
(202) 293-7999 (FAX)

National Vaccine Information Center
512 W Maple Ave, #206
Vienna, VA 22180
(703) 938-3783
(703) 938-5768 (FAX)

NPND (National Parent Network on Disabilities)
1800 Prince St, Suite 115
Alexandria, VA 22314
(703) 684-6763 (Voice/TDD)
(703) 836-1232 (FAX)

STOMP (Specialized Training of Military Parents)
c/o Washington PAVE
12208 Pacific Highway SW
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

ADOPTION
AASK (Adopt a Special Kid)
657 Mission St, Ste 303
San Francisco, CA 94105
(415) 543-2275
(510) 451-2023 (FAX)

Architectural Accessibility
Center for Accessible Housing
North Carolina State University
School of Design
Box 8613
Raleigh, NC 27695-8613
(919) 515-3082 (Voice/TDD)
(919) 515-3023 (FAX)

Birth Defects
Association of Birth Defect Children
5400 Diplomat Cir, Ste 270
Orlando, FL 32810
(407) 629-1468 (Voice/FAX)

Adoptive Families of America
3333 Highway 100 N
Minneapolis, MN 55422
(612) 535-4829
(612) 535-7808 (FAX)

Children's Adoption Support Services
3824 Legation St NW
Washington, DC 20015
(202) 362-3264

National Adoption Center
1500 Walnut St, Ste 701
Philadelphia, PA 19102
(800) 862-3678
(215) 735-9988
(215) 735-9410 (FAX)

National Resource Center for Special Needs Adoption
16250 Northland Dr, Ste 120
Southfield, MI 48075
(313) 443-7080
(313) 443-7099 (FAX)

NPND: National Parent Network on Disabilities
1800 Prince St, Suite 115
Alexandria, VA 22314
(703) 684-6763 (Voice/TDD)
(703) 836-1232 (FAX)

STOMP: Specialized Training of Military Parents
PO Box 1932, Box 120
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

These national organizations are information and advocacy resources for parents and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on specific areas of concern to the families of children and adolescents with disabilities.
RESPITE CARE
ARCH National Resource Center
800 Eastowne Dr, Ste 105
Chapel Hill, NC 27514
(800) 473-1727
(919) 490-5577
(800) 473-1727
Chapel Hill, NC 27514
800 Eastowne Dr, Ste 105
RESPITE CARE
25 Pocono Rd
St. Clares-Riverside Medical Ctr
Clearinghouse
American Self-Help
SELF-HELP
(919) 490-4905 (FAX)
25 W 43rd St, Rm 620
CUNY Grad School, University Ctr
Clearinghouse
National. If-Help
Clearinghouse
CUNY Grad School. University Ctr
25 W 43rd St, Rm 620
New York, NY 10036
(212) 642-2944
(212) 648-1205
South Windsor, CT 06074
1776 Ellington Rd
Special Education and Rehab
TRAVEL
Custom Equipment for Special Kids
SPECIAL DESIGNS, inc
P.O. Box 130, Gillette, NJ 07933
(908) 464-8825
PO Box 130, Gillette, NJ 07933
Circle #71

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• BETTY PENDLETON, M.S., Member, New York State Developmental Disabilities Planning Council, New York, NY
• HARVEY PRESSMAR, President, Corporation for Opportunity Expansion, Newton, MA.
• SIGFRIED R. PUESCHL, M.D., Ph.D., M.P.H., Dir., Child Dev. Ctr., Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI
• JEROME ROTH, D.O., Professor of Pediatric Ophthalmology, University of Houston, Houston, TX
• HAMILYN Rousso, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
• BARBARA J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
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Circle #71

Chairman of the Board.

That's my son Jedediah. He's the reason I started Special Designs Inc. You see, as a parent of a disabled child, I had a lot of trouble finding furniture to fit my son's special needs. Furniture that's durable and sturdy, easy to adjust and easy to take along to a restaurant or to Grandma's. Furniture that looks like it belongs in a home—not in a hospital. Finally, I got tired of looking and made it myself. Then it occurred to me—maybe other parents have the same needs. That's how it all began. If you want to know more about our full line of furniture for disabled children, call us at the number below, or write for a free catalog.

What's it like working for Jed? Easy. I've never had a more lovable boss.
-Peter Quense

P.O. Box 130, Gillette, NJ 07933
Amanda could hardly contain herself as they set her chair into the wheelchair swing...it seemed like she’d been waiting for this for a hundred years. She gripped the swing tightly between her fingers, took a deep breath and said, “I'm ready!” Then, as they put the swing into motion, her hesitant smile became an ear-to-ear grin. For the very first time in her eight-year-old life, Amanda was swinging.

For Amanda and others like her, our special seven-week summer program is a place where children with multiple disabilities, ages 5-21, can discover the joys of achievement.

The opportunity to make new friends...learn new skills...and increase independence awaits! We combine functional academics in special education classrooms, lifeskills in home-like environments, individualized therapies, exciting leisure/recreation activities in community-based settings and caring, professional staff members for a summer full of smiles.

Enroll Now For Summer '94!
Summer Session: June 20 - August 5
Application Deadline: April 1, 1994
You Asked DynaVox To Do Even More...

"I want to tell a story."

"I want to spell and talk faster."

"I want to communicate faster with my associates."

Introducing DynaWrite.

DynaVox Was Just The Beginning.

When we first introduced the revolutionary new DynaVox* augmentative communication aid, the response was overwhelming.

Because people found that DynaVox's modern, user-friendly technology was so much easier to learn than old-fashioned codes, most of them could begin using it in less than half an hour.

In fact, DynaVox made everyday communication so enjoyable, they wanted to go on to even greater challenges.

Introducing DynaWrite.

That's why we've created DynaWrite*, the new software package for DynaVox that helps people compose longer, more complex messages, faster and easier than ever before.

DynaWrite uses a form of artificial intelligence called "word prediction," which analyzes as you write, and offers logical choices for the next word, based on the rules of grammar and a built-in 40,000-word dictionary.

Users can select from these choices with a single keystroke, so they can compose messages twice as fast as with ordinary letter-by-letter typing.

Finished compositions can then be saved, reloaded, and re-edited as needed, and spoken by the DynaVox, or output to a printer.

Dedicated To Communication.

And because the DynaVox is a totally self-contained communication aid, you get all this capability without having to buy a separate computer and speech synthesizer, or learn specialized computer skills.

No other single device can offer the complete spectrum of communication — from symbols, written words, and advanced word prediction, to the highest quality synthesized speech in the world. So no other device can offer the value DynaVox can.

A Straightforward Commitment.

And that's no accident. It's a direct reflection of our commitment to augmentative communication.

Because we know it takes more than just technology — it takes a thorough understanding of language, continuing support, and practical, affordable solutions — to keep pace with your growing needs.

So if you know someone who might benefit from the DynaVox — and from new DynaWrite software — we urge you to contact your therapist. Or give us a call at 1-800-544-1778.

We Hear You.

TECHNOLOGY INC.

Circle #68
This WIZARD® Will Amaze You!

Comfortable and fully adjustable, the WIZARD offers tilt-in-space, a fully reclining back, and elevating legrests... A magic act that no other pediatric wheelchair can perform, and it's standard with every unit!

The WIZARD easily separates into two components weighing less than 20 lbs. each.... Mom can effortlessly load the WIZARD into the trunk!

The WIZARD offers these advantages

- Made of strong steel tubing, the durable WIZARD frame is guaranteed for the Lifetime of the User.
- Grows with your child from age 1 to 10 without having to purchase an expensive growth kit.
- Tackles any terrain with its heavy duty 8"x2" front caster tires.

By SNUG SEAT®, INC. Providing Technologies For Mobility, Positioning & Transportation Since 1987

1-800-336-7684
Fax 1-704-847-9577
In Canada 1-800-667-3422

Circle #69
National Resources for Specific Disabilities and Conditions

Aarskog Syndrome
Aarskog Syndrome Parent Support Group
c/o Shannon Caranci
62 Robin Hill Ln
Levittown, PA 19055-1411
(215) 943-7131

Acidemia, Organic
Organic Acidemia Association
c/o Carol Barton
2287 Cypress Ave
San Pablo, CA 94806
(510) 724-0297

Acoustic Neuroma
See also: Neurofibromatosis
Acoustic Neuroma Association
PO Box 12402
Atlanta, GA 30355
(404) 237-8023
(404) 237-2704 (FAX)

Adrenal Hypoplasia
See also: Growth Disorders
Congenital Adrenal Hypoplasia Support Association
801 County Rd. #3
Wrenshall, MN 55797
(218) 384-3863

Agenesis of the Corpus Callosum (ACC)
ACC Network
86 N Main St
Orono, ME 04473
(207) 866-2062
(207) 581-3120 (FAX)

Aicardi Syndrome
Aicardi Syndrome Awareness and Support Group
29 Delavan Ave
Toronto, ON
Canada M5P 1T2
(416) 481-4095

Aicardi Syndrome Newsletter
5115 Troy Urbana Rd
Casstown, OH 45312
(513) 339-6033 (Voice/FAX)

Albinism & Hypopigmentation
National Organization for Albinism and Hypopigmentation
1530 Locust St, Box 29
Philadelphia, PA 19102
(800) 473-2310
(215) 545-2322 (FAX)

Allergy
See: Asthma & Allergy

Alopecia Areata
National Alopecia Areata Foundation
1006 Howard Rd
Warminster, PA 18974

Amputation
See also: Limb Disorders
American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (FAX)

Aplastic Anemia Foundation
PO Box 22689
Baltimore, MD 21203
(800) 747-2820

Anemia, Aplastic
Aplastic Anemia Foundation of America
PO Box 22689
Baltimore, MD 21203
(800) 747-2820

Anemia, Fanconi
Fanconi Anemia Research Fund/Support Group
66 Club Rd, Ste 390
Eugene, OR 97401
(503) 687-4658
(503) 687-0548 (FAX)

Angelman Syndrome
Angelman Research Group
University of Florida/Genetics
Box J-296, JHM HC
Gainesville, FL 32610-0296
(904) 392-4104
(904) 392-3051 (FAX)

Anorectal Malformations
Pull-thru Network
1 Circle Rd
Darien, CT 06820
(203) 655-6288

Aphasia
National Aphasia Association
Young People’s Network
PO Box 1887
Murray Hill Station
New York, NY 10156-0611
(800) 922-4622

Arginase Deficiency
See: Urea Cycle Disorders

Argininosuccinic Aciduria
See: Urea Cycle Disorders
National Resources for Specific Disabilities and Conditions

Arnold-Chiari Syndrome
See also: Syringomyelia
Arnold-Chiari Family Network
c/o Maureen & Kevin Walsh
67 Spring St
Wayne, MA 02188
(617) 926-3238

Arthrogryposis Multiplex
Arthrogryposis
(800) 283-7800
Atlanta, GA 30309

American Juvenile Arthritis Organization
(617) 337-2368
Weymouth, MA 02188

Ataxia
See also: Ataxia, Cerebellar Hypoplasia
Ataxia and Allergy Foundation of America
1125 15th St NW
Washington, DC 20005
(202) 466-7343
(800) 466-7342
(202) 466-7940 (FAX)

Attention Deficit Disorder
See also: ADD, ADHD, Attention Deficit Hyperactivity Disorder
Children with Attention Deficit Disorders
495 NW 70th Ave, Ste 109
Plantation, FL 33317
(305) 587-3700
(305) 587-4599 (FAX)

Autism
See also: Autism Spectrum Disorder
Autism Society of America
7910 Woodmont Ave, Ste 650
Bethesda, MD 20814
(800) 227-5404
(800) 227-5405 (FAX)

Balance Disorders & Dizziness
See also: Vestibular Disorders
The EAR Foundation
2000 Church St, Box 111
Nashville, TN 37236
(800) 545-4327 (Voice/TDD)
(615) 329-7807

Pen Pal Support Group for Chronic Dizziness & Balance Disorders
Box 305
Elliott, IA 51532
(712) 767-2325

Batten’s Disease
Batten’s Disease Support and Research Association
2600 Parsons Ave
Columbus, OH 43207
(800) 448-4570
(614) 445-4161

Beckwith-Wiedemann Syndrome
Beckwith-Wiedemann Support Network
3206 Braeburn Cir
Ann Arbor, MI 48108
(800) 837-2976 (Parents only)
(313) 973-9721 (FAX)

Bereavement Support
A.M.E.N.D. (Aiding Mothers & Fathers Experiencing Neonatal Death)
4324 Berrywood Terr
St Louis, MO 63128
(314) 487-7582

Center for Loss in Multiple Birth PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123

Compassionate Friends
PO Box 3696
Oak Brook, IL 60522-3696
(708) 990-0010
(708) 990-0246 (FAX)

Brain Damage
Andrew Blake Foundation
Box 866
Winona, MN 55987
(507) 452-5734

Brain Diseases
Children’s Brain Diseases Foundation
350 Parshus Ave, Ste 900
San Francisco, CA 94117
(415) 665-6259
(415) 863-3452 (FAX)

Brain Tumors
American Brain Tumor Association
2720 River Rd, Ste 146
Des Plaines, IL 60018
(800) 866-2282 (consumer line)
(708) 827-9910
(708) 827-9918 (FAX)

Cancer
American Cancer Society
PO Box 190429
Atlanta, GA 31119-0429
(404) 816-7800
(404) 816-9443 (FAX)

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave, Ste 460
Bethesda, MD 20812-14
(800) 366-2223
(301) 578-2886 (FAX)

Corporate Angel Network
Westchester City Airport, Bldg 1
White Plains, NY 10604
(914) 328-1313
(914) 328-3938 (FAX)

G.I. Polyposis and Hereditary Colon Cancer Registry
Center for Medical Genetics
Johns Hopkins Hospital
600 N Wolfe St
Baltimore, MD 21287-4922
(410) 955-3875
(410) 955-0484 (FAX)

Intestinal Multiple Polyposis and Colorectal Cancer
c/o Ann Fagan
Reese’s Crest, PO Box 11
Coney Island, PA 18215
(717) 459-1200

Carbamyl Phosphate Synthetase (CPS) Deficiency
See: Urea Cycle Disorders

Cardio-Facio-Cutaneous Syndrome
CFC Support Network
157 Alder Ave
McKee City, NJ 08232
(800) 545-4327 (Voice/TDD)
(800) 886-2282 (consumer line)

Cataracts
PACK: Parents of Cataract Kids
179 Hunter Ln
Devon, PA 19333
(215) 293-1917
(215) 721-9121

Celiac Sprue
See also: Gluten Intolerance
Celiac Sprue Association
PO Box 31700
Omaha, NE 68131-0700
(402) 558-0600

Central Hypoventilation Syndrome, Congenital
Congenital Central Hypoventilation Syndrome Parent Network
1 Maple St
Oneonta, NY 13820

Cerebral Palsy
United Cerebral Palsy Association
1522 K St NW, #1112
Washington, DC 20005
(800) 872-5837
(202) 842-1266 (Voice/TDD)
(202) 842-3519 (FAX)

Charcot-Marie-Tooth (CMT) Disease
Charcot-Marie-Tooth Association
Crozer Mills Enterprise Center
601 Upland Ave
Upland, PA 19015
(215) 495-7486
(215) 495-7429 (FAX)

Charcot-Marie-Tooth International
1 Springbank Dr
St Catharines, ON
Canada L2S 2K1
(906) 987-3630
(906) 987-8753

CHARGE Syndrome
CHARGE Syndrome Foundation
2004 Parkade Blvd
Columbia, MO 65202-3121
(314) 442-7604

Chromosomal Disorders
Support Group for 9p-
675 N Round Table Dr
Las Vegas, NV 89110
(702) 451-0888

Support Group for Monosomy 9p
43034 Kiepner Nickel Plate Rd
La Grange, OH 44050
(216) 775-4255

Trisomy 9 International
Support Group
Children’s Hospital of Michigan
3901 Beaubien Blvd
Detroit, MI 48201-2196
(313) 745-4513
National Resources for Specific Disabilities and Conditions

Chromosome 17p-
See: Smith-Magenis Syndrome

Chromosomes 18 & 13
Chromosome 18
Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657-4968
(210) 657-4968 (FAX)
Support Organization for Trisomy 18, 13 and Related Disorders
2982 S Union St
Rochester, NY 14624
(716) 594-4621 (Voice/FAX)

Chromosome 18
Chromosomes 18 & 13 Support Organization
(210) 657-4968
San Antonio, TX 78247
(210) 657-4968

Chromosome Deletions
Chromosome Deletion Outreach
PO Box 532
Center Moriches, NY 11934
(516) 878-3510

Chromosome Inversions
National Center on
Chromosome Inversions
1029 Johnson St
Des Moines, IA 50315
(515) 287-0847 (FAX)

Citrullinemia
See: Urea Cycle Disorders

Cleft Palate
Cleft Palate Foundation
1218 Grandview Ave
Pittsburgh, PA 15211
(800) 242-5338
(412) 481-1376
(412) 481-0847 (FAX)

Prescription Parents
PO Box 161
West Roxbury, MA 02132
(617) 527-0878

Cockayne Syndrome
See also: Progeria
Share and Care
1294 S St
North Valley Stream, NY 11580
(516) 825-2284

Coffin-Lowry Syndrome
Coffin-Lowry Syndrome Foundation
PO Box 10033
Bainbridge Island, WA 98110
(206) 842-1523

Cornelia de Lange Syndrome
Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355
(800) 753-2357
(203) 693-0159
(203) 693-6819 (FAX)

Craniofacial Disorders
AboutFace
99 Crowns Ln, 3rd Floor
Toronto, ON
Canada M5R 3P4
(800) 225-3223
(416) 944-3223
(416) 944 2488 (FAX)

AboutFace USA
PO Box 737
Warrington, PA 18976
(800) 225-3223
(215) 491-0603 (FAX)

Children's Craniofacial Association
10210 N Central Expressway
Ste 230, LB37
Dallas, TX 75231
(214) 368-3590
(214) 368-3599 (FAX)

FACES—National Association for the Craniofacially Handicapped
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(615) 267-3124 (FAX)

Let's Face It
PO Box 711
Concord, CA 94521
(503) 371-3186

National Foundation for Facial Reconstruction
317 E 54th St, Rm 901
New York, NY 10016
(800) 225-3223
(212) 283-6656
(212) 283-7534 (FAX)

Cri Du Chat Syndrome
The 5p- Society
11069 Oakmont
Overland Park, KS 66218
(913) 469-8900

Crohn's Disease & Ulcerative Colitis
Crohn's & Colitis Foundation of America
386 Park Ave S, 7th Floor
New York, NY 10016-8804
(800) 343-3637
(212) 779-4098 (FAX)

Crouzon's Disease
See also: Craniofacial Disorders
Crouzon's/Meniere's Support Network
PO Box 12791
Piscataway, NJ 08854-2791
(732) 445-1743

Cyclic Vomiting Syndrome
Cyclic Vomiting Syndrome Association
13180 Caroline Ct
Erm Grove, WI 53122
(414) 844-8842
(414) 821-5494 (FAX)

Cystic Fibrosis
Cystic Fibrosis Foundation
6931 Arlington Rd
Bethesda, MD 20814
(800) 344-4823
(301) 951-4422
(301) 951-6378 (FAX)

Cystinosis
See also: Kidney Disorders
Cystinosis Foundation
1212 Broadway, Ste 830
Oakland, CA 94612
(800) 392-8458

Cytochrome C Oxidase Deficiency
Cytochrome C Oxidase Deficiency Parental Research and Support Foundation
1935 Park View Pl
Aliquippa, PA 15001
(412) 375-6193

Deaf-Blind
See also: Hearing Impairments, Visual Impairments
DB-LINK: National Information Clearinghouse on Children Who are Deaf-Blind
345 N Womnont Ave
Monmouth, OR 97361
(800) 532-2373
(800) 854-7013 (TDD)

Helen Keller National Center for Deaf-Blind Youths and Adults
111 Middle Neck Rd
Sands Point, NY 11050
(516) 944-8900
(516) 944-8637 (TDD)

Dermatomyositis
See: Polymyositis & Dermatomyositis

Diabetes Insipidus
Diabetes Insipidus and Related Disorders Network
c/o Beth Perry
Rt 2, Box 198
Creston, IA 50801
(515) 782-7838

Diabetes Mellitus
American Diabetes Association
National Service Center
1660 Duke St
Alexandria, VA 22314
(800) 232-2472
(703) 549-1500
(703) 683-2890 (FAX)

Canadian Diabetes Association
15 Toronto St, Ste 1001
Toronto, ON
Canada M5C 2E3
(416) 363-3373
(416) 363-3393 (FAX)

Juvenile Diabetes Foundation International
432 Park Ave S, 16th Floor
New York, NY 10016
(800) 533-2873
(212) 889-7575
(212) 889-7571 (FAX)

Digeorge Syndrome
Information and Support for DiGeorge Syndrome Families
c/o Natalie Ward
27859 Lassen St
Castiar, CA 91364
(805) 294-3623

DiGeorge Syndrome
1 January
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Down Syndrome
Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710
(516) 221-4700
(516) 221-4311 (FAX)

Canadian Down Syndrome Society
12837 76th Ave, Ste 206
Surrey, BC
Canada V3W 2V3
(604) 599-6009
(604) 599-6165 (FAX)

International Foundation for Genetic Research
400 Penn Center Blvd, Ste 721
Pittsburgh, PA 15235
(412) 823-6380
(412) 829-7304 (FAX)

Dysautonomia
Dysautonomia Foundation
20 E 46th St, Rm 302
New York, NY 10017
(212) 949-6644
(212) 682-7625 (FAX)

Dyslexia
See also: Learning Disabilities
Dyslexia Research Institute
4745 Centerville Rd
Tallahassee, FL 32308
(904) 893-2216
(904) 393-2440 (FAX)

Dystonia
Dystonia Medical Research Foundation
One E Wacker Dr, Ste 2900
Chicago, IL 60601-2001
(312) 755-0198
(312) 321-571u (FAX)

Ehlers-Danlos Syndrome
Ehlers-Danlos National Foundation
P.O Box 1212
Southgate, MI 48195
(313) 282-0180
(313) 282-2793 (FAX)

Epilepsy
See also: Seizure Disorders
American Epilepsy Society
638 Prospect Ave
Hartford, CT 06105
(203) 232-0819 (FAX)

Fragile X Syndrome
National Fragile X Foundation
1441 York St, Ste 215
Denver, CO 80206
(800) 688-8765
(303) 333-6155
(303) 333-4369 (FAX)

Freeman-Sheldon Syndrome
Freeman-Sheldon Parent Support Group
509 E Northmont Way
Salt Lake City, UT 84103
(801) 364-7060

Galactosemia
Parents of Galactosemic Children
20981 Solano Way
Boca Raton, FL 33433
(407) 852-0266

Gaucher Disease
See also: Neurometabolic Disorders
National Gaucher Foundation
19241 Montgomery Village Ave
Ste F 21
Gaithersburg, MD 20879
(301) 990-3800
(301) 990-4898 (FAX)

Glaucoma
Foundation for Glaucoma Research
490 Post St, Ste 830
San Francisco, CA 94102
(415) 986-3763 (FAX)

Gluten Intolerance
See also: Celiac Sprue
Gluten Intolerance Groups of North America
Box 23053
Seattle, WA 98102 0353
(206) 325-6980
(206) 850-2394 (FAX)

Glycogen Storage Disease
Association for Glycogen Storage Disease
PO Box 896
Durant, IA 52747
(319) 785-6038
(319) 785-6038 (FAX)

Goldenhar Syndrome
Goldenhar Syndrome Research & Information Fund
8829 Glenaeles Ln
Darien, IL 60561
(708) 910-3939 (Voice/FAX)

Hemifacial Microsomia/Goldenhar Syndrome
Family Support Network
84 Gleniffer Hill Rd
Richboro, PA 18954
(215) 364-3199

18

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Granulomatous Disease, Chronic
See also: Wegener Granulomatosis

Chronic Granulomatous Disease Association
c/o Mary Hurley
2616 Morancy Rd
San Marino, CA 91108
(818) 441-4118

Group B Strep
Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344 (Voice/FAX)

Growth Disorders
See also: Dwarfism, Short Stature

Human Growth Foundation
7777 Leesburg Pike
Falls Church, VA 22043
(703) 883-1776 (FAX)
(800) 451-6434
(800) 451-6434

Group B Strep Association
7777 Leesburg Pike
Falls Church, VA 22043
(703) 883-1776 (FAX)
(800) 451-6434
(800) 451-6434

The MAGIC Foundation for Children's Growth
1327 N Harlem Ave
Oak Park, IL 60302
(708) 383-0808
(708) 383-0899 (FAX)

Hallerman-Streiff Syndrome
Hallerman-Streiff Support Group
1387 Beulah Park Dr
Lexington, KY 40517
(606) 273-6928

Head Injuries
National Head Injury Foundation
1776 Massachusetts Ave NW, Ste 100
Washington, DC 20036-1904
(800) 444-6443 (helpline)
(202) 296-6443
(202) 296-8850 (FAX)

Hearing Impairments
Alexander Graham Bell Association for the Deaf
3417 Volta PI NW
Washington, DC 20007-2778
(202) 337-5220 (Voice/TDD)

American Society for Deaf Children
814 Thayer Ave
Silver Spring, MD 20910
(301) 942-2732 (Voice/TDD)

Auditory-Verbal International
2121 Eisenhower Ave
Alexandria, VA
(215) 253-6616
(215) 253-4434 (TDD)
(215) 253-6709 (FAX)

Better Hearing Institute
PO Box 1840
Washington, DC 20013
(800) 327-9355 (Voice/TDD)
(703) 750-9302 (FAX)

Canadian Hearing Society
217 Spadina Rd
Toronto, ON
Canada M5R 2V3
(416) 964-9955
(416) 964-0023 (TDD)
(416) 964-2066 (FAX)

Defa-REACH
3521 12th St NE
Washington, DC 20017
(202) 675-6700 (Voice/TDD)
(202) 547-0547 (FAX)

The EAR Foundation
2000 Church St, Box 111
Nashville, TN 37236
(800) 545-4327 (Voice/TDD)
(615) 329-7807

Hearing Now
9745 E Hampden Ave, Ste 300
Denver, CO 80231-4923
(303) 648-4327 (Voice/TDD)
(303) 695-7789 (FAX)

International Hearing Society
20361 Middlebelt Rd
Livonia, MI 48152
(810) 521-5247
(313) 478-2610
(313) 478-4520 (FAX)

John Tracy Clinic
806 W Adams Blvd
Los Angeles, CA 90007
(888) 522-4582 (Voice/TDD)
(213) 748-5481
(213) 747-2924 (TDD)
(213) 749-1651 (FAX)

LISTEN
PO Box 27213
Tempe, AZ 85284
(602) 921-3886 (Voice/TDD)

National Association for the Deaf
814 Thayer Ave
Silver Spring, MD 20910-4500
(301) 987-1788
(301) 987-1789 (TDD)
(301) 987-1791 (FAX)

National Cued Speech Association
PO Box 31345
Swanton, OH 43558
(419) 825-5575

Hemophilia
Canadian Hemophilia Society
1450 City Councilors, Ste 840
Montreal, PQ
Canada H3A 2E6
(514) 848-0903
(514) 848-9661 (FAX)

Hemorrhagic Telangiectasia, Hereditary
HHT Foundation International
PO Box 8037
New Haven, CT 06530
(800) 443-6389
(313) 561-2357
(313) 561-4585 (FAX)

Hirschsprung Disease
See also: Intestinal Pseudo-Obstruction Syndrome
American Hirschsprung Disease Association
222 Source St
Brattleboro, VT 05301
(802) 257-0603

Histiocytosis
Histiocytosis Association of America
606 New York Rd
Glassboro, NJ 08028
(800) 548-2758
(609) 881-4911
(609) 589-6614 (FAX)

Holoprosencephaly
See also: Craniofacial Disorders
Holoprosencephaly—Fighters of Defects Support Group
3032 Brierston St
Pittsburgh, PA 15219
(412) 687-6437

Heart Disorders
American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
(800) 242-8721
(214) 573-6300
(214) 706-1341 (FAX)

Congenital Heart Anomalies—Support, Education & Resources
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575

Hemophilia
Canadian Hemophilia Society
1450 City Councilors, Ste 840
Montreal, PQ
Canada H3A 2E6
(514) 848-0903
(514) 848-9661 (FAX)

National Hemophilia Foundation
110 Greene St, Rm 303
New York, NY 10012
(212) 219-8180
(212) 966-9247 (FAX)

Hemorrhagic Telangiectasia, Hereditary
HHT Foundation International
PO Box 8037
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(313) 561-2357
(313) 561-4585 (FAX)

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606 New York Rd
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(609) 881-4911
(609) 589-6614 (FAX)

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(412) 687-6437

Hunter Syndrome
See: Mucopolysaccharidosis

Hurler Syndrome
See: Mucopolysaccharidosis
Hydrocephalus
Guardians of Hydrocephalus
Research Foundation
2618 Ave Z
Brooklyn, NY 11235
(718) 743-4473
(718) 743-1171 (FAX)

Hydrocephalus Association
870 Market St, Ste 955
San Francisco, CA 94102
(415) 776-4713

Hydrocephalus Support Group
PO Box 4236
Chesterfield, MO 63006-4236
(314) 532-8228

National Hydrocephalus
Foundation
460 N Michigan Ave, Ste 1102
Chicago, IL 60611-4102

Hyperoxaluria
See: Ocular & Hyperoxaluria

Hypopigmentation
See: Albinism & Hypopigmentation

Ichthyosis
Foundation for Ichthyosis and
Related Skin Types
PO Box 20921
Raleigh, NC 27619
(919) 781-0679 (FAX)

Intestinal Pseudo-
Obstruction Syndrome
See also: Hirschsprung Disease

Incontinence
Help for Incontinent People
PO Box 5-4
Union, SC 29379
(800) 252-3337
(803) 579-7900
(803) 579-7902 (FAX)

Simion Foundation for
Incontinence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(708) 864-9758 (FAX)

Intraventricular
Hemorrhage
I.V.H. Parents
PO Box 56-1111
Miami, FL 33256-1111
(305) 232-0381
Compuserve: 72167,6333
(305) 232-9890 (FAX)

Joubert Syndrome
Joubert Syndrome
Parents-In-Touch Network
12348 Summer Meadow Rd
Rock, MI 49880
(219) 432-4310

Kidney Disorders
American Association of
Kidney Patients
111 S Parker St, Ste 405
Tampa, FL 33606
(800) 749-2257
(813) 251-0725
(813) 254-3270 (FAX)

American Kidney Fund
6110 Executive Blvd, Ste 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0989 (FAX)

National Kidney Foundation
30 E 33rd St, 11th Fl
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 689-9261 (FAX)

Polycystic Kidney Research
Foundation
922 Walnut St, Ste 411
Kansas City, MO 64106
(800) 753-2873
(816) 421-1869
(816) 421-7208 (FAX)

Klinefelter Syndrome
Klinefelter Syndrome
and Associates
PO Box 119
Roseville, CA 95661-0119

Klinefelter's Syndrome
Association of America
PO Box 93
Pine River, WI 54965

Lactate-Dehydrogenase
Support Group
4156 Library Rd
Windsor, CT 06095

Lactic-Acidosis
Lactic-Acidosis Support Group
PO Box 480282
Denver, CO 80248-0282
(303) 287-4953

Landau-Kleffner
Syndrome
See also: Aphasia, Epilepsy

Lantau-Kleffner
Syndrome
See also: Aphasia, Epilepsy

Lissencephaly
Lissencephaly Network
716 Autumn Ridge Ln
Fort Wayne, IN 46804
(219) 432-4310

Learning Disabilities
Association of Canada
323 Chapel St, Ste 200
Ottawa, ON
Canada K1N 7Z2
(613) 238-5721
(613) 235-5391 (FAX)

Limb Disorders
See also: Amputation

Limb Development
Foundation
936 Delaware Ave
Buffalo, NY 14209
(716) 762-9997

Limboskephaly
Lissencephaly Network
716 Autumn Ridge Ln
Fort Wayne, IN 46804
(219) 432-4310

Leprosy
American Leprosy Missions
1 ALM Way
Greenville, SC 29601
(803) 543-3131
(800) 271-7040
(800) 271-7052 (FAX)

Leukemia
Leukemia Society of America
600 Third Ave, 4th Fl
New York, NY 10016
(212) 573-8484
(212) 856-9888 (FAX)

Leukodystrophy
See also: Neurometabolic
Disorders

Lentil Disorders
United Leukodystrophy
Foundation
2304 Highland Dr
Sycamore, IL 60178
(815) 728-5483
(815) 895-3211
(815) 895-2432 (FAX)

Leukemia Society of America
600 Third Ave, 4th Fl
New York, NY 10016
(212) 573-8484
(212) 856-9888 (FAX)

Leukodystrophy
See also: Neurometabolic
Disorders

Learning Disabilities
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(412) 344-0224 (FAX)

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222 Lincoln St
West Lafayette, IN 47906
(317) 743-3634

Lung Diseases
American Lung Association
1740 Broadway
New York, NY 10019
(212) 315-8700
1740 Broadway
N Canton, OH 44720
(216) 896-4455

Lupus Erythematosis
The American Lupus Society
3914 Del Amo Blvd, Ste 922
Torrance, CA 90503
(310) 542-8891

Lupus Syndrome
National Marfan Foundation
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8712 (FAX)

Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
Support Group for Medium-Chain Acyl-CoA Dehydrogenase Deficiency
805 Montrose Dr
Greensboro, NC 27410
(336) 896-4455

Mecnium Albright Syndrome
McCune Albright Syndrome
Division of the MAGIC Foundation
3167 Greensburg Rd
N Canton, OH 44720
(216) 862-4455

Malignant Hyperthermia
Malignant Hyperthermia Association of United States
PO Box 191
Westport, CT 06881-0191
(203) 847-0407
(203) 840-1772 (FAX)

Maple Syrup Urine Disease
See also: Neurometabolic Disorders
Families with Maple Syrup Urine Disease
Rt 2, Box 24-A
Flemingsburg, KY 41041
(606) 849-4679

Marfan Syndrome
National Marfan Foundation
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8712 (FAX)

Maroteaux-Lamy Syndrome
See: Mucopolysaccharidosis

Mental Illness
Federation of Families for Children's Mental Health
1021 Prince St
Alexandria, VA 22314-2971
(703) 684-7710
(703) 684-9555 (FAX)

Mental Retardation
Canadian Association for Community Living
4700 Keelie St
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Canada M3J 1P3
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(416) 681-2023 (TDD)
(416) 681-5701 (FAX)

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(817) 261-6003
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(817) 277-3481 (FAX)

Mental Retardation/Mental Illness
National Organization of the Dually Diagnosed
110 Prince St
Kingston, NY 12401
(800) 331-5362
(914) 331-4336
(914) 331-4569 (FAX)

Miller Syndrome
See: Nager and Miller Syndromes

Mitochondrial Disorders
Mitochondrial Disorders Education and Support Exchange
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(412) 375-6193

Muscular Dystrophy
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New York, NY 10017
(617) 860-0501

Muscular Dystrophy Support Group
1747 Pennsylvania Ave NW, Ste 950
Washington, DC 20006
(800) 532-7667
(817) 571-5711

Myelin Disorders
Myelin Messenger Newsletter
c/o Ruth Anderson
HC-29, Box 886
Stable Ln
Prescott, AZ 86301-8868
(602) 529-2000
(602) 529-5300 (FAX)

Myeloproliferative Disease
MPD Research Center
2220 Tiemann Ave
Baychester, NY 10469
(800) 435-7673
(718) 231-0230
(718) 252-2133

Mucolipidosis Type IV
Families with Mucolipidosis Type IV
39521 Rowen Ct
Alinquippa, PA 15001
(412) 375-6193

Mucopolysaccharidosis
See also: Neurometabolic Disorders
National Mucopolysaccharidosis Society
17 Kraemer St
Hicksville, NY 11801
(516) 931-6338
(516) 822-2041 (FAX)

Multiple Sclerosis
Multiple Sclerosis Society
733 3rd Ave, 6th Fl
New York, NY 10017
(800) 532-7667
(212) 996-3240

Myoclonus
Myoclonus Families United
1564 E 34th St
Brooklyn, NY 11234
(718) 525-2133

Myositis Ossificans
Progressive (FOP)
See: Fibrodrasplasia Ossificans Progressiva (FOP)
National Resources for Specific Disabilities and Conditions

N-Acetyl Glutamate Synthetase (NAGS) Deficiency
See: Urea Cycle Disorders

Nager and Miller Syndromes
See also: Craniofacial Disorders
Nager and Miller Syndromes Support
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(708) 729-0701
(708) 724-6449 (Voice/FAX)
(219) 289-5611 (In Indiana)

Neonatal Illness/Prematurity
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9041 Colgate St Indianapolis, IN 46268-1210
(317) 872-9913 (Voice/FAX)

Neurofibromatosis
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National Neurofibromatosis Foundation
141 Fifth Ave, Ste 7-S
New York, NY 10010-7105
(212) 529-6094 (FAX)
(212) 460-8980
(800) 942-6825 (Voice/TDD)
(301) 577-0016 (FAX)

Neurofibromatosis, Inc.
805 E 121st Terr Kansas City, MO 64116
(818) 992-0500
(619) 282-1161
(603) 224-4085

Ollier’s Disease
Ollier’s Disease Self Help Group
PO Box 52616
Shaw AFB, SC 29108-1521
(830) 287-8214 (FAX)
(813) 287-8214 (FAX)

Ornithine Transcarbamylase (OTC) Deficiency
See: Urea Cycle Disorders

Osteogenesis Imperfecta
Osteogenesis Imperfecta Foundation
5005 W Laurel St, Ste 210
Tampa, FL 33607
(813) 287-8214 (FAX)
(813) 287-8214 (FAX)

Osteomyelitis
United Ostomy Association
36 Executive Pk, Ste 120
Irvine, CA 92714-6744
(800) 826-0826
(714) 660-8624
(714) 660-9262 (FAX)

Oxalosis & Hyperoxaluria
Oxalosis & Hyperoxaluria Foundation
PO Box 1632
St Louis, MO 63144
(800) 484-9698 (ext 5100)
(212) 525-8140 (Voice/FAX)

Pallister-Killian Syndrome
Pallister-Killian Family Support Group
4255 Fifth Ave SW
Houston, TX 77227
(713) 266-9617
(800) 926-4797

Peutz-Jeghers Syndrome
See: Polyposis

Phenylketonuria (PKU)
Children’s PKU Network
10515 Vista Sorrento Pkwy
San Diego, CA 92121
(813) 455-0400
(818) 455-0400

National Phenylketonuria Foundation
6301 Tejas Dr
Pasadena, TX 77503
(713) 467-4602

National PKU News
c/o Virginia Schuett
8869 Woodlawn Ave NE, Ste 116
Seattle, WA 98115
(206) 525-8140 (Voice/FAX)

Pigment Disorders
See: Albinism & Hypopigmentation, Vitiligo

Polymyositis & Dermatomyositis
National Support Group for Polymyositis & Dermatomyositis
PO Box 890
Cooperstown, NY 13326
(607) 547-5446

Polyposis
Familial Polyposis Registry
Mount Sinai Hospital
600 University Ave, Ste 1157
Toronto, Ontario
Canada M5G 1X5
(416) 586-8334
(416) 586-8644

Porphyria
American Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617

Progeria
International Progeria Registry
c/o W Ted Brown, M.D., Ph.D.
NY State Inst. for Basic Research in Developmental Disabilities
1050 Forest Hill Rd
Staten Island, NY 10314
(718) 494-5363
(718) 494-1026 (FAX)

Proteus Syndrome
Proteus Syndrome Association
805 E 121st Terr
Kansas City, MO 64116

Pseudoxanthoma Elasticum (PXE)
National Association for Pseudoxanthoma Elasticum
1884 Cherry St
Denver, CO 80220-1146
(303) 321-6347

Psoriasis
National Psoriasis Foundation
6600 SW 92nd, Ste 300
Portland, OR 97223
(503) 244-7404
(503) 245-0626 (FAX)

Purine Metabolic Disorders
Purine 24
5424 Beech Ave
Bethesda, MD 20814
(301) 530-0354

Reflex Sympathetic Dystrophy Syndrome
Reflex Sympathetic Dystrophy Association
116 Haddon Ave, Ste D
Haddonfield, NJ 08033
(609) 795-8845
(609) 795-8845 (FAX)

Retinitis Pigmentosa
See also: Visual Impairments
Retinitis Pigmentosa International Society for Degenerative Eye Diseases
PO Box 900
Woodland Hills, CA 91365
(800) 344-4877
(818) 992-0500
(818) 992-3265 (FAX)

RP Foundation
Fighting Blindness
1401 Mt Royal Ave, 4th Floor
Baltimore, MD 21217
(800) 683-5555
(410) 225-9400
(800) 683-5551 (TDD)
(410) 225-3936 (FAX)

Retinoblastoma
See also: Visual Impairments
National Retinoblastoma Parent Group
110 Allen Rd
Bow, NH 03304
(603) 224-4085


dated Parent
### National Resources for Specific Disabilities and Conditions

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<tr>
<th>Condition</th>
<th>Organization</th>
<th>Address</th>
<th>Phone Numbers</th>
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<tbody>
<tr>
<td>Rett Syndrome</td>
<td>International Rett Syndrome Association</td>
<td>9121 Piscataway Rd, Ste 2B, Clinton, MD 20735</td>
<td>(301) 856-3334, (800) 818-7388, (301) 856-3336 (FAX)</td>
</tr>
<tr>
<td>Rubella, Congenital</td>
<td>Rubella Project</td>
<td>Developmental Disabilities Ctr St Luke’s Roosevelt Hospital Ctr 428 W 59th St New York, NY 10019</td>
<td>(212) 523-6280, (212) 523-7818 (TDD), (212) 523-6241 (FAX)</td>
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<tr>
<td>RSH Syndrome</td>
<td>See: Smith-Lemli-Opitz Syndrome</td>
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<td>Rubinstein-Taybi Syndrome</td>
<td>Rubinstein-Taybi Parent Group</td>
<td>c/o Lorrie Baxter PO Box 146 Smith Center, KS 66967</td>
<td>(913) 697-2984</td>
</tr>
<tr>
<td>Russell-Silver Syndrome</td>
<td>See also: Growth Disorders, Short Stature</td>
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<td>Scheie Syndrome</td>
<td>See: Mucopolysaccharidoses</td>
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<tr>
<td>Scleroderma</td>
<td>Scleroderma Federation</td>
<td>Peabody Office Bldg One Newbury St Peabody, MA 01960</td>
<td>(508) 535-6600, (508) 535-6696 (FAX)</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>National Scoliosis Foundation</td>
<td>72 Mount Auburn St Watertown, MA 02172</td>
<td>(617) 926-0397, (617) 926-0398 (FAX)</td>
</tr>
<tr>
<td>Seizure Disorders</td>
<td>Seizure Disorder Support Group &amp; Newsletter</td>
<td>26 Stavola Rd Middletown, NJ 07748-3728</td>
<td>(908) 957-0714</td>
</tr>
<tr>
<td>Short Stature</td>
<td>Little People of America</td>
<td>PO Box 9897 Washington, DC 20016</td>
<td>(800) 243-9273 (info line)</td>
</tr>
<tr>
<td>Sick Cell Disease</td>
<td>American Sickle Cell Anemia Association</td>
<td>10300 Cameggie Ave Cleveland, OH 44106</td>
<td>(216) 229-8600, (216) 229-4500 (FAX)</td>
</tr>
<tr>
<td>Spina Bifida</td>
<td>Spina Bifida Association of America</td>
<td>4590 MacArthur Blvd NW, #250 Washington, DC 20007-4226</td>
<td>(800) 621-3141, (202) 944-3285, (202) 944-3295 (FAX)</td>
</tr>
<tr>
<td>Spinal Cord Injuries</td>
<td>American Paralysis Association</td>
<td>500 Morris Ave Springfield, NJ 07081</td>
<td>(800) 225-0292, (201) 379-2690, (201) 912-9433 (FAX)</td>
</tr>
<tr>
<td>Spina Bifida Association of Canada</td>
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<tr>
<td>Spina Bifida USA</td>
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<tr>
<td>Sotos Syndrome</td>
<td>Sotos Syndrome USA</td>
<td>937 Shandra Dr Reston, VA 22094</td>
<td>(703) 709-0568</td>
</tr>
</tbody>
</table>
**National Resources for Specific Disabilities and Conditions**

**Syringomyelia**
See also: Arnold-Chiari Syndrome
American Syringomyelia Alliance Project
PO Box 1586
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (FAX)

**Tay-Sachs Disease**
See also: Neurometabolic Disorders
National Tay-Sachs and Allied Diseases Association
2001 Beacon St, Ste 204
Brookline, MA 02146
(617) 277-4463
(617) 277-0134 (FAX)

**Thalassemia**
See: Cooley's Anemia
National Thalassemia Foundation
8023 Johnson St
Bayside, NY 11361-2861
(718) 279-9596 (FAX)

**Thrombocytopenia-Absent Radius (TAR) Syndrome**
Thrombocytopenia-Absent Radius Syndrome Association
212 Sherwood Dr, RD 1
Linwood, NJ 08221-9745
(609) 927-0418

**Tourette Syndrome**
Tourette Syndrome Association
42-40 Bell Blvd
Bayside, NY 11361-2861
(718) 224-2999
(718) 279-9596 (FAX)

**Treacher Collins Syndrome**
Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(802) 649-3020

**Tuberous Sclerosis**
National Tuberous Sclerosis Foundation
1255 Vauhall Rd
Richmond, VA 23234
(908) 851-2731

**Vascular Malformations**
National Vascular Malformations Foundation
8320 Nightingale
Dearborn Heights, MI 48127
(313) 274-1243

**Vestibular Disorders**
See also: Balance Disorders & Dizziness
Vestibular Disorders Association
PO Box 4467
Washington, DC 20005
(800) 424-8666
(202) 467-5081

**Visual Impairments**
See also: Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Stargardt Disease
American Council of the Blind
1155 15th St NW, Ste 720
Washington, DC 20005
(800) 424-8666
(202) 467-5081

**Visual Impairments**
See also: Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Stargardt Disease
American Council of the Blind
15 W 16th St
New York, NY 10011
(800) 232-5463
(212) 620-2000

**Visual Impairments**
See also: Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Stargardt Disease
American Printing House for the Blind
1839 Frankfort Ave, PO Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405
(502) 895-1509 (FAX)

**Vitreitis**
National Vitreitis Foundation
PO Box 6337
Tyler, TX 75711
(903) 534-2925
(903) 534-8075 (FAX)

**Von Hippel-Lindau Syndrome**
See also: Ataxia, Balance Disorders & Dizziness
Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd
Brookline, MA 02146
(617) 232-5946 (evenings)
(617) 734-8233 (FAX)

**Wegener Granulomatosis**
See also: Granulomatous Disease, Chronic
Wegener Granulomatosis Support Group
PO Box 1518
Platte River City, MO 64079-1518
(800) 277-9474

**Williams Syndrome**
Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(313) 541-3630
(313) 541-3631 (FAX)

**Wilson's Disease**
Wilson's Disease Association
PO Box 75324
Washington, DC 20013
(703) 636-3003 (Voice/TDD)
(703) 636-3014

**Wolf-Hirschhorn Syndrome (4p-)**
4p- Parent Contact Group
c/o Becky & Tom Richardson
3200 Rivanna Ct
Washington, DC 20013
(703) 491-0309

**Xeroderma Pigmentosum**
See also: Ataxia, Balance Disorders & Dizziness
Xeroderma Pigmentosum Support Group and Newsletter
Virginia Ct
Amherst, OH 44001
(216) 282-1460

**Xeroderma Pigmentosum Registry**
Xeroderma Pigmentosum Registry
Ne. J. Jersey Medical School
Dept of Pathology, Rm C-520
Medical Science Bldg 185 S
Orange Ave
Newark, NJ 07103-2714
(201) 982-4405
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Sunnyvale, CA 94087
Phone 408·985·7200
Fax 408·243·3731

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P.O. Box 150, New Kent, Virginia 23124

Circle #18
Parent Training and Information Centers

ALABAMA
Special Education Action Committee
PO Box 161274
Mobile, AL 36616-2274
(800) 222-7322 (in AL)
(205) 478-1208 (Voice/TDD)
(205) 473-7877 (FAX)

Northern Coalition for Parent Training and Information
Matrix, A Parent Network and Resource Center
PO Box 6541
San Rafael, CA 94903
(415) 499-3877
(415) 507-9457 (FAX)

Northern Coalition for Parent Training and Information
Parents Helping Parents
535 Race St, Ste 140
San Jose, CA 95126
(408) 288-5010
(408) 288-7493 (FAX)

Northern Coalition for Parent Training and Information
Parents Helping Parents
1801 Vincente St
San Francisco, CA 94116
(415) 534-0722
(415) 81-1065 (FAX)

Tear of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805-6546
(714) 533-8275 (Voice/TDD)
(714) 533-2533 (FAX)

ARKANSAS
Arkansas Disability Coalition
10002 West Markham, Ste B7
Little Rock, AR 72205
(501) 221-1330 (Voice/TDD)
(501) 221-9067 (FAX)

FOCUS
2917 King St, Ste C
Jonesboro, AR 72401
(501) 935-2750
(501) 221-1330 (Voice/TDD)
(501) 931-1111 (FAX)

ARKANSAS
Arkansas Disability Coalition
10002 West Markham, Ste B7
Little Rock, AR 72205
(501) 221-1330 (Voice/TDD)
(501) 221-9067 (FAX)

FOCUS
2917 King St, Ste C
Jonesboro, AR 72401
(501) 935-2750
(501) 221-1330 (Voice/TDD)
(501) 931-1111 (FAX)

ARIZONA
Pilot Parent Partnerships
2150 E Highland Ave, Ste 105
Phoenix, AZ 85016
(602) 468-3001 (Voice/TDD)
(602) 468-3001 (FAX)

Northern Coalition for Parent Training and Information
Parents Helping Parents
100 W Cerritos Ave
Anaheim, CA 92805-6546
(714) 533-8275 (Voice/TDD)
(714) 533-2533 (FAX)

COLORADO
PEAK Parent Center
6055 Lehman Dr, Ste 101
Colorado Springs, CO 80918
(800) 284-0251
(719) 531-9400
(719) 531-9403 (TDD)
(719) 531-9452 (FAX)

CONNECTICUT
Connecticut Parent Advocacy Center
5 Church Ln
PO Box 579
East Lyme, CT 06333
(800) 445-2722 (in CT)
(203) 739-3089 (Voice/TDD)
(203) 739-7460 (FAX)

DELAWARE
Parent Information Center of Delaware
700 Barksdale Rd, Ste 6
Newark, DE 19711
(302) 366-0152
(302) 366-0178 (TDD)
(302) 366-0276 (FAX)

DISTRICT OF COLUMBIA
COPE
PO Box 90498
Washington, DC 20090-0498
(202) 526-6814
(202) 832-2180 (FAX)

FLORIDA
Family Network on Disabilities
5510 Gray St, Ste 220
Tampa, FL 33609-3510
(813) 289-1122 (Voice/TDD)
(813) 289-7460 (FAX)

GEORGIA
Parents Educating Parents
Georgia ARC
1851 Ram Runway, Ste 104
College Park, GA 30337
(404) 761-2745 (Voice/TDD)
(404) 761-3150
(404) 761-2258 (FAX)

HAWAII
AWARE/Learning Disabilities Association of Hawaii
200 N Vineyard Blvd, Ste 310
Honolulu, HI 96817
(808) 536-2280 (Voice/TDD)
(808) 537-6780 (FAX)

Parent Training and Information Programs (PTIs) are funded by the Division of Personnel Preparation, Office of Special Education Programs, U.S. Department of Education. Their stated mission is "to provide training and information to parents to enable them to participate more effectively with professionals in meeting the educational needs of children with disabilities."

PTIs can help parents to:
- Understand their children’s specific needs;
- Communicate more effectively with professionals;
- Participate in the educational planning process; and
- Obtain information about relevant programs, services and resources.
Parent Training & Information Centers

IDAHO
Idaho Parents Unlimited
Parent Education Resource Ctr
4696 Overland Rd, Ste 478
Boise, ID 83705
(800) 242-4785 (in ID)
(208) 342-5884 (Voice/TDD)
(208) 342-1408 (FAX)

ILLINOIS
Designs for Change
6 N Michigan Ave, Ste 1600
Chicago, IL 60602
(312) 857-9292
(312) 857-1013 (TDD)
(312) 857-9299 (FAX)

Family Resource Center on Disabilities
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(800) 952-4199 (in IL)
(312) 933-3513
(312) 933-3519 (TDD)
(312) 939-7297 (FAX)

INDIANA
Indiana Resource Center for Families with Special Needs
833 E Northside Blvd, Bldg 1, R South Bend, IN 46617
(800) 332-4433 (in IN)
(219) 234-7101
(219) 234-7279 (FAX)

IOWA
Iowa Pilot Parents
33 N 12th St
PO Box 1151
Fort Dodge, IA 50501
(712) 937-4777
(515) 576-5870 (Voice/TDD)
(515) 576-8209 (FAX)

KANSAS
Families Together
1023 SW Gage Blvd
Topeka, KS 66604
(913) 237-6343 (Voice/TDD)
(913) 237-6385 (FAX)

KENTUCKY
Kentucky Special Parent Involvement Network
2210 Goldsmith Ln, Ste 118
Louisville, KY 40218
(502) 456-0923
(502) 456-0893 (FAX)

LOUISIANA
Project Prompt
4323 Division St, Ste 110
Metairie, LA 70002
(504) 766-7738
(504) 766-7738 (Voice/TDD)
I-911
I-0246 (FAX)

MAINE
Special-Needs Parent Information Network
PO Box 2067
Augusta, ME 04338-2067
(800) 870-7746
(207) 582-2504 (Voice/TDD)
(207) 582-3638 (FAX)

MARYLAND
Parents Place of Maryland
7257 Parkway Dr, Ste 210
Hanover, MD 21076
(410) 712-0900 (Voice/TDD)
(410) 712-0902 (FAX)

MASSACHUSETTS
Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(800) 331-0688 (in MA)
(617) 482-2915
(617) 695-2393 (FAX)

MICHIGAN
Citizens Alliance to Uphold Special Education
313 S Washington Sq, Ste 040
Lansing, MI 48933
(800) 221-9105 (in MI)
(517) 485-4084 (Voice/TDD)
(517) 485-4145 (FAX)

Parents are Experts
23077 Greenfield Rd, Ste 205
Southfield, MI 48075
(313) 557-5070 (Voice/TDD)
(313) 557-4456 (FAX)

MINNESOTA
PACER Center
4826 Chicago Ave S
Minneapolis, MN 55417
(800) 537-2237 (parents, in MN)
(612) 827-2966 (Voice/TDD)
(612) 827-3065 (FAX)

MISSOURI
Missouri Parents Act
1722 S Glenstone, Ste 125
Springfield, MO 65131
(800) 743-7634 (in MO)
(417) 882-7434 (Voice/TDD)
(417) 882-8413 (FAX)

MPACT—Kansas City Office
1115 E 65th St
Kansas City, MO 64131
(816) 333-6833
(816) 333-5685 (TDD)
(816) 333-2267 (FAX)

NEVADA
Nevada Parent Connection
3380 S Arville Blvd, Ste J
Las Vegas, NV 89110
(800) 508-4464 (in NV)
(702) 252-0259, ext. 112 & 113
(702) 252-8780 (FAX)

NEW HAMPSHIRE
Parent Information Center
151A Manchester St
PO Box 1422
Concord, NH 03302-14226
(800) 232-0986 (in NH)
(603) 224-6299
(603) 224-7005 (Voice/TDD)
(603) 224-4365 (FAX)

NEW JERSEY
Statewide Parent Advocacy Network
516 North Ave E
Westfield, NJ 07090
(908) 654-7726
(908) 654-7880 (FAX)

NEW MEXICO
EPICS Project
Parents Reaching Out
1127 University Blvd NE
Albuquerque, NM 87102
(800) 524-5176 (in NM)
(505) 842-9045 (Voice/TDD)
(505) 842-1451 (FAX)

EPICS Project SW
Communication Resources
PO Box 788
412 Camino Don Tomas
Bernalillo, NM 87004
(505) 867-3396 (Voice/TDD)
(505) 867-3398 (FAX)

NEW YORK
Advocates for Children of New York
24-16 Bridge Plaza S
Long Island City, NY 11101
(718) 729-8866 (Voice/TDD)
(718) 729-8931 (FAX)

Parent Network Center
1443 Main St
Burlington, NY 12420
(800) 724-7408 (in NY)
(716) 885-1004
(716) 885-3527 (TDD)
(716) 885-9597 (FAX)

Resources for Children
with Special Needs
200 Park Ave S, Ste 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (FAX)

NORTH CAROLINA
Exceptional Children's Assistance Center
PO Box 16
Davidson, NC 28655
(800) 962-6917 (in NC)
(704) 892-1321
(704) 892-5028 (FAX, call first)

Families First Coalition
301 Eola Rd
Morganton, NC 28655
(800) 822-3477 (in NC)
(704) 433-2662
(704) 438-6457 (FAX)

NORTH DAKOTA
Pathfinder Parent Training and Information Center
1600 Second Ave SW
Minot, ND 58701
(800) 245-5840 (in ND)
(701) 852-9426
(701) 838-9324 (FAX)

OHIO
Child Advocacy Center
1821 Summit Rd, Ste 303
Cincinnati, OH 45237
(800) 821-2400 (in OH)
(513) 821-2400 (Voice, TDD)
(513) 821-2442 (FAX)

Ohio Coalition for the Education of Handicapped Children
933 High St, Ste 106
Worthington, OH 43085
(614) 431-1307 (Voice/TDD)
(614) 382-2399 (FAX)

January 1994
OLYOKA
Parents Reaching Out in Oklahoma Project
1917 S Harvard Ave
Oklahoma City, OK 73128
(800) 759-4142
(405) 681-9710 (Voice/TDD)
(405) 685-4006 (FAX)

OREGON
Oregon COPE Project
999 Locust St, NE
Salem, OR 97303
(503) 373-7477 (Voice/TDD)
(503) 373-7477 (FAX, call first)

PENNSYLVANIA
Mentor Parent Program
Rt 257, PO Box 718
Seneca, PA 16346
(800) 447-1431 (in PA)
(814) 676-8615
(814) 676-8615 (FAX)

Parent Education Network
333 E 7th Ave
York, PA 17404
(800) 522-5817 (Voice/TDD in PA)
(717) 845-9722 (Voice/TDD)
(717) 848-3654 (FAX)

Parents Union
for Public Schools
311 S Juniper St, Ste 602
Philadelphia, PA 19107
(215) 546-1166
(215) 731-1688 (FAX)

PUERTO RICO
Asociacion de Padres Por Bienestar de Ninos Impedidos de PR
PO Box 21301
Rio Piedras, PR 00928-1301
(809) 763-4665
(809) 765-0345
(809) 765-0345 (FAX)

RHODE ISLAND
Rhode Island Parent Information Network
Independence Sq
500 Prospect St
Pawtucket, RI 02860
(800) 464-3399 (in RI)
(401) 727-4144 (Voice)
(401) 727-4151 (TDD)
(401) 725-9960 (FAX)

SOUTH CAROLINA
PRO-PARENTS
2712 Middleburg Dr, Ste 102
Columbia, SC 29204
(800) 759-4776 (in SC)
(803) 779-3859 (Voice/TDD)
(803) 252-4513 (FAX)

SOUTH DAKOTA
South Dakota Parent Connection
PO Box 84813
Sioux Falls, SD 57118-4813
(800) 640-4553 (in SD)
(605) 335-8844 (Voice/TDD)
(605) 335-8504 (FAX)

SOUTH DAKOTA
South Dakota Parent Connection
PO Box 84813
Sioux Falls, SD 57118-4813
(800) 640-4553 (in SD)
(605) 335-8844 (Voice/TDD)
(605) 335-8504 (FAX)

TENNESSEE
Support and Training for Exceptional Parents
1805 Hayes St, Ste 100
Nashville, TN 37203
(800) 721-0867
(800) 21-2422 (FAX)

WASHINGTON
PAVE/STOMP Specialized Training of Military Parents
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

Touchstones
6721 51st Ave S
Seattle, WA 98118
(206) 588-1741 (Voice/TDD)
(206) 984-7520 (FAX)

WASHINGTON
West Virginia Parent Training & Information Center
104 East Main St
Colonial Village, Ste 3-B
Clarksburg, WV 26301
(800) 281-1436 (Voice/TDD in WV)
(304) 624-1436 (Voice/TDD)
(304) 624-1438 (FAX)

TEXAS
Partners Resource Network
277 N 18th, Ste 2
Beaumont, TX 77707-2713
(800) 866-4726
(409) 838-2366
(409) 838-2351 (FAX)

Project PODER
2300 W Commerce, Ste 205
San Antonio, TX 78207
(800) 682-9747
(210) 222-2637
(210) 222-2638 (FAX)

Special Kids
PO Box 61628
Houston, TX 77208-1628
(713) 643-9576
(713) 643-6291 (FAX)

UTAH
Utah Parent Center
2290 E 4500 S, Ste 110
Salt Lake City, UT 84117
(801) 272-1051
(801) 272-8907 (FAX)

VERMONT
Vermont Parent Information Center
1 Mill St
Burlington, VT 05401
(800) 639-7170 (in VT)
(802) 658-5315
(802) 658-5395 (FAX)

WASHINGTON
West Virginia Parent Training & Information Center
104 East Main St
Colonial Village, Ste 3-B
Clarksburg, WV 26301
(800) 281-1436 (Voice/TDD in WV)
(304) 624-1436 (Voice/TDD)
(304) 624-1438 (FAX)

WEST VIRGINIA
West Virginia Parent Training & Information Center
104 East Main St
Colonial Village, Ste 3-B
Clarksburg, WV 26301
(800) 281-1436 (Voice/TDD in WV)
(304) 624-1436 (Voice/TDD)
(304) 624-1438 (FAX)

WIYOMING
Wyoming PIC
5 N Lobban
Buffalo, WY 82834
(800) 660-9742 (in WY)
(307) 684-2277 (Voice/TDD)
(307) 684-5314 (FAX)

WISCONSIN
Parent Education Project of Wisconsin
2192 S 60th St
West Allis, WI 53219
(800) 231-8382 (in WI)
(414) 328-5520

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Circle #42 Photo used by permission Bigfoot 4X4 Inc. St. Louis, MO
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- Severe Maladaptive Behavior
- Physical Disability

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1-508-478-5597

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Exceptional Parent

January 1994
Parent to Parent (P-P) programs provide one-to-one emotional and informational support to parents of children who have special needs. This is done by carefully matching trained and experienced “veteran” parents with parents who are newly referred to the program. The veteran parent provides the kind of support that can only come from someone who has “been there.”

The following state-by-state listing of local P-P programs was provided by The Beach Center on Families and Disabilities. For more information on P-P programs, contact the Beach Center at The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, (913) 864-7600.
Parent To Parent Programs

**Matrix: Parent Network and Resource Center**
555 Northgate
San Rafael, CA 94903
(415) 499-3877

**Family Support Network**
1800 N Bush St, Ste 201
Santa Ana, CA 92706
(714) 836-5511

**Family Support Network**
3010 W Harvard St, #D
Santa Ana, CA 92704-3914

**Circle of Hope**
1015 Cedar St
Santa Cruz, CA 95060
(408) 335-7404

**Valley Parents Support Group**
PO Box 5973-272
Sherman Oaks, CA 91413

**DIRECT Link for the DisABLED**
PO Box 1036
Valencia, CA 91329

**Cleft Parent Guild**
Sonora, CA 95370
(209) 928-3688

**AVENUES**
PO Box 5192
Sonora, CA 95370
(209) 928-3688

**Cleft Parent Guild**
14764 Nanny St
Whittier, CA 90604
(310) 874-3300

**COLORADO**
Sturge-Weber Foundation
PO Box 480931
Aurora, CO 80046
(303) 552-2882

**SKIP of Colorado**
930 S Kittredge Way
Aurora, CO 80017
(303) 368-8733

**Child Language Ctr, Univ of CO**
CB-409, Dept CD-55
Boulder, CO 80302
(303) 492-5375

**PEAK Parent Ctr**
6055 Lehman Dr, #101
Colorado Springs, CO 80918
(719) 531-9400

**Bridges**
7475 Dakin, Ste 635
Denver, CO 80221
(303) 428-0310

**Colorado Cleft Palate Association**
755 S Clay St
Denver, CO 80219
(303) 924-4710

**Little People of America**
Front Range Chapter
7117 E Euclid Dr
Englewood, CO 80111
(303) 740-4905

**Effective Parents Project**
255 Main St
Grand Junction, CO 81501
(303) 241-6050

**Parents Reaching Out**
710 Kipling, #303
Lakewood, CO 80215
(303) 238-0240

**Mile High Down Syndrome Association**
PO Box 620847
Littleton, CO 80162
(303) 797-1699

**Parent-Professional Partnership**
1077 Laurie Cir
Meeker, CO 81641
(303) 387-3491

**Parents as Partners in Special Ed**
11130 Harris Way
Thornton, CO 80215
(303) 452-5958

**CONNECTICUT**
Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06222-1273
(800) 223-8355

**Western Connecticut Association for Human Rights**
11 Lake Ave Ext
Danbury, CT 06811
(203) 792-3540

**Connecticut Cleft Lip and Palate Parent Group**
10 Starr Pl
East Hampton, CT 06424
(203) 267-4816

**Lower Fairfield Cty Parent to Parent**
ARC of Greenwich
50 Glenville St
Greenwich, CT 06831
(203) 329-1721

**Parents Available to Help**
830 Elm St
New Haven, CT 06511
(203) 488-9640

**Parent to Parent Network of CT**
The Family Center
181 E Cedar St
Newington, CT 06111
(203) 924-5268

**Oxford Special Ed Support**
10 White Gate Rd
Oxford, CT 06879
(203) 426-7649

**Connecticut Traumatic Brain Injury Association**
1800 Silas Deane Hwy, Ste 224
Rocky Hill, CT 06067
(203) 721-8111

**Parent Sharing**
PO Box 254
West Simsbury, CT 06092
(203) 282-0280

**NAMI CAN of Woodbridge**
8 Country Club Dr
Woodbridge, CT 06525
(203) 397-9269

**DELAWARE**
Parent Information Center of Delaware
700 Barksdale Rd, Ste 6
Newark, DE 19717
(302) 366-0152

**DISTRICT OF COLUMBIA**
Easter Seal Society
1200 15th St NW
Washington, DC 20009
(202) 223-2342

**FLORIDA**
Neo-Care
PO Box 160683
Altamonte Springs, FL 32716
(407) 283-4317

**Gold Coast Down Syndrome Organization**
22626 SW 65 Terrace
Boca Raton, FL 33428
(407) 451-2163

**Parent to Parent of Pinellas Cty**
1998 Sun Tree Blvd
Clearwater, FL 33763-4339
(813) 461-3541

**Parent to Parent of Wakulla Cty**
R 6, Box 8814
Crawfordville, FL 32327
(904) 926-7826

**Parent to Parent of Walton Cty**
R 5, Box 185
Pensacola, FL 32514
(904) 474-7656

**Parent to Parent of St Lucie Cty**
PO Box 162
Port Salerno, FL 34992-0162

**NICU Parent Support Group**
JHM Health Ctr, Box J-296
Gainesville, FL 32607
(904) 392-6427

**Parent to Parent of Alachua Cty**
4805 SW 45th St
Gainesville, FL 32608
(904) 377-1827

**Parent to Parent of Polk Cty**
4440 Spring Ln
Lakeland, FL 33811
(813) 564-8058

**Families At Mayport are Exceptional**
PO Box 205, NAVSTA
Mayport, FL 32228
(904) 240-5226

**Parent to Parent**
Gainesville, FL 100296
(904) 377-1827

**Parent to Parent—Hispanic**
1911 SW 6th St
Miami, FL 33147
(305) 223-7379

**Parent to Parent of Miami**
5555 SW 93rd Ave
Miami, FL 33165
(305) 271-9797

**IVH Parents**
PO Box 56-1111
Miami, FL 33156
(305) 522-3613

**Special Parents**
409 Dixie Rd
Milton, FL 32570
(904) 432-4513

**Parent to Parent of North Brevard**
PO Box 526
Mims, FL 32754-0526
(407) 383-0410

**Parent to Parent of Collier Cty**
4875 6th Ave SW
Naples, FL 33999
(813) 455-1522

**Veteran Intensive Care Parents**
PO Box 2700
Pensacola, FL 32513-2700
(904) 474-7656

**Special Parents**
PO Box 15362
Pensacola, FL 32514

**Parent to Parent of Martin Cty**
PO Box 162
Port Salerno, FL 34992-0162

**Parent to Parent of St Lucie Cty**
422 NW Concord Dr
Port St Lucie, FL 34983
(407) 876-3284

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**January 1994**
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Parent To Parent Programs

Union County Pilot Parents
PO Box 57
Creston, IA 50801
(515) 782-2917

Autism Society of the Quad Cities
4712 Belle Ave
Davenport, IA 52807
(319) 359-5414

Parent Educator Connection
MPRRC, Drake Univ
Des Moines, IA 50311
(515) 271-3936

Special Care Parents
1922 E 12th St
Des Moines, IA 50316
(515) 255-5943

Patient-Parent Representative Program
Div of DD
Univ of Iowa
Iowa City, IA 52242
(319) 356-1419

Epilepsy Support Group
426 Sherrylyn Blvd
Pleasant Hill, IA 50317
(515) 263-0370

Parent-Educator Connection
102 S Main, AEA 4
Sioux Center, IA 51250
(712) 722-1931

Parent to Parent Support Group
2320 S Olive
Sioux City, IA 51106
(712) 274-2838

Parent to Parent of Nebraska
133 Lillian
West Des Moines, IA 52501
(515) 682-6467

KANSAS

Parent to Parent of Garden City
Box 148
Deerfield, KS 67838
(316) 426-6213

Parent to Parent of Butler Cty
Special Families
1432 W Olive
El Dorado, KS 67042
(316) 321-3274

Parent to Parent of Flint Hills
1722 Yucca Ln
Emporia, KS 66801
(316) 342-6954

Parent to Parent of NW Kansas
Box 15
Gum, KS 67734
(913) 462-6857

Parent to Parent of Haskell Cty
2512 N 75th St
Kansas City, KS 66109
(913) 299-2027

Parent Outreach
1146 S 3rd St
Louisville, KY 40203

LOUISIANA

Neonatal Intensive Care Unit—Parents
10538 Shemoo
Baton Rouge, LA 70815
(504) 293-3562

Parent Conference on Special Ed
Louisiana Dept of Education
PO Box 94034
Baton Rouge, LA 70804-9064
(504) 342-3636

Louisiana Rett Syndrome Foundation
7529 Sailfish Dr
Lake Charles, LA 70605
(318) 474-5772

Parent to Parent of Louisiana
The Family Support Program
Children's Hospital
200 Henry Clay Ave
New Orleans, LA 70118
(504) 896-9268

Concerned Parents for Students
1022 Gulf Ln
Shulphur, LA 70663
(318) 528-2191

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338-2067
(207) 582-2504

Parent to Parent
United Cerebral Palsy of Northeastern Maine
103 Texas Ave
Bangor, ME 04401
(207) 941-2885

Mid-Coast Children's Services
11 Maple St
Rockland, ME 04841
(207) 594-8474

York Cty Parent Awareness
150 Main St
MidTown Mall
Sandford, ME 04073
(207) 324-2337

MARYLAND

Maryland Infants and Toddlers Program
PO Box 1022
Baltimore, MD 21201
(410) 539-3300

Parent to Parent
Special Needs
111 Dodge St
Beverly, MA 01915
(508) 927-5843

Parent to Parent of Birth Defects Services
Children's Hospital, Fagen 10
300 Longwood Ave
Boston, MA 02115
(617) 735-7037

Parent to Parent
1505 Commonwealth Ave
Boston, MA 02135
(617) 783-3900

Federation for Children with Special Needs
95 Berkeley St, Ste 202
Boston, MA 02116
(617) 482-2915

National Tay-Sachs & Allied Diseases Association
2001 Beacon St, #204
Brookline, MA 02146
(617) 277-4463

South Shore Parent to Parent
South Shore ARC
250 Elm St
Hancock, MA 02343
(617) 335-3023

Massachusetts Down Syndrome Congress
PO Box 86
Melrose, MA 01176
(617) 742-4440

Learning Disabilities Association
76 Cranbrook Rd, Ste 299
Cockeysville, MD 21030-3479
(301) 265-6193

Parents of Preemies
23020 Wild Hunt Dr
Gaithersburg, MD 20882
(301) 253-6534

Parents of Preemies
2822 Chasbar Ct
Gaithersburg, MD 20879

Anne Arundel Cty Infants & Toddlers Program
160 Funko Rd
Glen Burnie, MD 21061
(410) 222-6911

Epilepsy Foundation of America
4350 Garden City Dr
Landover, MD 20785
(301) 459-3700

Montgomery Cty ARC
11600 Nebel St
Folkstone, MD 20852
(301) 984-5792

MASSACHUSETTS

Cape Ann Early Intervention
111 Dodge St
Beverly, MA 01915
(508) 927-5843

Parent to Parent of Birth Defects Services
Children's Hospital, Fagen 10
300 Longwood Ave
Boston, MA 02115
(617) 735-7037

Greater Boston Parent to Parent
1505 Commonwealth Ave
Boston, MA 02135
(617) 783-3900

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(617) 482-2915

National Tay-Sachs & Allied Diseases Association
2001 Beacon St, #204
Brookline, MA 02146
(617) 277-4463

South Shore Parent to Parent
South Shore ARC
250 Elm St
Hancock, MA 02343
(617) 335-3023

Massachusetts Down Syndrome Congress
PO Box 86
Melrose, MA 01176
(617) 742-4440

January 1994
Parent To Parent Programs

National MPS Society
3260 Old Farm Ln
Walled Lake, MI 48390
(313) 363-4412

MINNESOTA
People to People, One-to-One Support
514 N Cedar
Owatonna, MN 55060
(507) 451-0576

Midstate Pilot Parents
PO Box 1536
St Cloud, MN 56302
(612) 253-6844

Parents for Parents (NICU)
Vetern Parents (PICU)
280 N Smith Ave, Ste 245
St Paul, MN 55102
(612) 220-6731

Pilot Parents in Ramsey Cty
425 Etna St, #35
St Paul, MN 55106
(612) 778-0727

Turner's Syndrome Society of the US
768-214 Twelve Oaks Ctr
15500 Wayzata Blvd.
Wayzata, MN 55391-1416
(612) 475-9944

MISSOURI
Missouri Head Injury Association
3632-A W Truman Blvd
PO Box 84
Jefferson City, MO 65102-0084
(314) 893-2444

Pilot Parents Program
PO Box 10984
Springfield, MO 65808
(417) 883-2593

MONTANA
Pilots Parents, Let’s Unite for Kids
1500 N 30th St
Billings, MT 59101-3298
(406) 657-2055

Quality Life Concepts
600 6th St NW
PO Box 2506
Great Falls, MT 59403
(406) 452-9531

Osteogenesis Imperfecta Foundation Peer Contact Network
PO Box 768
Manhattan, MT 59741-0768
(406) 284-6038

Parents of Children with Special Needs
School of Ed
University of Montana
Missoula, MT 59812
(406) 542-1390

NEBRASKA
Exceptional Parents Night Out
PO Box 622
Hastings, NE 68901
(402) 463-5611

Pilot Assistance Office
310 W 24th
 Kearney, NE 68847
(308) 236-6867

Pilot Parents
1707 Polk
Lincoln, NE 68505
(308) 324-4428

Pilot Parents Program,
ARC-Capital
215 Centennial Mall S,
#410
Lincoln, NE 68508
(402) 463-5611

Pilot Parents Program,
ARC-Preschool
215 Centennial Mall S,
#410
Lincoln, NE 68505
(402) 463-5611

Down Syndrome
Parent to Parent
ARC of Essex County
7 Regent St
Livingston, NJ 07039
(201) 535-1181

JERSEY
Cleft Lip and Palate
Support Group
510 Douglas Dr
Cherry Hill, NJ 08034
(609) 492-6554

Parent Support, ARC Bergen-
Passaic Cty
481 A Edward Ross Dr
Elmwood Park, NJ 07407
(201) 797-0100

Family Support Services
Program
NJ Association of the Deaf-Blind
28 Kennedy Blvd
E Brunswick, NJ 08816
(908) 249-4433

Association for Special Children
and Families
Supporting Special Parents
PO Box 494
Hewitt, NJ 07421
(201) 728-3744

NEW MEXICO
Parents of Children
with Special Needs
National MPS Society
3260 Old Farm Ln
Walled Lake, MI 48390
(313) 363-4412

Parents of Children with Special Needs
School of Ed
University of Montana
Missoula, MT 59812
(406) 542-1390

NEBRASKA
Exceptional Parents Night Out
PO Box 622
Hastings, NE 68901
(402) 463-5611

Pilot Assistance Office
310 W 24th
 Kearney, NE 68847
(308) 236-6867

Pilot Parents
1707 Polk
Lincoln, NE 68505
(308) 324-4428

Pilot Parents Program,
ARC-Capital
215 Centennial Mall S,
#410
Lincoln, NE 68505
(402) 463-5611

Down Syndrome
Parent to Parent
ARC of Essex County
7 Regent St
Livingston, NJ 07039
(201) 535-1181

Association for Children with
Russell-Silver Syndrome
22 Hoyt St
Madison, NJ 07940
(201) 377-4531

Parents Encouraging Parents,
ARC-Morris Chapter
PO Box 123
Morris Plains, NJ 07950
(201) 326-9750

NEW MEXICO
Parents Reaching Out,
Alamogordo
PO Box 3631, BRS-A
Alamogordo, NM 88311
(505) 437-9290

Parents of Preterm Infants
Network
Univ of New Mexico Hospital
Dept of Pediatrics
Albuquerque, NM 87131
(505) 277-3946
Parents for Behaviorally Different Children
1720 Louisiana NE, Ste 204
Albuquerque, NM 87110
(505) 285-0430

PRO Parent to Parent Network
1127 University NE
Albuquerque, NM 87102
(505) 842-9045

PRO Parent Support Network
4106 Winchester
Las Cruces, NM 88001
(505) 522-5669

NEW YORK
Parent-Friend: One to One
New York Easter Seal Society
845 Central Ave
Albany, NY 12206
(518) 436-8785

Newborn & Family Support Services Network
North Central Bronx Hosp
3424 Kosswath Ave
Bronx, NY 10467
(718) 519-4797

Headway for Brain Injured
856 Ridge Rd
Buffalo, NY 14141
(716) 822-2261

Prader-Willi Alliance of New York
40 Holly Ln
East Hills, NY 11577
(516) 621-2445

Levittown Hydrocephalus Support Group
Satellite Information Ctr
59 Market Ln
Levittown, NY 11756

Young Adult Institute
New York League for Early Learning
460 W 34th St
New York, NY 10001
(212) 563-7474

The Jewish Guild for the Blind
Downstate Resource Network
15 W 65th St
New York, NY 10023
(212) 793-6327

Parents of Special Children
PO Box 5357
Oswego, NY 13126
(315) 343-6480

Parent Assistance Committee on Down Syndrome
208 Lafayette Ave
Peekskill, NY 10566
(914) 739-4085

St Charles Early Intervention Program
501 Myrtle Ave
Port Jefferson, NY 11777
(516) 331-6400

Parents Available to Help
Special Care Nursery
Vassar Hospital
Poughkeepsie, NY 12601
(914) 454-4500

The Family Connection
Family Resource Center/WIHD
121-C Cedarwood Hall
Valhalla, NY 10595
(914) 265-1343

Parent to Parent
239 Champion Ave
Webster, NY 14580
(716) 265-3778

NEVADA
Nevada Specially Trained Effective Parents
6200 W Oakey
Las Vegas, NV 89102
(702) 870-7050

Nevada Parent Network
University of Nevada, Reno
REPC, College of Education/278
Reno, NV 89557-0082
(702) 784-4921

NORTH CAROLINA
Parent to Parent
Rt 2, Box 178-A
Angier, NC 27501
(919) 639-0172

Parents Reaching Out to Parents of Children with Special Needs
PO Box 638
Biscoe, NC 27209

Family Support Network of The High Country
Appalachian State Univ
Edwin Duncan Hall
Boone, NC 28608
(704) 262-6089

Parent Support Group
63 N Canton Rd
Canton, NC 28716
(704) 452-497

Family Support Network—Orange, Durham, Chatham Cty
UNC Chapel Hill
CB#7340, Chase Hall
Chapel Hill, NC 27599
(919) 966-2841

University of North Carolina Craniofacial Center
School of Dentistry
Chapel Hill, NC 27599-7450
(919) 966-2275

Family Support Network of North Carolina
CB# 7340
University of North Carolina
Chapel Hill, NC 27599
(919) 966-2841

Family Support Network of Metroolina
PO Box 35466
Charlotte, NC 28235
(704) 563-6111

Family Support of the Albermarle
1601 Forest Dr
Elizabethtown City, NC 27909
(919) 338-6987

Cape Fear Association of Parents Helping Parents
3403 Melrose Rd
Fayetteville, NC 28304
(919) 966-8430

Family Support Network
1623 N Webb St
Gastonia, NC 28052
(704) 854-4339

Family Support Network, Goldsboro
719 East Ash St
Goldsboro, NC 27530
(919) 580-0330

Family Support Network of Greater Greensboro
Womens Hospital of Greensboro
801 Green Valley Rd
Greensboro, NC 27408
(919) 574-6507

Family Support Network of Eastern North Carolina
Irions Bldg, ECU Campus
Greensboro, NC 27858
(919) 757-4494

Western Carolina Parents of EC Henderson County
PO Box 1454
Hendersonville, NC 28793
(704) 685-3336

Special Families Support Group
PO Box 35466
Hickory, NC 28602
(704) 326-5909

Family Support Network/Hope Network
4051 4th St NW
Hickory, NC 28601
(704) 328-9496

Tri Cty Local Unit/Autism Society of NC
Rt 2, Box 314
Hickory, NC 28601
(704) 256-5242

Family Support Network of Catawba Cty
2740 6th St NE
Hickory, NC 28601
(704) 327-4857

Parent Support Group
YMCA
112 Gatewood
High Point, NC 27262
(910) 882-4126

Family Support Network of Davidson Cty
36 Vance Cir
Lexington, NC 27292
(704) 246-4105

Parents Resource Organization
Rt 2, Box 430
Mocksville, NC 27028
(919) 598-3311

HOPE: Helping Other Parents Through Empathy
300 Enola Rd
Morganton, NC 28655
(704) 433-2877

Family Support Network of the Neuse Area
1405 S Glenburnie Rd
New Bern, NC 28562
(919) 633-0242

Parents Encouraging Parents
PO Box 1318
Pisgah Forest, NC 28768
(704) 884-5649

Family Support Network of Wake Cty
11304 Coachman’s Way
Raleigh, NC 27614
(919) 848-7383

Caring Parents
1506 Laurel St
Roanoke Rapids, NC 27870
(919) 535-5887

Parent Program
Rt 4, Box 1555E
Rutherfordton, NC 28478
(919) 966-2841

Tuberous Sclerosis Connection NC Tuberous Sclerosis Association
1005 Indianhead Cir
Snow Hill, NC 28580
(919) 747-8592

Family Support Network
Rt 11, Box 369A
Statesville, NC 28677
(704) 876-4821

Parent Support Group
257 Long Chapel Rd
Weaverville, NC 28787
(704) 645-3546

January 1994
Parent To Parent Programs

Celebrating Families of Children/Adults with Special Needs

16 Vassar Dr
Dayton, OH 45406
(513) 273-0990

Special Needs Information Ctr
PO Box 87
Girard, OH 44420
(216) 545-2837

Miami Valley Down Syndrome Association
1444 Beaver Creek Ln
Kettering, OH 45429-1240
(513) 949-9888

Families in Touch
Mental Health Assn of Licking Cty
65 Messimer Dr
Newark, OH 43055
(614) 522-1351

Family Information Network of NW Ohio
1 Stranahan Sq, #540
Toledo, OH 43604
(419) 242-9587

OKLAHOMA

Parents of Children with Down Syndrome
R 3, Box SA-65
Tuttle, OK 73089
(405) 680-7151

OREGON

Parent Network Program
ARC of Lane Cty
45 W Broadway, Ste 205
Eugene, OR 97401
(503) 343-5256

Caring Parents
2825 Barnett Road
Medford, OR 97504
(503) 773-6281

NICU Parent Support Group
Rogue Valley Medical Ctr
2825 Barnett Rd
Medford, OR 97504
(503) 770-4233

Parents Supporting Parents
6901 SW 8th Ave
Portland, OR 97219
(503) 244-6719

Parent to Parent Program, Tri Cty
718 W Burnside, #316
Portland, OR 97217
(503) 244-7729

Oregon COPE Project
999 Locust St NE
Salem, OR 97303-5299
(503) 373-7477

PENNSYLVANIA

Family Outreach
836 E 15th St
Chester, PA 19013
(215) 872-6313

Brain Injury Support Groups, Headed On
595 W State St
Dulles, PA 18901
(215) 345-2439

Parent Support Center
252 Waterford St
Edinboro, PA 16412
(814) 734-5610

Living Unlimited
UHRC
Penn State Univ
Elizabethtown, PA 17022
(717) 367-1116

Westmoreland Cty
Parent to Parent
1228 Brinkert Rd
Greensburg, PA 15601
(412) 832-1063

Down Syndrome Support Group
of Lancaster Cty
c/o S June Smith Ctr
23 N West End Ave
Lancaster, PA 17603
(717) 299-4289

Hemifacial Microsomia/Goldenhar Syndrome
Family Support Network
6 Country Lane Way
Philadelphia, PA 19115
(215) 677-4787

Intensive Caring Unlimited
910 Bent Ln
Philadelphia, PA 19118
(215) 233-4723

Parent Specialist Education Program
2350 W Westmoreland St
Philadelphia, PA 19140
(215) 229-4550

Parent to Parent
1001 Brighton Rd
Pittsburgh, PA 15233
(412) 322-6008

Parent to Parent
PO Box 322
Temple, PA 19560
(717) 321-2686

RHODE ISLAND

Parenting Programs
Parents Reaching Out
1 Simmons Road
Barrington, RI 02806
(401) 245-5241

Down Syndrome Society of Rhode Island
99 Bald Hill Rd
Cranston, RI 02920
(401) 463-5751

Parent Support Network
855 Waterman Ave, Ste D
East Providence, RI 02914
(401) 431-1240

Parent Training Program
Special Ed Program Services Unit
22 Hayes St
Providence, RI 02908
(401) 277-3505

Central Region Early Intervention
3445 Post Rd
PO Box 7789
Warwick, RI 02887-7789
(401) 739-2700

SOUTH CAROLINA

Parent to Parent Programs
Charles Webb Easter Seals Ctr
325 Calhoun
Charleston, SC 29401
(803) 722-7224

Family Connection of SC
2712 Middleburg Dr, Ste 103-B
Columbia, SC 29204
(803) 252-0914

National Information Clearinghouse for Infants with Disabilities
COD, Benson Bldg, 1st Fl
Columbia, SC 29208
(803) 922-9234

TENNESSEE

Project ECHO-ETSU Center for Early Childhood
PO Box 15, 520-A
Johnson City, TN 37614-0002
(615) 929-5662

Tennessee Infant-Parent Service for Hearing Impaired
2725 Island Home Blvd
Knoxville, TN 37920
(615) 579-2456

Parents and Post Op
801-TA teaberry Ln
Knoxville, TN 37919
(615) 691-2418

Whee Care
6019 Walnut Grove
Memphis, TN 38119
(901) 766-5023
Parent To Parent Programs
Parents of Special Children
PO Box 3196
Murfreesboro, TN 37133
(615) 849-1225

Parents Reaching Out
203 Burlington
Nashville, TN 37215
(615) 297-8129

TEXAS
Pilot Parents
2818 San Gabriel
Austin, TX 78705-3598
(512) 476-7044

Parent Care of Austin
1603 E 381/2 St

Austin, TX 78722
(512) 472-8351

Partners Resource Network
277 N 18th St #2
Beaumont, TX 77707
(409) 838-2366

Down Syndrome Guild
PO Box 821174
Dallas, TX 75382-1174
(214) 239-8771

Project KIDS
Dallas Ind. School District
12532 Nuestra
Dallas, TX 75130
(214) 490-8701

Tarrant Cty Society for Hearing
Impaired Infants & Youth
6416 Canyon Cir
Fort Worth, TX 76133
(817) 346-0421

Parent to Parent
3201 Ridgeview Ln
Irving, TX 75062
(214) 255-7815

Partners Resource Network
12602 Moss Hollow Ct
Live Oak, TX 78233
(512) 599-0719

Developmental Education
Birth to Two
1628 19th St
Lubbock, TX 79413
(806) 766-1172

Parent Case Management
Program
3001 S Jackson
San Angelo, TX 76904
(915) 949-9535

Craniofacial Anomaly Support
Association
3501 Oakhorne Dr
San Antonio, TX 78247
(512) 496-0270

Parent Help line
PO Box 7330, Station A
San Antonio, TX 78285
(512) 228-2222

38 Exceptional Parent

UTAH
Graduate ParentsPrimary
Children's Medical Ctr (NICU)
100 N Medical Dr
Salt Lake City, UT 84113-1100
(801) 588-3899

Parent to Parent
Univ of Utah Hospital
50 North Medical Dr, Rm 2553
Salt Lake City, UT 84132
(801) 581-2098

HOPEA Parent to Parent
Network
2290 E 4500 S, Ste 110
Sal; Lake City, UT 84117
(801) 272-1051

VERMONT
Vermont Interdisciplinary Team
for Intensive Special Ed
Center for DD/UAP
Univ of Vermont 499C
Waterman Bldg
Burlington, VT 05405-0160
(802) 656-4031

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(802) 649-3020

Parent to Parent of Vermont
1 Main St
69 Champlain Mill
Winooski, VT 05404
(802) 655-5290

VIRGINIA
Southwest Virginia
Parent to Parent
Developmental Services
Drawer II
Big Stone Gap, VA 24219
(703) 523-0682

Craniofacial Anomalies Clinic

Parent to Parent of
Southside Virginia

Parent to Parent,
Cowlitz/Wahkiakum Ctys

2008 Wakefield St
Petersburg, VA 23805
(804) 862-9940

The ARC of Cowlitz Valley
1129 Broadway
Longview, WA 98632
(206) 425-5494

Parent to Parent, Family and
Children's Service
1518 Willow Lawn Dr
Richmond, VA 23230
(804) 282-4255

Parent to Parent,
Roanoke Valley

Parent to Parent, Skagit Cty
PO Box 1833
Mount Vernon, WA 98273
(206) 757-7048

Parent to Parent Support Group

Parent to Parent, Island Cty

2110 Avenel Ave
Roanoke, VA 24015
(703) 774-3636

3597 350th Ave W
Oak Harbor, WA 98277
(206) 675-1409

Parents of Children with
Down Syndrome

Parent to Parent, Thurston Cty

451 Orchard St
Vienna, VA 22180
(703) 281-1211

WASHINGTON
Parent to Parent
c/o WCEL
1101 State St
Bellingham, WA 98225
(206) 671-3660

Parent to Parent, Kitsap Cty
The ARC of Kitsap Cty
3232 N Perry
Bremerton, WA 98310
(206) 377-3473

Parent to Parent, Lewis Cty
Infant/Toddler Development Ctr
156 NW Prindle
Chehalis, WA 98532
(206) 748-4359

Parent to Parent,
Whitman/Garfield/Asotin Ctys

Human Growth Foundation

The ARC Of Snohomish Cty
PO Box 602
Everett, WA 98206
(206) 258-2459

1251 Smith land Rd
Harrisonburg, VA 22801
(703) 433-5821

1703 E State St
Olympia, WA 98506
(206) 352-1126

Parent to Parent, Okanogan Cty

1452 Highland
Clarkston, WA 99430
(509) 758-9420

Harrisonburg-Rockingham
Parent to Parent

903 W 3rd
Moses Lake, WA 98837
(509) 765-3686

3020 Mansfield St
Roanoke, VA 24012
(703) 366-3551

UVA Medical Ctr
Box 376
Charlottesville, VA 22908
(804) 924-5801
7777 Leesburg Pike, Ste 202S
Falls Church, VA 22043
(800) 451-6434

Parent to Parent,
Grant/Adams/Lincoln Ctys

Parent to Parent, Snohomish Cty

Parent to Parent, Whatcom Cty
3778 Aldergrove Rd
Ferndale, WA 98248
(206) 366-3728

Twin Cty/Galax Parent to Parent

Parent to Parent,
Garys Harbor Cty

PO Box 931
Hillsville, VA 24343
(703) 236-2122

722 Queen Ave
Hoquiam, WA 98550
(206) 533-2187

PO Box 3051
Omak, WA 98841
(509) 826-0716

Parent to Parent, Ciallam Cty
2039 W 10th St
Port Angeles, WA 98362
(206) 457-1282

Parent to Parent
Support Program
1009 Georgiana St
Port Angeles, WA 98362
(206) 457-8355

Parent to Parent, Jefferson Cty
1435 Corona St
Port Townsend, WA 98368
(206) 385-7666

Parent to Parent,
Benton/Franklin Ctys
The ARC of Tri-Cities
767 Williams Blvd
Richland, WA 99352
(509) 943-2908

Parent to Parent Programs
State Office
The ARC-King Cty
10550 Lake City Way NE, Ste A
Seattle, WA 98125-7752
(206) 948-7322

Parent to Parent, King Cty
10550 Lake City Way NE, Ste A
Seattle, WA 98125-7752
(206) 364-4645

The Cleft Connection
CSHCN
Seattle-King County Health Dept
110 Prefontaine PI S, Ste 500
Seattle, WA 98104
(206) 296-4665

44
January 1994


Parent To Parent, Mason Cty
SE 290 Alpine Ave
Shelton, WA 98584
(206) 426-1005

Parent to Parent, Spokane Cty
The ARC of Spokane Cty
W 127 Boone Ave
Spokane, WA 99201
(509) 244-4499

Parent to Parent, Pierce Cty
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741

Parent to Parent, Clark Cty
The ARC of Clark Cty
PO Box 2608
Vancouver, WA 98668
(206) 254-1562

Parent to Parent, Walla Walla/Pacific Cty's
Dept of Human Services
PO Box 1595
Walla Walla, WA 99362
(509) 527-3278

Parent to Parent, Chelan/Douglas Cty's
PO Box 1
Wenatchee, WA 98807
(509) 782-4476

Parent to Parent, Yakima/Kittitas Cty's
603 S 18th Ave
Yakima, WA 98902
(509) 452-1382

WEST VIRGINIA

Autism Services Ctr
Pritchard Bldg, Ste 907
605 9th St
PO Box 507
Huntington, WV 25710-0507
(304) 525-8014

West Virginia Head Injury Fdn
PO Box 574
Institute, WV 25112-0574
(304) 766-4892

SW VIRGINIA

Parent to Parent, Mason Cty
SE 290 Alpine Ave
Shelton, WA 98584
(206) 426-1005

Parent to Parent, Spokane Cty
The ARC of Spokane Cty
W 127 Boone Ave
Spokane, WA 99201
(509) 244-4499

Parent to Parent, Pierce Cty
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741

Parent to Parent, Clark Cty
The ARC of Clark Cty
PO Box 2608
Vancouver, WA 98668
(206) 254-1562

Parent to Parent, Walla Walla/Pacific Cty's
Dept of Human Services
PO Box 1595
Walla Walla, WA 99362
(509) 527-3278

Parent to Parent, Chelan/Douglas Cty's
PO Box 1
Wenatchee, WA 98807
(509) 782-4476

Parent to Parent, Yakima/Kittitas Cty's
603 S 18th Ave
Yakima, WA 98902
(509) 452-1382

WISCONSIN

Pilot Parents
R 2, Box 434
Ashland, WI 54806
(715) 682-7171

Mothers United for Moral Support
150 Custer Ct
Green Bay, WI 54301
(414) 336-5333

D.E.A.F.
PO Box 23825
Green Bay, WI 54305-5825
(414) 437-7531

Wee-Life Parents
216A S Main St
PO Box 193
Lodi, WI 53555
(608) 592-4648

Brown County ARC
PO Box 12770
Green Bay, WI 54307-2770
(414) 498-2599

Cleft Lip and Palate Helpline
2808 E Newton Ave
Milwaukee, WI 53211
(414) 962-1053

Parent to Parent
ARC
818 6th St
Racine, WI 53403
(414) 634-6303

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FAX 310-539-3670
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You might be looking to give your children an edge in school. Or bring work home from the office. Or make the PTA newsletter look a little more professional.

The first step in finding the right computer is to ask a few simple questions.

**What do you really need in a computer?**

You can plunge into books thicker than the Peoria white pages to find the answer, immersing yourself in the megabytes and whosiwhatzits of computer terminology just to figure out your choices.

Or, you can look into a new kind of personal computer: Performa. The family Macintosh.

We started by putting everything together in one box, so you wouldn't have to figure out what components to buy. Plug the monitor into the computer, plug the power cord into the wall, and you're ready to go.

**What software do you need?**

The magic of a personal computer is that you can change what it does simply by changing the software.

You can turn the same computer from a powerful calculating tool into an artist's palette into an arcade game.

A Macintosh Performa arrives in your home with the most popular kinds of software already installed. So right out of the box, your family can do things like write a term paper, calculate the household budget, organize an entire scout troop or keep a mailing list of all your relatives. (Plug in an affordable Apple StyleWriter 11 or an affordable Apple LaserWriter printer, and all these projects take on the professional look of typeset documents.)

Of course, Performa also gives you the power to run thousands of other programs you can buy. If you use a computer at work, many of those same programs are available for the Macintosh Performa (from Lotus 1-2-3 to WordPerfect). And it lets your kids run many of the same software programs used in schools (more schools use Apple computers than any other brand).
Will everybody in the family be able to use it?

It doesn't matter how powerful a computer is if your family can't figure out how it works. Fortunately, Performa combines enough power to run a whole business with the practical simplicity of a Macintosh.

Performa even includes special software called At Ease™ that makes it easy for very young children to use.

Other computers may look simple in the store. But if you click the wrong button, you could find yourself staring at complex computer codes.

Are there any hidden costs?

Often, the base price of a computer doesn't include things you really need or want as soon as you get your computer home.

You may have to pay extra for basic things like sound and graphics. You may have to buy software separately. You may even have to pay extra for a keyboard, a mouse and a color monitor.

With Performa, all of these things are included for one affordable price. Every Performa model even includes a fax/modem.

Where can you get help if you need it?

Even with the easiest computer, you may have a few questions now and then. So every Performa includes unlimited toll-free telephone support. Better yet, should your Performa need service in the first year, we'll come to you.*

The built-in fax/modem even lets you send a fax directly from your desk to a fax machine (or connect, via telephone, to services like America Online and Prodigy).

The whole idea is to make owning a personal computer an incredibly satisfying experience. To find out how easy it can actually be, call us at 800-538-9696, ext. 215.

We'll give you the name and number of a Performa retailer near you. Then you'll discover the most important power a personal computer can bring your family. The power to be your best.

Performa

Apple

The Family Macintosh

* A computer should be easy to set up. So a Macintosh Performa requires no tools -- and even one of those.
Kennedy Krieger Institute
A comprehensive resource for children with disabilities

Call us to talk about your concerns. We can help.

(410) 550-9400/1-800-873-3377
707 North Broadway
Baltimore, MD 21205

Children’s Laughter is music to our ears.

Our dedicated staff at the Kennedy Krieger Institute is devoted to helping children and adolescents with physical, mental or educational disabilities. Through diagnosis, treatment and education, we can help find the key that unlocks the future for your child and your family.

Kennedy Krieger Institute, providing quality services for youngsters of any age with:

- Autism
- Technology Needs
- Motor and Language Delays
- Developmental Disabilities
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Other Special Needs

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD office.

Richard W. Fee
Executive Director
National Office
Suite 112, 3100 Arapahoe Avenue
Boulder, Colorado 80303
800-448-1071

Estate Planning for Persons with Disabilities
A Division of Protective Life Insurance Company

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- language development featuring the Hanen Program
- toys and games to train daily living skills

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(800) 828-1376

Circle #45
Circle #26
Circle #45
Circle #45
Circle #25
The Foundation for Technology Access (FTA) began in 1987 as a joint project of a grass-roots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer.

From a small group of parents, consumers and professionals, FTA has grown to become one of the nation's largest resources for helping adults and children with disabilities gain access to the benefits of adaptive technology.

FTA's most important means of promoting technology access may be its Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use.

Individual centers may also offer additional services. The following pages provide an up-to-date directory of ATA centers, with a description of the specific services offered by each.
<table>
<thead>
<tr>
<th>State</th>
<th>Program Name</th>
<th>Address</th>
<th>Phone Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAWAII</td>
<td>Aloha Special Technology Access Center</td>
<td>1750 Kalakaua Ave, #1008 Honolulu, HI 96826-3725</td>
<td>(808) 955-4464 (Voice/Fax) AppleLink: ALOHASTAC</td>
</tr>
<tr>
<td>ILLINOIS</td>
<td>Northern Illinois Center for Adaptive Technology</td>
<td>3615 Louisiana Rd Rockford, IL 61008-6195</td>
<td>(815) 229-2163 AppleLink: ICAT 1,2,3,4,5,8,9,10,12,14,16,17</td>
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<tr>
<td></td>
<td>Technical Aids &amp; Assistance for the Disabled Center</td>
<td>Vincennes, IN 47591-2764</td>
<td>(812) 882-3575 AppleLink: ATTIC 1,2,3,4,5,8,9,12,13,14,15,16,17</td>
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<tr>
<td></td>
<td>Adoption laws, curriculum adoption, parents on federal and state education</td>
<td>TUE 1950 W Roosevelt Road</td>
<td>(815) 229-2163 (FAX) AppleLink: TAAD 1,2,3,4,5,8,9,12,13,14,15,16,17</td>
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<tr>
<td>INDIANA</td>
<td>Assistive Technology Training and Information Center</td>
<td>3354 Pine Hill Dr PO Box 2441 Vincennes, IN 47591</td>
<td>(812) 886-0575 AppleLink: ATIC 1,2,3,4,5,8,9,12,13,14,15,16</td>
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<tr>
<td></td>
<td>Equipment, software and video loans</td>
<td>Bedford, IN 47421</td>
<td>(812) 823-3575 (FAX) AppleLink: AAC 1,2,3,4,5,8,9,12,13,14,15,16</td>
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<td></td>
<td>family support and advocacy</td>
<td>Bedford, IN 47421</td>
<td>(812) 886-0575 (FAX) AppleLink: AAC 1,2,3,4,5,8,9,12,13,14,15,16</td>
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<td>outreaching for training parents on federal and state educate</td>
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<td>12,14,15,16,17</td>
<td>Bedford, IN 47421</td>
<td>(812) 886-0575 (FAX) AppleLink: AAC 1,2,3,4,5,8,9,12,13,14,15,16</td>
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<td>Bedford, IN 47421</td>
<td>(812) 886-0575 (FAX) AppleLink: AAC 1,2,3,4,5,8,9,12,13,14,15,16</td>
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<tr>
<td>KANSAS</td>
<td>Technology Resources and Solutions for People</td>
<td>3023 Canterbury, Salina, KS 67401</td>
<td>(913) 827-0301 AppleLink: TRSP 1,2,3,4,5,8,9,10,11,12,14,16,17</td>
</tr>
<tr>
<td>KENTUCKY</td>
<td>Blue Grass Technology Center for People with Disabilities</td>
<td>169 N Limestone, Lexington, KY 40507</td>
<td>(606) 255-9951 AppleLink: BLUEGRASS 1,2,3,4,5,8,10,11,12,14,16,17</td>
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<td>1,2,3,4,5,8,9,12,13,14,15,16,17</td>
<td>Lexington, KY 40507</td>
<td>(606) 255-0059 AppleLink: BLUEGRASS 1,2,3,4,5,8,10,11,12,14,16,17</td>
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<tr>
<td></td>
<td>software lending library, classes, referral services, newsletter</td>
<td>Louisville, KY 40203-2257</td>
<td>(502) 574-1671 (FAX) AppleLink: DCCC 1,2,3,5,8,9,10,11,12,14,15,16</td>
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<tr>
<td>MARYLAND</td>
<td>Learning Independence</td>
<td>28 E Ostend St Ste 140 Baltimore, MD 21230</td>
<td>(410) 599-5462 AppleLink: LINC 1,2,3,4,5,8,9,10,12,14,16,17</td>
</tr>
<tr>
<td>MASSACHUSETTS</td>
<td>Massachusetts Special Technology Access Center</td>
<td>12 Mudge Way, 1-6 Bedford, MA 01730-2138</td>
<td>(617) 275-2446 AppleLink: MASTAC 1,2,3,5,6,8,10,11,12,13,16,17</td>
</tr>
<tr>
<td>MICHIGAN</td>
<td>Living &amp; Learning Resource Centre</td>
<td>601 W Maple St Lansing, MI 48906-5038</td>
<td>(800) 833-1996 (MI) (517) 487-0883 (517) 371-5898 (FAX) AppleLink: LLRCPIAM 1,2,3,4,8,9,12,14,16,17</td>
</tr>
<tr>
<td>MINNESOTA</td>
<td>PACER Center</td>
<td>4826 Chicago Ave S Minneapolis, MN 55417-1055</td>
<td>(612) 827-2966 (Voice/TDD) 612 827-3065 (FAX) AppleLink: PACER,CTR 1,2,3,4,5,8,9,10,12,13,14,15,16,17</td>
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<tr>
<td>MISSOURI</td>
<td>Technology Access Center</td>
<td>12110 Clayton Rd St Louis, MO 63131-2599</td>
<td>(800) 735-2466 (314) 569-8404/8100 (314) 993-5937 (314) 569-8400 (TDD) AppleLink: TACSTL 1,2,3,4,5,6,8,12,15,16,17</td>
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<tr>
<td>MONTANA</td>
<td>Parents, Let's Unite for Kids</td>
<td>1500 N 30th St Billings, MT 59101-0298</td>
<td>(406) 657-2055 (406) 657-2061 (FAX) AppleLink: PLUK 1,2,3,4,5,7,8,9,10,12,13,14,15,16,17,17, IEP support</td>
</tr>
<tr>
<td>NEW JERSEY</td>
<td>Computer Center for People with disabilities</td>
<td>9 Whippany Rd PO Box 272 Whippany, NJ 07981-0272</td>
<td>(201) 428-1455 AppleLink: CET 1,2,5,8,9,12,13,15,16,17</td>
</tr>
<tr>
<td>NEW YORK</td>
<td>Techspress Resource Center for Independent Living</td>
<td>409 Columbia St Utica, NY 13502</td>
<td>(315) 797-4642 (Voice/TDD) (315) 797-4747 (FAX) AppleLink: TECHSPRESS 1,2,3,4,5,7,8,9,10,11,12,13,14,15,16,17</td>
</tr>
<tr>
<td>NORTH CAROLINA</td>
<td>Carolina Computer Access Center</td>
<td>700 E Second St Charlotte, NC 28202-2880</td>
<td>(704) 342-3004 (Voice/FAX) AppleLink: CCAC 1,2,3,4,5,7,8,9,12,14,16,17</td>
</tr>
<tr>
<td>NORTH DAKOTA</td>
<td>Pathfinder Parent Training and Information Center</td>
<td>1600 2nd Ave SW Minot, ND 58701</td>
<td>(701) 852-9426/9436 (701) 838-9324 (FAX) AppleLink: PATHFINDER 1,2,4,5,7,8,14,15,17</td>
</tr>
</tbody>
</table>

**Key**

1. Hands-on computer demonstrations
2. Guided exploration and technical consultations
3. Technical assistance to employers
4. Equipment, software and video loans
5. Family support and advocacy
6. Computer camps
7. After-school programs
8. Public events and presentations
9. Minority and low-income outreach
10. Adapted toy programs
11. Toy library
12. Workshops
13. User groups
14. Early intervention services
15. Transition training for young adults
16. Technical support services
17. Final development

**January 1994**
Confidence, Independence, Success...

The Crotched Mountain Rehabilitation Center and School offers innovative academic, therapeutic, residential, and medical services designed to maximize the educational potential of physically and developmentally challenged children and young adults with:

- Head Injury
- Cerebral Palsy
- Spina Bifida
- Autism
- Down’s Syndrome
- Developmental, Behavioral, Emotional and Neurological Disorders
- Fetal Substance Exposure

The CMRC program includes:

- Fully Accredited Preparatory School Curriculum
- Modern Residential Group Homes
- Licensed Nursing Facility
- Day Students
- Total Communications Center
- Fully Adaptive and Accessible Sports Facility

CROTCHED MOUNTAIN
REHABILITATION CENTER INC

A subsidiary of the Crotched Mountain Foundation

51
Exceptional Parent 45
Empowering Individuals to Share Their God-given Gifts with the Community

St. John’s Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John’s Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

Services Provided

- Vocational Training
- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John’s Villa

For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future. Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages, inc.
A Model, Supportive Community For Mentally Retarded Adults

664EP School Street, Pembroke, MA 02359 (617) 293-5461

Anyone who has ever visited the Cardinal Cushing School and Training Center and Braintree St. Coletta Day School will no doubt express that the experience was inspirational. The two programs, operated by St. Coletta’s of Massachusetts, are reminders that miracles can happen when exceptional children are not treated as mentally disabled.

Established in 1947, St. Coletta’s has blossomed into two distinct schools with over 200 staff members. The philosophy of the organization is to provide an environment where developmentally-delayed children can develop their abilities in an atmosphere of confidence and joy. Today, the schools offer what may be the best educational programs available to exceptional children, consistently producing amazing results.

At the Braintree St. Coletta Day School, approximately 70 students ages 5-22, enjoy a staff ratio of 1-3 which enables instructors to provide a high degree of personal interaction. From occupational education and behavioral management - to the development of social and domestic skills - activities enable students to gain the highest possible degree of independence. A residential component is also available.

Exceptional Schools

Braintree St. Coletta Day School

Cardinal Cushing School and Training Center

St. Coletta’s of Massachusetts

John W. Shyne, Jr, President
(617) 826-6371
Hanover, MA

Located in Hanover, the Cardinal Cushing School and Training Center provides roughly 160 students with academic, vocational, and residential programs for all levels of developmentally-delayed children and young adults ages 6-22. With residential placement for 130 students - accommodating 30 day attendees - the programs guide students to a chosen career by instilling in them the academic, functional and social skills.

From culinary arts and hotel maintenance, horticulture, maintenance and more, students receive hands-on training. In addition, programs in theater and sporting, as well as the benefits of living alongside peers, further increase social development. After leaving the school, most students are able to find employment. In fact, a notable alumni is Chris Burke, star of the ABC TV series “Life Goes On,” introduced to performing arts through the school.

- Services Include -
  - Prader-Willi Program
  - Vocational Training
  - Independent Living Training
  - Adaptive Physical Therapy
  - Speech Therapy • Counseling
  - Community Skills • Summer Programs
  - Bi-Lingual (Spanish) Program

Exceptional Parent

January 1994
Berkshire Meadows - a place of “small miracles”

Hot water swirls and churns, limbs relax, movement eases. A child smiles. Soothed and buoyed by the bubbling warmth, he responds as his arms and legs are gently stretched, pushing against the flow of the water, relaxing back with it, each movement broader, smoother than the last.

Young bodies float in a broad expanse of bath-tub-warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex; laughter at splashes and water-antics; shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

The little boy described above does not wear a daytime brace to maintain his range of movement. Instead, once a week, he experiences the intense relaxation of the Hubbard tank. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more coordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young man in the therapeutic pool will also experience a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a movable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the children, when in the pool, to move in ways in which otherwise they cannot: if they cannot walk on land owing to poor strength or joint pain, they might be able to walk independently when in the water, or they might acquire real movement, instead of spasticity. Here, in the pool's supportive warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced - and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multi-faceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are developmentally delayed and multiply disabled. Nestled in the heart of the Berkshire Hills, the attractive and carefully-designed campus also houses several cheerful residences and a Learning Center equipped with state-of-the-art teaching aids. The program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of pre-cognitive, cognitive, pre-vocational and independent living skills. There is an open-door visiting policy, with each client’s family encouraged to participate in all aspects of their child’s program.

At Berkshire Meadows we believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Ms. Gail Charpentier, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

Circle #6
Special Care for Special People
Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 600-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure

THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601

Circle #77  John P. Stewart, M.D., Resident Physician

Our software can help your special child!
Laureate’s award-winning software is designed by clinical experts to meet the unique needs of special infants and children. Our FREE book, Sequential Software for Language Intervention, tells how Laureate’s talking programs can help your child build critical language and cognitive skills.

Call today for your FREE copy of Sequential Software for Language Intervention.

Call for a FREE catalog, book, and video.
1-800-562-6801

Laureate
110 East Spring Street
Winooski, VT 05404
1-802-655-4755

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We Have It In Abundance

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Ninety Years
St. Coletta School
W4955 Highway 18
Jefferson, Wisconsin 53549

Circle #74

Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta’s, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Coletta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills, personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.
State Assistive Technology Programs

ALABAMA
Alabama Department of Education
Division of Rehabilitation Services
2129 East South Blvd
Montgomery, AL 36111
(205) 281-8780

ALASKA
Assistive Technologies of Alaska
400 D St, Ste 230
Anchorage, AK 99501
(907) 274-0138 (Voice/TDD)
(800) 770-0138 (Voice/TDD)
(907) 274-1399 (FAX)

ARKANSAS
Arkansas Increasing Capabilities Access Network
2201 Brookwood, Ste 117
Little Rock, AR 72202
(501) 666-8900 (Voice/TDD)
(501) 666-8901 (Voice/TDD)
(501) 666-8902 (Voice/TDD)
(501) 666-8903 (FAX)

CALIFORNIA
Independent Living Division
California Dept of Rehabilitation
830 K St Mall, 2nd Fl
Sacramento, CA 95814
(916) 324-3055

COLORADO
Colorado Assistive Technology Project
Rocky Mountain Resource and Training Institute
6355 Ward Rd, Ste 310
Arvada, CO 80004
(303) 422-2942 (Voice/TDD)
(303) 420-8675 (FAX)

CONNECTICUT
Connecticut Assistive Technology Project
Bureau of Rehabilitation Services
10 Griffin Rd N
Windsor, CT 06095
(203) 288-2042
(203) 288-9590 (FAX)

DELAWARE
Delaware Assistive Technology Initiative
Applied Science and Engineering Laboratories
University of Delaware
A.I. duPont Institute
1600 Rockland Rd, Rm 154
Wilmington, DE 19899
(302) 651-6790
(302) 651-6794 (TDD)
(302) 651-6793 (FAX)

DISTRICT OF COLUMBIA
RESNA Technical Assistance Project
1101 Connecticut Ave NW, Ste 700
Washington, DC 20036
(202) 851-7140 (Voice/TDD)
(202) 223-4579 (FAX)

IDAHO
Idaho Assistive Technology Project
123 W Third St
Moscow, ID 83843
(208) 885-9429
(208) 885-6849
(208) 885-9056 (FAX)

ILLINOIS
Illinois Assistive Technology Project
110 ILES Park Pl
Springfield, IL 62718
(800) 852-5110 (In state only—Voice/TDD)
(217) 522-7985 (Voice/TDD)
(217) 522-8067 (FAX)

INDIANA
Indiana Attain (Accessing Technology Through Awareness in Indiana) Project
Indiana Family and Social Services Admin
Division of Aging and Rehabilitation Services
402 W Washington St, Rm W453
PO Box 7083
Indianapolis, IN 46207-7083
(800) 545-7763
(812) 855-9396
(812) 855-9630 (FAX)

IOWA
Iowa Program For Assistive Technology
Iowa Univ Affiliated Program
Univ Hospital School
Iowa City, IA 52242
(603) 331-3027
(319) 353-6386
(319) 356-8284 (FAX)

GEORGIA
Georgia Tools For Life
Division of Rehabilitation Services
2 Peachtree St NW, Ste 23-411
Atlanta, GA 30303
(800) 767-9119
(404) 594-4960
(404) 677-3084
(404) 677-3085 (TDD)
(404) 677-3086 (FAX)

HAWAII
Hawaii Assistive Technology System
677 Ala Moana Blvd, Ste 403
Honolulu, HI 96813
(808) 532-7110 (Voice/TDD)
(808) 532-7120 (FAX)

The following programs are administered by the National Institute on Disability and Rehabilitation Research. They offer a wide range of information on assistive technology devices and services. This list was provided by the RESNA Technical Assistance Project, a federally funded project which provides consultation and information to state programs and the general public. For more information, contact the RESNA Technical Assistance Project, 1101 Connecticut Avenue, NW, Washington, DC 20036, (202) 851-1140.
## State Assistive Technology Programs

<table>
<thead>
<tr>
<th>State</th>
<th>Name</th>
<th>Address</th>
<th>Phone Numbers</th>
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<tr>
<td><strong>KANSAS</strong></td>
<td>Life Span Institute</td>
<td>PO Box 738, Parsons, KS 67357</td>
<td>(316) 421-6550 Ext 1890/1854</td>
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<td></td>
<td>KENTUCKY Kentucky Assistive Technology Services Network</td>
<td>Coordinating Center, 427 Versailles Rd, Frankfort, KY 40601</td>
<td>(502) 564-4665 (Voice/TDD) (502) 564-3976 (FAX)</td>
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<tr>
<td><strong>LOUISIANA</strong></td>
<td>Louisiana Technology Assistance Network</td>
<td>PO Box 3455, Baton Rouge, LA 70821-3455</td>
<td>(504) 342-4419 (FAX) (504) 342-2471 (Voice/TDD) (504) 342-4419 (FAX)</td>
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<tr>
<td><strong>MAINE</strong></td>
<td>Maine Consumer Information and Technology</td>
<td>Training Exchange (Maine CITE) Coordinating Center, Univ of Maine at Augusta</td>
<td>University Heights, Augusta, ME 04330 (207) 621-3195 (Voice/TDD) (207) 621-3193 (FAX)</td>
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<tr>
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<td>Maryland Technology Assistance Program</td>
<td>Governor’s Office for Handicapped Individuals, 300 W Lexington St, Box 10</td>
<td>Baltimore, MD 21201 (800) 836-4827 (410) 333-4975 (FAX) (410) 333-6674 (FAX)</td>
</tr>
<tr>
<td><strong>MASSACHUSETTS</strong></td>
<td>Massachusetts Assistive Technology Partnership Ctr</td>
<td>Children’s Hospital, 300 Longwood Ave, Boston, MA 02115</td>
<td>(617) 727-5540 (617) 735-9743 (TDD) (617) 735-7820 (617) 235-6854 (TDD) (617) 727-5540 (FAX)</td>
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<td><strong>MICHIGAN</strong></td>
<td>Michigan Assistive Technology Project</td>
<td>Michigan Dept of Education Rehabilitation Services, PO Box 30010, Lansing, MI 48909</td>
<td>(517) 373-4056 (517) 373-4058 (FAX)</td>
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<td><strong>MINNESOTA</strong></td>
<td>Minnesota Star Program</td>
<td>667 Cedar St, St. Paul, MN 55155</td>
<td>(800) 331-3027 (612) 297-1554 (612) 296-9962 (TDD) (612) 297-7200 (FAX)</td>
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<td><strong>MISSISSIPPI</strong></td>
<td>Mississippi Project Start</td>
<td>300 Capers Ave, Bldg 3, Jackson, MS 39215-1698</td>
<td>(601) 354-6891 (Voice/TDD) (601) 354-6080 (FAX)</td>
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<td><strong>MISSOURI</strong></td>
<td>Missouri Assistive Technology Project</td>
<td>Univ of Missouri-Kansas City, Rm 177 EDUC, 5100 Rockhill Rd, Kansas City, MO 64110-2499</td>
<td>(816) 235-5342 (816) 235-5339 (800) 647-8558 (TDD) (816) 235-5270 (FAX)</td>
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<td>MonTech</td>
<td>The Univ of Montana MUARID, MonTech, 634 Eddy Ave, Missoula, MT 59812</td>
<td>(406) 243-5676 (406) 243-2349 (FAX)</td>
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<td><strong>NEBRASKA</strong></td>
<td>Nebraska Assistive Technology Project</td>
<td>301 Centennial Mall S, PO Box 94987, Lincoln, NE 68509-4987</td>
<td>(402) 471-0734 (402) 471-3647 (Voice/TDD) (402) 471-0117 (FAX)</td>
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<td><strong>NEVADA</strong></td>
<td>Nevada Assistive Technology Project</td>
<td>Rehabilitation Division, Community-Based Services Dept, 711 S Stewart St, Carson, NV 89710</td>
<td>(702) 687-4452 (702) 687-3388 (TDD) (702) 687-3292 (FAX)</td>
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<td><strong>NEW HAMPSHIRE</strong></td>
<td>New Hampshire Technology Partnership Project</td>
<td>Institute on Disability, Ten Ferry St, Concord, NH 03301</td>
<td>(603) 224-0630 (Voice/TDD) (603) 228-3270 (FAX)</td>
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<td><strong>NEW JERSEY</strong></td>
<td>New Jersey Technology Assistance Resource Program</td>
<td>Labor Building, Room 806, CN 938, Trenton, NJ 08625.</td>
<td>(609) 292-7496 (609) 292-7556 (609) 292-4616 (FAX)</td>
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<td><strong>NEW MEXICO</strong></td>
<td>New Mexico Technology Assistance Program</td>
<td>435 St. Michael’s Dr, Bldg D, Santa Fe, NM 87503</td>
<td>(800) 866-2253 (Voice/TDD) (505) 827-3532 (Voice/TDD) (505) 827-3746 (FAX)</td>
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<td><strong>NEW YORK</strong></td>
<td>New York State Triad Project</td>
<td>Office of Advocate for the Disabled One Empire State Plaza, Tenth Fl Albany, NY 12223-0001</td>
<td>(518) 474-2825 (518) 473-4231 (TDD) (518) 473-6005 (FAX)</td>
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<td><strong>PENNSYLVANIA</strong></td>
<td>Pennsylvania’s Initiative on Assistive Technology</td>
<td>Institute on Disability/UAAP, Pitcrt Hall Annex 433 (004-00) Philadelphia, PA 19122</td>
<td>(215) 204-1356 (800) 204-7428 (Voice/TDD) (215) 204-6336 (FAX)</td>
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<td><strong>PUERTO RICO</strong></td>
<td>Project Director</td>
<td>University of Puerto Rico Station, Rio Piedras, PR 00931</td>
<td>(809) 754-8926</td>
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<td><strong>RHODE ISLAND</strong></td>
<td>Office of Rehabilitation Services</td>
<td>40 Fountain St, Providence, RI 02903</td>
<td>(401) 421-7005</td>
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<tr>
<td><strong>SAMOA</strong></td>
<td>American Samoa Division of Vocational Rehabilitation</td>
<td>Dept of Human Resources Pago Pago, American Samoa, 96799</td>
<td>(684) 633-2336 (684) 633-7183</td>
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<tr>
<td><strong>SAMOA</strong></td>
<td>American Samoa Division of Vocational Rehabilitation</td>
<td>Dept of Human Resources Pago Pago, American Samoa, 96799</td>
<td>(684) 633-2336 (684) 633-7183</td>
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</table>
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South Carolina Assistive Technology Program
Vocational Rehabilitation Dept
PO Box 15
1410-C Boston Ave
West Columbia, SC 29171-0015
(803) 822-5404 (Voice/TDD)
(803) 822-4301 (FAX)

SOUTH DAKOTA
Dakota Link
1925 Plaza Blvd
Rapid City, SD 57702
(800) 645-0673 (Voice/TDD)
(605) 394-1876
(605) 394-5315 (FAX)

TENNESSEE
Tennessee Technology Access Project
Office of Assistive Technology—Central Office
Doctor’s Bldg, Ste 300
706 Church St.
Nashville, TN 37243-0675
(800) 732-5059 (in TN)
(615) 741-7441
(615) 741-0770 (FAX)

TEXAS
Texas Assistive Technology Project
The University of Texas at Austin
UAP of Texas
Dept of Special Education, EDB 306
Austin, TX 78712
(512) 471-7621

UTAH
Utah Assistive Technology Program
Ctr for Persons with Disabilities UMC 6855
Logan, UT 84322
(800) 333-8824
(801) 750-1982
(801) 750-2355 (FAX)

VERMONT
Vermont Assistive Technology Project
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Waterbury, VT 05671-2305
(802) 241-2620 (Voice/TDD)
(802) 241-3052 (FAX)

VIRGINIA
Virginia Assistive Technology System
4900 Fitzhugh Ave
Richmond, VA 23230
(804) 367-2442
(804) 367-2445 (Voice/TDD)
(804) 367-2440 (FAX)

WASHINGTON
DSHS/DVR
PO Box 45340
Olympia, WA 98504-5340
(206) 438-8049

WEST VIRGINIA
West Virginia Assistive Technology System
Division of Rehabilitation Services
Capital Complex
Charleston, WV 25305-0890
(800) 841-8436
(304) 766-4698
(304) 293-7294 (FAX)

WISCONSIN
Division of Vocational Rehabilitation
PO Box 7852
1 W Wilson St, Rm 950
Madison, WI 53707-7852
(608) 266-5395
(608) 267-6720
(608) 266-9599 (TDD)

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National Institutes of Health
US Dept of Health and Human Services
9000 Rockville Pike
Bldg 31, Rm 8A-16
Bethesda, MD 20892
(800) 352-9424
(301) 496-5751

Social Security Administration
6401 Security Blvd
Baltimore, MD 21235
(800) 772-1213 (Voice Hotline)
(800) 325-0778 (TDD Hotline)
(410) 965-7700 (Voice)
(410) 965-0695 (FAX)

Office of Special Education and Rehabilitative Services
US Office of Education
Switzer Bldg
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Centers for Disease Control National AIDS Clearinghouse
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Rockville, MD 20849-6003
(301) 458-5231
(301) 342-2437 (English hotline)
(301) 344-7432 (Spanish hotline)
(301) 243-7012 (TDD)
(301) 738-6616 (FAX)

National Institute of Allergy and Infectious Diseases
Office of Communications
Bldg 31, Rm 7A50
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5717
(301) 402-0120 (FAX)

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
PO Box AMS
9000 Rockville Pike
Bethesda, MD 20892
(301) 495-4484
(301) 587-4352 (FAX)

Cancer Information Service
National Institutes of Health
Office of Cancer Communications
Bldg 31, Rm 10A16
9000 Rockville Pike
Bethesda, MD 20892
(800) 422-6237

National Information Center for Children and Youth With Disabilities
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Washington, DC 20013
(202) 416-0300 (Voice/TDD)
(202) 416-0312 (FAX)

National Institute on Deafness and other Communication Disorders Information Clearinghouse
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(800) 241-1044 (Voice)
(800) 241-1055 (TDD)
(301) 565-4020
(301) 402-0018 (FAX)

National Diabetes Information Clearinghouse
PO Box NDIC
9000 Rockville Pike
Bethesda, MD 20892
(301) 488-2162
(301) 907-8906 (FAX)

National Digestive Diseases Information Clearinghouse
PO Box NDDIC
9000 Rockville Pike
Bethesda, MD 20892
(301) 468-6344
(301) 907-8906 (FAX)

ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children
1920 Association Dr
Reston, VA 22091
(800) 328-0272
(703) 205-8241 (Voice/TDD)
(703) 205-9252 (FAX)

Clearinghouse on Disability Information
Office of Special Education and Rehabilitative Services
Dept of Education
330 C St SW
Switzer Bldg, Rm 3132
Washington, DC 20202-2524
(202) 205-8241 (Voice/TDD)
(202) 205-9252 (FAX)

Educational Resources Information Center (ERIC)
Central ERIC
U.S. Dept of Education
Washington, DC 20208
(202) 219-2289
(202) 219-1817 (FAX)

National Clearinghouse on Family Support and Children's Mental Health
Portland State Univ
PO Box 751
Portland, OR 97207-0751
(800) 628-1696
(503) 725-4165 (TDD)
(503) 725-4180 (FAX)

National Health Information Ctr
National Institutes of Health
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797

National Heart, Lung, and Blood Institute
Education Programs Info Ctr
PO Box 30105
Bethesda, MD 20824-0105
(301) 251-1222
(301) 251-1223 (FAX)

National Information Clearinghouse for Infants with Disabilities and Life-threatening Conditions
Univ of South Carolina
Benson Bldg
Columbia, SC 29208
(800) 922-9234 ext. 201
(803) 777-6058 (FAX)

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Washington, DC 20207
(301) 504-0424
(301) 304-0124 (FAX)

National Kidney and Urologic Diseases Information Clearinghouse
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9000 Rockville Pike
Bethesda, Md 20892
(301) 468-6345
(301) 907-8906 (FAX)

National Maternal and Child Health Clearinghouse
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McLean, VA 22102
(703) 821-8955 ext 254, 265
(703) 821-2098 (FAX)

National Institute of Mental Health
5600 Fishers Ln, Rm 15C05
Rockville, MD 20857
(301) 443-4513

Minority Health Resource Center
PO Box 37337
Washington, DC 20013-7337
(800) 444-6472
(301) 565-5112 (FAX)
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National Information Center for Orphan Drugs and Rare Diseases
Office of Orphan Products Development
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Washington, DC 20013-1133
(301) 443-2043
(800) 300-7469
(301) 443-4915 (FAX)

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HEALTH Resource Ctr
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284
(202) 939-9320 (Voice/TDD)

National Rehabilitation Information Clearinghouse
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(800) 346-2742 (Voice/TDD)
(301) 588-9284 (Voice/TDD)
(301) 587-1967 (FAX)

National Sudden Infant Death Syndrome Resource Ctr
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955
(703) 821-2098 (FAX)

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2 Annabelle Ln  
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(201) 966-6894 (FAX)  
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Special Health Systems
90 Englehard Dr
Aurora, ON
Canada L4G 3V2
(905) 841-1032
(905) 841-6162 (FAX)
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STANDING EQUIPMENT

Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353 (FAX)
(414) 459-9070 (FAX)
For free information circle 110 on
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J. A. Preston Corp
PO Box 89
Jackson, MI 49204-0089
(800) 631-7277
(800) 245-3765 (FAX)
For free information circle 44 on
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Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(410) 550-8217 (FAX)
(410) 550-9000
Baltimore, MD 21205

Mulholland Positioning Systems
PO Box 391
Santa Paula, CA 93060
(805) 525-7165
For free information circle 52 on
Reply Card.

Ortho-Kinetics Inc
W220 N507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (FAX)
For free information circle 100 on
Reply Card.

Prime Engineering
4838 W Jacqueyln #105
Fresno, CA 93722
(209) 276-0991
(209) 276-3544 (FAX)
For free information circle 62 on
Reply Card.

Quickie Designs
2842 Business Park Ave
Fresno, CA 93727-1328
(559) 456-8916
For free information circle 93 on
Reply Card.

Rifton Equipment
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8065 (FAX)
See our ad on page 63.

Special Design
PO Box 130
Gillette, NJ 07933
(908) 484-8825
See our ad on page 7.

TOYS AND HOBBIES

D. Brady & Associates
PO Box 487 EP
Flourtown, PA 19031
(215) 247-1588
(215) 247-4121 (FAX)
For free information circle 5 on
Reply Card.

Innovative Products Inc
830 South 48th St
Grand Forks, ND 58201
(800) 950-5185
(701) 772-5264 (FAX)
See our ads on pages 27, 56.

PI Bear Co Inc
821 Main
PO Box 189
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (FAX)
See our ad on page 65.

TRICYCLES

Triald Inc
3 Commercial Dr
Cumberland, MD 21502
(301) 759-3525
See our ad on page 72

View Point Manufacturing
PO Box 108
Spanish Fork, UT 84660
(801) 798-0181
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VANS/ VAN CONVERSION

Action Mobility
1925 10th Ave N
Lake Worth, FL 33461
(407) 582-6500
(800) 432-1459 (FL only)
For free information circle 32 on
Reply Card.

Advanced Conversions
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Fort Worth, TX 76111
(817) 834-1003
For free information circle 117 on
Reply Card.

Arcola Mobility
51 Kero Rd
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(619) 507-8500
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Reply Card.

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1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(719) 946-4670 (FAX)
For free information circle 115 on
Reply Card.

Chrysler P-Cap Resource
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(800) 255-9877
(313) 597-3501 (FAX)
For free information circle 90 on
Reply Card.

Crow River Industries Inc
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688
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Reply Card.

Drive Master Inc
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709

DuraMed Driving Systems Inc
1543 15th St
Augusta, GA 30901
(800) 637-1378

Ford Mobility Motoring Program
PO Box 529
Bloomfield Hills, MI 48303-9857
(800) 952-2249
See our ad on the inside front
cover.

Forward Motions Inc
214 Valley St
Dayton, OH 45404
(513) 222-5001

General Motors
Mobility Program
3044 W Grand Blvd
Detroit, MI 48202
(800) 323-9395
For free information circle 32 on
Reply Card.

S. D. Enterprises
28936 Phillips St
Elkhart, IN 46514
(800) 373-3661
(219) 282-3324 (FAX)
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2441 E. Chambers
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(602) 243-2700
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(313) 340-5000
(313) 340-5025 (FAX)
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Waltham, MA 02254
(617) 894-0069
Consumer Care Products Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (FAX)
For free information circle 109 on Reply Card.

Convaid Products Inc
PO Box 2458
Rancho Palos Verdes, CA 90274
(310) 539-6814
(310) 539-3670 (FAX)
See our ad on page 39.

Damaco
20542 Plummer St
Chatsworth, CA 91307
(800) 432-2434
For free information circle 133 on Reply Card.

Dowd Rental
100 Main St
Buffalo, NY 14202
(716) 883-8188
Eagle Sportschairs
2351 Parkwood Rd
Snellville, GA 30278
(404) 972-0763
(404) 985-4885 (FAX)
For free information circle 21 on Reply Card.

Electric Mobility
1 Mobility Plz
Sewell, MO 63002
(314) 995-7058
For free information circle 148 on Reply Card.

Everest & Jennings
1100 Corporate Square
St. Louis, MO 63132
(314) 995-7058
For free information circle 148 on Reply Card.

Invacare
899 Cleveland St
Elyria, OH 44036
(216) 329-6696
For free information circle 143 on Reply Card.

Kushall of America
708 Via Alondra
Camarillo, CA 93012
(800) 654-4768
For free information circle 47 on Reply Card.

Mulholland Positioning Systems
PO Box 391
Santa Paula, CA 93060
(805) 525-7165
For free information circle 96 on Reply Card.

Permobil Inc
68 Gill St
Woburn, MA 01801
(617) 932-9009
(617) 932-0428 (FAX)
For free information circle 96 on Reply Card.

Quickie Designs
2842 Business Park Ave
Fresno, CA 93727-1328
(800) 456-8168
For free information circle 92 on Reply Card.

Rehabco
1513 Olmstead Ave
Bronx, NY 14202
(718) 829-3800
Snug Seat
1081 Independence
Matthews, NC 28106
(704) 847-0772
See our ad on page 10.

Stroller-Pack
134 N Franklin St
Juneau, AK 99801
(800) 487-9652
(907) 463-4981 (FAX)
See our ad on page 51.

WHEELCHAIRS/SCOOTERS
Amigo Mobility
6693 Dixie Hwy
Bridgeport, MI 48722
(800) 248-9130
For free information circle 144 on Reply Card.

Bruno Independent
Living Aids Inc
1780 Executive Dr
PO Box 84
Oconomowoc, WI 53066
(800) 887-8183
(414) 567-4341 (FAX)
See our ad on page 30.

ALL OTHER SERVICES
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Database of Assistive Technology
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(301) 588-9284
(301) 587-1967 (FAX)
For free information circle 91 on Reply Card.

Cumberland Hospital for Children and Adolescents
PO Box 150
New Kent, VA 23124
(800) 368-3472
(804) 966-5639 (FAX)
See our ad on page 24.

Global Export Marketing (GEM)
International Marketing
2 Annabelle Ln
Florham Park, NJ 07932
(201) 966-0220
(201) 966-6894 (FAX)
See our ad on page 30.

LINC HiBBS
c/o Parents Helping Parents
Electronic Bulletin Board
535 Race St, #140
San Jose, CA 95126
(408) 294-6933 (BBS)
(408) 288-5010 (Voice)
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Enteral Nutritional Products - Pediatrics & Adults
625 Cleveland Ave
Columbus, OH 43226
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PO Box 9506
Rancho Santa Fe, CA 92067
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Crib's & Youth Beds
HARD Manufacturing Co., Inc
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The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

Grocery Services
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PO Box 9001
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Columbus, OH 43235
(800) 242-2460
ATTENDs YOUTH BRIEFs. Filt children $55-$515.00 (90), Free Delivery. Mention this ad to receive a free tub of Attends Disposable Washcloths ($8.25 value) with your first order! We also carry Depend, Serenity, other items. Call for our Free Catalog!

Care Containment Products
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(402) 494-1744
We carry a full-line of reusable diapers and pull over plastic pants. Available in all sizes. Write for more information and FREE brochure.

Quality Care Incontience Products
PO Box 762
Woodstock, MD 21163
(800) 494-4984
Diapers/ Briefs up to 48" waist; Training Pants to 42" Overnight Pants 20"-44"; Bed Pads; Flushable Liners. Prints available!

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901 1/2 Main St
Hopkins, MN 55343
(612) 933-8231
TOP DRAWERS offers waterproof products for girls and boys of all ages and adults. 100% cotton diapers and bright colorful nylon covers are washable and reusable. Discreet home delivery. Free catalog available. Please call for more information.

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(408) 288-5010 Voice
Electronic bulletin board housing hundreds of resources for families and professionals caring for children with special needs. Resource directory, file database, Internet mail and more! No on-line charges. Settings: N-S, I, up to 14,400 baud, 24 hours.

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Transfer-Belt padded four handled, makes transfer much easier. Gummy chair wheelchair transforms into a car seat, allows tooting thru seat.

Software
GW Micro
310 Ridget St
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Call (219) 483-3625.
People that are blind, visually impaired, hearing impaired and other disabilities can benefit from GW Micro's Vocal-Eyes, Sounding Board and other products providing voice output on your PC computer.

Microsystems Software
600 Worcester Rd
Framingham, MA 01701
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HandWARE enables and improves access to PCs for the mobility-impaired, speech-impaired and hearing-impaired. Works with all-off-the-shelf programs, generic switches and industry-standard speech synthesizers. $26.25.

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(508) 879-9000
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KID-KART
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Belgrade, MT 59714
(800) 388-5278
The Kid-E-Plus is a lightweight primary use chair sturdy enough to enable outdoor mobility. The Kid-E-Plus Modular Positioning System will accommodate special children within the full spectrum of severity, adjustable to allow growth. Two mobility bases available. Kid-Kart also makes custom positioning systems.

Van Conversion Dealers
Connecticut
Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River, Ricon, ICS, EZ Lock, and EMC touch pad systems. 31 yrs. of service to the disabled community. Please call for more information.

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(800) 432-1459 in FL
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B & R Mobility Services Inc
914 E Skyway Ave
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(813) 933-5452
Complete mobility equipment dealer. NMEDA Quality Assurance Program. Charter member with 5 star rating. Call for information.

Georgia
DuraMed Driving Systems Inc
1543 15th St
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(912) 894-0069
Custom driving systems, wheelchair lifts, elevators, van conversions. IMS, Mobile Tech. Crow River, Ricon, EMC, MPO, EZ Lock, NMEDA & MED group.

Indiana
Alternative Mobility
28244 Ciley St
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(219) 293-0367
Van and auto modifications, lift, tie down, raise roof, lowered floors, driving aids. NMEDA Members. Please call for more information.

Forward Motions Inc
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Full-size Mini-Van modifications, new used lift, drop floor, raised roof, lock down, driving equip. NMEDA member. Owned by person with a disability.

Kentucky
Forward Motions Inc
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(513) 222-5001
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New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Burma, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

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New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Burma, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.
**Books for Parents & Professionals**

**WALKABOUT** "A story of ABILITIES:" the potential of your child. Reggie proves he is not a "forever child" with a 1,300 mile hike around WA State: $15 ppd. **Balance Pubs.,** P.O. Box 447-X, P.O. Box 1081, Stevens Point, WI 54481.

**BORN THIS WAY:** An inspirational story about a man battling Cerebral Palsy. Copies available for $5.95. Write to **Don Zivney,** 1600 Sherman Ave., Apt. 110, Stevens Point, WI 54481.

**Turtle Books** provide a bridge of understanding for your children with disabilities, their siblings & friends. Send for a FREE Turtle Book brochure to **Jason & Nordic Publishers,** P.O. Box 411 Houlkayburg, PA 61718 or FAX (814) 696-4250.

**Handicapped In Walt Disney World®** is the complete access guide for children or adults with disabilities. Peter Smith, the author, is a paraplegic. 302 ppgs. $13.95 (8.5 x 11 incl.). **Southpark Publishing Group, Inc.,** P.O. Box 4111, Dept. EP, Charlottesville, VA 22904. Ages 7-up $14.95. Ages 7-up $21.95. Includes workbook & audio cassette. **Callirobics,** P.O. Box 6534, Dept. EP, Charlottesville, VA 22906. (800) 769-2891.

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**Interax Video Sign Language Course.** Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure, $199 (+$4.50 s/h). **Interax Training, Inc.,** P.O. Box 473106, Garland, TX 75047-3106. (800) 242-5583.

**Videotapes**

**Free Book Catalog:** The 1993 Special Needs Catalog features a collection of valuable books for children with disabilities and their parents on Down Syndrome, CP, autism, spec. ed. and more. Please contact **Woodbine House,** 615 Fishers Ln., Rockville, MD 20852, (800) 843-7323.

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**Barrier Free Systems Inc** 165 Freeman's Bridge Rd Scotia, NY 12302 (518) 346-4169 We sell and install equipment in the aid of transportation for the physically challenged. For more information, give us a call! **Drive-Master Inc** 9 Spielman Rd Fairfield, NJ 07004 (201) 808-9709 Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech, Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

**Pennsylvania**
**Drive-Master Inc** 9 Spielman Rd Fairfield, NJ 07004 (201) 808-9709 Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech, Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information.

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ATTENTION DEFICIT DISORDER

ATTENTION DEFICIT DISORDER
ADHD AND ADD SYNDROMES
(Second Edition)
by Dale R. Jordan
(PE038) Book $14.00
(PE038) Videotape (50 minutes, 1/2" VHS) $98.00
This book describes how attention deficit-hyperactivity disorder (ADHD) and attention deficit disorder without hyperactivity (ADD) interfere with classroom learning, behavior at home, job performance and social skills development, and it gives guidelines for working successfully with ADHD and ADD in children, adolescents, and adults. Teachers, counselors, and parents will find this videotape to be informative and helpful in dealing with the ADD Syndrome child. Four types of ADD patterns are distinguished.

HELP! THIS KID’S DRIVING ME CRAZY!
THE YOUNG CHILD WITH ATTENTION DEFICIT DISORDER
by Lynne Adkins and Janis Cady (Videotape) by Jane Judy, Lynne Adkins and Janis Cady
(PE040) Videotape (13 minutes, 1/2" VHS) $89.00
This videotape presentation is designed to provide information about the nature and typical behavioral characteristics of young children with attention deficit disorder, to increase awareness of the special needs experienced by young children with attention disorder, and to offer suggestions on how to foster the development of appropriate behavior, including attention behavior. An attractive 64 page booklet, available separately, reiterates much of the important information covered in the program.

MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH ATTENTION DEFICIT-HYPERACTIVITY DISORDER
(Third Edition)
by Ronald J. Friedman and Guy T. Doyal
(PE039AD) $24.00
In this latest revision the authors combine the most current medical and psychological research findings with their 20 years’ clinical experience with children with ADHD and their families. Written in a clear nontechnical manner, the book will be useful to parents, educators, and anyone interested in improving the lives of children with ADHD and their families.

AUTISM

AUTISM ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
by Toni Flowers
(PE039OD) $29.00
The activities in this practical book are in an easy-to-read format. Each activity is designed to tell educators what they are doing, why they are doing it, and what materials they will need to teach the activity. The activities are adaptable for children of all levels. The blackline masters are primarily for children with autism but can also be used with other severely handicapped children.

AUTISM INFORMATION AND RESOURCES FOR PARENTS, FAMILIES, AND PROFESSIONALS
by Richard L. Simpson and Paul Zions
(PE043OD) $24.00
Parents and family members who experience the frustration, concern, and uncertainty of living with a youngster with autism will appreciate this resource book, presented in a question-and-answer format. An appendix at the end of the text gives service organizations, professional periodicals, books, and videotapes where parents and other interested persons can find additional information on autism.

CHILDREN WITH AUTISM
A Parents’ Guide
Edited by Michael Powers, Psy.D.
(WB0170D) 248 pp. $14.95
Suggested by many as the first book on autism that families should read, CHILDREN WITH AUTISM provides a complete introduction to autism, while easing the family’s fears and concerns as they adjust to and cope with their child’s disorder. This book answers questions and gives hope to parents coping with this perplexing disorder. It is highly recommended reading for families.

WHEN SNOW TURNS TO RAIN
One Family’s Struggle to Solve the Riddle of Autism
by Craig Schulze
(WB029AM) 216 pp. $14.95
WHEN SNOW TURNS TO RAIN is a father’s moving personal account of his son Jordan’s perplexing disorder — later onset autism. From Jordan’s birth through his eighth year, Schulze describes his son’s transformation from a happy, engaging toddler to a progressively disconnected child with autism. This poignant story echoes that of thousands of other families with children with autism.

CHILDREN WITH AUTISM
A Parents’ Guide
Edited by Michael Powers, Psy.D.
(WB0170D) 248 pp. $14.95
Suggested by many as the first book on autism that families should read, CHILDREN WITH AUTISM provides a complete introduction to autism, while easing the family’s fears and concerns as they adjust to and cope with their child’s disorder. This book answers questions and gives hope to parents coping with this perplexing disorder. It is highly recommended reading for families.

DISABLEMENT, GENERAL

ADAPTIVE PLAY FOR SPECIAL NEEDS CHILDREN STRATEGIES TO ENHANCE COMMUNICATIONS AND LEARNING
by Carolina Ramsey Musselwhite
(PE0420D) $27.00
Adaptive play refers to play that has been altered in form, complexity, or intent to serve the needs of children with disabilities. This book summarizes recent advances in using play as a learning tool, developing adaptive play materials, teaching specific skills through play, and supporting the use of play in all settings.

A READER’S GUIDE FOR PARENTS OF CHILDREN WITH MENTAL, PHYSICAL, OR EMOTIONAL DISABILITIES
Third Edition
by Cory Moore
(WB0320D) 248 pp. $14.95
A READER’S GUIDE is an indispensable tool for parents, teachers, and librarians — virtually anyone who needs to find the most current, authoritative information in print about children with disabilities. This useful annotated bibliography lists more than one thousand books and other resources on disabilities. Each listing has been carefully selected for parents.

To order, use the order form on page 80, or call 1-800-635-1910
CHILDREN WITH EPILEPSY
A PARENTS' GUIDE
Edited by Helen Reisner
(WB0160D) 314 pp.
$14.95
CHILDREN WITH EPILEPSY offers valuable knowledge and support to parents of a child with epilepsy. With chapters on diagnosis, medications, daily care, family life, advocacy, and special education, this book provides an in-depth look at epilepsy, and its various treatments, as well as its impact on the child and family.

CHILDREN WITH TOURETTE SYNDROME
A PARENTS' GUIDE
Edited by Tracy Haerle
(WB012PD) 434 pp.
$14.95
This parents' guide to Tourette Syndrome explains the disorder, including its symptoms, causes, and medications, as well as the disorders which are commonly linked with it. Other chapters cover family life, education, advocacy, and legal rights. Parent Statements appear throughout, offering insight, advice, and encouragement for the reader.

CHOICES IN DEAFNESS
A PARENTS' GUIDE
by Sue Schwartz, Ph.D.
(WB0250D) 212 pp.
$14.95
Parents of children with hearing impairments face a difficult decision — which method of communication is the most appropriate for their child? With its clear, objective descriptions of the three predominant communication methods, CHOICES IN DEAFNESS provides valuable guidance in sorting out the options.

DISABLED, FEMALE AND PROUD!
STORIES OF TEN WOMEN WITH DISABILITIES
by Harilyn Rousso with Susan Gushee O'Malley and Mary Severance
(GW003EP) $12.95
(Limited Supply)
Offers young women with disabilities empowering role models and the powerful message that they have full lives ahead of them. Offers parents and educators a unique way to help young people learn that making choices — about school, work, family, love — is what being disabled, female and proud is all about.

DOES YOUR CHILD HAVE EPILEPSY?
(SECOND EDITION)
by James E. Jan, Robert G. Ziegler and Giuseppe Erba
(PG0360D) $22.00
Written by three well-known pediatric specialists, this book provides information on the most common type of seizures, causes, principles of treatment, investigations and outcome, with a wide range of helpful suggestions from infancy to early adulthood. This book is highly recommended for parents and grandparents of children with epilepsy, older children with seizures and their siblings, teachers, health professionals, and other caregivers.

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
by Montie Mace
(TP0280D) $12.95
The Illustrated Directory of Disability Products is what being disabled, female and proud is all about. This Directory shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

TROUBLE WITH SCHOOL
A FAMILY STORY ABOUT LEARNING DISABILITIES
by Allison & Kathryn Dunn
(WB028LD) 32 pp. $9.95
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A PARENT'S GUIDE TO DOWN SYNDROME
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The LANGUAGE OF TOYS teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises. The activities and exercises use everyday toys, books, and games to stimulate speech and language development, so there is no need for specialized toys or equipment. This book is useful for all children with special needs.

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CHILDREN WITH MENTAL RETARDATION
A PARENTS' GUIDE
Edited by Romayne Smith, M.A, CCC-SLP (WB006MR) 437 pp. $14.95
This book is a complete guide to everything parents need to know about raising their child and meeting her varied medical, therapeutic, and educational needs. Children with mild to moderate mental retardation, whether diagnosed at birth or in early childhood, require more help than usual in all areas of development, and their parents need to be well informed and involved every step of the way.
DIFFERENCES IN COMMON STRAIGHT TALK ON MENTAL RETARDATION, DOWN SYNDROME, AND LIFE by Marilyn Trainer (WB009MR) 236 pp. $14.95

In this engaging collection of essays, Marilyn Trainer draws on her experience as the mother of a child with Down syndrome, now in his twenties. With candor and humor, she brings a fresh, candid outlook to the challenges, hopes, and fears of family life — a life shaped by a child with Down syndrome, but one which strikes a common chord in all of us.

SPEAKEASY PEOPLE WITH MENTAL HANDICAPS TALK ABOUT THEIR LIVES IN INSTITUTIONS AND IN THE COMMUNITY by Karin Melberg Schwier (PE044MR) $16.00

In this unique and compelling collection, people labeled mentally handicapped speak honestly and powerfully about their lives in large institutions and in the community. Through intimate interviews, the author has captured the dreams, fears, frustrations, and humor of people who were exiled for being different but battled social barriers to establish independence. Emerging from these pages are colorful, resilient, and thoughtful individuals.

THE CONQUEST OF MENTAL RETARDATION by Burton Blatt (PE047MR) $38.00

The author lays out the basics of the field — history, classification, and definitions — but he also discusses controversies; nature versus nurture, deinstitutionalization versus institutionalization, and the educability hypothesis. Moreover, each of these topics is placed within a broader context — social, political, and moral. A single, powerfully felt conviction infuses the whole: One’s value as a human being does not have to be preserved.

GENERAL DEVELOPMENTAL DISABILITIES PSYCHOSOCIAL ASPECTS by George S. Baroff (PE0640D) $27.00

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IT ISN'T FAIR! SIBLINGS OF CHILDREN WITH DISABILITIES Edited by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D. (EP001EP) $14.95

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L. Mark Russell, a co-author, is an attorney and is one of the nation's leading authorities on life and estate planning for families who have a child with a disability. Mr. Russell's earlier book, Alternatives, published in 1983, has been considered a definitive resource on this subject.

THE EARLY INTERVENTION DICTIONARY: A MULTIDISCIPLINARY GUIDE TO TERMINOLOGY
by Jeanine Coleman, M.Ed.
(WB030E1) $16.95
The EARLY INTERVENTION DICTIONARY defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services. Entries are alphabetized, and include the most frequently used terms in the areas pediatric medicine, early childhood education, OT, PT, audiology, counseling, social work, and more. A great resource for parents.

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55 Annual Income Tax Guide by L. Mark Russell
Our yearly journey through the income tax wilderness.
Over the past 20 years, Congress has passed major legislation to improve opportunities for children and adults with disabilities and their families. Early intervention services were first included in legislation passed in 1986. To provide a context for understanding available programs, Pascal Trohanis ("Early Intervention—A National Overview") offers a broad perspective on the history and current implementation of specific federal regulations. "Perspectives on Early Intervention" presents the early intervention experiences of four parents—Christel Dawkins, Mona Freedman, Cassie Johnston and Judie Walker. In "A Graduation for Two," Teresa M. Rafferty shares some reflections on her daughter’s, and her own "graduation" from early intervention.

As members of Congress return to Washington, health care reform is on the agenda. In our editorial report, we discuss some specific concerns of the disability community within the context of the significant positive reforms proposed by the President. We also present the all-too-common story of a family’s struggle to deal with their children’s staggering health care bills. We urge all of our readers—and their children—to get involved in the reform process.

Last summer, we announced that President Clinton had nominated Judith E. Heumann for the key leadership role of Assistant Secretary for Education and Rehabilitative Services. In this issue, an interview with Judy launches our new regular department, "Role Models." We are delighted to give parents and children a chance to get to know this talented, energetic leader who was once excluded from her local elementary school because she was considered a "fire hazard." We also thank Ilse Heumann, Judy’s mom, for sharing some wonderful family photos.

Income taxes are an annual concern. In our "Annual Income Tax Guide," attorney and author L. Mark Russell provides practical information for parents of children with disabilities or chronic illnesses.

Many readers felt a kinship with the parents in the film Lorenzo’s Oil as they struggled to convince health professionals to recognize the treatment they had devised for their seriously ill child. A few months ago, the national media reported that "Lorenzo’s Oil" had been tested and did not work. This month’s Research page, however, presents a more complete and balanced report.

More News

Recent issues of U.S. News & World Report have included two articles for our readers’ "required reading" lists. The cover story of December 13, 1993, "Separate and Unequal: How special education programs are cheating our children and costing taxpayers billions each year," is an important critique. "The Mothers of Invention: How a mighty grass-roots movement of parents with disabled kids is changing the nation" (January 10, 1994) is an inspiring story of dedication. Both articles feature parents whose stories have been in Exceptional Parent.

I am honored to announce that four terrific individuals have agreed to serve on our editorial advisory board: Stanley Greenspan, David Hersh, Steven Perlman and Peggy Mann Rinehart.

I am meeting many parents of children with disabilities who are active participants in professional education—educating physicians, teachers, and therapists about the lives of their families. I am also meeting a number of professionals who are interested in increasing the role of parents in professional education. I would like to hear from both parents and professionals about their involvement in such programs.

Many thanks to the hundreds of readers who returned the surveys we sent out to a sample of subscribers. The 40 percent return rate demonstrates that our readers are truly exceptional!

Special Renewal Offer

Our transformation to a monthly magazine has caused confusion for some readers as well as for our subscription office. To end the confusion and reward our loyal readers, every reader will receive a special renewal offer very soon. Please watch for it!
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LETTERS

Letters to the Editor

A Fine Purpose

After an extremely long ISP (Individual Service Plan) meeting, I fell into bed exhausted, but was revived by reading Carol Abbott’s article, “A Fine Purpose” (October 1993).

I want to thank her for sharing their lives and the life of their son Brian in such a warm and articulate way. The article is such a wonderful tribute, not only to Brian, but also to the many other wonderful children with severe physical, mental and medical disabilities. It reminds me of the value of each life, that wonderful “beingness” of each God-given person. I was truly blessed.

S.B.
Washington

I was very encouraged by Carol Abbott’s story about her son Brian. I was deeply moved to read of Brian’s life and of Carol’s search for answers as to why this “tragedy” had befallen her family.

I believe all of us who have been touched by a child with a disability, believers in a higher being or not, come to question God as to His purposes. For some, when the questions appear unanswered, faith in God wanes and life goes on without Him. How very sad. For others who will not be satisfied without an answer, the answer inevitably comes.

Thank you for printing Carol’s article in Exceptional Parent. I have been a subscriber for almost a year and have until now been disappointed by the absence of faith-inspiring material. While I realize this is not a “religious” magazine, many of us hurting parents believe deeply in God and His grace and depend on Him daily. Thank you for helping to meet a need of mine.

N.J.S.
New York

Just a short note to let you know that I very much enjoyed the article, “A Fine Purpose.” Ms. Carol Abbott really wrote this article with her heart. A special thanks to her for being able to write down so well what I feel myself.

L.L.
Ontario, Canada

Liberty and Choices

Thank you for your editorial, “Liberty and Choices for All” (June 1993). The fervor with which the proponents of inclusion promote their belief is disconcerting. It is fine to have strong beliefs, but it is just plain uncomfortable to read documents that imply that to value any other model is wrong.

Thoughtful parents, thoughtful educators and thoughtful advocates recognize that the beauty of our country lies in choice. A continuum of services for children with disabilities—from residential to full inclusion—gives each of us the power to make our own decisions. Let’s respect this gift. Your editorial states the need for respect well. It is appreciated.

V.A.D.
Oregon

Parent-Teacher Cooperation

Thank you for the articles, “Parent-Teacher Cooperation: A Shared Responsibility” and “Effective Parent Advocacy: How to Take Charge” (September 1993). They contained valuable information. I had to laugh over the statement, “Visit your child’s classroom to see how she spends a typical day. Parents are always welcome.” That is not true at all schools! The school

P.F. Responds—It’s not about labels!

In the April/May issue of Exceptional Parent, the headline “Documentary About Learning Disability Wins Academy Award” appeared above a news item about the film Educating Peter, the story of a student with Down syndrome.

In the July/August issue, Exceptional Parent printed my letter expressing distress at the headline’s implication that a film about Down syndrome is a film about learning disabilities. Five letters in the October and November/December issues expressed offense at what I wrote.

I’m sorry. My quarrel was never with those parents or their children! My quarrel was with Exceptional Parent and its editors. They know the difference between learning disability and mental retardation, but let a carelessly worded headline slip by them.

I am not guilty of the insensitivity and ignorance of which those letters to the editor accuse me. Apparently, however, I am guilty of poorly expressing a point I still believe must be made. I desperately hope that this time I can make my point without offending anyone.

It may help to know that I had three sons. My own beloved firstborn son had a mucopolysaccharidosis—a progressive degenerative disease. He was big, well and bright until he was four, but then became gradually dwarfed, ill and retarded until he died at 15. P.B. of Georgia, watching his intelligence fade was heartbreaking.

Our second son is profoundly deaf. He has had a wonderful education, but that was never a foregone conclusion. We fought tooth and toenail to first, learn what we should do so that he would be able to do all he could do. Then we worked equally hard to find the programs that would help us do it. That sometimes meant we had to create the programs.

Our third son is the one with learning disabilities (LD). When my children were small, services existed for children with mental retardation. There were proven methods for teaching children with impaired hearing. But learning disabilities were not understood at all. Neither diagnostics nor programs were available. That they exist now (and that some children with Down syndrome benefit from them) is due in part to parents and professionals who have been my friends and support in the Learning Disabilities Association (LDA).

continued on page 44
system we belong to has refused to let mothers observe in a classroom. It makes a parent wonder why.

J.A.
Texas

Diabetes Insipidus—Wrong Advice
You gave M.R.P., Pennsylvania (Parents Search—November/December 1993) the wrong advice by referring her to the Juvenile Diabetes Foundation. Diabetes insipidus has no relation to diabetes mellitus—so-called “juvenile diabetes,” but technically referred to as “insulin-dependent diabetes mellitus.” Diabetes insipidus is due to a deficiency of anti-diuretic hormone, not insulin.

R.J.K.
Maryland

I am the parent of a child with diabetes insipidus. An excellent resource is the newsletter from the Diabetes Insipidus and Related Disorders Network (c/o Beth Perry, Rt. 2 Box 198, Creston, IA 50801, 515-782-7838).

M.C.A.
Maryland

Feedback
I’m writing to tell you how my life has changed so much since I started receiving your magazine a year ago.

My daughter Christine is two years old. She has cerebral palsy, cortical blindness, mental retardation and a seizure disorder. I could never bring myself to even say these diagnoses before. I did nothing but cry, pray, hope and wish things were different. I could not understand why or how this could happen. Day by day, nothing seemed to change. I’d have a doctor’s appointment and leave upset. I’d see another baby and cry. I’d think of what she would have or could have been doing and I’d cry. I never gave up on prayers. I always loved and accepted her. It wasn’t until later that I knew why God gave her to me.

I started receiving your magazines and reading them over and over. It seemed everyone felt the same way in the beginning. I started to understand more. I felt that God had chosen me and all these other parents.

My friends and family pass the magazine around and it helps all of us understand. We read parts to our older daughter, Theresa, so she knows her sister isn’t the only one and that she is special like these children.

Thanks to Exceptional Parent, I understand my baby a lot better and I will never give up on her.

C. G.
New Jersey

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become more of a scholarly journal and less of a magazine for an at-home parent. There is much less encouragement from parent to parent.

I am still changing diapers on an eleven-year-old, trying to balance medicines with seizures, preparing meals, doing laundry, coordinating the rest of the family and loving every one of them. Advocating in formal situations is not what I do most. And I'd like to hear from parents who know where I am, because they remember what it was like. Few articles lately have spoken my language.

In the November/December 1993 issue, for instance, the only things of interest to me were Parents Search. Parents Respond. Parenting and Fathers' Voices. The Children's Page used to be good with sibling input. I would often share it with my three "normal" kids, but no longer.

I have been putting off writing this for several months to see if things would change. They didn't. So I am getting things off my chest. I still appreciate the work you're doing. Thanks.

C.O. Washington

Fathers' Voices

Special thanks for adding a column for fathers, the "forgotten parent." I have had the pleasure of receiving Mr. May's newsletter for the past year. We need more circulation of his materials as you are doing.

Your decision to publish on a monthly basis is an excellent one also, since so many of the issues in which we are involved are fast-moving and need monthly attention.

M.M. Florida

Search Letters Pay Off

Thanks to Exceptional Parent, a nationwide network has been formed for parents with children with insufficient myelination.

Less than a year ago, we were all in the dark, getting no information from any organization on this disorder. Today, we are united and growing, thanks to your magazine for printing my Parents Search letter. I had such a big response that I started the Myelin Messenger newsletter (c/o Ruth Anderson, 11C-29, Box 686, Stable Lane, Prescott, AZ 86301-7435).

Now, we are not alone and hope future parents will not be left in the dark. With the advent of magnetic resonance imaging, it is likely many more children will be diagnosed with this disorder.

Your magazine is a wonderful resource for all of us. I look forward to each issue and read it from cover to cover, it's dog-eared when I finish it. But I pass it on to another grateful parent anyway.

R.A. Arizona

I am grateful to everyone who responded to my Parents Search letter on large-size, pull-up style diapers. I have contacted Kimberly-Clark, the company that manufactures Pull-Ups, and they have told me that their research and development department is currently working to develop Pull-Ups in larger sizes.

The more consumer information Kimberly-Clark has, the sooner they will be able to get this product on the market. I have sent them all the letters I received from readers of Exceptional Parent. If you have not written yet, or have more information for them, please write to: Kimberly-Clark Corporation, Attn: Consumer Services, P.O. Box 349, Neenah, WI 54957-9953.

Also, in response to suggestions to use non-disposable, pull-up style diapers, most parents will find that school systems will not accept anything but disposable diapers.

G.M.F. New Jersey

Young Artists Wanted

Exceptional Parent is now using children's artwork to illustrate feature articles and departments. We invite your children to share their work with our readers. Send artwork to: Exceptional Parent Children's Art 209 Harvard St., Suite 303 Brookline, MA 02146-5005

Put the picture's title, along with the child's name and address, on the back of the submitted artwork.

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- HOWARD SHAWNE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
- CAPOL TINGEY, Ph.D., Parent, Psychological, Western Rehabilitation Hospital, Sandy, UT
- HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
- IRVING KENNETH ZOLLA, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA
**Sibling Seeks Pen Pal**
I am an 11-year-old girl who has a brother with autism. I would like a pen pal who has a sibling with a disability.

*J.A.*
*Texas*

**Coping with Uncontrollable Seizures**
My friend has a 21-year-old son with partial complex seizure disorder uncontrollable by medication. He had several brain scans and is currently undergoing diagnostics to see if he is a candidate for surgery. Possible surgical procedures are subdural electrode implants and epidural pegs.

Matt is learning to live with his epilepsy and is living independently for the first time, but is still unable to work and drive. His best friend is in college on the East Coast and he feels all alone. He feels like he is the only person in this situation. He is in dire straits emotionally. Please contact us if you know of anyone else in this or a similar situation.

*J.M.W.*
*New York*

**LD—Resources for Dealing with the System**
I am the mother of a nine-year-old boy with several significant learning disabilities. I am interested in corresponding with other parents who are facing (or who have solved) the same kinds of challenges. Could you please help me find some parent resources to deal with the educational system and the learning process?

*K.R.*
*California*

**Transporting Two Non-ambulatory Children**
I am the mother of three boys, two of whom have multiple disabilities and are non-ambulatory. Nick is five years old, and can sit independently for short periods of time. Chris is almost two years old and is very close to sitting independently. I am in search of a way to transport both boys single-handedly.

Nick has a custom-fitted wheelchair that works well. Chris is comfortable in a stroller at this point. The difference in the boys’ ages and heights creates a problem. If something works well for one, it doesn’t work well for the other.

My ideal form of transportation would be something that is easily transportable by folding to fit in the trunk of a car or the back of a van. It should be adjustable to fit the growth of my sons. Also, if possible, it should be something that can be hooked together for a single person’s use, but can also be taken apart for two people to use.

If anyone has any suggestions in finding a long-lasting, affordable and safe form of transportation, I would appreciate your help.

*D.H.*
*Ohio*

**College with a Personal Attendant?**
I am the parent of a 15-year-old daughter who has cerebral palsy. She uses a motorized wheelchair and is unable to dress, bathe or transfer out of her wheelchair by herself. She will always need an attendant to help her. She also has difficulty writing, and gets frustrated using her computer because she is a one-finger typist.

My daughter is an honor student and wants to attend college. Either my husband or myself must help her with her homework now—we do all the writing—but we will be unable to do this for her when she’s attending college. I would like to hear from anyone who has had experience with a person unable to write who was able to attend college. How did they complete written assignments? I also would like any information on colleges for a person who would need attendant care.

*N.T.*
*New York*

**Ideas for PTO Activities**
My five-year-old son is in his fourth year in a preschool program for kids with special needs. We have a parent-teacher organization that meets monthly. Sometimes, we have speakers or a family activity or talk about fundraising. The participation is very poor. I would like to hear from other parents about their school groups.
Tenth Chromosome Inversion

We have two lovely daughters—Shelby, twenty-three months and Rebecca, three months. Both girls have an inverted tenth chromosome. Geneticists have told us that this inversion is not known to cause birth defects. (My husband has this inversion and there is no familial history on either side of any birth defects.) In fact, after the birth of our first daughter, they told us that there was little if any chance of a recurrence. They were as shocked as we were when our second daughter showed up with almost identical problems.

Shelby had a small ventricular septal defect and patent ductus arteriosus not requiring surgery, a major esophageal reflux requiring G-tube placement, hydronephrosis on the left and a non-functional kidney on the right with major ureteral reflux requiring corrective surgery. She also has developmental delays. Her younger sister had coarctation of the right aortic branch, a small ventricular septal defect and similar problems with her stomach and kidneys.

Of course, we would like to know why. But most of all, we would like to know we are not alone.

P.U.
Pennsylvania

Riding the School Bus

Our son is seven years old and mildly autistic. During the four years he has been in school, either his dad, the baby-sitter or I have driven him to school. Our family has found this to be a very satisfactory arrangement. Almost every one of our son's teachers, however, has urged us to have our son ride the school bus instead. They say they believe very strongly that riding the school bus is an important part of going to school. Is there any research that supports the idea that riding the school bus is better than having a family member drive the child in a car? Are the teachers likely to prefer the bus for reasons they are not discussing?

N.S.
New York

Three Kids, Three Disabilities

I'm the parent of three beautiful children who bring my husband and I great joy and happiness. But we are upset that all three have totally different impairments. Brian is three-and-a-half years old. He doesn't have a diagnosis except developmental delays, sensory integration dysfunction and "slow-to-warm-up" syndrome. He also has asthma. He is still unable to dress or undress himself, is not toilet-trained and cannot ride a tricycle or catch a ball. Cognitively, he is either normal or above average for his age.

Joshua is 19 months old. He has septo-optic dysplasia, oculo-cutaneous albinism and a hypoplastic left kidney with reflux. He is also hypoglycemic. I've been searching for a long time for any family who may have a child with both septo-optic dysplasia and albinism. Josh is the first that our geneticists are aware of. Developmentally, Josh is right on target, except for things that require vision, because he is legally blind.

Corey is two months old. He was born with a rare heart defect, hypoplastic right heart syndrome. His prognosis is uncertain, so we consider each day he's with us a gift. He underwent open-heart surgery immediately after birth and faces two more surgeries by his first birthday. It's not a cure but a band-aid. He also appears to have optic nerve hypoplasia or optic nerve atrophy.

We have had extensive genetic counseling and no one can determine...
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why our children all have impairments, and why all three children have something different. I would like to hear from anyone who might be able to give us some insight. I would also like to hear from anyone who is in a similar situation—how they cope emotionally, how they find time for themselves, how they find time to be just a “normal mom” instead of always dealing with doctors, therapists and bills.

P.G., Pennsylvania

**PDD/Autism and Muscular Dystrophy**

Our six-and-a-half-year-old son was diagnosed at 15 months with pervasive developmental delay/autism. At three, we learned he also has Duchenne muscular dystrophy. The specialists who deal with our son have no other patients with this dual diagnosis. We are interested in hearing from parents of children with the same diagnosis to compare notes and perhaps shed some light on our special children.

J.M.F., Massachusetts

**Trisomy 19Q**

Our son is four-and-a-half years old and has Trisomy 19Q. He is the eleventh reported case in genetic history. Jacob’s development is significantly delayed. He has Tetralogy of Fallot, severe hypotonia and seizures. He is G-tube fed and considerably underweight. He weighs 22 pounds and is visually impaired, so he wears glasses. Presently, he is on medication for seizures and constipation.

Jacob is making progress in sitting up with assistance and is walking with a Rifton walker. He cannot talk or crawl, but he is a professional roller. He pulls himself forward with his arms, his legs dragging behind. He gets around the house by rolling or scooting on his back. Jacob is a very active and social child who charms everyone she meets.

We have been on a worldwide search for another child like Jacob. I’ve written to more than 100 different genetic research centers, national information services, support organizations and medical facilities with no success. We would love to hear from other parents of children like Jacob who have similar problems.

D.L. and R.R.
North Carolina

---

**Rasmussen’s Syndrome**

My nine-year-old daughter has recently been diagnosed with Rasmussen’s Syndrome. She has undergone two craniotomies to stop the motor seizure activity. She is currently using a walker and is on numerous anti-seizure medications. I would appreciate any information from other families who have dealt with this syndrome, as her future prognosis remains uncertain due to the limited number of children with this condition.

S.K.J.
Nebraska

**Langer-Giedion Syndrome**

Our two-year-old daughter Ariel was born with a deletion in the long arm of her eighth chromosome (8q-123.1-24.22). At six weeks of age, she was diagnosed with Langer-Giedion syndrome, also called Trichorhinophalangeal Syndrome Type II. We have been searching without success for another family affected by this very rare syndrome.

Ariel has many of the characteristics that are common to this syndrome: slow-growing, sparse hair; large, low-set ears; bulbous nose; thin lips; multiple skeletal anomalies and short stature. Some additional problems she has which are not usually associated with this syndrome are multiple heart defects, severe feeding difficulties—Ariel is gastrostomy fed—and recurrent episodes of undiagnosed, uncontrollable vomiting that occur every two to three weeks and last two to five days.

Ariel currently scoots on her bottom to get around, but we are confident that she will be walking within the next year. She uses American Sign Language to communicate, as her speech is delayed. Cognitively, Ariel appears to be doing very well. She has an excellent attention span and already knows over 40 signs. Ariel is a very active and social child who charmed everyone she meets.

We would very much like to correspond with other parents of children with Langer-Giedion Syndrome and/or undiagnosed episodes of vomiting. We are looking forward to hearing from you!

A.R. and R.R.
Minnesota

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Circle #45
Parents Respond

**G-Tube**

T.G. (October 1993) is the parent of 28-month-old Joseph who was born prematurely and suffered a grade IV brain hemorrhage. Joseph has feeding difficulties and is currently underweight. Though his doctor recommended G-tube placement, T.G. wondered whether this would be beneficial since Joseph also has reflux.

I read your letter while I was sitting in the doctor’s office, waiting to have my son’s recently placed G-tube checked. Your letter could have been written about my own son, Jake. He was a 32-week preemie who also suffered a grade IV bleed. He is now 31 months old and is unable to hold his head up or do much of anything for himself.

Our decision to have a G-tube placed was an agonizing one. We felt we were taking a step backward since he was able to eat to some extent. However, each of his feedings was taking up so much of our time with such little result. Jake always had a reflux problem, so we shared the same concerns as you. Our coping ability and Jake’s tolerance were nearly exhausted.

Our neurologist, pediatrician and gastroenterologist all recommended a G-tube. (Jake was 28 months old and weighed 17 pounds.) A nissen was also performed to prevent any occurrence of reflux or aspiration. This procedure is actually more difficult than the G-tube placement, but well worth it.

Although there were some initial difficulties, now we are so glad that we decided to go ahead with it. Feedings are easier, and Jake has gained weight. Our stress level is down, his comfort level is up, and we feel we are able to spend more quality time with him. It is a slightly difficult transition, but once learned, benefits the entire family. His diet consists of Pediasure with fiber, pear juice and water. His medicines go directly into the tube as well. (Jake has a button and I also recommend you inquire about that.)

---

**Puberty and Autism**

P.K. (September 1993) is the parent of a nine-year-old girl with autism who is rapidly approaching puberty. P.K. was concerned about how to handle the onset of her daughter’s menstruation since she usually removes her clothes during the night.

I’m the parent of a 15-year-old daughter who has mental retardation with some autistic characteristics. My daughter wets during the night. We had a problem with her pulling her disposable briefs off and tearing them up. In the winter, I used a safety pin to hold the zipper up on blanket sleepers. She’s very strong, however, so I was afraid she would break the pin and get hurt. Then my mother made her some one-piece pajamas that zipped in the back. They worked great until the summer, when she made them short-sleeved and short in the legs. She used a thin cotton knit material.

When my daughter began menstruation, we had two problems: the
pads were too wide and in the blink of an eye, she would reach into her pants, pull the pad off and throw it. I found that the extra long size with wings solved the width problem. Because of the wings, I could make them very narrow. She now wears bib overalls and one-piece jump-suits to prevent her from reaching into her pants. She leaves the pad alone and we have no more embarrassing moments.

D.S., Michigan

Wide Shoes

D.M.G. (September 1993) was looking for a source of wide dress shoes for her 30-year-old daughter who has Down syndrome.

Your question wasn’t mundane. Finding wide shoes in an age-appropriate style is difficult. My 16-year-old daughter wants “in” shoes, but braces make them hard to find. We’ve found wide shoes in the Massey’s shoe catalog. P.O. Box 10088, Lynchburg, VA 24506-0088. The selections are limited in size four, but there are a few. Good luck!

No name or address given

Parents with Disabilities

C.L.B. (November/December 1993) has a neuro-muscular disease, and is also the parent of two preschoolers, one of whom is a four-year-old boy with autism. Her situation has become even more difficult since her husband passed away last spring. She wondered how other parents with physical disabilities cope with everyday problems.

I have been a subscriber to Exceptional Parent since shortly after my daughter was born in July, 1991. So many letters and articles in Exceptional Parent have touched me, but none more than yours since I am also a disabled parent of a child with a disability.

My daughter has Larsen’s syndrome, a rare congenital disorder involving multiple joint dislocation, characteristic facial features and in Emily’s case, a potentially serious instability of the cervical spine. Although Larsen’s is considered rare, her case was immediately diagnosed since she inherited it from me, her mother. All the genetic counseling I received prior to my marriage indicated that there was virtually no risk of my bearing an affected child. Now, the risk is known to be 50-50 and this weighs heavily on my mind when considering more children.

In your letter, you asked how disabled parents cope with everyday problems. First, I realized that I have no choice but to cope. She is my daughter and I love her with all my heart.

Next, we organize our surroundings to make my life easier. It may sound simplistic, but I have found that comfortable, supportive furniture eases the back pain I suffer due to my dislocated hips. In our former apartment, we also had diaper-changing tables both upstairs and downstairs. Recently, we moved to a one-level apartment since Emily is not likely to handle stairs for some time to come. She can now walk with a walker, but there are still many occasions when I must lift and/or carry her! My husband does all the heavy housework and assists with most household chores.

I realize, however, that you are a widow. Do you have the financial resources to employ a housekeeper or home health aide? If not, do you have insurance which might cover such services for you, based on your condition? Or do you have other family or friends that would be willing to help out with everyday activities?

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I realize that these suggestions aren't original. No one more than me understands the physical and emotional pain of disability. Just remember that somehow we will always manage to get through the rough times, because we have to do it for our kids.

E.L.K.
New York

Semilobar Holoprosencephaly
M.M.R. (November/December 1993) is the parent of a ten-month-old daughter, Chloe who has been diagnosed with Semilobar Holoprosencephaly. Chloe was given a bleak diagnosis, but is now doing quite well. M.M.R. wondered about her true potential.

I have a four-year-old daughter with Semilobar Holoprosencephaly and Hydrocephalus. Dara's original pediatric neurologist suggested that we not consider any habilitative programs since her life expectancy was short. We also were given a very bleak prognosis.

Four years later, she has made remarkable progress. Dara now cancrawl around anywhere. She can use a walker for short periods of time. She speaks in single words and can name many items. Her vocabulary consists of approximately one hundred words. She just learned to count to ten. She loves sing-along videos and books.

Dara is enrolled in the three-to five-year-old program in our public school. It is unbelievable how much difference the stimulation, learning and other children have made in her life.

I encourage you to take Chloe to appropriate therapies. I cannot say enough about how speech, occupational and physical therapies have helped Dara. The knowledge, support and friends I've gained through taking her to her therapies has also helped me.

As I have been typing this letter in my office, Dara has been playing on the floor, "reading" papers from the trash, trying to pound on my keyboard and singing the ABC's.

J.S., Illinois

Cochlear Implants
C.N. (October 1993) asked about the pros and cons of cochlear implants for children with multiple disabilities in addition to profound deafness.

I am a parent of a two-and-a-half-year-old child with multiple disabilities
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S.A.
Iowa

EME and Nonoxynol-9 Spermicide

M.D. (October 1993) is the parent of five-and-a-half-month-old Austin who has been diagnosed with Early Myoclonic Encephalopathy Syndrome (EME). Austin was conceived while his parents were using the contraceptive sponge with Nonoxynol-9 spermicide. M.D. was looking for other parents of children with EME, and also wondered if other parents of children with disabilities had used Nonoxynol-9 at conception or during pregnancy.

It was amazing to me how familiar your situation sounded. Our 22-month-old son, Scott, has been diagnosed as having cerebral palsy and a multiple seizure disorder. Two of the types of seizures he has are called myoclonic and tonic-clonic seizures. He also suffers from startle reflex and constant muscle spasms. Until recently, his seizures have always been very difficult to control—at one point, he was having seizures every 10 minutes. Scott is severely developmentally delayed. He has very little head and body control, and like Austin, is cortically blind.

Most interesting to me is that Scott was also conceived while we were using a contraceptive sponge with Nonoxynol-9 spermicide. We had two completely healthy children before Scott was born. Our second child was only five months old. We planned no other children, so like you, we had no reason to believe I was pregnant. I would be very interested to know if you find other parents with the same or similar circumstances.

S.H.
Alabama

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Circle #6
On October 8, 1986, P.L. (Public Law) 99-457, amendments to the Education of the Handicapped Act (EHA) became law. These amendments included a national reform agenda for increased and improved services for young children with special needs—birth to six years—and their families. This agenda was fueled by the needs of these children and by the documented benefits of early intervention and preschool services. The legislation also recognized the unique role of families by mandating services not only to children with disabilities, but also to their families. In October 1991, this reform agenda was updated through amendments to the Individuals with Disabilities Education Act (IDEA).

Today, a number of accomplishments can be traced to the nationwide reform effort that began in 1986. All states currently provide services to young children with disabilities and their families. For children in the age range of birth to three, almost 40 states now provide an entitlement to early intervention services. All states ensure the provision of public educational services to all eligible three-through five-year-olds.

Three major portions of IDEA—Part H, Section 619 and EEPCD—have been particularly important to the expansion and improvement of services to young children with disabilities.

Infants and Toddlers with Disabilities (Part H)

Part H of IDEA—a 1986 amendment to what was then known as EHA—was a major piece of federal legislation dealing with services to the very youngest children with disabilities. Part H did not require states to provide early intervention to children from birth to age three, but it offered assistance to states (or territories) that were interested in serving this age group. Under Part H, participating states received federal help in planning and implementing systems of comprehensive, multi-disciplinary, interagency programs for all eligible young children and their families.

Part H requires that statewide service-delivery systems fit each state's unique needs and characteristics. Participating states are asked to work with local communities in designing a family-centered, collaborative, culturally competent and high quality service system. Each governor must designate a lead agency within the state government to plan and oversee the operation of this system. This lead agency is advised and assisted by a gov-
error-appointed Interagency Coordinating Council (ICC) representing various agencies, service providers, universities and parents.

Preschoolers with Disabilities (Part B/Section 619)

Section 619 of IDEA (an amendment to a previous portion of Part B of the EHA) created greater funding incentives to states to provide a “free appropriate public education” to all eligible three- through five-year-old children with disabilities by the 1991-92 school year. Family services and programming variations are encouraged. In addition, all other requirements of a state’s Part B plan for special education and related services—Individualized Education Program (IEP), due process, and Least Restrictive Environment (LRE)—must be met.

Early Education Program for Children with Disabilities (EEP CD)

EEPCD expanded EHA projects known as the Handicapped Children’s Early Education Program. Today, there are over 130 EEP CD projects nationwide. These projects include model demonstration programs, research institutes, inservice training projects, outreach programs and technical assistance. Together, these projects seek to provide information on effective programs and techniques, demonstrate collaboration and inter-project networking and expand the quality and quantity of services to young children.

Accomplishments

Programs across the country are using a variety of collaborative and creative strategies to meet the challenges posed by the Part H and Section 619 of the IDEA legislation. For example, all states have or are developing:

- Coordination plans and agreements with other federal programs serving children and families;
- Policies regarding eligibility, individualized service plans, service coordination, transitions, least restrictive/most natural environments, procedural safeguards, child identification, health care and diversity;
- Ways to coordinate multiple funding sources to enable their systems to operate effectively and efficiently;
- Broad dissemination of information on successful programs and procedures that will benefit services to children and families;
- A high level of volunteer and collaborative participation, including involvement in the State Interagency Coordinating Council, the council task forces and its committees and local and regional activities;
- Methods to ensure that all professional personnel—early interventionists, teachers, occupational and physical therapists, speech

A National Overview

by Pascal Trohanis

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pathologists, psychologists and nurses—are qualified; and

• Public awareness programs, especially related to child identification activities.

Through IDEA, Congress has established a national reform agenda that seeks to expand the opportunities of early intervention and preschool services to more young children with disabilities and their families. IDEA aims to enhance child development, minimize the likelihood of institutionalization and provide much-needed support to families. The promises and dreams of IDEA are becoming a reality through the formation of partnerships, use of new knowledge, tapping of resources and hard work of America's citizens.

Pascal Trobants, Ph.D., is director of the National Early Childhood Technical Assistance System (NECTAS) of the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill. For more than 20 years, he has been involved in a variety of efforts to improve and expand services for young children with special needs and their families.

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ERIC Exceptional Parent

February 1994
Christel Dawkins, Mona Freedman, Cassie Johnston and Judie Walker are able to offer unique perspectives on early intervention. First, they are parents of children with disabilities who benefited from early intervention programs in their local communities. Then, in the years following their own children's graduation from early intervention, all four became involved professionally with the provision of services to young children in their own states and communities. Christel Dawkins was a parent member of the Intergroup Coordinating Council in her home state of Louisiana; Mona Freedman is coordinator of the Family Support Network for the Maryland Part 1 lead agency; Cassie Johnston is coordinator for the Birth to Six Project of Washington state's Parent Training and Information (PTI) Center, and Judie Walker is co-director of Pilot Parent Partnerships. Arizona's PTI Center. Some portions of this article first appeared in the Early Childhood Bulletin published by NEC-TAS at the Federation for Children with Special Needs, Boston, MA.

Christel Dawkins:

When my son was two years old he made no sounds and little eye contact. Will was so beautiful and looked so healthy that no one would believe me when I said there was something wrong. It took a year to get an evaluation and diagnosis of severe language disability. Professionals recommended that I place him in a classroom with non-verbal children learning to sign. Nobody would listen to me when I said that this child would talk. It took another year before I heard his first word—but he did talk.

At eight years of age, Will is now classified as learning disabled. He is in a regular classroom with speech therapy and resource help. He has plenty of friends, is on the soccer team and sings in the children's choir at church. This year he was "narrator" in the second grade Christmas play.

No one knows my child—his strengths, how to motivate him and exactly what he needs—as well as I do. As the parent of a child with special needs this is especially true. In those first months after Will was diagnosed, it was difficult to express this to the professionals working with him. Sometimes all I could do was cry. It was my child's speech therapist who realized that I needed at least as much help as my child. Her careful nurturing of a trusting relationship with the whole family turned us around.

I am also the sibling of a woman with profound disabilities. In the fifties, my parents were given the option of no help at all or letting the state do what was "right"—institutional care. I saw my sister's steady decline and my parents' powerlessness to make changes.

Services have changed dramatically since then. The "family-centered approach" has become the foundation of early intervention. Families are seen as having enormous strengths and making the critical difference that enables a child to reach his or her potential.

In the family-centered approach, families are allowed to choose their role at each stage and professionals are there not to direct, but to support the family.
and provide services. Sometimes the family assumes the leadership role, but not always. One mom told me that her role was to love her baby. It is wonderful when professionals recognize the incredible importance of the roles we each choose to play. Nobody was trying to get that mom to assume the role of “advocate” or “case manager.” Early intervention works when everyone involved makes a real effort to keep lines of communication open and to collaborate as a team.

Cassie Johnston:

For me, the value of early intervention began when someone validated my concerns about my daughter’s development. We had many positive interactions with professionals when they saw us as key players. Early intervention also connected us with parent organizations that provided support, information and skills. All of these things helped us become active team leaders for Suzanne. Some professionals probably saw me as an over-involved parent. But last year, Suzanne’s speech therapist said that she could “see how all the work and commitment in those early years really paid off.”

For the past four years, I have worked at Washington PAVE (Parents Are Vital for Education), the Parent Training and Information Center for Washington state. Before becoming a paid employee, I did volunteer work and attended many of the PAVE workshops and conferences. PAVE’s support was critical for me in those early years.

In my position with PAVE, I have provided support and mentoring to Interagency Coordinating Council (ICC) parents and at the same time, represented a parent perspective among Part H staff members. In the beginning my work felt like a dance—I was afraid of stepping on toes. But then I realized that people hear different music and dance to the music they hear. I have learned to hear and dance to a lot of different music over the last five years. Some I like better than others, but I have come to respect it all.

Mona Freedman:

During infancy, my second-born twin, Andrea, was diagnosed with low muscle tone. She was extremely slow in reaching developmental milestones. Once we admitted that our child had disabilities, our family seemed to become different than other families. We had to deal with professionals, attend IEP meetings and make what seemed like a million appointments. Andrea’s twin sister was often left behind with a baby-sitter. Parenting twins can be very challenging, but having a developmentally delayed twin added to the struggle.

When Andrea first began receiving services at 18 months of age, progress was slow. As time went on, however, we began to see some positive changes. Our little girl started to flourish and thrive!

Andrea is now seven years old. She is in first grade in the inclusion program at our local elementary school. She has learning disabilities, but she loves “regular” school.

I now work as coordinator of the Family Support Network within Maryland’s Infants and Toddlers Part H Program. Part H has generated and supported change at the state level, but now we are shifting our focus to the local level. Using trained “veteran” parents of older children with disabilities as coordinators, local networks have access to all new parents entering the system and can link them immediately with existing support services.

We know now that parents who have learned how to network and support each other become better able to solve their own problems and rely less on professionals. And a better informed parent, naturally, becomes a more effective member of the decision-making team.

Judie Walker:

At Pilot Parent Partnerships, we recognize that families of babies and young children may not seek us out for information on “their rights” or about “what they need to do.” We have learned, however, that if we ask them about their dreams and visions for their child and family—and really listen—then we can share with them the ways in which the laws can help them achieve those dreams.

When parents are beginning to find out about their child’s disability and special needs, they often hear only what the child won’t or can’t do. Parents may not be devastated by the fact that their child has a disability, but many are devastated by all the negative things that people say or by the condolences they offer. By talking with another family who has a child with similar needs, families begin to see a more balanced picture. They learn to smile and laugh again. They learn they will be able to be a family—not by someone telling them how, but by offering a living example. Families find out they are not alone. The experienced family offers the new family information and support that helps break the initial isolation.

We get acquainted with families by listening to them and offering information they request. To establish the initial contact we inform community physicians, health care providers, and human service workers about our work and how we might enhance their efforts to build a relationship with the family. We model respect for the family and family decisions.

Pilot Parent Partnerships doesn’t tell parents what to do, but listens and offers information and strategies to help them address their priorities. We meet families where they are because we can remember our own feelings of being the “new” parent. We help families to create new visions of possible and desirable futures.
This speech was delivered in June 1990, on the occasion of my three-year-old daughter’s “graduation” from her early intervention program.

It is appropriate that parents walk with their children at this particular graduation. The first reason for this is that our children need us to get wherever it is they’re going—they will, for a long time. But over the last three years, we have come to realize that they also are our co-pilots. They have taken us down many roads we didn’t expect to travel. They have introduced us to each other. And they have brought us to places in our minds and hearts that we didn’t know existed.

The second reason is that we parents are graduating from this program just as surely as our children. Long before the staff began talking about family empowerment, some of us parents were very blunt about why we were here. We came because we needed it. If our children also benefited in some way, well, that was even better. But we were the clients in need of service. We came in bad weather, with colds, throughout the long summer—because we needed to.

The lessons we learned here would fill a book, and someday they might. But a few thoughts come to mind immediately. I don’t presume to speak for all the families graduating from this program, but I do speak for myself and a number of others whom I feel privileged to call friends.

We learned a lot about love, unconditional love. And acceptance. At first, the diagnosis of a disability seems like a cruel joke. But then the reality sets in. You realize that all the hopes and dreams a parent normally has for a new baby may not come true—the trips to the playground, the Little League games you wanted to coach, the books or plays you wanted your child to enjoy. You realize that he may not attend your alma mater, and she is not going to be the prettiest bride there ever was. The death of these dreams is a very significant loss—it is a pain that never ever goes away—and so your child may not be very easy to love at first.

For months, you nurse your disappointment while caring for a little person who may have mental retardation, who may have blood drawn weekly from the veins of his neck, who may be unable to move from the blanket on which you lay him, or who can’t see you clearly or hear your voice. Then something happens. One day, you realize that this little person has shown more patience, more good humor, more even-temperedness, more perseverance and more acceptance of you and his world than you have ever known. That little person smiles at you in his own way and lets you know that he’s been waiting for you—waiting until you were ready—and he has a special place in his heart for you.

Then you realize why you have been given this little person. It isn’t because you’re some kind of saint. He is here to teach you never to take a spoken word for granted or consider a child’s step ordinary. He is here to teach you about a strong spirit, acceptance, loyalty and love in the face of difficulty.

The other lesson that jumps out at me when I think of this program was taught by the other parents. I met these parents first in my assigned support group; later, they became my friends. The lesson is to love and not to judge—not to judge another’s motives, pain, sincerity or circumstances. I was not judged by these parents, many of whom faced far more difficult situations than I. If I was frustrated by my daughter’s delay in walking, or worried about her minor ear operations, or angry at being tied down at home, my friends would listen, understand and sometimes make me laugh. No one ever denied my pain by telling me to just be thankful that she could stand up, or that she didn’t need open heart surgery or that at least I had another normal child. For this, I thank you.

I still find it amazing that people with children of such tremendously different levels of ability could share, sympathize, and come away refreshed and encouraged by each other. I find it amazing that parents of children with some of the most severe disabilities in the program would babysit for my children so that I could get away for the weekend. I find it amazing that we could come together to appreciate and celebrate the little and big milestones in our children’s lives.

To be sure, there have been some tears—some of our little friends are not even here to share his day—but there
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Circle #103
have been so many more laughs. So many more days and nights when you came away knowing that you’d be okay, that you could manage, that you weren’t the only one in this boat.

I couldn’t leave without saying how impressed I have been by the dedication of the staff who work with our children. During the past three years, we have met many professionals and volunteers who have never failed to believe in our children or in us. You are a national treasure, and we thank you.

I would also be remiss if I didn’t express appreciation to all the spouses, grandparents and friends who have supported us. It would have been impossible to get our children everywhere they had to go without the people who transported them, baby-sat for our other children and helped in other ways.

Like all graduates, we parents are a little nervous. We came here timid and full of questions. Now we have learned the ropes and have even been bold on several occasions. So now we face a future that is not as simple as our past. To leave early intervention is to acknowledge that our children are getting older and that some of our questions remain unanswered. But I believe that if we remember well the lessons we have learned here, we will learn to live with the questions. And our children will continue to be the wind beneath our wings.

**Epilogue**

Last September, my daughter Dana, now six years old, began attending the local elementary school her 10-year-old brother also attends. She is partially mainstreamed in a kindergarten class and rides the regular school bus with other neighborhood youngsters. Dana also participates in Daisy Girl Scouts, religious education and dance classes.

The support I continue to receive from other parents I met through early intervention remains a constant in my life. Although our children have gone their separate ways, our parent support group continues to meet every month or so to exchange information and support each other through the ups and downs of our children’s lives.

Another thing that doesn’t change after early intervention is the need for parents to continue to learn not only about their own children’s disability, but also about the educational system, inclusion and other issues. Monitoring your child’s education can be so overwhelming, but it’s absolutely necessary.

The third thing that doesn’t change is that parents are still their children’s primary teachers. This is true even though their children may spend the majority of their day someplace else with experts. Parents of children without disabilities impart their values and learning to their children through everyday activities—reading, shopping trips and household chores. We must do the same for our children with disabilities. This is critical in developing our children’s self-esteem and making them feel like an integral part of the family.

Teresa M. Rafferty is the mother of six-year-old Dana, and ten-year-old Devin. She is a freelance health care writer and president of the PTA at the elementary school her two children attend. Her husband, Tom, is employed by the State of New Jersey as an administrator for Medicaid.
FATHERS’ VOICES

I’m Bryan’s Dad and Part of His Team

by Bob Craig

A
fer several years of par-
ing a child with special needs, I am well aware of how easy it is for fathers to feel left out of the process. The family is much more than “mother and child” and needs to be considered as such. Early childhood specialists at all levels have much more experience with, and may feel more comfortable with mothers.

Have you—as a father—ever have been at a therapy session, parent conference or doctor’s visit and felt that no one was talking to you? If so, it’s time to take action! Don’t allow yourself to be left out. Parenting any child is hard work; parenting a child with special needs is especially tough. Everyone who is in contact with your child on a regular basis must be pulling in the same direction—including you. We don’t need to be on the same rope, but we all need to pull in the same direction.

There are many things that we as fathers can do to remain involved in the complex parenting process. My son, Bryan, has diplegic cerebral palsy. During his early days of diagnosis and treatment, it helped me to be the keeper of records. After each significant visit, we asked for a written report. By tending this file, I could keep track of what was going on—even during visits I couldn’t attend.

Staying involved means asking questions. At each doctor’s visit or parent conference, come prepared with a few questions of your own. Ask your questions as early as possible during each meeting. This keeps service providers mindful of your involvement.

You may not be able to attend therapy sessions with regularity, but you can know all the people your child is seeing, and you can know what they do. It’s useful if you can dedicate a few of your vacation days each year to stay in touch with your child’s therapists. Ask therapists to recommend specific things that you and your child can work on together—you can call them “father’s projects”—and ask for occasional “after-hours” sessions or meetings. Fathers often can provide a different approach toward solving the same problems that Mom is working on. This will give her some essential respite also.

Whatever you do, stay involved! It’s important for you as a parent. It’s important for your child with special needs. And it’s an important statement to professionals on behalf of all the fathers who will come after you.

Mary Ellen and Bob Craig share 10 acres of West Virginia hillside with six-year-old Bryan and nine-year-old Erick, two dogs and numerous wild turkey and deer. Craig works as an instrument specialist at the Robert C. Byrd Health Science Center at the University of West Virginia. Bryan is a full participant in his kindergarten program and Erick is doing well in the third grade. When not chasing after his sons, Craig participates on the West Virginia Family Support Council, the West Virginia Family Voices Campaign and the West Virginia Assistive Technology System.
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Circle #153
Judy Heumann

Part One

Clinton Appointee talks about growing up with a disability

Judy Heumann, Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS), U.S. Department of Education, was interviewed by Exceptional Parent in December 1993. An activist and policy-maker, Heumann worked on Section 504 of the Rehabilitation Act and its reauthorization, the Individuals with Disabilities Education Act, the Americans with Disabilities Act and federal policy guidance governing the provision of personal assistance services to individuals with significant disabilities. She was the first wheelchair rider to be hired by the New York City public schools. Heumann was also co-founder and vice president of the World Institute on Disability, a public policy/research/training organization. This is the first part of our interview.

I am 46 years old. I have been disabled since I had polio at the age of three. I was born in Philadelphia, but grew up in Brooklyn, New York. I come from a family where both my parents were strong advocates. I don't think they were advocates prior to my having my disability. They learned how to become successful advocates to get what they felt I needed to have.

I started my education at home. I was accepted by other kids in the neighborhood even though I was on home instruction during the day. After school, when the kids came home, I played with my friends. I went to Hebrew school; I was in Brownies and Girl Scouts. I took piano lessons and singing lessons and was very, very involved. Outside of going to school, I was able to do the same things as everybody else in the neighborhood.

When I was about nine and a half, I started going to public schools in a segregated program and to camp. I went to Camp Oakhurst and Camp Jened, special camps in New York State. I went to segregated camps, and when I started school, I went to a segregated school.

I was a nine-year-old fire hazard
My mom and a number of other mothers had worked to convince the Board of Education not to force kids in wheelchairs into home instruction. So the Board designated some regular schools in Brooklyn and the other boroughs for kids in wheelchairs to attend. Perhaps there was more than one school in each borough, but there were not very many. I attended segregated classes in a regular elementary school; we weren't integrated for lunch or recess or anything.

The only reason I was in separate classes in elementary school was because I couldn't push my own wheelchair or walk, and I needed help going to the bathroom. I was in classes with children who had different types of disabilities. The more significant their disabilities were, the more they were regarded as not being capable. At that point in my life, I think I learned that people were written off because of the significance of their disability. If they were in a wheelchair, that was a problem. If they were in a wheelchair and had a speech disability, that was a bigger problem. And if they were in a wheelchair and had a speech disability and had some learning disabilities, that was an even bigger problem. I think this attitude primarily existed in the adults, but it obviously had an adverse impact on us children.

I was bused at least an hour and a half each way to school, when the school in my district was four blocks from my house—maybe ten minutes away. But I wasn't allowed to go to
High School and College
When I was older, I got bused to Sheepshead Bay High School in East Flatbush, even though Erasmus Hall High School was the one in my district. In high school, I was in a quasi-integrated setting. My classes were with non-disabled students, but I had homeroom with disabled students. I didn't get to participate in many after-school activities because of transportation problems.

I went to college at Long Island University in Brooklyn. I majored in Speech and Theater because the state rehabilitation agency wouldn't support a major in Education. Students had to demonstrate that they could get a job related to their majors. I could get a job as a speech therapist.

But I was interested in teaching. I knew that I was eventually going to take classes in education so that I could teach. At that time—in the sixties—you only needed twelve credits to become a teacher, because there was a teacher shortage. So as I was beginning my junior year, I started taking classes in education. I also contacted the American Civil Liberties Union to let them know that I thought that I might have a problem once I completed my coursework, because I knew of no people who used wheelchairs who had been hired as teachers. They told me to take the classes and call back if there was a problem. So I took my twelve credits. Nobody in education ever asked me why I was taking these classes. And nobody from the state rehab agency ever asked me either.

Becoming a Teacher
When I graduated in 1970, I registered to take the teaching exam for New York State. The exam included medical, written and oral exams. I passed my oral and written exams; I was failed on the medical exam because of my disability.

I had a friend who was a student reporter for the New York Times. He was able to get a Times reporter to do a story about my situation. The next day, there was an editorial in the New York Times. And the day after that, I was on The Today Show (NBC-TV) with Bob Herman. Then I got a cou-
I think we need to look at disabled children and adults like other minority groups. I think we need to recognize that being different isn’t necessarily negative.

The Board of Education settled out of court, and I started teaching that September. They found a job for me in the same elementary school I had attended. It was a regular school that had a number of special classes in a separate wing. I taught special education classes for one year without a license. The next year, they moved the regular second grade class down to the first floor. So for my second year there, I taught regular second grade. The next year, they sent all the disabled kids to another school, but I stayed and taught the regular students.

Disabled In Action

While I was teaching in New York, I became very involved in a group called Disabled In Action (DIA), a civil rights organization run by disabled people. We started that group because I had gotten lots and lots of letters and phone calls from disabled people and their families and friends when I was in the newspapers and appearing on TV and radio. When I was doing my interviews, I didn’t just talk about trying to get a teaching job. I talked about things that were going on for disabled people all the time—the basic types of discrimination that disabled people faced. A lot of people contacted me to say they were having similar experiences and felt it important that these issues were being discussed. A number of friends and I decided that we would take all these letters and phone calls and invite people to come to a meeting. And DIA came out of that meeting.

DIA was involved in lots of different issues—anything from access on streets, to access in buildings, to the Rehabilitation Reauthorization Act, to working on the civil rights provisions in the Rehabilitation Act.

On Segregation

The fact that I went to segregated educational settings and camps while growing up was not all negative. The positive part was getting to meet other disabled kids. I think it is very important that disabled children and teenagers meet and have opportunities to socialize with disabled people.

I think it is interesting that in the deaf community, we have accepted that deaf children need to be educated with sufficient numbers of other deaf children—not only to learn academics, but also for socialization purposes. The same type of attention hasn’t been paid to kids with other types of disabilities.

I think that sometimes parents of disabled children think that it’s better for their kids not to be around other disabled kids because they want to help them become more integrated. I think that attitude is a big mistake. I think we need to look at disabled children and adults like other minority groups. I think we need to recognize that being different isn’t necessarily negative.

For me, being able to become friends with disabled kids helped me feel better about myself. Now, as I travel around the country and talk with parents, I do hear some parents say that they believe that it is important for their disabled children to have experiences with their disabled peers. But they are forced to make a choice—to put the child in an inclusive program or to put the child in a segregated program. I don’t think it should have to be an either-or situation. I think that parents need to speak for themselves and with their children and tell the schools that they feel it’s important for their children to have social experiences with other disabled kids. It’s equally important for the non-disabled children to be able—whenever possible—to be exposed to numbers of children with all types of disabilities.
Since its introduction in September, we have reported regularly on the progress of President Clinton’s health care reform proposal. We have received many letters urging us to continue these reports. We also have heard from a number of parents who shared their concerns—based on various reports—that children with disabilities may be shortchanged under the currently proposed plan. In December, for example, the Associated Press reported on a hearing during which members of the Senate Finance Committee had acknowledged that children with “birth defects or chronic health problems could be excluded from coverage under President Clinton’s plan…”

In reviewing the following reports and commentaries, it is essential to remember that despite perceived inadequacies—the President’s proposal offers major reforms that vastly improve many aspects of the current health care system.

Current concerns

Two specific gaps in coverage for children with disabilities have been identified—outpatient rehabilitation services and “customized” durable medical equipment. The proposal’s coverage for outpatient rehabilitation services emphasizes the restoration of physical or intellectual functioning following “illness or injury.” Accordingly, it appears to omit long-term, outpatient services that many children with disabilities require to maintain current abilities and prevent future problems. Such outpatient services might include physical therapy, occupational therapy and speech and language therapy. Administration officials agree that this issue and have urged concerned citizens to contact members of Congress to advocate for the necessary coverage.

“Durable medical equipment” includes seating systems, wheelchairs and many other products. The health reform plan appears to cover “durable medical equipment” and “prosthetic and orthotic devices,” while “customized devices” are excluded. Limiting coverage to “off-the-shelf” equipment presents a problem since devices for children are often customized—or individualized. Current health insurance coverage typically has similar limitations requiring parents to pay the difference in cost between the “generic” and “customized” versions of a product. This difference in cost, however, can be substantial.

Knowledgeable advocates have raised additional questions about how other services for children with disabilities will be covered. These include Medicaid payments for early intervention services, so-called “related services” such as therapies within special education programs, and EPSDT (Early and Periodic Screening, Diagnosis and Treatment) services. Concerns have also been raised about coverage for home care and community-based services for people with severe disabilities. Though the reform proposal includes some important services of this kind, it allows individual states to place restrictions on eligibility and types of services provided.

Write Now!

This month’s coverage of health care reform includes our adaptation of a recent call to action prepared by the Exceptional Parent 33
Consortium of Citizens with Disabilities. We also bring you the personal story of a Virginia family that was forced into bankruptcy by health care costs. We asked Larry Allen to share his family’s story because it is all too typical of the health care horror stories that could be written by many families of children (or adults) with disabilities. Anne Lauritzen tells a similarly frightening story in the Informational Forum on page 42. The National Parent Network on Disabilities also urges everyone to get involved (see page 41).

We urge our readers is to make contact with their representatives in Congress. Do not hold back! Parents of children with disabilities and many dedicated advocates are struggling against the vast resources of those in our society who prefer the status quo.

In fact, we believe that it is time for our elected officials to receive letters from the most important individuals involved—children with disabilities and special health care needs. Though most parents and organizations are understandably cautious about involving their children in public advocacy campaigns, we believe that letters from children as well as parents are needed to sufficiently dramatize the urgency of reform in health care for all individuals with disabilities. We hope our readers will encourage their children to write such letters and will send copies to us so that we may publish some in future issues of Exceptional Parent.

Remember—just a few months ago, the “Brady Bill” was facing imminent defeat in Congress. A dramatic groundswell from everyday citizens turned the tide—the “Brady Bill” is now law. The health care reform proposals before Congress are vulnerable. The administration and members of Congress from both political parties are under enormous pressure to “settle for less.” This pressure is very powerful—but not insurmountable.

Health Care Taxes

Any discussion of taxes makes elected officials and many citizens very anxious. It may well be necessary to address the need for additional tax revenues to pay for the critical changes in health care that are needed by children and adults with disabilities. However, we believe that the actual net cost to each family for health care—including current health insurance premiums, actual health care expenses which are not covered and possible health care taxes that may be required—may not increase. In addition, we believe that the health security that President Clinton proposes will greatly decrease the ever-present fear hanging over the heads of most Americans—what if a member of my family needs health care and it isn’t covered? Think of it—this may be the decade when we will put aside our fears of both nuclear annihilation and catastrophic health needs! The load off our minds could do wonders for our health.

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Circle #86

February 1994
Health care reform represents an historic moment in American society—one which may not recur for many years. Children and adults with disabilities and their families cannot wait that long for lifetime health care security. Thanks to the leadership of President Bill Clinton and First Lady Hillary Rodham Clinton, we have the opportunity to convince members of the United States Congress to establish a federally-guaranteed right to health care for each American regardless of age, pre-existing condition, current health status, employment status or income.

Unfortunately, many special interests in this $939 billion sector of the country’s economy (one-seventh of the gross domestic product) want to maintain the status quo. To that end, they are expending millions of dollars in an attempt to convince the public and members of Congress that we do not need major health care reform and that we cannot afford it. This is a fascinating conclusion since the United States now spends more dollars per capita on health care than any other country, but is the only country in the free world that does not have a national right to health care.

Now, it’s up to the 535 members of the United States Congress. We must begin to act today in a united disability voice to help them develop the “political will” to vote for legislation that guarantees a national right to comprehensive health care for all Americans. The President’s Health Security Act was officially introduced in November as [Senate bill] S. 1757 and [House of Representatives bill] H.R. 3600. All other bills [ . . . have been introduced—except for the President’s plan and the “Single Payer” plans (S. 491 and H.R. 1200)—are dangerous to children and adults with disabilities. As Congress begins to work on these bills, your action is needed to ensure that they properly address issues affecting people with disabilities.

Health care reform is the most critical issue that Congress will address in 1994. The results will directly impact the life of every child and adult with a disability in this nation. We in the disability community must convince Congress and the nation that we will not accept—and in fact, will vigorously oppose—tinkering, band-aid solutions masquerading as true reform. We will accept nothing less than comprehensive, lifetime health care security that is guaranteed by law to every single child and adult in America.

Every American with a disability, their family, friends, advocates and service providers in every community must get involved in the health care reform debate immediately. Congress must hear from us now. Your national disability advocates cannot compete with the multi-million dollar budgets of the health insurance, hospital, physician, pharmaceutical, and nursing home industries. Their lobbyists and well-funded political action committees (PACs) are formidable opponents to reform. Your action can and will make the difference!

Time is of the essence! Some Congressional subcommittees are planning to complete their work on the bills as early as the end of February in preparation for votes by the full House and Senate. You, as a voting constituent, must tell your Congressional representatives that you expect them to vote for health care reform that meets the needs of people with disabilities. Tell them about your personal family experiences. People with disabilities and their families must convince members of Congress that long-term services reform is an essential part of health care reform. Throughout this process, we all must work to protect, strengthen and improve the provisions of the bills as they affect children and adults with disabilities and their families. Without establishing the right to health care, it will not matter what is included in the comprehensive benefit package. The one message we must all say loud and clear is to support the President’s commitment to make health care a right for all Americans.

Adapted from an “Action Alert” published by the Consortium for Citizens with Disabilities
Being asked to relate our family’s story has proven to be an emotional roller coaster ride. To this day, we aren’t sure where, when and how this will end. We thank God every day for allowing us to enjoy the good times and accept the bad times as dark moments that will pass.

Our story began in 1978, with the birth of our oldest daughter. Shortly after Michelle’s birth we received a phone call from her doctor, who told us that she had sickle cell anemia. We had no idea what to expect.

We realize that we are one major illness away from bankruptcy again.

Michelle didn’t get sick until she was three. When she had her first crisis, a painful episode requiring hospitalization, we had a rude awakening—our health care carrier refused to pay some of her bills. As Michelle got older, her medical problems worsened, requiring more frequent and longer hospitalizations. The bills kept growing, yet our income was getting smaller.

Our next step was to talk with some financial counselors, all of whom recommended declaring bankruptcy. One month after filing Chapter 13, we needed to bring Michelle to the hospital. The hospital refused to administer treatment, demanding to know how the bills would be paid. It took our attorney four hours to explain the situation before they would even examine her. The worst part was realizing that if the hospital continued to deny her treatment, we had nowhere else to turn—the other area hospitals were not as well equipped.

At this point, my wife had to quit her job. Michelle was getting sick more often and someone had to be with her when she was ill—whether or not she was hospitalized. We learned this the hard way when Michelle was almost given a chemotherapy treatment intended for another child with the same first name.

Our second son, Larry, was born in 1983. Prenatal testing showed that he was healthy. In 1985, my wife became pregnant with our third child, Michael. Again, prenatal tests for sickle cell anemia came back negative. But this time the tests were wrong. At three months of age, Michael was diagnosed with sickle beta thalassemia.

Matthew’s illness was much worse than his sister’s. By the time he was two years old, he had already been hospitalized 15 times. Michael’s doctor told us to prepare for the worst, because his body was wearing out. They didn’t think he would live another six months, but we could see too much life in Michael to give up. We knew we had to find help elsewhere, so we moved to another state where our children could receive better medical care.

In the last 15 years, we have never had one moment when we could sit back, relax and regroup. We are still dealing with a tremendous emotional and financial burden. We realize that we are one major illness away from bankruptcy again. There are constant challenges—keeping the
utilities turned on, paying the mortgage and keeping food on the table.

In 1993, my wife and I were invited to a human genetics conference, where we heard about some of the research into new technologies that may one day lead to cures for many genetic disorders. We also heard from others experiencing similar problems financing health care. This was an emotional lift. For so long, we had felt like we were all alone with these problems.

Prior to this conference, if we had been asked to relate our story to others, we would have talked about the pain our children endure and the guilt and depression we as parents live with everyday. We would have spoken about our loneliness and fear. About being told we’d be better off on welfare. About feeling out of place—even around family and friends. And about worrying that I might lose my job, because when both children are sick, it requires both of us to take care of them. But, now there is one more thing we can speak of—hope.

Larry and Michelle Allen live in Chesterfield County, VA with their three children. They are members of the Mid-Atlantic Regional Human Genetics Network (MARHGN) and the Virginia Sickle Cell Awareness Program of the Medical College of Virginia (VASCAP). Their son Michael was Virginia’s 1993 sickle cell poster child.

Meeting the Governor: As his state’s 1993 sickle cell poster child, Michael, along with his mother and sister Michelle, met Virginia Governor Douglas Wilder.

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February 1994
My son wears a bright red helmet for protection. No, he's not an all-pro linebacker; he's a child who has been diagnosed with a "neurodevelopmental delay"—though medical professionals debate whether apraxia might be a more appropriate description. Lacking a precise diagnosis, Mike is simply a three-year-old who is more clumsy than the norm.

I've had a love/hate relationship with the helmet from the start. At first, I resented the fact that Mike needed to wear one at all. The first plastic ones the physical therapist showed me looked so clinical and strange. They were also inappropriate for our humid southern climate. Mike would sweat profusely whenever he wore his new headgear.

We shopped around in many toy and bike shops to find just the right helmet. For a few months, he wore one that seemed to need adjusting every time he sneezed. After further experimentation, we bought the helmet he now wears. Despite its startling red color, it is more forgiving and needs less attention than any other we'd tried.

Like most parents, I hated the idea of my child needing any special equipment that would instantly allow him to be labeled as "different" or having "special needs." While a helmet is not as obvious an aid as a wheelchair or hearing aid, there still aren't many children toddling around with one. But after Mike fell against a glass table at the bank and needed 12 stitches, my husband and I decided the protection his helmet provided was more important than the stares, questions and comments it elicited.

When strangers at restaurants and other public places would ask about the helmet, my responses ranged from simple explanations of Mike's situation to outright rudeness. I wondered whether people using wheelchairs, walkers or other, more standard aids got as many foolish questions as we did, and why strangers felt they had the right to know everything about my child.

I remember the time when just as someone asked about the helmet, Mike tripped over a nonexistent piece of dirt and fell to the floor. "I can see why he needs it!" one of them said, and they all laughed. It bothers me enough that he needs the helmet, but stupid comments like this hurt a lot also.

These days I have a more assertive attitude about handling situations with the helmet. Last month, I took Mike and his brother to a local indoor playground that had slides, ball pits to jump in, and mazes to climb through. We were having fun until an employee approached us. Another patron had complained that the helmet had "bumped" her child and the manager wanted me to either remove the helmet or else "watch Mike like a hawk." As if I don't always watch Mike as carefully as I can when I'm in these places!

Would a place like this ask a person with a walker to get rid of it? Would they tell a child with a hearing aid to take it off? I was so stunned that it was ten minutes before I recovered enough to ask if I could speak to the manager, only to be told that he or she had left. I was too angry to just leave and pretend the incident had never happened. When I got home, I wrote the manager a letter. Later, I got a very sincere letter of apology with some gift certificates for a return visit.

Not every situation involving Mike's helmet has been hurtful. We've learned to keep our sense of humor. Once, when asked about Mike's helmet at synagogue, I replied that he wore it in lieu of a yarmulke. This explanation was accepted with no further questions.

Then there was the time our family was out shopping for a new car. The salesman kept peering at Mike. I
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Health Care Reform Misses Persons with Disabilities

by Larry Searcy
Director of NPND
Government Relations

Currently, the Clinton health care reform proposal does not adequately address the needs of children or adults with disabilities. This omission has been admitted by Judy Feder, Deputy Assistant Secretary of the Department of Health and Human Services in testimony before the Senate and pointed out by Dr. C. Everett Koop, former U.S. Surgeon General, in remarks he recently made.

We must make our concerns known to the Congress as never before or face the likelihood of a national health care system that is less responsive to the needs of our children than our current system.

Your members of Congress must hear from you now about the need to assure that people with disabilities be included in any plan of national health care. Most importantly, they must understand that we are united, we have a common voice in Washington, and we are closely watching what our Congresspersons do to respond to our needs.

If your Congressional representatives do not hear from you, the chances of attaining reform that meets the needs of people with disabilities are slim to nonexistent.

What to do:

- Meet with your members of Congress at their local offices.
- Be assertive. insist on seeing your Congressperson or Senator face-to-face. Failing that, insist on seeing the local Chief of Staff.
- Participate in town meetings, open forums, hearings, and similar events where your national politicians will be present.
- Work with other disability and consumer-oriented groups (e.g., family, children, women's, religious, professional, labor, and business organizations) to send a coordinated message to your elected politicians.
- In addition to joint letters and meetings, consider staging public events like consumer hearings around your state that highlight the health needs of persons with disabilities. Whatever sort of events you plan, aim at gaining coverage in the local press.
- Contact your physician and related health professionals and solicit their support. Ask them to communicate with their professional organizations in support of services needed by children and adults with disabilities.
- Prepare personal stories about the importance of health care and long-term services reform. Tell your real-life horror stories about:
  - Non-treatment of health conditions or about discrimination in the present health care system;
  - Impoverishment or other severe financial circumstances stemming from costly health insurance premiums, high medical expenses or unfair existing insurance practices;
  - Work disincentives resulting in continued unwanted dependency on public assistance.
- Write and encourage others to write letters or op-ed articles for the local paper on the health care experiences and needs of people with disabilities.

What to Say:

1. People with disabilities and those who work with and care about them want health care reform. Reform must be accomplished now! It cannot be put off!
2. Access to high quality health care is the right of all Americans, including people with disabilities.
3. The minimum acceptable health care benefits package must be comprehensive and include habilitative and
rehabilitative therapies, customized durable medical equipment, home health services, mental health and substance abuse services—without arbitrary caps or limits.

4. Long-term services and personal assistance services must be a part of the benefits package.

5. Discriminatory practices such as pre-existing condition exclusions must be eliminated. The health care system must comply with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.

6. Consumer involvement must be a part of the system. The system must have built-in consumer protections and quality assurance mechanisms to ensure that people with disabilities get the services that they need.

7. People must not lose access to services that they presently have either through private coverage or Medicaid.

8. A full array of prevention services such as Early Periodic Screening Diagnosis and Treatment must be kept in place. We must also keep Medicaid services that are often utilized in conjunction with Part H services or supportive services provided in conjunction with Individualized Education Plans mandated in IDEA.

9. Identify yourself as a member of or as supporting the National Parent Network on Disabilities.*

   Please do your part to make health care and long-term services a reality. Let's make sure that our children and adults with disabilities are not left out of legislation that will impact us for the next twenty years or more!

* Excerpted from an “NPND alert” sent to NPND members on December 15, 1993. The full alert and the NPND “Principles of Health Care Reform” are available to all NPND members. This information was based on data compiled by the Consortium for Citizens with Disabilities.

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My son Drew, now 18 years old, was born with spina bifida. Because of the spina bifida, Drew has neurological, orthopedic, urological, hearing and cognitive impairments. He is paralyzed below the waist and uses a customized wheelchair. Five to six doctors are required to maintain Drew’s health. At least two of his specialists are located in another state.

Drew’s medical needs have forced our family to put him on the comprehensive health insurance policy that Nebraska has developed for those with pre-existing conditions who have not been able to obtain other insurance. Drew’s current policy serves his basic needs—other than that we pay a $120.00 per month premium just for him, and the insurance company continues not to understand how his unique medical needs differ from those of the generally healthy population.

Because we have chosen this policy for Drew we cannot access the Medicaid system. We could drop this policy and get him covered by Medicaid, but then we would be less able to take Drew to the out-of-state specialists he needs. It puts us in a continuous dilemma regarding the best care for him and its continuing costs. We incur many costs every month that are never covered by his current insurance policy but might be covered by Medicaid.

As I read the information about health care reform in the newspaper and from disability coalitions, it seems that the plan does not address the need for specialized health care for many citizens, particularly those with disabilities. I am disturbed that the plan still has an acute care/institutional bias and does not place enough emphasis on family, home and community services. Coverage must go beyond the illness and injury perspective to include those with congenital conditions and aging. Persons with physical disabilities do not improve in their functions to a point of wellness, but they need maintenance and rehabilitative services and supports in order to function in the community.

To maintain his health, health care reform must give Drew a plan that is based on his needs—he will need long-term care in the home and community. He will need home supports, access to specialists in other states, access to physicians that have specialized knowledge about his disability, physical and occupational therapy, hearing aids covered by insurance and customized equipment.

I support universal access for all citizens, with no pre-existing condition exclusions; the guaranteed comprehensive benefit package; portability and the recognition that long-term care is a crucial component.

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“**All Children Belong**
to Hold National Teleconference

“All Children Belong,” a national inclusion awareness and training program supported by the DeWitt Wallace—Reader’s Digest Fund, will hold its first national teleconference training event on March 9, 1994. The three-hour session—currently scheduled to begin at 1:30 p.m. EST—will focus on providing an overview of supported inclusive education and community-wide supported inclusion. Participating project sites will be able to interact with the national “All Children Belong” training staff.

If you are interested in gaining access to the teleconference please contact Larry Searcy at the National Parent Network on Disabilities (703-684-6765).
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Director Retail Sales.

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Winston Churchill, Albert Einstein and Hans Christian Anderson had learning disabilities. Some children with LD have that kind of potential—some are talented or gifted—but almost all are thought at one time or another to be lazy and unmotivated. Or retarded.

By definition they are not retarded! Learning disability is a specific diagnosis. It includes the presumption of normal or better intelligence. It requires remediation based on that presumption. For an authority like Exceptional Parent to use “Down syndrome” and “learning disability” interchangeably alters that presumption.

This really is not about labeling. It is about differential diagnosis. I am probably especially sensitive to this because our three sons had needs so like and so unlike those of his brothers. We had to strive constantly to find what was best for each of them individually—always with the prayer that if we came as close as we could to making right decisions for each one, the impact on the whole family would be right, too.

So, M.P. of Indiana, when you say you’re certain of my motivation, and ascribe to me a motive that’s not mine, I have to try again to say it better.

P.P. of Ohio, no, of course, kids with learning disabilities are not more valuable. But they are as valuable and as entitled to education specific to their needs. I never meant that “those with cognitive developmental delays are less deserving of service,” but the truth is that they have had much more service for many more years than children with learning disabilities.

E.P.K. of New York, I loved reading that your son will graduate from high school with a “full academic diploma!” I love that, but I would not love him more than I’d love those who never learn so much. As our child’s retardation became more and more profound, our love grew and grew. You’re right, it’s not about “an IQ number.”

P.B. of Georgia thought my remarks insensitive and based on ignorance. I hope I’m neither. I have known many children with Down syndrome and read of even more. In all the years I’ve subscribed to Exceptional Parent, my favorite article was one called “Proof of the Pudding,” a mother’s story of a beautiful and accomplished little girl who had Down syndrome (May/June 1974).

That was my favorite, though I have twice been published in Exceptional Parent myself. “Loving a Special Child,” about my eldest son, was reprinted in Readers Digest. “Tribute to a C Student,” about my son with learning disabilities, has been reprinted in a lot of school newsletters.

For many years I have been volunteer editor of Our Kids magazine for the Parent Section of the Alexander Graham Bell Association for the Deaf. I have done everything I’ve known to do to make things better for my children—and yours. I always thought my biggest contribution had been writing about our children, so it’s ironic that I could not write a letter to the editor without offending those with whom I feel I share the most.

I hope that the five who wrote (and any other readers who were hurt by what I wrote) will understand now. If I still haven’t made my point, I hope you’ll forgive me. I never meant to hurt you or your children.

Phyllis Feibelman
3637 Longview Lane
Mobile, AL 36608
(Name and address printed by request)
Many children with physical disabilities need assistance in order to best use their abilities and be comfortable while lying down, sitting or standing. Positioning refers to the process of establishing the most effective way to assist such a child. When properly positioned, a child has the postural support needed to interact with people and activities without being concerned with losing balance or falling and has better control of body movements. Proper positioning can improve circulation, breathing and digestion. It may also prevent some bone deformities, muscle problems and skin problems.

This article focuses on buying equipment for seating. Accordingly, the terms “seating/positioning equipment” or “system” will be used. The buying guidelines in this article also apply to other types of positioning equipment. Choosing the best seating/positioning system for a child requires time and effort, but it is time well spent. Here are some tips that can help.

Adopt a team approach when considering equipment choices. In addition to parents and child, the team may consist of an occupational therapist and/or physical therapist, a technical person such as a rehabilitation engineer, a physician knowledgeable about positioning, and an adaptive medical equipment dealer. Teachers, social workers or rehabilitation nurses may also make useful suggestions. The team approach should be an ongoing process, as there is always new knowledge and equipment available that may help your child.

For some children, readily available seating systems can be adapted to meet the child’s specific needs. The companies listed at the end of this article are sources for such systems. For other children, however, highly individualized systems may need to be created: some clinical settings are equipped to create these. Medical equipment dealers will often be glad to give names of other parents as references. This can be helpful, but remember that what works for one child may not necessarily work for yours. Every child is a unique individual, and is likely to have different positioning needs.

If the equipment is covered by health insurance, be sure to review the insurance company’s contract with the manufacturer or the adaptive medical equipment dealer. Sometimes, insurance companies have contracts with some manufacturers and not others. Accordingly, there could be problems with payment.

Before purchasing equipment, be sure you and your child can test it out on a trial basis. Also, make sure the dealer and or clinician is willing to provide training and follow-up for parents, other key adults and the child. When ordering equipment from a specific manufacturer, deal with the manufacturer’s authorized local supplier, as this will simplify your relationship with the company you choose.

Most manufacturers offer custom-made models—if your child needs one, make sure parts and repair are easily available. Make sure the product offers a warranty, and see if it can be repaired locally. Also, consider leasing or renting a system, especially if the child’s condition is expected to change.

Be cautious about multi-purpose products (i.e., commode shower chair wheelchairs) that perform many functions but none as well as a product designed for a specific application.

Above all, ask questions—about anything that may come to mind. Here are some frequently voiced concerns:

- Adaptable: The seating positioning system should fit perfectly at the first use, but will it be able to grow with your child? As your child’s skills evolve, can the chair be adapted without costly new parts? Equipment can be expensive; consider the price spread out over years of use.

continued on page 50
## Positioning & Seating Directory

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<tr>
<th>Company</th>
<th>Address/Location</th>
<th>Phone Numbers</th>
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<tbody>
<tr>
<td>Accu-Back</td>
<td>1475 E Del Amo Blvd, Carson, CA 90745</td>
<td>(800) 272-8888</td>
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<tr>
<td>Accumec</td>
<td>32 Race St, San Jose, CA 95126</td>
<td>(408) 294-3100</td>
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<tr>
<td>adaptAbility</td>
<td>PO Box 515, Colchester, CT 06415-0515</td>
<td>(800) 243-9232</td>
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<tr>
<td>Adaptive Engineering Lab</td>
<td>4403 Russell Rd, Bldg 2A, Unit 3, Mukilteo, WA 98275-5018</td>
<td>(800) 327-6080</td>
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<tr>
<td>Alagold</td>
<td>1920 S Court St, PO Box 4959, Montgomery, AL 36103</td>
<td>(805) 834-6900</td>
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<tr>
<td>Alimed</td>
<td>297 High St, Dedham, MA 02026</td>
<td>(800) 225-2610</td>
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<tr>
<td>American Ergonomics</td>
<td>200 Gate Five Rd, Ste 215, Sausalito, CA 94965</td>
<td>(415) 332-5635</td>
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<tr>
<td>Apar</td>
<td>95 Rantoul St, Beverly, MA 01915</td>
<td>(508) 927-9236</td>
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<td>Back Ease</td>
<td>PO Box 5283, Louisville, KY 40205</td>
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<td>Backsaver Products</td>
<td>53 Jeffrey Ave, Holliston, MA 01746</td>
<td>(617) 429-5940</td>
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<td>Bailey Manufacturing</td>
<td>118 Lee St, Lodi, OH 44254</td>
<td>(900) 321-9372</td>
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<td>Bauerfeind USA</td>
<td>1590 N Roberts Rd #314, Kennesaw, GA 30144-3679</td>
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<td>Bell-Horn</td>
<td>451 N 3rd St, PO Box 3408, Philadelphia, PA 19123</td>
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<td>Bodycare</td>
<td>315 Glimer Ferry Rd, Ball Ground, GA 30107</td>
<td>(800) 858-9888</td>
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<tr>
<td>Bodyline Comfort Systems</td>
<td>3730 Koni Rd, Jacksonville, FL 32257</td>
<td>(800) 874-7715</td>
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<td>C F Wood Industries</td>
<td>7021 W Augusta Ave, Ste 108, Glendale, AZ 85303</td>
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<td>Canadian Posture &amp; Seating Center</td>
<td>PO Box 1473, Station C, Kitchener, Ontario N2G 4P2</td>
<td>(519) 743-8224</td>
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<tr>
<td>Canadian Wheelchair Mfg Ltd</td>
<td>1312 Blundell Dr, Mississauga, Ontario L4Y 1M5</td>
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<td>Canyon Products</td>
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<td>Cascade Designs</td>
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<td>CHS International</td>
<td>PO Box 21067, 550 39th Ave NE, Columbia Heights, MN 55421</td>
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<td>Columbia Medical Mfg</td>
<td>PO Box 633, Pacific Palisades, CA 90272</td>
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<td>Comfort Med</td>
<td>6050 Interchange Dr SW, Atlanta, GA 30338-1603</td>
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<td>Comfy Back/Evans</td>
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<td>Commander Omni Company</td>
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<td>Community Playthings/Rifton Equipment</td>
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<td>Consumer Care Products</td>
<td>PO Box 884, 810 N Water St, Sheboygan, WI 53082</td>
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<td>Contour Fabricators</td>
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<td>Convaid Products</td>
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<td>Crazy Creek Products</td>
<td>1401 S Broadway, PO Box 1050, Red Lodge, MT 59068</td>
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<td>Custom Rehab Equipment</td>
<td>609 NE Schuyler St, Portland, OR 97212</td>
<td>(800) 547-4611</td>
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<td>Danmar Products</td>
<td>221 Jackson Industrial Dr, Ann Arbor, MI 48103</td>
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<td>Dermacare</td>
<td>7651 National Turnpike, Louisville, KY 40214</td>
<td>(800) 826-4550</td>
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<td>Double K Products</td>
<td>915 W Lehigh Ave, PO Box 1087, Englewood, CO 80150</td>
<td>(303) 781-4019</td>
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<td>Duro Med Industries</td>
<td>301 Lodi St, Hackensack, NJ 07602</td>
<td>(800) 526-4753</td>
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<td>Dynamic Systems</td>
<td>RT 2, Box 182B, Leicester, NC 28748</td>
<td>(704) 683-3523</td>
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<td>Elyon</td>
<td>PO Box 20548, Bradenton, FL 34203</td>
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<td>Embracing Concepts</td>
<td>40 Humboldt St, Rochester, NY 14609</td>
<td>(800) 962-5542</td>
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<tr>
<td>Equipment Shop</td>
<td>PO Box 33, Bedford, MA 01730</td>
<td>(617) 275-7681</td>
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<td>ERGO-EEZE</td>
<td>PO Box 22623, Phoenix, AZ 85017-2263</td>
<td>(602) 789-0877</td>
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<td>ETAC USA</td>
<td>2325 Parklawn Dr, Ste P, Waukesha, WI 53186</td>
<td>(800) 678-3822</td>
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<td>Everest and Jennings</td>
<td>1100 Corporate Sq Dr, St Louis, MO 63132-2908</td>
<td>(800) 235-4661</td>
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<td>Flaghouse</td>
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<td>(800) 221-5185</td>
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<td>Foam Products</td>
<td>4747 Bronx Blvd, Bronx, NY 10470</td>
<td>(800) 283-4362</td>
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<td>Folio Products</td>
<td>1341 Sherman Dr, Unit A, Longmont, CO 80501</td>
<td>(800) 356-4125</td>
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<td>Frank Stubbins</td>
<td>4518 Vanowen St, Burbank, CA 91505</td>
<td>(800) 223-1713</td>
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<td>Fred Sammons Co</td>
<td>Box 32, Brookfield, IL 60513-0032</td>
<td>(312) 323-517</td>
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<td>Freedom Designs</td>
<td>2241 Madera Rd, Simi Valley, CA 92065</td>
<td>(800) 331-8551</td>
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<td>G E Miller</td>
<td>540 Nepperhan Ave, Yonkers, NY 10701</td>
<td>(900) 431-2924</td>
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<td>Gendron</td>
<td>400 E Lugbill Rd, PO Box 197, Archbold, OH 43502</td>
<td>(800) 337-2521</td>
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<td>George H Snyder Enterprises</td>
<td>5809 NE 21st Ave, Fort Lauderdale, FL 33308</td>
<td>(900) 772-6526</td>
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<tr>
<td>Golden Fleece International</td>
<td>14240 60th St N, Clearwater, FL 34620</td>
<td>(800) 562-7326</td>
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The following list of seating/positioning equipment manufacturers was provided by ABLEDATA, an Assistive Technology database located at the National Rehabilitation Information Center (NARIC). For more information, contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216.
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Circle #17
Purchasing Seating Equipment Tips for Parents

continued from page 45

- **Stability:** When the system is designed to attach to a wheeled base, does it attach easily? Is it stable and secure when the child is seated? If there are wheels, check the brakes/wheel locks carefully. Be wary of suction cups on the wheeled base, does it attach easily? Is it stable and secure when the child is seated? If there are wheels, check the brakes/wheel locks carefully. Be wary of suction cups on the base—do they have the potential to slip.

- **Ease of Operation:** Other people will need to work with the child's system. Will friends, teachers and baby-sitters be able to understand how it works? Check the seat belt/restraint buckles. Do they pinch? Can they adjust differencing thicknesses of clothing? Is there enough padding?

- **Portability:** Can your child be safely transported in the system?

- **Sleep:** Can your system be easily cleaned? Is it waterproof? If your child is incontinent, request a waterproof cover over the area that needs protection. Are the fabrics machine washable/dryable? Do they feel good in hot or cold weather?

- **Aesthetics:** Go for bright, bold colors. Drab colors can be dispiriting to your child's self-esteem. When choosing, however, consider function first.

---

**Resources**

Thanks to the following seating/positioning experts for their contributions: Allen Siekman, Director of Seating & Positioning, Avanti by Invacare, Elyria, OH; Michael Caan, Ph.D., President, Columbia Medical Mfg., Pacific Palisades, CA; Terrand B. Grail, Ph.D., President, Consumer Care Resources, Inc., Minneapolis, MN; Sue Garvin, Senior Product Manager, Preston, Jackson, MI. ■

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February 1994
RESEARCH

ALD—Balancing Hope Against Reality

by Hugo W. Moser

My wife Ann and I have been concerned with Adrenoleukodystrophy (ALD) since 1978 and now work on little else. The current situation with ALD is a perfect example of the hopes and controversies that arise when as yet unproved, still imperfect therapies emerge for a previously untreatable disorder.

The last 15 years have seen a number of exciting developments in diagnosis, prenatal screening and carrier detection. And recently, the ALD gene itself has been isolated. Wholeheartedly supporting our efforts has been a fine and extremely valuable parents’ organization—the United Leukodystrophy Foundation (ULF)—now in its twelfth year. Parents value all the advances that have been made, but in the absence of effective therapy, these advances are “flat” and unsatisfactory.

In search of therapies

During our 12-year association with the ULF, we have come to realize that if we lose credibility with parents, we lose everything. We must always inform families of the facts, as we understand them at any given moment. The facts can be painful. Sometimes it is impossible to tell the truth to families without shattering their hopes and creating despair. To help reduce such despair and in a genuine effort to advance the capacity to treat, we offer all patients the chance to enroll in therapeutic protocols that have a rational basis and are free of inappropriate risk. These experimental treatments are monitored by an expert Institutional Review Board and have the full knowledge and endorsement of the ULF.

Our primary and increasingly passionate efforts are directed toward the search for an effective therapy for ALD. We are deeply concerned and frustrated that treatments are still so imperfect. Current hopes rest with dietary therapy, bone marrow transplantation and—in the more distant—gene therapy. In addition, we are studying families in which some members are affected by the rapidly progressive form of the childhood disease, while their affected brothers, uncles or grandfathers have only the milder, adult form. Understanding the ways in which the rapidly progressive form of the illness develops may lead to the ability to alter these mechanisms.

Success of current therapies

Though “Lorenzo’s Oil” was a good and highly rational idea, research has shown that it is of little or no benefit to patients who already have significant neurological problems by the time they start this therapy. However, our recent data suggest that “Lorenzo’s Oil” may help to prevent the onset of neurological problems if it is started before such symptoms are present.

Bone marrow transplantation is a promising therapy for ALD—but only when performed early in the course of the illness using a well-matched marrow donor. Gene therapy is a great hope also, but its use is a number of years away.

The rapid progression of the most serious and common form of ALD—the childhood cerebral form—is caused by a brain inflammatory response. At this moment, we do not have a therapy for this form of the disease. We are about to initiate an entirely new treatment, however. If successful, this therapy will work by suppressing the inflammatory response of the brain.

Tuberous Sclerosis Gene Identified

Researchers have identified one of two genes for tuberous sclerosis complex (TSC). The gene for TSC2 on chromosome sixteen has been found; the search for the gene for TSC1 on chromosome nine continues. TSC is an autosomal dominant genetic disease affecting one in 6000 live births. As many as 60 percent of new TSC cases are new mutations. Progress in gene identification may lead to the availability of an accurate screening and diagnostic genetic test for TSC in the next few years. For more information or to volunteer to serve as a research participant, contact the National Tuberous Sclerosis Association, 8000 Corporate Dr., Ste. 120, Landover, MD 20785, (800) 225-6872.

Car Seat Warning

The National Highway Traffic Safety Administration (NHTSA) has asked us to warn parents that a rear-facing child safety seat should never be used in the front seat of an air-bag-equipped vehicle. An inflating air bag could strike the child seat with enough force to cause serious head and chest injuries. A vehicle’s back seat is the safest place for any child safety seat. For more information, call NHTSA’s Auto Safety Hotline—(800) 424-9393.
ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

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February 1994
Annual Income Tax Guide
by L. Mark Russell

It's everyone's favorite time of the year once more—time to think about taxes! As you no doubt know, tax law is very complicated. It is important that you understand it, however, so you can take advantage of all the deductions and credits to which you are entitled.

Unclaimed deductions and credits cost families hundreds, sometimes thousands, of dollars every year. This is especially true of families who have a member with a disability. These families are often entitled to deductions and credits which are unavailable to others. Sometimes even accountants are unaware of the possibilities. This article will summarize items that are of particular interest to families with members who have disabilities.

Exemptions For Dependents
You can take a deduction of $2,350 for yourself, and for each person who is your dependent. This is true whether or not the dependent has a disability. For example, if you have two dependents, and you and your spouse file a joint tax return, you will be entitled to a deduction of $9,400 ($2,350 x 4).

In most cases, it is relatively simple to determine whether a person is a dependent. If you provide more than half the person's support and the person is related to you, the deduction is generally permissible. You determine whether you have provided more than half the dependent's support by comparing the amount you contributed to the entire amount of support received from all sources, including the dependent's own funds and government funds. Support is not limited to necessities. Support includes money spent to provide food, shelter, clothing, education and medical and dental care; but it also covers money spent on recreation, allowances, gifts and vacations.

Medical insurance premiums—including premiums you pay for supplementary Medicare coverage—are included in the total support you provide for the dependent. Medical insurance benefits the child receives, however, including basic and supplementary Medicare benefits, are not considered support.

If a dependent receives Social Security benefits and uses them toward his or her own support, this is considered support provided by the dependent. State benefit payments based on need generally are considered support provided by the state. For example, Aid to Families with Dependent Children (AFDC) payments are not considered support provided by the parent. They are considered support provided by the state.

Scholarships received by your dependent are not considered support. This also includes the value of education, room and board provided for your dependent. This would also apply to a scholarship for a child with mental retardation to attend an educational program if the program certifies that it is making an effort to educate or train the child, even if the payments are made by the state. For example, suppose the state pays $30,000 for your daughter's room, board and tuition at a residential facility that qualifies as an educational organization. In the same year, you provide $5,000 as her only other support. You may still claim her as a dependent because the scholarship is not included.

You cannot take an exemption for your child if he or she was 19 or older at the end of the year and had a gross income during the year of more than $2,350. If your child is a student under the age of 24, this "gross income test" does not apply. If you claim your child as a dependent, however, your child cannot claim a personal exemption on his or her own return.

Limitations on the Medical Expenses Deduction
You are entitled to an income tax deduction for medical expenses for yourself and for your dependents. For this deduction, a dependent is defined as above, so that the "gross income test" does not have to be satisfied. The person must
have qualified as your dependent when the medical services were provided or when the bill was actually paid.

A number of hurdles must be passed before medical expenses may be deducted. First, medical expenses are deductible only to the extent that they exceed seven-and-a-half percent of your adjusted gross income. For example, if your adjusted gross income for the year is $30,000, you will only be able to deduct expenses in excess of $2,250 (7.5% of $30,000).

Second, medical expenses may be deducted only if you itemize deductions. Taxpayers who do not have significant itemized deductions are entitled to take the standard deduction instead. The standard deduction is equal to $6,200 for married taxpayers filing joint returns and $3,700 for singles. If you take the standard deduction, you will not be entitled to deduct medical expenses. Similarly, you cannot take the medical expense deduction if you use Form 1040A or Form 1040 EZ, because you must figure the deduction on Schedule A, Form 1040—commonly called the “long form.”

Third, you cannot deduct expenses that are paid by insurance. You can deduct expenses that you pay (and that are not reimbursed by your insurance company).

As a result of these limitations, the medical expense deduction may not be available to many families. However, the deduction can be very valuable for many others.

Defining “Medical Expenses”

According to the IRS, a deductible medical expense includes “any amount paid for the diagnosis, cure, mitigation, treatment, or prevention of disease; or for the purpose of affecting any structure or function of the body; and transportation cost on a trip primarily for and essential to medical care.” This definition is construed very broadly so that many expenses that you may not think are qualifying are deductible medical expenses. You can use the worksheet on page 57 to keep track of your deductible medical expenses.

Avoiding IRS Reviews

Many parents with children who have disabilities deduct larger amounts of medical expenses than other families. As a result, they may draw special notice from the Internal Revenue Service. The IRS computer may single out taxpayers who deduct proportionately higher medical expenses in relation to their income level for review. To reduce the IRS's suspicions, you can describe your child's disability in a letter written by yourself or your child's doctor and attach it to your tax return. In case your tax return is reviewed, however, store your receipts and canceled checks carefully. One key to good tax planning is good record keeping.

Tax Credits

In addition to the tax deductions described above, a variety of tax credits also may be available to you. Tax credits can be even more valuable than tax deductions because they are subtracted directly from taxes due. For example, if you are in a 28 percent income tax bracket, a $2,000 deduction will reduce your taxable income by $2,000. However, this represents a savings on your tax bill of only $560 (28% of $2,000). A $2,000 tax credit, on the other hand, reduces your tax bill by $2,000.

**Child and Dependent Care Credit.** If you pay someone to care for a dependent so that you and your spouse can work, attend school or look for work, you may be entitled to take the Child and Dependent Care Credit. If your adjusted gross income is $10,000 or less, your credit is generally equal to 30 percent of work-related child care expenses. The 30 percent figure is reduced by one percent for each $2,000 or part of $2,000 of adjusted gross income above $10,000 until the percentage is reduced to 20 percent for income above $28,000. The limit on work-related child care expenses is $2,000 for one qualifying dependent and $1,400 for two or more dependents. The credit is computed on Form 2441 if you file Form 1040, or Schedule 2 if you use Form 1040A.

For example, suppose a widower pays a housekeeper $5,000 a year to take care of his home and his daughter while he is working. He earns $20,000 during the year. Even though he spent at least $5,000, the maximum work-related expenses he can claim are $2,100. This is because he has only one qualifying dependent, his daughter. Therefore, the largest credit he can claim is 25 percent of $2,100, or $525. (The 25 percent credit is calculated by reducing the 30 percent credit by one percent for every $2,000 of income above $10,000. Since the widower had income of $20,000, the 30 percent credit is reduced by five percent.) If the widower had two children, the credit would be 25 percent of $1,400, or $350. If the man's income exceeded $28,000, the credit would be 20 percent of qualifying expenses.
A. Are you a subscriber to Exceptional Parent?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Name

Occupation/Title

Company/Association

Address

City State Zip

Phone Fax

B. Annual Household Income (include all family members)

<table>
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<th>Income Range</th>
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<th>No</th>
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</thead>
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<tr>
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<td>2</td>
</tr>
<tr>
<td>$30,001 - $40,000</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>$40,001 - $50,000</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

C. Do you live in a(n):

<table>
<thead>
<tr>
<th>Type</th>
<th>Own</th>
<th>Rent</th>
</tr>
</thead>
<tbody>
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<td>Home</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Apartment</td>
<td>9</td>
<td>10</td>
</tr>
</tbody>
</table>

D. In all, how many automobiles do you and others in your household own or lease?

<table>
<thead>
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<th>No</th>
</tr>
</thead>
<tbody>
<tr>
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<td>12</td>
</tr>
<tr>
<td>Two</td>
<td>13</td>
<td>14</td>
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<tr>
<td>Three or more</td>
<td>15</td>
<td>16</td>
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E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

<table>
<thead>
<tr>
<th>Duration</th>
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<th>No</th>
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<td>One month</td>
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<tr>
<td>Nine months</td>
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<td>20</td>
</tr>
<tr>
<td>One year</td>
<td>21</td>
<td>22</td>
</tr>
</tbody>
</table>

Free Product & Service Information

Issue Date: February 28, 1994
Expiration Date: May 31, 1994
## Medical Expenses Worksheet

1. Transportation costs for taking your child to special schools, institutions, hospitals, doctors, clinics, pharmacies, etc.
   a. Mileage (90¢ per mile) or actual expenses (gas/oil)
   b. Parking
   c. Tolls
   d. Cost of an attendant to accompany child
   e. Cost of attendant to accompany child on school bus

2. Medical Expenses (standard)

3. Hospital Expenses (standard)

4. Medicine—Drugs and vitamins prescribed by a doctor only

5. Special Education Expenses
   a. Tests and evaluations at special school
   b. Special instruction in Braille, lip-reading, speech
   c. Tutoring by a qualified teacher if recommended by a doctor
   d. Room, board and tuition at residential facility if main reason for attending is to alleviate medical condition

6. Sheltered Workshop Expenses—payments to a sheltered workshop for the provision of services

7. Special Equipment
   a. Any special equipment prescribed by a doctor. May include air conditioning, ramps, elevators, etc.
   b. Repair of special equipment (excluding TDDs)
   c. Closed-captioned television or decoder

8. Attendant Care
   a. Nursing services
   b. Meals for attendants

9. Aids for Persons with Visual Impairments
   a. Audio tapes
   b. Special typewriters
   c. Special lenses or other visual aids
   d. Cost of care of guide dogs

10. Lifetime-Care Payments—Non-refundable advance payments to a private institution to insure that they will care for your child in the future

11. Transitioning Expenses—Costs involved in helping a person with mental retardation adjust to life in a community setting

12. Miscellaneous
   a. Expenses involved in providing "pampering exercises"
   b. Disposable diapers for incontinent child or adult, if prescribed by a doctor
   c. Special foods and beverages (e.g., formula for tube feeding)—Costs in excess of what would have been spent for "regular" food
   d. Dental care
   e. Eyeglasses, contact lenses, eye examinations
   f. Hearing aids, batteries, hearing evaluations
   g. Wheelchairs, braces, other adaptive equipment
   h. Birth control pills
   i. Legal sterilization
   j. Oxygen equipment and oxygen
   k. Medical and hospital insurance premiums (see formula in tax form)
   l. Social Security tax for worker providing medical services
   m. Cost and care of dog or other animals used as aids to persons with disabilities
   n. Legal abortion

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St. Louis, MO 63136

Send in this coupon for a free catalog and Attends coupon, or call us toll-free at 1-800-538-1036.
Earned Income Credit. If your income is below $23,050 and you had a child with a disability living with you for at least 6 months during the year (or any minor child without a disability), you may be entitled to the Earned Income Credit. If the credit exceeds the amount of taxes owed, you can get a refund. You should use Schedule IC to claim the credit. The credit is equal to the sum of the following three components:

1. The basic credit is determined by multiplying your earned income by a percentage which varies, depending on the amount of your income and the number of qualifying dependents. The maximum credit is $1,434 if you have one qualifying child and $1,511 if you have more than one qualifying child.

2. The young child credit is available if you have a child who was under the age of one on December 31. The maximum credit is $388. However, if you are claiming the Child and Dependent Care Credit as described above, you cannot claim the young child credit for the same child.

3. The health insurance credit is available for premiums paid to provide health insurance for a qualifying dependent. The maximum credit is $465 and the amount claimed cannot also be claimed as a medical expense deduction.

For more information...

Obviously, figuring your taxes can be very complicated. More information on tax planning, as well as information relating to the important topic of planning for your child's life after your death, can be found in the book Planning For The Future by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph and Richard W. Fee. Easy to read and understand, the 400-page book is a comprehensive guide to the life- and estate-planning process, and contains all the information—personal care, financial and legal—that parents must consider as they plan for their children's lives after their own deaths. The book can be ordered from the Exceptional Parent Library, P.O. Box 8045, Brick, New Jersey 08723, 1-800-535-1910. The cost is $24.95, plus $3.50 shipping and handling.

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DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at 1-800-344-1778.

We Hear You.
Court Backs Private School Choice

The Supreme Court has ruled that parents who place a child with disabilities in a private school because the public school system failed to meet the child's needs, may be eligible for tuition reimbursement under the federal Individuals with Disabilities Education Act (IDEA), even if the private school is not approved by the state.

On November 9, 1993, the court issued a unanimous decision in Florence County School District Four v. Carter, upholding a lower court's order that the Florence County (South Carolina) school system reimburse the Carter family $35,000 for their daughter's three years at the Trident Academy, a private school for children with learning disabilities that was not approved by the state. At issue in the case was whether or not parents have the right to make a private school placement without school district approval, whether parents making such a placement can seek reimbursement, and whether parents can be reimbursed for a placement in a nonapproved private school.

Shannon Carter's parents placed her at Trident Academy after objecting to the IEP developed by the Florence County school district and requesting a due process hearing. When the due process hearing determined that the school's IEP was inadequate, Shannon's parents filed suit claiming that the school had failed to meet its obligation under the IDEA to provide Shannon with a "free appropriate public education." The parents sought reimbursement for Shannon's tuition and other costs incurred by her placement at Trident. The lower court found that the public school's proposed program was "wholly inadequate" for Shannon, while the private school provided her with "an excellent education in substantial compliance with all the substantive requirements" of IDEA.

The court's opinion, written by Justice Sandra Day O'Connor, affirmed that public schools have the responsibility to provide an appropriate placement or risk paying for whatever alternative placement the parents may find. O'Connor's opinion warned, however, that parents who "change their child's placement...without the consent of the state or local school officials, do so at their own financial risk." They will be entitled to reimbursement only if they can convince a federal judge that the public program violated IDEA and that the private program was appropriate under IDEA mandates. O'Connor also cautioned that total reimbursement may not be awarded if the court determines that the cost of the private educational program was "unreasonable."

Students with Disabilities in Regular Classes

The U.S. Department of Education has released a report to Congress showing that as of December 1991, more than 1.6 million students with disabilities—about a third of such children—were being educated in regular classrooms. This represented an increase of almost 100,000 students over the previous year's total.

"Historically, we have had two education systems, one for students with disabilities and one for everybody else," said Judith Heumann, assistant secretary for special education and rehabilitative services. "We are working to create one education system that values all students. The regular classroom in the neighborhood school should be the first option for students with disabilities. Administrators and teachers must receive the training and help they need to make that the best option as well."

The report also contained these findings:

• The two-thirds of students with disabilities who were not served primarily in regular classes were in resource rooms (35%), special classes (25%), special schools (5%), residential facilities (0.8%) or hospitals (0.7%).

• While more than 78 percent of students with speech or language impairments attended regular classes, only seven percent of students with mental retardation were included in regular classes.

• Within three to five years after high school, 20 percent of students with disabilities were functioning independently in living arrangements, social relationships and employment. Another 43 percent were functioning independently in at least two of these categories. Many, however, were working at relatively low-skill, low-paying jobs.
The FAS Primer presents an overview of the physical and behavioral characteristics of individuals with Fetal Alcohol Syndrome/Effect. It also recommends strategies for working with children who have FAS/FAE. Contact the Fetal Alcohol Network, 158 Rosemont Ave., Coatesville, PA 19320-3727; $6.00 including postage/handling.

The Staff is a newsletter published by Aaron’s Associates, 6114 Waterway, Garland, TX 75043, (214) 226-9855. It has articles of interest to children who stutter and their parents. Many articles are written by children themselves. Subscriptions are $15/year (nine issues).

Hope Through Research: Cerebral Palsy is a new brochure published by the National Institute of Neurological Disorders and Stroke (NINDS). Free copies can be obtained by contacting NINDS at 9000 Rockville Pike, Bldg 31, Room 8A-16, Bethesda, MD 20892, (800) 352-9424.

A "Toy Resource List" that gives developmental rather than chronological ages for various toys is available from the National Federation of the Blind. An addendum will be available in August 1994. The list is free. Contact: NFB POBC, Committee on the Blind Multi-Handicapped Child, 1912 Tracy Road, Northwood, OH 43619, (419) 666-6212.

Understanding Klinefelter Syndrome: A guide for XYX Males and Their Families describes currently available treatments and early childhood development, and offers advice for parents on deciding whom to tell—and how much to tell—about their son's extra chromosome. Related sections offer tips for detecting language problems early, helpful hints for teachers and advice for parents seeking special educational services. The booklet also deals with adolescence, testosterone treatment, sexuality, infertility and health considerations that are unique to XYX males. The booklet is available free from The National Institute of Child Health and Human Development, P.O. Box 29111, Washington, DC 20040, (301) 496-5133.

New publications from the PACER Center (4826 Chicago Ave. South, Minneapolis, MN 55417, 612-827-2966) include: Begin the Between: Planning for the Transition from High School to Adult Life ($5.00), Supported Employment: A Step-by-Step Guide ($8.00) and Speak Up For Health ($10.00), a guide for parents of adolescents with chronic illnesses and disabilities as they prepare their children to make independent health care decisions.

Our Children, Our Hopes ($35.00 purchase or $10.00/three-week rental) is a 15-minute, closed-captioned videotape in which African American parents of children with disabilities discuss their unique experiences. All prices include postage/handling.

The Human Growth Foundation (7777 Leesburg Pike, Falls Church, VA 22043, 800-451-6434) offers the following free publications: Patterns of Growth, Growth Hormone Deficiency, Turner Syndrome, Intrauterine Growth Retardation, Achoondroplasia, Short & OK: A Guide for Parents of Short Children, Short Stuff (written and illustrated by a nine-year-old boy with growth hormone deficiency about his experience with growth hormone therapy).

The Helmet

continued from page 39

could tell that he was trying to figure out why a three-year-old was wearing a helmet. As he strapped Mike's car seat into the shiny new car for a test drive, his curiosity won out and he asked, "Why is he wearing that helmet?"

"It's for protection," I replied, slipping behind the wheel of the new car. "It's because I'm such a bad driver. I've been in the emergency room, but the helmet has saved him many other trips. Perhaps I've benefited as well—dealing with situations involving Mike's helmet has taught me a lot about how to handle people, and I've learned not to worry so much about other people's perceptions and reactions."

Joni Pelta is an at-home mother, room parent and active volunteer in her children's schools. She and her husband, Murray, reside in suburban Atlanta and have two children—Mark, age six and Michael, age four. Before becoming a "domestic goddess," Joni earned an MBA from the University of Southern California, was editor and senior market analyst at a newsletter in California and worked as a market researcher in Chicago.
Children in Beckley, West Virginia participated in a number of activities during last October’s “National Disability Awareness Month.” Adults with disabilities visited every class at Cranberry-Prosperity Elementary School and answered children’s questions. Older students read books about people with disabilities and parents of younger students borrowed books to read with their children. In physical education classes, teacher Susan Davis offered children the opportunity to “experience” briefly what it is like to have a disability by donning waxed paper glasses, wearing ear protectors or trying out adaptive equipment like wheelchairs, walkers, crutches and communication boards. Students were also encouraged to put their thoughts in writing.

These essays were written by Amanda Sears, Andrea Black and Dane Toney, students in Debby Aliff’s second grade classroom. Amanda has spina bifida.

I know someone special to me. She is a very special person to everyone. She is like us in every way. She is someone I really like. This person is Amanda Sears.

—Andrea Black

It’s hard getting up the steps. I know I have a disability. When I go to the store, the other kids stare at me. Mom says to stare back, but I don’t. I try walking, but I fall down. Sometimes I can walk 20 steps. The doctor said that I will walk by myself maybe.

—Amanda Sears

Familiar Faces

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers’ Photos, Exceptional Parent, 209 Harvard Street, Suite 309, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child’s full name, age at the time photo was taken, address and daytime phone number, and identify everyone else in the photo. If you like, you can also write a few sentences about your child/family. Then look for a familiar face in an upcoming issue!

Eight-month-old Jacob Wilkins
CHILDREN WITH EPILEPSY: A PARENTS' GUIDE
Edited by Helen Reisner (WB0160D) 344 pp. $14.95
CHILDREN WITH EPILEPSY offers valuable direction and support to parents of a child with epilepsy. With chapters on diagnosis, medications, daily care, family life, advocacy, and special education, this book provides an in-depth look at epilepsy, and its various treatments, as well as its impact on the child and family.

A READER'S GUIDE FOR PARENTS OF CHILDREN WITH MENTAL, PHYSICAL, OR EMOTIONAL DISABILITIES
Third Edition by Cory Moore (WB0320D) 248 pp. $14.95
A READER'S GUIDE is an indispensable tool for parents, teachers, and librarians — virtually anyone who needs to find the most current, authoritative information in print about children with disabilities. This useful annotated bibliography lists more than one thousand books and other resources on disabilities. Each listing has been carefully selected for parents.

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
by Monte Mace (TP0260D) $12.95
The Illustrated Directory empowers parents and persons with disabilities by widening choices about products. There are many products available — if you know where to find them. Sadly, many retail outlets do not carry a wide choice of products. This Directory shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

CHOICES IN DEAFNESS: A PARENTS' GUIDE
by Sue Schwartz, Ph.D. (WB0250D) 212 pp. $14.95
Parents of children with hearing impairments face a difficult decision — which method of communication is the most appropriate for their child? With its clear, objective descriptions of the three predominant communication methods, CHOICES IN DEAFNESS provides valuable guidance in sorting out the options.

THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
by Monte Mace (TP0260D) $12.95
The Illustrated Directory empowers parents and persons with disabilities by widening choices about products. There are many products available — if you know where to find them. Sadly, many retail outlets do not carry a wide choice of products. This Directory shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.

CHILDREN WITH TOURETTE SYNDROME: A PARENTS' GUIDE
Edited by Tracy Haerle (WB0160D) 340 pp. $14.95
This parents' guide to Tourette Syndrome explains the disorder, including its symptoms, causes, and medications, as well as the disorders which are commonly linked with it. Other chapters cover family life, education, advocacy, and legal rights. Parent Statements appear throughout, offering insight, advice, and encouragement for the reader.

DOES YOUR CHILD HAVE EPILEPSY? (SECOND EDITION)
by James E. Jan, Robert G. Ziegler and Giuseppe Erba (PE0360D) $22.00
Written by three well-known pediatric specialists, this book provides information on the most common type of seizures, causes, principles of treatment, investigations and outcome, with a wide range of helpful suggestions from infancy to early adulthood. This book is highly recommended for parents and grandparents of children with epilepsy, older children with seizures and their siblings, teachers, health professionals, and other caregivers.

To order, use the order form on page 64, or call 1-800-535-1910
LIVING WITH A PHYSICAL DISABILITY
by Jill Krementz
(SSIDPD) $18.00
Portrays the indomitable spirit of children who live with disabilities. This book is an inspiring gift of hope from 12 children ranging in age from six to 16 whose physical disabilities include blindness, dwarfism, paralysis, birth anomalies, spasticity and CP. Captured in text and photos, these children tell their own stories and speak with candor about their lives.

TEACHING THE YOUNG CHILD WITH MOTOR DELAYS:
A GUIDE FOR PARENTS AND PROFESSIONALS
by Marcj J. Hanson and Susan R. Harris
(PEO4PD) $27.00
This easy-to-read guide bridges the gap between parents and professionals who work with movement-impaired children between the ages of birth and three years. The 228-page book has two purposes: to provide information to parents on how motor development influences other areas of child development and to provide teaching strategies and therapy activities for use in the home.

THE WHEELCHAIR TRAVELER:
by Douglass R. Annand
(WTO15PD) $20.00
A practical dictionary of information for the traveler with a disability. Includes accessibility ratings of hotels/motels in the U.S., Canada and Mexico and useful tips for comfortable travel. Although written for adults, it provides helpful information for parents traveling with a child with a disability.

EXCEPTIONAL PARENT LIBRARY

To order, use the order form on page 64, or call 1-800-535-1910

**EXCEPTIONAL PARENT LIBRARY**

**DIFFERENCES IN COMMON STRAIGHT TALK ON MENTAL RETARDATION, DOWN SYNDROME, AND LIFE** by Marilyn Trainer (WB009MR) 236 pp. $14.95

In this engaging collection of essays, Marilyn Trainer draws on her experience as the mother of a child with Down syndrome, now in his twenties. With candor and humor, she brings a fresh, candid outlook to the challenges, hopes, and fears of family life — a life shaped by a child with Down syndrome, but one which strikes a common chord in all of us.

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**SPEAKEASY PEOPLE WITH MENTAL HANDICAPS TALK ABOUT THEIR LIVES IN INSTITUTIONS AND IN THE COMMUNITY** by Karin Melberg Schwier (PE044MR) $16.00

In this unique and compelling collection, people labeled mentally handicapped speak honestly and powerfully about their lives in large institutions and in the community. Through intimate interviews, the author has captured the dreams, fears, frustrations, and humor of people who were exiled for being different but battled social barriers to establish independence. Emerging from these pages are colorful, resilient, and thoughtful individuals.

---

**THE CONQUEST OF MENTAL RETARDATION** by Burton Blatt (PE047MR) $38.00 (Hardcover)

The author lays out the basics of the field — history, classification, and definitions — but he also discusses controversies; nature versus nurture, deinstitutionalization versus institutionalization, and the educability hypothesis. Moreover, each of these topics is placed within a broader context — social, political, and moral. A single, powerfully felt conviction infuses the whole: One’s value as a human being does not have to be deserved.

---

**THE CHILD WHO NEVER GREW** by Pearl S. Buck

The Woodbine House edition of THE CHILD WHO NEVER GREW brings back into print Buck’s inspiring account of her struggle to help her daughter with mental retardation. New material written especially for this edition, amplifies her story and gives the book an important historical perspective. This landmark book urges society forward toward greater awareness of people with mental retardation.

---

**IT ISN’T FAIR! SIBLINGS OF CHILDREN WITH DISABILITIES**

Edited by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D. (EP001EP) $14.95

Includes all the material published in Exceptional Parent since 1971 on the topic of relationships between sisters and brothers when one child has a disability. Features chapters by parents, siblings, and professionals.

---

**PLANNING FOR THE FUTURE** by Mark Russell (AP0240D) $24.95

A comprehensive guide for parents of children with disabilities. The 400 pg. softcover publication provides all the info. parents must consider as they plan for their child’s life after their own deaths. A comprehensive, authoritative treatment of the subject, it contains twelve chapters and three appendices designed to give all the information parents need to ensure a happy and meaningful life for their children after they die. It draws on the authors’ extensive personal experience in planning for families with children who have disabilities. L. Mark Russell, a co-author, is an attorney and is one of the nation’s leading authorities on life and estate planning for families who have a child with a disability. Mr. Russell’s earlier book, Alternatives, published in 1983, has been considered a definitive resource on this subject.
“CHRYSLER MADE IT EASY FOR US TO GET INTO A NEW VEHICLE.

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At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

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EXCEPTIONAL PARENT

PARENTING YOUR CHILD WITH A DISABILITY

5TH ANNUAL MOBILE ISSUE

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A New Car, Van or Light Truck...Adaptive Equipment...and On-the-Spot Cash!
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Welcome to our fifth annual mobility guide. Each year, in articles like “Wheeled Mobility Selection: A Guide for Parents,” “Doing What Works Best,” and “Powered Mobility for Your Child,” we provide information about wheeled mobility and the range of choices available to meet the individual needs of children and teenagers. Special thanks to our friends at ABLEDATA who provided information for the article on wheeled mobility selection and the product directories. In addition to being a database of thousands of products, ABLEDATA offers many services which are described in “The ABLEDATA Database of Assistive Technology.”

Parenting is what Exceptional Parent is all about—about Paul J. Karch and his daughter (“Rachel, Say ‘Hi’”), about the Kratz family’s memorable trip to the mall (“Lost in the Mall”), and about Judy Horton teaching someone else’s child about her own (“In Defense of My Daughter“). Each of these articles shares the adventures of everyday family and community life from the most important experts—parents.

In “Our Civil War Over Residential Care,” Richard Haddad describes how some parents and professionals have “allowed ideology to bury their compassion,” with the result that parents do not find the help they need to make very complicated decisions on behalf of their children. This article should inspire all of us to respect each other’s choices and appreciate that we share a common goal—the creation of opportunities and options for children and adults with disabilities, and their parents.

Readers were delighted to get to know Judy Heumann, Assistant Secretary of Education, Office of Special Education & Rehabilitative Services (OSERS), via our interview with her (February 1994). In Part Two, she shares her perspective on policy priorities and other challenges.

In this issue, we also are pleased to feature material on health care from Peggy Mann Rinchart—parent, journalist, and member of our Exceptional Parent Editorial Advisory Board. Our readers also discuss the critical issue of health care reform in Letters to the Editor. As in the past, we urge everyone to actively advocate for the kinds of changes needed to insure decent health care for children with disabilities and special health care needs—and for all other citizens as well. With this issue, we welcome another new member to the Editorial Advisory Board—Dina Loebl of New York University.

Meetings

In January, Joe Valenzano, Terri Sutera and I met in Washington with many dedicated parents and professionals involved in early intervention programs and other efforts to serve children and families. It was exciting to interact with so many devoted people, to learn about services for families and to get feedback about the magazine. In this issue, on the Children’s Page, we are following one suggestion we received—that we continue to include materials from siblings as well as children with disabilities. As spring arrives, we look forward to meeting many more readers at meetings throughout the country.

Children’s Art and Reader Photos

Exceptional Parent is now using children’s artwork to illustrate feature articles and departments. We invite your children to share their work with our readers. Put the picture’s title along with the child’s name and on the back of submitted artwork.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers? On a separate sheet of paper, write your child’s full name, age at the time photo was taken, address and daytime phone number, and identify everyone else in the photo. You can also write a few sentences about your child/family.

Send artwork and photos to: Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146.

Weather or Not

Earthquakes, snowstorms and other disruptive “natural events” resulted in the February issue being received late by many readers. Unfortunately, the production of this issue was similarly delayed.
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A Lifeline
Enclosed are many years of Exceptional Parent magazines. We have saved them all. Now, perhaps you can pass them on to someone else who can use them. Exceptional Parent was truly a lifeline for us, especially in the first few years of Karl's life. Trying to find out what was wrong and how we could fix it seemed to consume us.

Today, Karl is 24 years old and lives in a group home quite near us. He is a wonderful young man and has touched the lives of so many people. He has been an altar boy at our parish for 11 years! He is well known and loved by many people.

In December 1991, we noticed a small lump on the back of his neck. To make a long story short, Karl was diagnosed with lymphoma and had six rounds of chemotherapy. He was very sick with the chemotherapy. As always, he was cheerful and accepted what had to be done. We have learned a lot from our son!

A.J., Illinois

Search Letter Helps
I am a big admirer of your magazine. I never thought in a million years that you would run my Search letter, but I am so glad you did. Last month, I made contact with another woman who had a son with Asperger's syndrome. She was the first parent I have ever talked to who really understood. If she started a sentence, I finished it, and vice versa. I cannot tell you what strength and power that gave me. Once again, many thanks!

L.N., Oregon

Health Care Concerns
My daughter has cerebral palsy and epilepsy. She cannot do anything for herself. She is a very happy, smiling child that knows no one as a stranger.

I am a low income person who does not abuse the system in any way. My daughter receives SSI and Medicaid. I have a number of concerns about health care reform.

One concern has to do with durable medical equipment. In order for my daughter to be transported to school, she has to have a wheelchair. Medicaid will buy one new wheelchair every five years. In between new chairs, Medicaid pays for repairs. My daughter received her first wheelchair in 1989. Before school started last fall, her chair needed to be reconstructed to fit her, and other parts of the chair needed adjustment and replacement. The cost of the new chair in 1989 was $2,500. In 1993, the reconstruction and other adjustments cost $3,500. Why didn't Medicaid just buy a new chair and save the $3,500 they put into a worn out chair? My daughter becomes eligible to receive a new chair six months after these expensive repairs on the old one.

The government accuses people of abusing the system. The way I see it is that their own rules cause abuse!

P.D., Indiana

■ Thank you for the article on the government's proposed health care plan and how it applies to individuals with disabilities. I agree that it is time to stop denying health care coverage to individuals because they have disabilities, but there are many other questions we must ask.

The current health care proposal from our President would stop "unnecessary treatment." Does that mean that if you have a physical disability, you won't be able to get surgery or therapy just because these interventions won't "cure" your condition? Will some be more equal than others when it comes to providing health care to people with disabilities?

As the parent of a son with a disability, I was very excited about the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). It seemed like so many opportunities were opening for him. The IDEA and the ADA recognize the fact that all members of our society are important and precious, but I am suspicious of the President's health care plan. I want to know the truth now before a doctor tells me that my son can't have treatment because it won't "fix" his disability.

Please join me in writing to your legislators. And don't forget to drop a line to the Clintons as well.

S.M., Missouri

■ I have eagerly been reading every scrap of information I can get my hands on concerning health care reform, including the articles in Exceptional Parent. The more I uncover about the President's plan, however, the more alarmed I become.

As the mother of three children, two of whom have disabilities, there are a number of things that I'm concerned about in the President's plan. I'm worried that there will be fewer specialists, and longer waits for an appointment when one is needed. I'm concerned that health care will be rationed, creating long waiting lists for hospital surgeries and sophisticated diagnostic tests. My daughter, who suddenly developed cataracts, would have lost her vision completely if she had been forced to wait that long to have them removed. Instead, she was in surgery less than two weeks after we first discovered her condition and is now making progress with her visual skills.

To be fair, there are some good things about the plan as well—things like prohibiting insurers from denying coverage or charging exorbitant premiums to those who have pre-existing conditions and making health care more available to low-income people. I just don't think the President is going about it in the right way.

There are a number of other plans being proposed. You would be doing the readers of this publication a tremendous service by informing them about all of the proposals.

D.E.C., Massachusetts

LETTERS

We welcome all letters from readers—reactions to articles, suggestions, opinions, complaints. Write or fax:
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Circle #168
Parents Search

Jacobsen's Syndrome

We have a 28-month-old daughter who has been diagnosed with an eleventh chromosome deletion at q24.1, also called Jacobsen's Syndrome. Symptoms include a triangularly-shaped head, high palate, congenital heart defects, developmental delays and physical growth retardation. Our daughter is doing very well in many areas, but is delayed in gross motor and speech skills. I am interested in talking with parents who have a similarly diagnosed child.

E.H.
Indiana

Chromosome Translocation

My five-and-a-half-year-old son has been diagnosed recently with a complex translocation between chromosomes five and six with some segments flipping upside down. It is not known if genetic material was lost. He has had one positive and two negative Fragile X tests. He has a normal EEG and MRI, but has a seizure disorder. He also has mild mental retardation, swallowing difficulties, global developmental delays, speech difficulties, a heart murmur and autistic tendencies.

Doctors, genetic counselors and NORD have been unable to tell me anything about my son's chromosomal abnormality. They all tell me that there isn't another documented case like his. I'd welcome information or referrals from anyone who can help.

K.H.
Washington

Congenital Cytomegalovirus

Our two-year-old son has congenital cytomegalovirus (CMV). Chase was given the “orphan drug” Ganciclovir or DHPG (dihydroxy propoxymethyll guanine) for six weeks after birth as part of the Ganciclovir study at Arkansas Children's Hospital.

Chase has intracerebral calcifications and profound left sensorineural hearing loss, and is developmentally delayed. He is in an early intervention program and receives occupational, speech and physical therapy. We are eager to correspond with other families who have a child with congenital CMV.

P.G. & B.G.
Arkansas

Macroglossia

As the parent of a beautiful premature girl born at 28 weeks gestation, I am interested in finding parents of other children with a condition known as macroglossia, or enlarged tongue. Sarah is currently undergoing genetic testing to find out if she has any other birth defects or any of the many syndromes that are sometimes associated with this condition. I would like to hear from parents who have had children with macroglossia to find out about the treatments their children receive and exchange experiences.

C.K.H.
Ohio

48XXX Syndrome

Our four-year-old daughter has 48XXX syndrome. Her pathologist told us that there are only about thirty known cases of this very rare syndrome. Our daughter has a severe speech impediment. Her muscle tone is low, and she wears Phillips splint braces. Her cognitive development and fine motor skills are age appropriate. We would like to know if there are others with this syndrome.

N.T.
Indiana

Parents with Learning Disabilities

My husband and I have a dilemma and don’t know who to ask for help. We both have learning disabilities. My husband is severely dyslexic and I am mildly dyslexic and dysgraphic. We both have been tested and received some assistance in overcoming our difficulties. We are now concerned about our two-year-old daughter. Considering our track record, chances are good that she will also have some form of learning disability. We had considered placing her in a local parochial school when she is old enough to start kindergarten. Unfortunately they do not have the capabilities to handle children with learning disabilities.

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Exceptional Parent

170

March 1994
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March

Circle #167 171 Exceptional Parent 7
We need to know at what age she will be old enough to be tested and where the testing can be done. I was 16 and my husband was 30 before our learning disabilities were properly diagnosed. If my daughter has inherited our learning disabilities, I have no intention of letting her go through the emotional scarring we went through.

D.G.
Indiana

Cart for Ventilator
I have a two-and-a-half-year-old, active son who is on a ventilator. He rolls, sits, and is starting to crawl. His therapists believe he will walk. I would like suggestions for a compact, lightweight cart to hold his ventilator and oxygen that would allow him to be independently mobile.

L.J.
Maryland

Catheterization Help
My granddaughter was born with spina bifida and hydrocephalus. As a result, she has no bladder control. To empty her bladder, she must be catheterized every four hours. At present, a small feeding tube is being used as a catheterizing device. She is reaching the age of adolescence and wants to learn to catheterize herself, however, it is very difficult for her to insert the catheter in the appropriate place while sitting on the toilet. The visiting nurse tried to teach her one catheterization technique, but it did not work.

Are there readers of your magazine who have had a girl that needed to learn this procedure? We would appreciate hearing from any family that would be willing to share a method that worked for their child.

B.F.S.
Vermont

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Generalized Dystonia
My sixteen-year-old daughter, Angela, was diagnosed with torsion dystonia at age fifteen. Torsion dystonia is a neurological disorder characterized by involuntary, sustained muscle contractions. This causes twisting, repetitive movements and abnormal postures. Angela's dystonia has progressed throughout her body and causes a lot of pain in her hips. She has spasms, jerks and tremors which accompany the dystonic movements, and is now in a wheelchair.

Adjusting to dystonia has been very difficult for everyone in our family—but especially for Angela. Since generalized dystonia is relatively rare, she knows no other teenagers with this condition. She is having a difficult time emotionally. Are there any other families reading this who have had to learn to cope with a non-curable, progressive disability that strikes their child during the teen years? I'd especially like to make contact with parents of dystonic teenagers.

L.R.
California

Inclusive School Districts in New England
We have a six-year-old daughter with special needs who presently attends a kindergarten with full inclusion. We are very pleased with her progress in the program and would like to continue a similar program. We are trying to relocate to New England and seek assistance in finding school districts with full inclusion.

J.H.
Ohio

March 1994


Lennox-Gastaut Syndrome

Our 22-month-old son, Benjamin, began having seizures at 10 months. Until then, he had seemed to be developing normally except that he'd always seemed quite distant and aloof. He rarely made eye contact with us. He was not interested in toys or any form of play. Recently, he began having atonic (drop attack) seizures; at one point having as many as 50 per day.

His initial diagnosis was infantile spasms, but the doctors now say he has Lennox-Gastaut syndrome. I also believe he has autistic-like symptoms. He is completely non-verbal and seems to understand only his name. He grinds his teeth occasionally. As for toys, he is only interested in tops or other things that spin.

We are searching for parents of a similar child, or anyone with a suggestion as to how I could simply get my beautiful son to look into my eyes. It is hard not knowing how to get through to him. Is there anyone out there who knows what we are going through?

D.S. G.J.S.
New York

Werdnig-Hoffman Disease?

My daughter is 27 months old. She was diagnosed with Werdnig-Hoffman disease—also known as Spinal Muscular Atrophy, Type I—at the age of five and a half months. We are unsure if this is an appropriate diagnosis for her, because she has done extremely well and far outlived her original prognosis.

She is healthy, but her muscle tone has not improved. She has had very few respiratory infections. She has absolutely no head control and is like a rag doll. Her neck muscles are especially atrophied. She is extremely bright and talks all the time. She has no facial weakness. Her upper body is weaker than her lower body. She has very little use of her arms, but can kick her legs and pushes with them when she is laying on the floor. This is unusual because Werdnig-Hoffman disease usually affects the lower body more than the upper body. She even wiggles her body!

I would like to correspond with any parents who might have a child with a similar condition. We have met lots of parents through the spinal muscular atrophy organization, but our daughter is different from most of their children. She seems flippier but also has a lot more movement. We would appreciate any enlightening information anyone could share with us.

J.B.
Wisconsin

Arthrogryposis Multiplex Congenita

My eight-month-old daughter, Rachel, was born with both dislocated hips and clubfeet. Her arms and legs are both very contracted. Her hands are tightly clenched. She does not move her arms or legs. Rachel has been diagnosed with Arthrogryposis Multiplex Congenita (AMC).

Bloom Syndrome

My two children—ages four and seven—were recently diagnosed with Bloom syndrome. Bloom syndrome is an extremely rare genetic disease in which children do not grow normally. My children are fed via G-tube while they sleep every night. Doctors tell me that my daughter will never be taller than four feet, six inches; and that my son will never be taller than four feet, nine inches. We can live with short stature, but I also understand that they are at risk for many different types of cancer, usually occurring by age 22. I would be very interested in hearing from anyone with a child who is similarly diagnosed.

C.H.
New Jersey

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Ri 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-8518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1994 Resource Guide (January 1994).
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March 1994

Rachel has good head control. She's very bright and talkative. She can lift her legs up by using her stomach muscles. While on her back, she can bounce her legs by using her hips. She sometimes moves her thumbs, toes and feet. Rachel sits up very well without any support. She wears splints on her feet and hands. She uses her head, nose and hands to play with her toys.

I hope I can hear from other parents of children with AMC. I want to know how these children get around when they are older? I don't know much about this condition and would appreciate any information I can get.

A.J. Pennsylvania

Celiac Sprue

I'm looking for another parent who has a child with celiac sprue, a digestive disease which prevents the digestion of gluten/wheat products. I'd love to hear from another parent who has a child with this condition.

S.L.W. Florida

Myotubular Myopathy in X-linked form

We are trying to locate children with X-linked myotubular myopathy (also known as X-linked centronuclear myopathy). We have been gathering information on as many affected boys as we can locate in hopes of sparking an interest in more research. To date, we have located 20 children in the United States and one in Canada.

G.S & P.S. Texas

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Asperger's Syndrome/Landau-Kleffner Syndrome

L.N. (November/December 1993) has a five-year-old son who was recently diagnosed with Asperger's syndrome. Because of an abnormal EEG, however, doctors are now considering the possibility of Landau-Kleffner syndrome instead. L.N. and her husband were desperately searching for information about both syndromes.

While Asperger's syndrome is often referred to as "high functioning" autism, individuals with Asperger's syndrome have a less severe language disorder than those with more "classical" autism, many of whom are essentially nonverbal. However, they have impaired social interaction and relatedness—they fail to maintain appropriate social "distance," misinterpret subtle social cues and show a lack of true reciprocity in social attachment. They may have exceptional rote memory. Like most individuals with autism, those with Asperger's syndrome are visual learners but may have difficulty comprehending spoken language, particularly nuance, subtlety and abstraction.

Landau-Kleffner syndrome refers to young children who appear to be developing normally in all areas—including language—until about two to six years of age. Then, the child's language regresses as he or she develops a seizure disorder which appears to have a focus in the area of the brain concerned with language. The behavior of these children may be indistinguishable from autism. About half of these children recover language function.

For more information about autism in general, write to the Autism Society of America at their new location (7910 Woodmont Ave., Suite 650, Bethesda, MD 20814) or call their information and referral number, 1-800-328-8476.

R.J.K. Maryland

My seven-year-old son, David, was diagnosed with Landau-Kleffner syndrome (LKS) at age five. I received a great deal of information from the United States Department of Health and Human Services. Information is also available from CANDLE (Childhood Aphasia, Autism, Neurological Disorders, Landau-Kleffner and Epilepsy, 4414 McCampbell Dr., Montgomery, AL 36106, 205-271-3947).

My son developed normally until age three. At that time, his language skills began to regress, and he became increasingly hyperactive. We placed him in an early-intervention program. When he was four, we met a speech and language therapist who recommended that we consult a pediatric neurologist. By this point, David's language skills had regressed to two words. He was in "his own little world" and his behavior was often unpredictable.

An abnormal EEG, his medical history and two weeks of additional testing in a hospital confirmed the diagnosis of LKS. David went through a six-month regimen of injections of ACTH. His EEG normalized, but there was no improvement in receptive or expressive speech. Around the age of five, his speech began to return. He also started to become more interested in the world around him.

Today, David is in a full-time learning support class, but mainstreamed for several subjects. He is a very bright child and loves to learn. He receives speech and language therapy four times per week. He is progressing beautifully, although his social development is behind by several years. He has emerged from "his own little world."

L.M.P. Pennsylvania

Parents with Disabilities

C.L.B. (November/December 1993) has a neuro-muscular disease, and is also the parent of two preschoolers, one of whom is a four-year-old boy with autism. Her situation has become even more difficult since her husband passed away last spring. She wondered how other parents with physical disabilities cope with everyday problems.

I am a mother with multiple sclerosis and four boys aged eight, five, three and one. My eight-year-old son was recently diagnosed with Attention Deficit Disorder, but his true condition may be closer to Tourette syndrome. My five-year-old son was born with Down syndrome, and has developed insulin-dependent diabetes, lactose intolerance, celiac sprue and intestinal malabsorption syndrome. I also feel emptiness, frustration and anger when no one seems willing to help or understand.

We have tried to get in-home medical respite for years and cannot. I thought there was no one else with similar circumstances, but when I read your letter I cried.

M.J. Illinois

Your letter touched my heart. I can offer no advice or suggestions—only empathy and my story. Exceptional Parent has done a wonderful thing in making me aware that my family is not alone.

Our second son, Daniel, was born with a rare genetic metabolic defect. He was medically fragile with multiple severe disabilities including profound retardation and blindness. He required around-the-clock care for his five-and-a-half years of life.
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Despite all his problems, he was a happy and charming boy—far exceeding any goal or life expectancy ever mentioned. He met his match last April in the form of mononucleosis and died in my arms.

I developed a non-specified connective tissue disease—an arthritis-type condition—during my pregnancy with Daniel. It caused loss of strength in my joints. It is in my fingers, wrists, elbows, shoulders, hips, knees and feet.

With this condition, Daniel's care was difficult. I had no secret for getting through my days. I pushed myself to the breaking point daily. My love and devotion to Daniel made it all possible because I never knew if that day would be his last. We received only 15 hours of nursing respite care per month.

Our youngest daughter, Rachel, was the first child in the world to be tested prenatally for Daniel's condition. Her birth helped our family beyond belief. We all had something to look forward to—her future. And she gave her older brother, Nathan, someone with whom to share his burdens.

Daniel's life was very hard for most of our friends to bear. We lost most of our friends. As you have probably also experienced, people become uncomfortable with such misfortune and really distance themselves from it.

We will think of you often and please find comfort in that. It is all we can give, but it is given with understanding and love.

G.R. & B.R.
Oregon

Undiagnosed
W.J.R. & T.R. (November/December 1993) are looking for a child who is similar to their 11-month-old son Dakota. Dakota is developmentally delayed and has dysmorphic features which include slightly protruding, wide-spaced eyes, low-set ears, nose with flattened bridge, high palate and simian creased left palm. His heart has an atrial ventricular valve dysplasia with a possible mild AV-valve stenosis. Extensive medical and genetic testing has failed to yield a diagnosis.

Our 13-month-old son, Michael, has so many of the same characteristics as Dakota that I had to write immediately! Michael is developmentally delayed. He has widely spaced low-set ears which tilt slightly to the rear, flattened bridge, high palate, low muscle tone, broad hands and toes. We know of no heart problems, but this area of his body has not been screened. He was born with a slightly malformed penis (hypospadias) that was surgically corrected.

At this point, Michael's neurologist believes that he has Opitz-Frias syndrome (also known as "G syndrome"). Yours is the first case I have heard of that is so similar to mine. I also think it is interesting to note that we both live in New Jersey; this just adds to my personal theory concerning environmental factors.

J.P. & D.P.
New Jersey

Leber's Congenital Amaurosis
R.S. & V.S. (November/December 1993) are the parents of five-year-old Courtney who has Leber's congenital amaurosis. In addition to visual problems, Courtney has mild retardation with neurological and speech problems. She is still in diapers and drools a lot. Her parents did not know of other children with Leber's who have problems in addition to vision.

We are the parents of a four-and-a-half-year-old boy who has been diagnosed with "complicated" Leber's congenital amaurosis. We don't know Jon's visual acuity, but suspect he is in the 20/100 range. He is very interested in books with large print, and he is able to manipulate a computer. He uses a white cane for better mobility in outdoor or unfamiliar surroundings. Jon is also profoundly deaf and was diagnosed with "floppy baby syndrome" (hypotonia) when he was about six months old.

At about six months of age, we enrolled Jon in a "generic" early intervention program and registered him with the New Jersey Commission for the Blind. When he was 14 months old, we transferred him to an early intervention program designed specifically for children with visual impairments.

Shortly after beginning this program, Jon's hearing was tested. Just before his second birthday, we learned he was deaf. So we found another early intervention program—this one for deaf and hearing impaired children—and Jon went to both programs for one year. It was a hectic pace, but certainly worth it! At the program for visually impaired children, he learned to use the vision he has and developed orientation and mobility skills. At the program for hearing impaired children, he began to learn sign language and develop interpersonal skills. He is now in his second year of preschool at the school for deaf and hard of hearing children, and we still receive support services—a teacher of the visually impaired, orientation and mobility instruction, computer specialists and physical education consultant—from the Commission for the Blind.

Jon has come such a long way in his short lifetime and we are so very proud of his accomplishments. None-theless, we often feel that his diagnosis has isolated us from both blind

---

You are not alone! After reading your letter, I just had to write to you. Dakota seems very similar to my son, Michael, who is also "undiagnosed."

Michael is 15 months old and has features that sound very similar to Dakota's. Michael has some features such as bilateral atresia of the ear canals—with resulting hearing loss, unusual defects of the left eye, and atrial-septal heart defect. He was also born with an omphalocele (his intestines were outside of his body) that was repaired by surgery at birth.

Michael also has had every conceivable test. All have been normal including several high resolution chromosome analyses. Of course, this disappointed the doctor who was absolutely convinced that Michael had Down syndrome because of his facial features and the simian creases on his hands.

Like Dakota, Michael is developmentally delayed. He has been assessed at the six- to seven-month level in all areas. He is involved in early intervention and has already far surpassed what the medical field expected of him. We are proud of his very accomplishment, and are convinced that he will surprise us all.

I was most compelled to write to you because we also live in New Jersey. We have "toured" hospitals in New Jersey and Pennsylvania, searching for answers. The uncertainty of the future is the hardest thing to deal with. We too are desperate for a diagnosis.

K.C. & M.C.
New Jersey
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---

I have an eight-year-old daughter with Leber's congenital amaurosis. Lauren seems to have much more involvement than your daughter. We know that Lauren has usable vision but don't know how much. Like Courtney, her vision has improved since she was younger. Lauren is non-ambulatory and non-verbal. She has severe mental retardation. She has had intractable seizures since she was about two-and-a-half years old.

You mentioned problems with drooling and diapers. Lauren always drooled a lot but in the last two years, this has improved a lot through no specific intervention. Lauren wears pull-up diapers. A teacher suggested we try potty training about a year ago. I thought she was crazy, but we tried it. It was really more like "potty timing," but Lauren does surprisingly well considering that she cannot communicate her need to go. The pull-ups are much easier to put on and take off than diapers. Since Lauren can stand well with balancing support this really has made life easier.

G.F.
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Vicki Bertolli, Parent

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When Brian was born on June 16, 1982, with a myelomeningocele, we didn’t realize that spina bifida would be the lesser of his problems. When he was one month old, he began having episodes of apnea—he stopped breathing when he cried. The apnea turned out to be a symptom of Arnold-Chiari syndrome, a malformation of the brainstem. Brian underwent three major brainstem surgeries in his first three years. This caused additional developmental delays, upper-body weakness and range-of-motion loss in his arms.

Unrealistic Expectations

By eighteen months, Brian was standing with support, and we planned to start gait training when he was two years old. My expectations for his progress were based on the knowledge of older children who had waist-level spinal lesions like his. I saw these children getting up and down from the floor and walking. I believed that Brian would follow a similar pattern. Naively, I thought through the timing of having a second child—Brian would get braces at this time; he’ll ambulate at some later time; after that, we could have a baby.

Perhaps it was over-eagerness, or hesitation to make predictions. Whatever the cause, professionals never gave us any lower, more realistic expectations to counter our observations of other children with spina bifida. I understand that low expectations may hinder progress, but unrealistically high expectations, as we learned, may lead to burnout and failure.

A torturous year

When Brian started gait training, he was a highly verbal, friendly and cheerful two-year-old. The next year of our lives was tor-

Standing beside me in the church parking lot, an acquaintance asked, “Is he pretty much confined to that thing now?”

The words stung, and I was immediately on the defensive. “He” was our five-year-old son, Brian, who has spina bifida. “That thing” was his black and red sports wheelchair. “Confined” usually means trapped.

I could have asked my friend to call that “thing” a wheelchair. I could have pointed out that Brian is far less confined in his chair than out of it, because his walking is exhausting and very slow. I could have said that he never feels free when he is in his “wheels.” They’re fast, they’re sleek, they’re fun—at least, that’s what Brian’s words and actions tell me. I could have said all that, but I didn’t. My friend’s casual question was like a pronouncement of failure.

I now realize that the failure I felt at my friend’s words that day just wasn’t real. Choosing to use a wheelchair is not a failure. Failure means failing to do what works best.
turous. There were no qualified therapists in our area. We began by going to a city two hours away and working with a good pediatric therapist every day for a week; after that, we were on our own. I became Brian’s primary therapist.

We worked every day for three months before Brian took an unassisted step. These daily therapy periods included crying, episodes of apnea and my frustration and anger. I thought that his slow progress was my fault. I thought that I had to put Brian through an emotional wringer to help him “work through the fear.” I wish I could go back and erase some of those experiences.

Of course, there were happy moments. Every flicker of success brought overreactions of joy and praise. I baked a cake and invited friends over to celebrate those few, hard-won steps.

After six months, Brian could take three unsteady steps. He showed much courage, but his fear and total lack of desire to walk were mountains we had to climb daily. After a year, he walked fifty feet, but it required fifteen minutes and constant coaxing.

**Blowing the Whistle**

When Brian turned three, the consulting therapist suggested teaching him to get up and down from the floor. Almost every time we went through this exercise, Brian would cry and have apnea. As his “therapist,” I felt driven to work through this agony, but my motherly instincts wanted to protect him.

Finally, the truth became obvious. After three years of reading—in *Exceptional Parent* and elsewhere—that parents need to make the final decisions regarding their child’s treatment, I realized that it was time to blow the whistle. It had come down to a choice between being a good therapist or a good mother. I was sure of my decision: I was ready to throw the braces and walker out the window.

The therapist convinced me to compromise. She had seen children change their attitudes and start making rapid progress when they turned six or seven. We agreed to step back to a more comfortable schedule and hang on.” We stopped working on new skills and cut down on Brian’s walking time, but kept using the standing table in order to strengthen his bones.

**Braces and Burnout**

Our experience with burnout taught us some very important lessons:

- **Parents decide:** With therapy, as with every other aspect of the child’s treatment, we are the best judges.
- **Therapists advise:** Physical therapists—like all professionals—have a responsibility to encourage, to motivate and even to press the parents; but they are limited in their knowledge of the whole child. Consider the therapy schedule as advice, not law.
- **Use a therapist, or be prepared:** Therapy must be reinforced at home, but try to have a qualified physical therapist do the primary work with the child. If you must be both therapist and parent, plan carefully. Know how you will approach difficult tasks, when you will push and how to make it a positive experience for the child.
• **Blow the whistle:** When the child is suffering undue stress, take responsibility for stopping or changing the therapy regimen.

• **Take one step back:** For Brian, stepping back to a less stressful routine boosted his confidence. Continually asking for “just a little bit more” can make a child feel that he is never quite good enough.

• **Let the child initiate progress:** Our scaled-back therapy regimen gave Brian an opportunity to begin a new challenge when he felt ready, rather than always feeling one step behind.

• **Communicate with the therapist:** The therapist will never have a complete picture of your child without your feedback. Communicating our stress better and sooner would have saved us some grief.

• **Take time to live:** With all the medical, dental, optical and therapy appointments Brian faces, it’s important for us to emphasize that he should take time to enjoy life, even if that means slowing down the therapy process.

• **Affirm, Affirm, Affirm!** We continually tell Brian and ourselves that we are doing our very best with a very difficult job.

**Moving Forward**

For the last five years, Brian has been mainstreamed in a public elementary school. He maintains above-average grades and sings in the annual school talent show. For the first three years, he walked in braces briefly during adaptive physical education classes and stood in a standing table for one hour a day. In third grade, realizing that walking was still too slow and demanding to be practical, we decided to continue having Brian stand for one hour a day at school while using a wheelchair for all mobility. That’s the way he likes it, and it has worked very well.

Interestingly, as we were choosing the pictures to accompany this story, Brian eliminated all the pictures that showed him in his braces. He explained that he would be embarrassed for others to see him with braces and a walker. “They would think there was something really wrong with me,” he said. So much for projecting our viewpoints onto our children!

The bottom line is that Brian has never had any desire to ambulate with braces, and still doesn’t. He seems to know what he can do and is satisfied with that. Because of his daily standing, he maintains the potential to walk if he changes his mind. We endangered that potential, however, by driving ourselves too hard.

Meanwhile, Brian pitches for his class kickball team, collects baseball cards and dreams of becoming a radio sportscaster. For us, taking one step back brought us two steps forward—happier and more ready to face the challenges ahead.

Kathy Olsen is a writer and speaker who lives in Texas with her husband, Lloyd, and two sons, eleven-year-old Brian and nine-year-old Mark. She is the author of Silent Pain: Finding God’s Comfort for Your Hidden Heartaches (NavPress, 1992; Call 1-800-366-7788 for ordering information.) and numerous articles. Kathy volunteers in her church and at the private school her sons now attend.
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Innovation in Mobility

Circle #85
Wheeled Mobility Selection: A Guide for Parents

In some respects, a wheelchair is like an automobile or a pair of shoes. It provides the interface between a body and the world around it. Like shoes, a proper fit is essential to enable a child to maximize her or his potential and feel comfortable moving around in the world. Like a car, design factors can take into account the user’s personal needs and interests.

Thirty years ago there would have been no need for an article on wheelchair selection. Someone needing a wheelchair would have gone to a doctor to get a prescription for a wheelchair. That chair would have been fairly standard in size and appearance—a heavy, metal chair with black or dark green upholstery. Nothing else was available.

Now, thanks to the variety of available wheelchairs and options, selecting the appropriate wheelchair can be a bewildering task. This article will provide information about wheelchairs, and describe wheeled mobility options in the marketplace today. This article will not discuss the variety of strollers that are available for younger children or for children who are unable to propel a wheelchair independently.

Considering Individual Needs

It is impossible to select an appropriate chair until a child’s needs have been assessed. This involves determining the level of necessary assistance and considering how the wheelchair will be used.

Wheelchair prescribers—occupational therapists, physical therapists, or other members of the clinical team—can determine how much assistance the wheelchair should provide. While some children with quadriplegia, for example, can only use powered wheelchairs, others may find that they are able to use a manual wheelchair or a powered scooter. These alternatives may more appropriately fit into the family’s lifestyle and are less expensive.

It also is important to determine how the wheelchair will be used. Will it be used indoors, outdoors and during transport in a van or car? Some children use a manual wheelchair in their homes, but use a powered chair outside and in school. For many families, the ability to fold a wheelchair or take it apart easily for traveling in a car is important.

The “Right” Chair

Once a child’s needs have been determined, the next step is to choose the “right” chair(s). Parents of a child who is new to using a wheelchair may wish to talk with more experienced parents about their likes and dislikes. There is nothing like practical experience to provide feedback on specific features that may be desirable, as well as those that should be avoided. Prescribers and medical equipment dealers, who often receive feedback from previous clients, can also be good sources of information. Finally, there are some written resources on wheelchairs now available (see below), and ABLEDATA, a database with information on more than 19,000 products for children and adults with disabilities, is a good source for information on specific wheelchairs (see page 56).
Wheelchairs come in many sizes, shapes and varieties to meet the diverse needs of a multitude of users who have differing levels of physical abilities and varying interests. Children with sufficient upper body strength often prefer to use a wheelchair that is propelled by arm strength, or what is called a manual wheelchair. Some children are unable to propel a wheelchair with their own arm strength. In such cases, they may prefer—or require—a wheelchair powered by batteries.

Wheelchair Components

- **Frame**: The development of new, lightweight materials for wheelchair frames has been one of the biggest breakthroughs in modern wheelchair technology. In contrast to the days when stainless steel was the only frame material available, today’s wheelchair frames may be made of chrome, aluminum, airplane aluminum, steel tubing, an alloy of chrome and lightweight materials, or other lightweight composite materials. The type of material used to construct the frame affects the overall weight and strength of the wheelchair.

  The two most common types of frames currently available are rigid frame chairs—where the frame remains in one piece and the wheels are released for storage or travel—and standard cross frame chairs which are foldable for transport or storage.

- **Upholstery**: Wheelchair upholstery must withstand daily use in all kinds of weather. Consequently, manufacturers provide a variety of options, ranging from cloth to new synthetic fabrics to leather. Many manufacturers also offer a selection of upholstery colors—everything from black to neon—to allow for individual preferences.

- **Seating System**: Since seating is often chosen on an individual basis, seating systems are usually sold separately from the wheelchairs themselves. However, some wheelchairs include seating and postural support systems. When selecting a wheelchair and seating system, it is important to ensure that the two components are compatible.

- **Brake Type**: On a manual wheelchair, “braking” is accomplished by applying the hands to the wheels. However, “parking brakes” or wheel locks are available in several different designs, and can be mounted at various heights for easy use.

- **Wheels/Tires**: Most wheelchairs use four wheels—two large tires at the back and two smaller casters at the front. The standard tire used for the rear wheels on

### Tire Options for Wheelchairs

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mag</td>
<td>Tires with oversized widths.</td>
</tr>
<tr>
<td>Off-road</td>
<td>“Knobby” tires with deep grooves designed to provide better traction on unpaved surfaces.</td>
</tr>
<tr>
<td>Pneumatic</td>
<td>Tires with air-filled tubes, similar to racing bicycle tires.</td>
</tr>
<tr>
<td>Radial</td>
<td>Tires reinforced with steel, similar to radial car tires.</td>
</tr>
<tr>
<td>Semi-pneumatic</td>
<td>Tires made from a combination of a solid rubber and air-filled tubing. Designed to reduce the possibilities of flats and to cushion the ride.</td>
</tr>
<tr>
<td>Solid</td>
<td>Tires without air spaces or tubes. Designed to be “flat-free,” but may provide a less smooth ride.</td>
</tr>
</tbody>
</table>
LIFE CAN STILL BE THE JOURNEY OF DISCOVERY YOUR CHILD DESERVES

REGAL PEDIATRIC 3-WHEEL, RWD SCOOTER

The REGAL PEDIATRIC was ergonomically designed to meet the special needs of your child. The REGAL PEDIATRIC offers these exclusive Bruno features: Custom Contoured, Adaptable Seating for superior lateral, thigh and lumbar support; 23 hardpoints in the seatback for the attachment of various support devices; 5 step platform for exceptional legroom; E-Z TILT™ with all driving adjustments selectable from the seated position and overall Proportional Sizing™ for your child's specific requirements.

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Circle #8
most wheelchairs is a pneumatic tire—a tire with air-filled tubes similar to those found on racing bicycles. The standard size for the large wheel is 24 inches, although smaller and larger sizes are available. Many manufacturers also offer other types of tires at extra cost. See “Tire Options for Wheelchairs” on page 24.

• **Footrests:** For rigid frame chairs, footrests usually are incorporated into the frame. Cross-brace folding chairs often have footrests that can swivel and, or be removed.

• **Armrests:** Many lightweight manual chairs are designed to be used without armrests. This makes it easier for the user to roll up to a desk or table, and many active wheelchair users prefer the streamlined look of a chair with no armrests. Armrests can be helpful, however, if the user has difficulty with upper body balance while seated.

## Manual Wheelchairs

Because the wheelchair market is changing so rapidly, there is no universally accepted terminology to describe the various kinds of manual wheelchairs. Most manual wheelchairs sold today, however, can be placed in one or more of the following categories:

• **Lightweight/Sports Chairs:** For a child with good upper body capabilities, the most popular type of wheelchair for everyday use is the lightweight manual wheelchair. Lightweight chairs provide maximum independent movement with minimal effort. Many children also prefer the sportier look of the lightweights.

• **Standard/Everyday Chairs:** A standard wheelchair is characterized by a cross-brace frame, built-in or removable arm rests, swing-away footrests, a mid- to high-level back, and push handles which allow non-occupants to propel the chair.

• **Child/Junior Chairs:** Children and young adults need chairs that can accommodate their changing needs as they grow. In addition, it is important that wheelchairs for children or teens be adaptable to classroom environments and be “friendly-looking” to help the user fit more readily into social situations. Manufacturers are becoming increasingly sensitive to these market demands and are attempting to address them with innovative chair designs and a variety of “kid-oriented” colors and styles.

• **Specialty Chairs:** Because of the diverse needs of wheelchair users, wheelchairs have been designed to accommodate many lifestyles and user needs. Chairs that can be propelled by one hand are available for children who have paralysis on one side. Rugged, outdoor chairs are available for outdoor activities. Aerodynamic three-wheeled racing chairs are used in racing events. Manual
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chairs that raise the user to a standing position are available for children who need or want to be able to stand. Generally, these and other specialized chair designs are manufactured by independent wheelchair manufacturers to meet the needs of specific target markets.

• Institutional/Nursing Home/Depot Chair: The least expensive type of chair available—an institutional chair—is designed for institutional usage only, such as transporting patients in hospitals. Since it is not fitted for a specific individual, it is not an appropriate alternative for anyone who desires independent movement.

Cost

Manual wheelchairs range in cost from approximately $500 for an institutional chair, to more than $4000 for a customized lightweight wheelchair with a number of options. Most lightweight manual chairs cost between $1800 and $2800. This price range is not intended, however, to suggest an “appropriate price” to pay for a wheelchair for any specific individual. Special accessories or customizations required to accommodate specific disabilities, for example, could put the actual purchase price much higher.

Powered Wheelchairs

Two basic styles of powered wheelchair are currently available. The traditional style looks like a standard manual wheelchair that has been reinforced to carry the extra weight of a power and control system. Typically, such wheelchairs are powered by a battery that is attached underneath the seat. Another style is a platform-model powered wheelchair in which the seating platform is located atop a power base. A variation on the power base concept is a chair that includes built-in lifts to allow the user to raise and lower the seating platform.

The selection process for a powered wheelchair should include evaluation of the child's physical status and abilities, and usage requirements. Physical considerations include posture, strength, sensation, visual acuity and perception, and the ability to learn how to use the wheelchair safely. An evaluation should consider use of the wheelchair in everyday settings, ability to get in and out of the wheelchair and capacity to perform needed activities from the wheelchair.

While a child's physical capabilities clearly are important factors to consider, it is also essential that the wheelchair fits into the child’s environment and the family's lifestyle. For example, the places where it will be used must be architecturally accessible. If the child cannot get into the bathroom at home using a particular wheelchair, that chair may not be a practical choice. Transportation considerations also are important. Is a van available to transport the individual in the chair, or does the chair need to fold so that it can be carried in the trunk?

The purchase price of a powered wheelchair rarely is less than $3,500; for the more deluxe models or those with specialized adaptations, the price can exceed $12,000. Like any major financial decision, purchase of a powered wheelchair should be undertaken with the utmost care to ensure that the product meets the needs of the user. For more information on selecting a powered chair, see “Powered Mobility for Your Child?” on page 33.
Unlike clothes, shoes, toys and some parents, the Zippie P500 can survive from childhood through adolescence unscathed.

That's because the Zippie P500 actually grows with kids, thanks to its wide range of adjustments and the innovative Zippie Growth Kit. Powered by a Direct Drive Motor System for maximum efficiency, the Zippie P500 lets kids get out there. Its programmable controller adjusts to meet their abilities. It even has a downsized power base, a kid-sized seating unit and 13 hot color options sure to please even the most cool-conscious youngster.

The Zippie P500 from Quickie...a chair kids and parents can agree on.

Terry Spees
Father, Parent & Registered Nurse

"The Zippie P500 is incredibly maneuverable. And Andrew loves the sleek design."
Scooters

An alternative to either manual or powered wheelchairs is a scooter, or three-wheeled cart. A scooter looks and operates much like a golf cart. The user sits in a chair seat that is contoured to fit the body and may include a special seating cushion. The scooter is propelled through use of a steering mechanism located in front of the user, similar to riding a bicycle. Scooters provide power at a lower cost than many regular four-wheeled powered wheelchairs. Scooters also are thinner than many wheelchairs, making them more maneuverable.

Resources on Wheelchair Selection

The resources listed in this section focus primarily on adult wheelchair users. However, some of the information provided is applicable to the selection of wheelchairs for children.


- This guide helps new wheelchair users select a wheelchair with the right dimensions and seat system depending upon the degree of disability, goals of the user, and the environment in which the chair will be used. It also provides information about proper use and maintenance of wheelchairs.


- This small, straightforward publication addresses the factors to be considered by wheelchair prescribers. It is filled with illustrations and practical suggestions for making prescription decisions. Though intended primarily for prescribers, the information in this guide would be of value to an individual selecting a wheelchair for personal use. The information about manufacturers and product availability is slightly dated, but the basic concepts presented remain useful.


- This resource was written by people with disabilities who have selected wheelchairs for many years, health care providers who prescribe wheelchairs, and researchers-engineers who participate in the development of new wheelchair designs.


- This 30-minute video discusses the options to be considered for someone purchasing a manual wheelchair.

ABLEDATA Fact Sheets. Available from: ABLEDATA, (800) 227-0216 or (301) 588-9284. Both numbers are for voice and TDD. Price: Single copies are FREE.


Wheelchair Standards

The American National Standards Institute (ANSI) recently approved a complete set of standards for wheelchairs. These standards consist of standard methods for measuring wheelchair components, and standard methods to test such things as a chair's strength, stability and turning radius.

The complete set of 18 standards is available from RESNA. These are very technical documents, probably of interest only to manufacturers and others who are going to conduct testing themselves. However, therapists and lay people may contact RESNA to request free summary documents that describe the standards in less technical language.

Invacare, one of the largest wheelchair manufacturers in the country, recently began advertising that its wheelchairs had been tested according to these standards. As consumers and therapists begin to ask for this information, it is expected that other manufacturers also will begin using the standards for testing—and advertising this fact to the public. Once this information becomes more readily available, it can be used by consumers and prescribers to make more informed purchasing decisions.


This article was adapted from information contained in ABLEDATA fact sheets written by Lynn Bryant. ABLEDATA Project Director. Individual fact sheets are available free from ABLEDATA, a database of more than 19,000 products for people with disabilities. Call (800) 227-0216 or (301) 588-9284. Fact sheets may also be downloaded to a computer. This service is available 24 hours a day from the free ABLEDATA electronic bulletin board system (301-589-3563). Two hundred twenty-four thousand subscribers have used the ABLEDATA database. Information specialists are on hand to assist callers locate the information they need. For a small fee, ABLEDATA can provide patrons with computer printouts of information on specific wheelchairs listed in the database. Costs are determined by the size of the database search requested. Searches of 20 products or less are free; the charge is $5 per hundred products thereafter.
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We're with you for life!
The suggestion to look into powered mobility may come from a therapist, a seating clinic or another parent—whatever the source, few parents welcome the recommendation with relief or enthusiasm. If your child has been focusing on therapy to develop skills for walking, considering an electric wheelchair—or “powered chair”—may seem akin to acceptance of permanent disability. You may feel like you are “giving in” or admitting failure. The suggestion may also come at the critical time of entry to school when changes in therapy supports and anxiety about school placement and success are prominent. Fears of injury to the child or to other children are quite reasonable! A rash of questions arise as families consider powered mobility: How old does my child have to be to consider powered mobility? How will my child benefit from a powered chair? What kind of skills does he or she need before trying powered mobility? How much will it cost?
Research Changes Opinions

Historically, powered mobility was reserved for adults. Even then, it was considered only as a last resort. Powered chairs were first made available to children with muscular dystrophy who were no longer able to propel a manual chair, or to older children who required rehabilitation following injuries. Professionals believed that if young children were given powered chairs, they would lose, or fail to develop the skills needed to walk. Professionals and parents also feared that children given powered chairs would be less motivated to participate in therapy programs aimed at developing muscle strength and coordination for walking, or that they would injure themselves—or peers that might get in their way—while learning to drive powered chairs.

Research in the past decade has shown that children as young as 24 months—an age by which able-bodied children are developing independent mobility skills—are able to safely operate powered mobility devices. Gaining independent movement through powered mobility also has been shown to have a positive impact on many aspects of a child’s development. Children improve spatial orientation, increase independence and demonstrate better social skills for getting along with peers, with no negative effects on motor development. Adults and other children acquire a new respect for the abilities of these children after seeing their initiative and problem-solving skills.

Based on this research, powered mobility is increasingly being made available to very young children. Professionals now believe that the use of powered mobility reduces the risk of further developmental and social delays by providing varied and appropriate experiences for children in their homes, schools and communities.

Technological Advances

The development of new technology has also contributed to the increasing use of powered mobility by young children. In the past, powered chairs were available only with standard proportional joysticks and child-sized sling seats on adult chair bases. Manufacturers now produce child-sized, user-friendly chairs with a variety of standard and alternate controls. Microcomputer controls that allow the use of alternate controls have also been commercially available for the last few years.

These technological advances also have benefited older children with poor muscle control who were previously hard to fit with powered mobility. A variety of new features can compensate for deficits in physical control.

Look into powered mobility if:

- The child has a need for independent mobility: For children who are at a normal or near normal level of intellectual development, the need for independent mobility may occur as early as one-and-a-half to two years of age, just as it would in their peers. Independent mobility allows a child to play, explore the environment, and participate in school or family activities. Sometimes, a child who shows frustration or misbehavior as a result of his or her lack of mobility may be demonstrating his or her readiness for powered mobility.

Fun with a purpose: Seven-year-old David controls a toy with a switch. This "fun" activity is preparing him to manipulate the controls of his new powered wheelchair.

- The child displays the skills that are required for powered mobility:
  - understands the concept of cause and effect.
  - understands one step commands, and
  - has adequate visual skills to perceive child-sized objects within a 10-foot radius.

Pre-driving skills can be developed by playing with switch toys, joystick- or switch-activated computer games, and participating in interactive games with peers.

- The child has at least one reliable movement for activating a switch that could be used to operate powered chair controls: The movement must be one that the child can repeatedly stop and start at will. It should also be a movement that the child can perform in a seated position. Many children can control a joystick, but powered chairs can also be driven with a variety of controls, so limited hand or arm control does not rule out powered mobility.

It is important to make the decision about switch location in consultation with your child’s therapist. You will want to choose a switch site that will not have a negative effect on the way a joint or muscle works, or use reflex movements that the therapist is trying to minimize.

- Family members are willing to accept powered mobility and supervise the child: Supervision of the young child with a powered chair is just as necessary as supervision of a child on a bicycle. Supervision prevents accidents and keeps the child from venturing into unsafe environments. Learning to drive a powered chair is like learning any other physical activity or sport; a child won’t perform well without regular supervised practice.

- The child has an accessible environment in which to use the powered chair: Many homes are not wheelchair accessible, but this should not preclude consideration of powered mobility. Using a powered chair for independent...
Wheelchair trials: Seven-year-old David tests out a powered wheelchair, while vision resource teacher Lenore Leonard (left), and seating equipment coordinator Stefanie Laurence (center) look on.

mobility at school may be valuable for the child's social development and participation. A child also may be able to use a powered chair outdoors—in the yard and neighborhood—while storing and charging the battery in the garage.

- A means of transportation for the powered chair is available: This might be public transit, the family van or a school bus.
- A manual wheelchair is not appropriate for the child: This might be because the child cannot propel a manual wheelchair in an energy-efficient manner and cover required distances in acceptable time. A manual wheelchair would also be inappropriate if abnormal movement patterns are used to propel it.

Other considerations

There will be other factors to think about as you consider powered mobility. It is important to obtain an assessment to determine the optimal seating and control method for a powered chair. This is especially important if the child has limited physical control. Many children also benefit from training in powered chair driving before prescription. A training program allows children to develop necessary skills and find the best driving method. See if your treatment center can offer such a program.

You must also plan for maintenance of the batteries and chair after purchase. Just like periodic automobile maintenance, this adds to the overall cost of the chair.

Weigh all these factors as you consider powered mobility for your child. Discuss them with therapists who are familiar with your child’s physical, intellectual and social skills. Consider what independent mobility with a powered chair has to offer your child. Even if a powered chair is just an interim measure while walking skills develop—or just used for long distances, playgrounds and shopping—the potential benefits are worth consideration and exploration!

Linda Petty is an occupational therapist in the Communication and Assistive Technology Department at Bloorview Children’s Hospital in Toronto, Canada. For the last 10 years, she has worked in clinics providing assessment, training and prescription of technical aids—including powered mobility controls—for children and young adults. Linda lives with her husband, Mark, in a 115-year-old family home outside Toronto. When not working or renovating the house, she enjoys gardening, windsurfing, making pottery and playing the piano.
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Directory of Wheelchair Manufacturers

Canadian Wheelchair Mfg
1360 Blundell Rd
Mississauga, Ontario
Canada L4Y 1M5
(416) 275-3960 (M, C)

Car Chair
Car Chair House, Station Rd
Industrial Estate
Halsham, Sussex BN27 2ES
England (M)

Chair Concern
13150 Paramount Blvd
South Gate, CA 90280
(213) 630-4220 (P)

Colours 'N Motion
1591 S Sinclair St, Ste A
Anaheim, CA 92806
(800) 992-8990 (M)

Convald Products
3541 A Lomita Blvd
Torrance, CA 90505
(800) 552-1020 (M)
See our ad on pg 20.

R J Cooper & Associates
24843 Del Prado, Ste 283
Dana Point, CA 92629
(800) 752-6637 (M, P, C)

Crown Medical
PO Box 132
Reynoldsburg, OH 43068
(614) 696-9803 (M)

Damaco/Freedom on Wheels
20542 Plummer St
Chatsworth, CA 91311
(800) 432-2434 (M, P, C)

DU-IT Control Systems Group
8765 Township Rd, #513
Shreve, OH 44676-9421
(800) 662-4548 (M, C)

Duro Products
28412 Mari Ila St
California Cruisers
21742 Marilla St
Chatsworth, CA 91311
(814) 718-2828 (M)

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681 (C)

Eric's House
12503 44th Drive SE
Everett, WA 98203-9000 (M)

ETAC USA
2325 Parklawn Dr, Ste P
Waukesha, WI 53186
(800) 678-3822 (M, C)

Everest and Jennings
110 Corporate Square Dr
St Louis, MO 63132-2908
(800) 235-4661 (M, P, C)

Everest & Jennings Canada
111 Snidercroft Rd
Concord, Ontario
Canada L4K 2J8
(416) 669-2381 (M, P, C)

Excel Mobility Products
636 Constitution Ave NE
Washington, DC 20002
(202) 544-0323 (P)

Falcon Rehabilitation Products
4404 East 60th Ave
Commerce City, CO 80022
(303) 287-6808 (M, P)

Folio Products
1341 Sherman Dr, Unit A
Longmont, CO 80501
(800) 356-4125 (P)

Gendron
400 E Lugbill Rd
PO Box 197
Archbold, OH 43502
(800) 556-4125 (P)

Golden Technologies
159 Penn Ave
Exeter, PA 18643
(609) 624-6734 (P)

Guardian Products
4175 Guardian St
Simi Valley, CA 93063
(800) 255-5022 (M)

Gunnell
8440 State St
Millington, MI 48746
(800) 551-0055 (M, C)

Hadoo Marketing Services
6601 NW 14th St, #2
 Ft Lauderdale, FL 33313-4579 (P)

Halls Wheels
PO Box 380784
Cambridge, MA 02238
(617) 628-7965 (M)

Hausted
927 Lake Rd, PO Box 710
Medina, OH 44256
(800) 428-7833 (M)

Hoveround
1748 Independence Blvd, Ste B1
Sarasota, FL 34234
(800) 964-6837 (P)

IDC
Chatuzange le Goubet
26300 Bourg de Peage
France (M)

Imex Healthcare
1671 Dell Ave, Ste 202
Campbell, CA 95008-6903
(408) 370-6381 (M)

Interior Mediquip
PO Box 187
Vernon, BC
Canada V1T 8Z7
(604) 544-1383 (M)

Invacare
PO Box 4028
899 Cleveland St
Elyria, OH 44035-2125
(800) 333-6900 (M, C)

Iron Horse Productions
8757 Township Rd
Columbus, OH 43260
(614) 999-2301 (M)

Kalen Medical—New Horizons
2310 East OrangeThorne Ave
Anaheim, CA 92806
(800) 678-4499 (M)

Kareco International
299 Rt 22 E
Green Brook, NJ 08812
(800) 852-7326 (M)

Kempf
1080 E Duane Ave, Ste E
Sunnyvale, CA 94086
(408) 773-0219 (P)

The types of wheelchairs manufactured by each listed company are designated by letter code: M=manual, P=powered, C=children's. Most companies manufacture young adult and adult manual wheelchairs. This list was provided by ABLEDATA, an assistive technology and adaptive communications database. For more information call ABLEDATA, (800) 227-0216.
<table>
<thead>
<tr>
<th>Company Name</th>
<th>Address</th>
<th>Phone Numbers</th>
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<tbody>
<tr>
<td>Kendall-Futuro</td>
<td>5405 Duport Cir, Ste A Cincinnati, OH 45150-2735 (513) 576-8000 (M, C)</td>
<td></td>
</tr>
<tr>
<td>Kid-Kart</td>
<td>126 Rosebud, Ste #1 Belgrade, MT 59714 (800) 388-5278 (M, C)</td>
<td>See our ad on pg 26.</td>
</tr>
<tr>
<td>Labac Systems</td>
<td>8955 S Rdgeline Blvd, Ste A Highlands Ranch, CO 80128 (800) 445-4402 (P)</td>
<td></td>
</tr>
<tr>
<td>Leisure Lift</td>
<td>100 Meriam Ln Kansas City, KS 66106 (800) 255-0285 (P)</td>
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<tr>
<td>Hugh Macmillan Rehabilitation Centre</td>
<td>350 Rumsey Rd Toronto, Ontario Canada M4G 1R8 (800) 342-1579 (M)</td>
<td></td>
</tr>
<tr>
<td>Medical Lab Automation</td>
<td>8110 Umlerton Rd Largo, FL 34641 (800) 237-1162 (M)</td>
<td></td>
</tr>
<tr>
<td>Medical Resource Companies of America</td>
<td>10670 N Central Expressway Dallas, TX 75231 (800) 583-6565 (P)</td>
<td></td>
</tr>
<tr>
<td>Meyra/Five Star Mobility</td>
<td>Mobility Manufacturing 5555 S Country Club Rd Tucson, AZ 85706 (800) 767-2668 (P)</td>
<td></td>
</tr>
<tr>
<td>Morgan Technology</td>
<td>2230 Wisconsin Ave Downers Grove, IL 60515 (800) 906-5493 (M)</td>
<td></td>
</tr>
<tr>
<td>Motovator</td>
<td>1732 Border Ave Torrance, CA 90501-3601 (310) 320-5941 (P)</td>
<td></td>
</tr>
<tr>
<td>Mulholland Positioning Systems</td>
<td>PO Box 391, 215 N 12th St Santa Paula, CA 93060 (805) 525-7165 (M, C)</td>
<td></td>
</tr>
<tr>
<td>Omni Manufacturing</td>
<td>4355 International Blvd Norcross, GA 30093 (800) 554-9215 (M)</td>
<td></td>
</tr>
<tr>
<td>Orthofab</td>
<td>500 Rue Desrochers Ville Vanier, Quebec Canada G1M 1C2 (418) 681-0667 (P)</td>
<td></td>
</tr>
<tr>
<td>Ortho-Kinetics</td>
<td>W220 N507 Springdale Rd PO Box 1647 Waukesha, WI 53187-1647 (800) 588-7786 (M, P)</td>
<td></td>
</tr>
<tr>
<td>Otto Bock</td>
<td>3000 Xenium Ln N Minneapolis, MN 55441 (800) 329-4058 (M)</td>
<td></td>
</tr>
<tr>
<td>Patient’s Personal Needs</td>
<td>75 Centre St Holbrook, MA 02343 (800) 289-4776 (M)</td>
<td></td>
</tr>
<tr>
<td>Peachtree Medical Systems</td>
<td>5002 N Royal Atlanta Dr, Ste P Tucker, GA 30084 (404) 939-1122 (P)</td>
<td></td>
</tr>
<tr>
<td>Peachtree Patient Center</td>
<td>3123 Presidential Dr Atlanta, GA 30340 (404) 457-0700 (P)</td>
<td></td>
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<tr>
<td>Permobil of America</td>
<td>6 B Gill St Woburn, MA 01801-1721 (800) 736-0925 (M)</td>
<td></td>
</tr>
<tr>
<td>Pin Dot Products</td>
<td>6001 Gross Point Rd Niles, IL 60648-4027 (800) 451-3553 (M)</td>
<td></td>
</tr>
<tr>
<td>Poirier S.A.</td>
<td>Usine des Roches-Fondettes 37230 Luynes FRANCE (M, C)</td>
<td></td>
</tr>
<tr>
<td>JA Preston</td>
<td>PO Box 89 Jackson, MI 49204 (800) 631-7277 (M, C) See our ad on the back cover.</td>
<td></td>
</tr>
<tr>
<td>Pride Health Care</td>
<td>71 S Main St Pittston, PA 18640 (800) 457-5438 (P)</td>
<td></td>
</tr>
<tr>
<td>Quest Technologies</td>
<td>766 Palomar Ave Sunnyvale, CA 94086-9716 (408) 736-3500 (P)</td>
<td></td>
</tr>
<tr>
<td>Quickie Designs</td>
<td>2842 Business Park Fresno, CA 93727 (800) 456-8168 (M, P, C) See our ads on pgs 17 &amp; 29.</td>
<td></td>
</tr>
<tr>
<td>Quickie Designs/Shadow Products</td>
<td>20604 84th Ave S Kent, WA 98032-1224 (800) 342-1579 (M)</td>
<td></td>
</tr>
<tr>
<td>Ranger All Season</td>
<td>PO Box 132 Minneapolis, MN 55441 (800) 225-3811 (P)</td>
<td></td>
</tr>
<tr>
<td>Redman Wheelchairs</td>
<td>945 E Ohio St #4 Tucson, AZ 85714-1694 (800) 727-6684 (M, P, C)</td>
<td></td>
</tr>
<tr>
<td>Rehab Centre for Children</td>
<td>631 Wellington Cres Winnipeg, Manitoba Canada R3M 0A8 (204) 452-4311 (M, C)</td>
<td></td>
</tr>
<tr>
<td>Rehabco</td>
<td>1515 Olmstead Ave Bronx, NY 14202 (716) 829-3800 (M, P, C)</td>
<td></td>
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<tr>
<td>RETEC USA</td>
<td>10 Centre Dr Orchard Park, NY 14127 (800) 777-3832 (P)</td>
<td></td>
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<tr>
<td>RolControl Products</td>
<td>6750 Worth Way Canarillo, CA 93012 (805) 386-4191 (P)</td>
<td></td>
</tr>
<tr>
<td>Rx Rocker</td>
<td>3541 Old Conejo Rd, #101 Thousand Oaks, CA 91360 (800) 762-5371 (M)</td>
<td></td>
</tr>
<tr>
<td>Samhall Rehab</td>
<td>300 Long Beach Blvd Stratford, CT 06497-7153 (800) 882-0098 (M, C)</td>
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<tr>
<td>Seidel Electronics</td>
<td>466 W Market St Akron, OH 44303 (216) 378-3817 (P)</td>
<td></td>
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<tr>
<td>Steven Motor Chair</td>
<td>120 N Gunter Siloam Springs, AR 72761 (501) 524-8448 (P)</td>
<td></td>
</tr>
<tr>
<td>Stroller-Pack</td>
<td>134 N Franklin St Juneau, AK 99801 (800) 487-9654 (M, C) See our ad on pg 46.</td>
<td></td>
</tr>
<tr>
<td>TM Innovative Products</td>
<td>830 South 48th St Grand Forks, ND 58201 (701) 772-5185 (P) See our ad on pg 43.</td>
<td></td>
</tr>
<tr>
<td>Tallahassee Therapeutic Equipment</td>
<td>9601 Miccosukee Rd, Lot 13 Tallahassee, FL 32308-9609 (800) 477-0487 (M) See our ad on pg 43.</td>
<td></td>
</tr>
<tr>
<td>Tarsys Engineering</td>
<td>101 Bartley Dr Toronto, Ontario Canada M4A 1C9 (415) 751-9992 (P)</td>
<td></td>
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<tr>
<td>Technovation</td>
<td>6373 W Glenbrook Rd Brown Deer, WI 53223 (414) 354-8895 (M)</td>
<td></td>
</tr>
<tr>
<td>Tetra Development Society</td>
<td>Plaza of Nations, Box 27 770 Pacific Blvd S Vancouver, BC Canada V6E 5E7 (604) 688-6484 (P, C)</td>
<td></td>
</tr>
<tr>
<td>Theradyne</td>
<td>21730 Hanover Ave Lakeview, MN 55044 (800) 328-4014 (M, P, C)</td>
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<tr>
<td>Top End by Action</td>
<td>4501 63rd Cir N Pinellas Park, FL 34665 (800) 332-8677 (M)</td>
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<tr>
<td>Tuffcare</td>
<td>2700 Saturn St A Brea, CA 92621-6704 (800) 367-6160 (M)</td>
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<tr>
<td>Up and Over Engineering</td>
<td>1509 Liberty St El Cerrito, CA 94530 (415) 233-1328 (M)</td>
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<tr>
<td>Valtec AG</td>
<td>Bleicheweg CH-5605 Dottikon Switzerland (M)</td>
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<tr>
<td>Voyager</td>
<td>68102 US Hwy 31 Lakeville, IN 46536-9738 (P)</td>
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<tr>
<td>Wheel Ring</td>
<td>199 Forest St Manchester, CT 06040 (203) 647-6596 (M, C)</td>
<td></td>
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<tr>
<td>Wheelchair Institute of Kansas</td>
<td>PO Box 777 La Crosse, KS 67548 (800) 537-6454 (M)</td>
<td></td>
</tr>
<tr>
<td>Wheelchair Store</td>
<td>12025 Shiloh Rd, Ste 230 Dallas, TX 75228 (800) 648-1884 (P)</td>
<td></td>
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<tr>
<td>Wheelsport International</td>
<td>105 W Dakota, Ste 114 Clovis, CA 93612 (209) 276-3271 (M, C)</td>
<td></td>
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<tr>
<td>Whitmyer Biomechanix</td>
<td>848 Blountstown Hwy, Ste H Tallahassee, FL 32304 (800) 476-0487 (M) See our ad on pg 43.</td>
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</tr>
<tr>
<td>Tarsys Engineering</td>
<td>101 Bartley Dr Toronto, Ontario Canada M4A 1C9 (415) 751-9992 (P)</td>
<td></td>
</tr>
<tr>
<td>Xil Wheelchairs</td>
<td>1020 Madera St, Ste 102 Chico, CA 95926 (800) 356-3554 (M, C)</td>
<td></td>
</tr>
<tr>
<td>Zyro Industries</td>
<td>PO Box 1008 Portland, OR 97207-1008 (800) 234-6006 (P)</td>
<td></td>
</tr>
</tbody>
</table>
Berkshire Meadows

A private, non-profit year-round residential school for children who are developmentally delayed and may be multiply disabled.

We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

Beautiful campus in the heart of the Berkshire hills, with cheery, comfortable semi-private rooms
Innovative learning center with unique, year-round curriculum
Hydrotherapy in an indoor therapy pool and hubbard tank
Augmentative communication systems developed along with total communication
Intensive physical therapy
Around-the-clock advanced medical care
Associations with leading specialists and major medical centers
Affiliation with SUNY
Parent association and open-door visiting policy

Gail W. Charpentier, Executive Director
Berkshire Meadows
249 North Plain Road
Housatonic, MA 01236
413/ 528-2523

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- Physical Therapy
- Occupational Therapy
- Speech and Language Therapy
- Communication Aids
- Special Education
- Music Therapy
- Special Medical Attention
- Adapted Recreational Activities

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215) 222-2566

You Asked DynaVox To Do Even More...

"I want to spell and talk faster."

Introducing DynaWrite.

DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call at 1-800-344-1778.

We Hear You.

Exceptional Parent 39
ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO in a city near you:

ABILITIES EXPO EAST
Edison, NJ
Raritan Expo Center
April 15-17, 1994

ABILITIES EXPO WEST
Anaheim, CA
Anaheim Convention Center
May 20-22, 1994

The #1 Show of Products and Services for People with Disabilities

Opportunities to try and buy on the Show floor
One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

Longest running show of its kind in the U.S.
Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

For more information on attending please call 203/256-4700.

SAVE ONE DOLLAR • SAVE ONE DOLLAR

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. Name and address must be completed to validate coupon.

Name ________________________________
Address ____________________________________________________________
City __________________________ State ________ Zip ______________
Telephone (___) _______ ____________ ________

Produced by Expocon Management Associates, Inc. and RCW Productions Inc.

New Jersey • California

March 1994
## Directory of Cushion Manufacturers

<table>
<thead>
<tr>
<th>Company</th>
<th>Address</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accu-Back</td>
<td>1475 E Del Amo Blvd, Carson, CA 90746</td>
<td>(213) 639-7992</td>
</tr>
<tr>
<td>Action Products</td>
<td>22 N Mulberry St, Hagerstown, MD 21740</td>
<td>(888) 228-7763</td>
</tr>
<tr>
<td>Activeaid</td>
<td>1 Activeaid Rd, PO Box 359, Redwood Falls, MN 56283-0359</td>
<td>(800) 533-5330</td>
</tr>
<tr>
<td>Adamin</td>
<td>39 Haven Ave, Bergenfield, NJ 07621</td>
<td>(888) 833-3725</td>
</tr>
<tr>
<td>Alagold</td>
<td>1920 S Court St, PO Box 4959, Montgomery, AL 36103</td>
<td>(205) 834-6900</td>
</tr>
<tr>
<td>Alexander Industries</td>
<td>PO Box 4913, Akron, OH 44310</td>
<td>(800) 345-7341</td>
</tr>
<tr>
<td>Alimed</td>
<td>297 High St, Dedham, MA 02026</td>
<td>(888) 225-2610</td>
</tr>
<tr>
<td>Allyn Air Seat</td>
<td>18 Millstream Rd, Woodstock, NY 12498</td>
<td>(914) 679-2051</td>
</tr>
<tr>
<td>Alpha Protech</td>
<td>903 W Center St, Bldg E, N Salt Lake, UT 84054</td>
<td>(800) 527-7889</td>
</tr>
<tr>
<td>Anna Dote</td>
<td>Box 40, Pullam Dr, W Middlesex, PA 16159</td>
<td>(888) 946-6132</td>
</tr>
<tr>
<td>Back Ease</td>
<td>PO Box 5283, Louisville, KY 40205</td>
<td>(502) 451-0394</td>
</tr>
<tr>
<td>Backsaver Products</td>
<td>53 Jeffrey Ave, Holliston, MA 01746</td>
<td>(617) 429-5940</td>
</tr>
<tr>
<td>Bandy Aids</td>
<td>423 State St, Bowling Green, KY 42101-1240</td>
<td>(800) 326-5173</td>
</tr>
<tr>
<td>Bauerfeind USA</td>
<td>1590 N Roberts Rd, #J14, Kennesaw, GA 30144-3679</td>
<td>(800) 423-3405</td>
</tr>
<tr>
<td>Bell-Horn</td>
<td>451 N 3rd St, PO Box 3408, Philadelphia, PA 19123</td>
<td>(800) 523-4518</td>
</tr>
<tr>
<td>Better Sleep</td>
<td>57 Industrial Rd, Berkeley, CA 94122</td>
<td>(908) 464-2200</td>
</tr>
<tr>
<td>Biotech</td>
<td>PO Box 7036, Grayslake, IL 60030</td>
<td>(800) 528-2158</td>
</tr>
<tr>
<td>Bodycare</td>
<td>315 Aimer Ferry Rd, Ball Ground, GA 30107</td>
<td>(800) 858-9888</td>
</tr>
<tr>
<td>Bodyline Comfort Systems</td>
<td>3730 Kori Rd, Jacksonville, FL 32257</td>
<td>(800) 874-7715</td>
</tr>
<tr>
<td>Canyon Products</td>
<td>10173 Groadon Way, Sacramento, CA 95827</td>
<td>(800) 211-5499</td>
</tr>
<tr>
<td>Cascade Designs</td>
<td>4000 1st Ave S, Seattle, WA 98134</td>
<td>(800) 527-1527</td>
</tr>
<tr>
<td>CHS International</td>
<td>PO Box 21067, Columbia, MO 65241</td>
<td>(800) 878-4550</td>
</tr>
<tr>
<td>Comfort Cover</td>
<td>1676 Industrial Blvd, Chula Vista, CA 92011</td>
<td>(619) 423-2118</td>
</tr>
<tr>
<td>Comfort Med</td>
<td>800 Interchange Dr SW, Atlanta, GA 30336-1603</td>
<td>(800) 527-3626</td>
</tr>
<tr>
<td>Comfy Back/Evans</td>
<td>1161 Lincoln Blvd, PO Box 988, Venice, CA 90294</td>
<td>(800) 272-6699</td>
</tr>
<tr>
<td>Commander Omni</td>
<td>PO Box 246, Garden City, NY 11530</td>
<td>(800) 645-4704</td>
</tr>
<tr>
<td>D A Schulman</td>
<td>7701 Newton Ave N, Brooklyn Park, MN 55444</td>
<td>(612) 561-2908</td>
</tr>
<tr>
<td>Danmar Products</td>
<td>221 Jackson Industrial Dr, Ann Arbor, MI 48103</td>
<td>(800) 783-1998</td>
</tr>
<tr>
<td>Dermacare</td>
<td>7651 National Turnpike, Louisville, KY 40214</td>
<td>(800) 626-4550</td>
</tr>
<tr>
<td>Duro Med Industries</td>
<td>301 Lodi St, Hackensack, NJ 07602</td>
<td>(800) 526-4753</td>
</tr>
<tr>
<td>Dynamic Systems</td>
<td>Rte 2, Box 129B, Leicester, NY 12748</td>
<td>(704) 660-5523</td>
</tr>
<tr>
<td>G E Miller</td>
<td>540 Nepperhan Ave, Yonkers, NY 10701</td>
<td>(800) 431-2924</td>
</tr>
<tr>
<td>Gaymar Industries</td>
<td>10 Centre Dr, Orchard Park, NY 14127</td>
<td>(800) 828-7341</td>
</tr>
<tr>
<td>Gendron</td>
<td>400 E Lugbill Rd, PO Box 197, Archbald, OH 43502</td>
<td>(800) 537-2521</td>
</tr>
<tr>
<td>Golden Fleece International</td>
<td>14240 60th St N, Clearwater, FL 34620</td>
<td>(800) 562-7326</td>
</tr>
<tr>
<td>Grandmar</td>
<td>1311 63rd St, Emeryville, CA 94608</td>
<td>(415) 428-0441</td>
</tr>
<tr>
<td>Grant AirMass</td>
<td>986 Bedford St, PO Box 3456, Stamford, CT 06905</td>
<td>(800) 243-5237</td>
</tr>
<tr>
<td>Hartwell Medical</td>
<td>6352 Corte Del Abeto, Carlsbad, CA 92009-1408</td>
<td>(800) 633-5900</td>
</tr>
<tr>
<td>Health and Medical</td>
<td>Techniques/Aquatherm, PO Box 2697, Smithtown, NY 11787</td>
<td>(800) 526-4296</td>
</tr>
<tr>
<td>HealthFLEX</td>
<td>127 Bowen Rd, Bennington, VT 05201-2017</td>
<td>(800) 782-8889</td>
</tr>
<tr>
<td>Healbo</td>
<td>5745 W Howard St, Niles, IL 60648</td>
<td>(800) 323-5444</td>
</tr>
<tr>
<td>Hermel Products</td>
<td>23 Britton Dr, Box 7345, Bloomfield, CT 06002</td>
<td>(800) 233-2342</td>
</tr>
<tr>
<td>Homedics</td>
<td>881 N Rochester Rd, Bldg H, Rochester Hills, MI 48306</td>
<td>(800) 333-8282</td>
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<tr>
<td>JA Preston</td>
<td>PO Box 89, Jackson, MI 49204-0089</td>
<td>(800) 631-7277</td>
</tr>
</tbody>
</table>

The following list of wheelchair cushion manufacturers was provided by ABLEDATA, an assistive technology and adaptive technology database. For more information call ABLEDATA, (800) 227-0216.

The Jay GS Cushion and Back, Manufactured by Jay Medical, Boulder, CO.

Embracing Concepts
40 Humboldt St, Rochester, NY 14609 | (800) 962-5544

Everest and Jennings
1100 Corporate Square Dr, St. Louis, MO 63132-2908 | (800) 235-4661

Frank Stubbs Company
4518 Vanowen St, Burbank, CA 91505 | (800) 223-1713

Heelbo
5745 W Howard St, Niles, IL 60648 | (800) 323-5444

Hermell Products
23 Britton Dr, Box 7345, Bloomfield, CT 06002 | (800) 233-2342

Homedics
881 N Rochester Rd, Bldg H, Rochester Hills, MI 48306 | (800) 333-8282

JA Preston
PO Box 89, Jackson, MI 49204-0089 | (800) 631-7277

See our ad on the back cover.
Directory of Cushion Manufacturers

JT Posey
5635 Peck Rd
Arcadia, CA 91006
(800) 423-4292

Jay Medical
PO Box 18653
Boulder, CO 80308-8656
(800) 649-7282
See our ad on pg 3.

Jefferson Industries
205 Nassau St
Princeton, NJ 08540
(800) 257-5145

Jay Medical
PO Box 18651
Boulder, CO 80308-8656
(800) 648-3282

Kees Goebel Medical Specialties
9663 Glades Dr
Hamilton, OH 45011
(800) 354-0445

Ken Mc Right Supplies
7456 S Oswego
Tulsa, OK 74136
(918) 492-9657

Kendall-Futuro
205 Nassau St
Princeton, NJ 08540
(800) 257-5145

Kees Goebel Medical Specialties
9663 Glades Dr
Hamilton, OH 45011
(800) 354-0445

Ken Mc Right Supplies
7456 S Oswego
Tulsa, OK 74136
(918) 492-9657

Larkotex
1002 Olive St
PO Box 449
Texarkana, TX 75501
(800) 972-3037

Lotus Health Care Products
31 Sheridan Dr
Naugatuck, CT 06770
(203) 723-1494

Luba Medical Supplies
6187 NW 167th St, #H24
Hamilton, OH 45011
(800) 334-4143

Med Foam
5250 Klockner Dr
Richmond, VA 23231
(800) 343-8112

Medical Devices International
3849 Swanson Ct
Gurnee, IL 60031
(800) 323-9035

Medical Specialties
4911 Wimot Rd
Charlotte, NC 28208
(800) 334-4143

Medpro
275 Highway 18
East Brunswick, NJ 08816
(800) 257-5145

Mor Loc
PO Box 427
Conover, NC 28613
(800) 438-9201

Otto Bock
3000 Xenium Lane N
Minneapolis, MN 55444
(800) 328-4058

PA Medical
PO Box 1286
Columbia, TN 38401
(615) 381-3422

PCP Champion
300 Congress St
Ripley, OH 45167
(800) 888-0867

Pin Dot Products
6001 Gross Point Rd
Niles, IL 60648
(800) 451-3553

Posture Comfort Cushion
59-29 174th St
Fresh Meadows, NY 11365
(718) 631-1734

Profex Medical Products
PO Box 16043
St Louis, MO 63105
(800) 325-0196

Quickie Designs
2842 Business Park
Fresno, CA 93727
(800) 456-8168
See our ads on pgs 17 & 29.

Roho
PO Box 658
Bellevue, IL 62222
(800) 356-2990

Roloke
5760 Hannum Ave
Culver City, CA 90230
(800) 533-8212

Scott Specialties
PO Box 129
Bellevue, KS 66935
(800) 255-7136

Sheepskin Ranch
3309 Winthrop, Ste 85
Fort Worth, TX 76116
(800) 366-9950

Skil Care
167 Saw Mill River Rd
Yonkers, NY 10701
(800) 431-2972

Southwest Technologies
2018 Baltimore
Kansas City, MO 64108
(800) 247-9951

Span America
PO Box 5231
Greenville, SC 29606
(800) 888-8752

Special Health Systems Ltd.
225 Industrial Parkway S
Aurora, ON
Canada LAG 3V5
(800) 263-2223

Spenco Medical
6301 Imperial Dr
Waco, TX 76712
(800) 433-3334

Spinal Technologies
1985 Rutgers Univ Blvd
Lakewood, NJ 08540
(800) 257-5145

Stat Medical
200 Debussk Ln
Powell, TN 37849
(800) 251-9864

Steridyne
3725 Investment Ln
Riviera Beach, FL 33404
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Circle #18
by Linda Kratz

Why must everyone stare at my child in his electric wheelchair? It seemed that every time we went to the mall, a restaurant or any other public place, everyone stared at my son. But were they really staring? I would have sworn they were...until a Saturday afternoon at the mall changed my mind.

I had waited until the last possible day to buy season passes to the amusement park. I knew the line in the mall would be long; I'd be waiting for at least two hours. I told my husband that I would be back later, but he decided he wanted to go along and take the kids—Brad, a very active four-year-old and Jerad, our ten-year-old who drives an electric wheelchair.

I tried to dissuade him. I have been to the mall on a Saturday with both kids—it's a fate I would not wish on anyone! But Steve insisted. “It'll be fun,” he told me. “I'll walk around the mall with the kids while you wait on line.”

So, we headed for the mall. I went in and began my wait at the end of a very long line, while Steve and the kids headed into the crowds.

I had been in line for only a few minutes when Steve rushed up with Brad in tow. Thrusting our four-year-old at me he exclaimed, “You hold him for a few minutes. He just took off on me and I had to chase him. Hang onto him while I go get Jerad.”

I knew that something like this would happen. I didn't get too excited until I started looking around the corner and didn't see Jerad coming. I'd assumed that Jerad was just a few feet behind. This was not the case.

The mall is about 2 blocks long. I was in a hallway near the middle. Steve had been at one end with both kids when Brad ran off. After catching him and handing him off to me, he went back to where he had left Jerad. You guessed it—Jerad was gone.

The woman just in front of me in line told me she would save my spot while I joined the search. Keeping a firm grip on Brad's hand, I ran down the mall toward the end where Jerad had been last seen. I looked in every store to see if I could spot him or evidence that he had been through there—toppled racks would've been a good clue. Every few feet, I stopped to ask passersby if they had seen a child driving an electric wheelchair. Nobody had seen him! Why—today, of all days—were people not staring?
Enjoying the great outdoors: Jerad, four-year-old Brad and dad. Steve, go for a bike at Lost Maples State Park.

My husband had notified mall security. While running down the mall, I heard loudspeakers blare, "We are looking for a lost child in an electric wheelchair. Please contact mall security if you see him."

"How in the world can you lose a child in a wheelchair?" I asked myself. This could only happen to us.

It took me about 15 minutes to get from one end of the mall to the other. Just as I reached the far end of the mall, I spotted Steve and Jerad coming out of the last store.

Steve had found him in the store "just driving around" being a normal 10-year-old. Since Jerad is legally blind—he has peripheral vision only—this is not something that I would let him do on his own. Fortunately, the mall has only one set of stairs, and he didn't go down that hallway.

I was so excited to see Jerad that all the anger I had been feeling was overcome by my joy. Never in my wildest dreams had I ever imagined losing Jerad—Brad, yes; but never Jerad. I wasn't really worried that anyone would take him—the electric wheelchair alone weighs 250 pounds. I was more concerned about him being frightened or driving off the stairs. At the same time, I was proud that Jerad was independent enough to make it from one end of the mall to the other.

As it turned out, Jerad was not at all upset at being left alone. In fact, he liked it. Until this past year, Jerad had been easily frightened and very dependent on us. We had worked very hard to make him more confident and independent. Can we take some of his new-found daring back?

This experience taught me just how normal our children really are. It also taught me that people are not always staring.

Linda Kratz lives in San Antonio, Texas with her husband and two sons. She is a co-founder of the Parent Information Exchange, a non-profit organization for parents of children with disabilities. She is also a member of the Texas Assistive Technology Partnership Council. Her first article for Exceptional Parent, "Electric Wheelchairs... Is it Giving Up or Giving?" appeared in October 1992.
Years ago we played with our fat baby and occasionally worried that the day would come when she would go out into the world, and the world would be cruel to her for no reason at all. That the day would come when the world would look upon the one we loved with all our hearts and see only the defect, the difference. Not her personality full of hope and alive with expectation, or her gentleness, or her terrific sense of humor or her precious little face with a beauty all its own. Just a syndrome named for Dr. Down.

"I'll be understanding," I said. "If some kid is mean, I'll explain to him about Kelly. It's really just a matter of education. Kids need to learn. They're afraid of what they don't understand."

"Yeah," said my husband. "Education. That's the thing to remember." And we looked at each other, and we looked at Kelly, and he muttered under his breath, "And then I'll rub the kid's nose off on the sidewalk." He took his fat baby girl and he hoisted her high in the air, and she laughed. He blew raspberries on her belly, and she gave forth her deep rolling chuckle.

Now that baby is eight years old, a person of fine sensibilities and definite opinions. Although we know she gets teased, we seldom see it.

But one day last year I saw it, on the playground of a church summer day care program for elementary school-aged kids. As we entered the yard one girl stage-whispered loudly to her two friends, "Look! There's that REE-tard. Ooooh, I hope she's not coming here!"

My eyes flew to Kelly's face where I saw a mask of stony indifference and icy dignity instantly install itself across her delicate features. And I knew that this was not the first time Kelly had experienced being summed up in the word "REE-tard."

The person in charge had heard this pronouncement too, but chose to pretend he had not. I politely pretended I had not heard it either. The little girls retreated to a corner of the playground, snickering and staring. There would be no room for Kelly at this particular inn. After many phone calls back and forth to discuss whether the center could meet her "needs," we ended up with no day care for the summer. (Her "needs" are these: She eats, plays, sleeps and loves to play with friends. She's a little poky and somewhat slow to catch on. She's seldom the only one.)

I hated myself for being tongue-tied. I hated Taylor, Texas. I hated the church. I hated that little girl. I hated her friends. I hated the day care worker and the director too.

We came home and Kelly went to her room to play with Heather, the imaginary friend who never fails her.

Kelly Horton, age eight.
husband, Jerry, came home, and I cried and raged. I resolved I would never allow a thing like that to happen to my child again in my presence. I stormed to the word processor and wrote a script for myself entitled In Defense of My Daughter. I committed it to memory.

Yesterday, a year later, I recited it to a young boy at the town swimming pool. He was putting on a macho act for his little friends as Kelly played by herself in the water. He twisted his mouth around and hung his tongue out in a grotesque parody of our brothers and sisters and children who have mental retardation. (Kelly does not have tongue thrust, but never mind that.) He pulled his hands up and bent them over at awkward angles and lurched around with his head contorted against his neck. (Kelly has no trace of cerebral palsy, but never mind that either.) The little boys stared at Kelly and laughed at their friend's cleverness.

I strode confidently to the side of the pool and caught his eye. "Come over here," I said. He glanced around nervously, hoping I was talking to someone else. "You!" I said loudly—Ursula the Sea Witch appears at Taylor Pool! He approached the rim of the pool. I did not crouch down in a friendly manner. I drew myself up even taller.

"You are making fun of my little girl," I said.
"No ma'am," he said. "I wasn't. No, really."
"You were too," I said. "And I want you to stop it. My daughter has Down syndrome. That's the way she was born. God made her just as he made you. That's the way he made her, and he does not make mistakes. He is ashamed of you for the way you are acting, and I am ashamed of you, and you should be ashamed of yourself."

"Yes, ma'am," he said to the Sea Witch whose voice had risen and now drew the attention of a major portion of the kiddie pool. His eyes were huge and full of fear, all bravado long since gone. I waited for the words to sink in.

"Please tell me you will never do that again," I said, committing him to a lifetime of disability awareness and inclusive behavior.

"Yes, ma'am," he said. "I mean, no ma'am. I won't."
"Thank you," I said. "She is my daughter, and I love her just like your own mom loves you. I won't let anyone hurt her feelings. Just like your mom won't let anyone hurt you"—I hoped this was true.

"Yes, ma'am," he repeated, tentatively backing away. He may have been uncertain of God's intentions in this matter, but made no mistake about mine.

He was thus demoted from tormentor to just another tow-headed eight-year-old with big blue eyes. Likewise, I hoped that Ursula the Sea Witch had become just some kid's mom as I returned to my bench.

Kelly had watched this exchange from a corner silently, a little alarmed that perhaps she had done something wrong. She stood transfixed in the water as the offender returned to his friends and began a game of chase.

Then, she looked up at me and smiled. "Look at me, Mommy," she said. "I stand on my hands." She dived down and stood on her hands, then surfaced, happily proclaiming, "I am a fish."

And my heart was sad, and my heart was happy.}

Judy Horton lives in Elgin, Texas, where she and her husband, Jerry, are developing a Christian community for people with mental retardation. Kelly, born in 1984, has Down syndrome. She is a valued member of a regular class in her local school.
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Circle #71

March 1994
Health Policy & Chronic Illness:
Collaborating to Influence the Health of Children

This may be the time to challenge some of the fundamental assumptions that underlie policy and program decisions for children and youth with disabilities.

That’s why more than 40 physicians and other health care providers, researchers, parents, educators and policymakers participated in last spring’s special working conference at the Wingspread Conference Center, Racine, Wisconsin, “Reclaiming the Health of Children: Towards a New Model of Child and Youth Health Services.”

“There needs to be a fundamental change in our thinking in this country,” Robert Wm. Blum, M.D., Ph.D., Director, Center for Children with Chronic Illness and Disability, explained. “We need to replace the myth of rugged individualism with the image of community where children are viewed as ‘ours,’ not ‘mine’ or ‘yours,’ if children with chronic illness and disabilities are to achieve their tremendous potential for success.”

To insure a healthy future for children, our current public and private service systems must become more comprehensive and integrated. Policies must capitalize on collaboration among education, health, social and economic support services.”

In one weekend, participants turned out five overarching recommendations in the areas of systems change. These recommendations were then presented at three meetings, one in Washington, DC, San Francisco and Minneapolis. These discussions brought together health care and education professionals, parents, researchers, and policymakers (who are national leaders) with the task of turning the recommendations into action and implementation plans.

“These meetings generated more than we had ever hoped,” Blum says. “Specifically, we were able to revise the recommendations, generate a very substantial scope of work and evolve a core set of next steps that we at the Center will be undertaking.”

The Center is working in close collaboration with other groups in five priority areas:

Health Policy & Chronic Illness

Turn to page 54
Do You Know Who Pays the Bills?

Chances are if you have a child with a chronic illness or disability who receives special education services, you may have a tough time sorting out that question.

You can usually figure out what comes "out-of-pocket." That's the cost of insurance premiums, co-payments and deductibles and any adaptive equipment or special service not covered by a program. Some of the funds come through local, state and federal education. Some bills may be paid by your insurance company or HMO. You might receive state and federal aid through Medicaid. You may pay for Medical Assistance as a "secondary" insurance plan. The county you live in may provide respite dollars or perhaps a preschool subsidy. Organizations like the Shriners or the Lions Club may contribute to the cost of services and equipment. In each case, your child "qualifies" for support based on the criteria of the funding source. It's a tangle.

Here's a list of services many families need. Who pays for them at your house? How much paperwork must you do? Perhaps it's time to talk to a single funding source.

- Health care professionals
- Insurance premiums
- Hospitalizations
- Co-payments and deductibles
- Durable medical equipment
- Prescription drugs
- Hearing aids or glasses
- Special supplies
- Home modifications
- Special van or automobile
- Special education services
- Special recreational programming
- Specialized child care
- Respite care
- Personal care attendant
- Health education
- Communication technology
- Other
The Hassle Factor

By Peggy Mann Rinehart

You can get a jump on health care reform by taking stock of the services your family and your child with a chronic illness or disability currently receive, and who provides them.

Here are some questions you may want to evaluate on a scale of one to five to take stock of your current health care status.

1. My child and family receive all preventive or primary health care, including immunizations, well-child check-ups, developmental, treatment, mental health care and support services.

2. My child’s school, health and medical, social or county services assessments are based on the things my child does every day (activities of daily living). Our physicians, teachers, therapists, social workers and other providers deliver services based on what our child can do.

3. List the name and telephone number of each case coordinator, case manager, or other person who recommends, assesses or approves services for your child. How many do you have?

4. List the name and number of the person(s) you call if there is an emergency.

5. Our teachers, physicians and social workers have a good understanding of the educational, medical and social services our child receives. They understand our child’s needs, communicate, and coordinate services with one another.

6. We are able to identify funding sources and/or pay for the services for our family.

SCORING:

Add up the number answered in each of the questions to determine your “Hassle Factor.” If your score is less than 10 points: You and your family have a remarkable handle on the services you need. Protect it!

If you score between 10 and 20, you’re struggling to get and keep the services you and your family need. If you score more than 20 points, like most of us, you are trying to figure out how to get access to quality and equitable health care services from inefficient systems and fragmented providers.

Seven Ways to Reduce the Hassle Factor

Local and state debates regarding health care reform may provide a good forum to discuss streamlining, coordinating and individualizing services for children and youth with chronic illness or disabilities and their families. Here are some ideas:

- **Assessments** Develop one standardized assessment for children and families to identify level and types of services.

- **Functional Definitions** Ask that your care plan be based on the needs of your whole child and family, not just on the disease or chronic condition.

- **Coordination** Coordinate services at a federal, state and local level. Limit the number of people responsible for coordination of care for individual children.

- **Partnerships** Teach and empower parents to become their child’s service coordinator. Develop a PTA equivalent for health care services.

- **Training** Integrate pre- and post-professional training of educators, health care providers and social service providers.

- **Continuing Education** Universities and medical schools should make room for community/parent consortium to develop courses, some of which are required for recertification or relicensure.

- **Financing** Untangle the funding streams by standardizing qualification criteria and let funding follow the child rather than forcing the child to chase after the funding.
A Window of Opportunity

Times of change produce windows of opportunity, and that may be true for children and youth with disabilities during the debates on health care reform.

Who would have predicted the Wall Street Journal would publish a letter written by the mother of a child with multiple disabilities, detailing the nightmares of managing the three bureaucratic systems of care for her child: school, social service and health? But they did, on January 6, 1994, when they published Marrianne M. Jennings' letter, "A Mother Talks to Mrs. Clinton."

Ms. Jennings details her frustration as she introduces Mrs. Clinton to the five or so caseworkers assigned to their daughter. "One is from Arizona’s Department of Developmental Disability. Another is with the Arizona Long Term Care. Another is with the Arizona Health Care Cost Containment System. Another is with APIPA, and I don’t know what that stands for. I lost track of acronyms, agencies and caseworkers long ago."

"... I am a lawyer who teaches and writes about administrative process. Yet this system is beyond my expertise. How do parents with language barriers, little or no knowledge of due process, and noncompulsive personalities cope?"

Now is the time to make your concerns known about health care reform and your child with disabilities. Make a list of all your questions and concerns, then write or call your local newspaper, television news program, congressional person or senator. Health care reform is news these days, and who is better able to talk about health care than those of us who have been trying to coordinate the care for our children with chronic illness or disability.

Health Policy & Chronic Illness

From page 51

- Move health care reform towards providing health care for children and youth that includes preventive, developmental, treatment and support services.
- Streamline service systems so that each child or youth and their families who require multi-agency, multi-provider assistance have a "Service Home." This would centralize care coordination for families and bring together educator, physician, nurse, social service provider and parent, along with appropriate mental health professionals, vocational counselors and others as appropriate to individual needs.
- Provide pre-service and continuing education for health, education, and social services professionals who work with children with special health care needs and their families.
- Restructure financing of services so that funds are flexible and based on the needs of the child and the family rather than those of the agency.
- Provide centralized, comprehensive, multi-disciplinary resources for providers working with children and youth who have chronic and disabling conditions.
Selecting a . . .

Summer Camp

Enrolling your child in a summer camp can be a rewarding experience for all concerned. *Exceptional Parent* asked camping experts what parents can look for when considering a summer camp.

At the outset, it's important to know what your child needs when evaluating camp programs. Be aware of your child's interests, capabilities, strengths and weaknesses, and consider programs accordingly. Ask about the goals of the camp by writing or calling the camp director. What is a typical day at camp like? What happens when the weather is bad? Can needed therapies be provided by trained staff?

Check the accreditations of the camp. Find out how many years the camp has been in operation—a camp with a longer history has probably learned how to meet children's special needs under varying circumstances.

Inquire about references—many camps will be happy to provide them, and the perspective of another parent can be very helpful. If possible, visit the camp to assess whether the environment is suitable to your child's needs. Ask about the quality of the accommodations—do the cabins have foundations? Are the tents on platforms? Are the water and toilet facilities monitored by local or state health departments?

Consider the age range of the campers, and check how they will be grouped. Ask if a camper "report card" or summary of activities is available at the end of the sessions. Do the activities reinforce skills learned during the rest of the year?

The staff is also an important consideration. Check the staff-to-camper ratio, as well as the supervisor-to-staff ratio. Are the staff experienced and trained in working with children with special needs? Does the camp use overnight staff to monitor camper safety? Are the staff trained in first aid and special health care needs? Are they knowledgeable in care and maintenance of adaptive equipment?

Another important factor to consider is medical needs. What are the camp's health services like? How is medication dispensed? Is there a full-time nurse or infirmary on-site? If not, is there a clinic nearby in case of emergencies?

Transportation is another issue. If the camp offers transportation for campers, are the vehicles and drivers properly licensed?

If possible, check out a variety of camps to find the one that appears best able to meet your child's needs.

—A.B.

Thanks to the following for their contributions to this article: Sonya Richards, Camp Amigo, Strouds, MI; Tom Bauer, Director, Camp Buckskin, Ely, MN; Bruria Bodek-Falik, Ph.D., Director, Camp Huntington, High Falls, NY; Raymond W. OnCharme, Ph.D., Director, The Learning Clinic, Brooklyn, CT; Lee Morone, Director, Le Mar, New York, NY; Ron Eydt, Director, Tall Pine Camp for Exceptional Citizens, Tellico Plains, TN.
The ABLEDATA Database of Assistive Technology
by Alynne Landers

While parents of children with disabilities are never totally prepared for the challenges they will encounter, assistive technology and adaptive equipment can resolve some of these challenges. Assistive technology can provide a means for children to be more independent, or to participate in activities with friends who do not have disabilities. However, the process of identifying the assistive technology products needed by each child is often easier than actually locating the equipment to accommodate those needs—and the parents' budget!

ABLEDATA is a single, comprehensive resource that parents can use to locate and compare assistive technology products. The number of choices available may surprise even the most well-informed. For example, ABLEDATA has information on nearly 900 products to make a home safe and accessible—including 353 products just for the bathroom! There are 310 computer-assisted instruction programs for students with disabilities. 126 adapted toys and 191 games designed for kids and teens with disabilities. In fact, ABLEDATA has information on more than 19,000 products!

ABLEDATA provides an internationally renowned database of information on assistive technology and rehabilitation equipment for all disabilities and all age groups. The project maintains and adds new records on products currently manufactured and distributed in the United States from approximately 2,500 domestic and foreign companies. In addition to commercially available products, the database also includes nearly a thousand “Do-It-Yourself” designs and prototype descriptions. Covering high-tech, low-tech and “no-tech” products designed for persons with disabilities, the scope of the database ranges from enlarged-handled utensils to the most sophisticated optical-character recognition devices (computer screen readers).

Entries in the ABLEDATA database include manufacturer and distributor information for each product, product features and specifications and pricing data in a format that permits easy comparison among products.

If you haven’t used ABLEDATA lately, you don’t know ABLEDATA!

ABLEDATA was started more than ten years ago by Marian Hall, an occupational therapist. Over the years, this collection of data has expanded from a manual system of boxed files to an extensive, recognized authority on assistive technology terminology and classification. ABLEDATA has evolved into a premier information and referral system available to individuals with disabilities, their parents, siblings or spouses, rehabilitation professionals, disability advocates and businesses looking to comply with the Americans with Disabilities Act (ADA).

Today, under the management of Macro International Inc., this data collection has reached “the next generation” of multiple computer-linked databases that provide immediate updates of information and terminology changes: an electronic bulletin board system—ABLE INFORM—and an IBM CD-ROM in Windows and DOS formats for personal computers. Parents who contacted ABLEDATA in the past are encouraged to access the system again to see all the quality, user-friendly enhancements implemented in the past two years.

Tapping into ABLEDATA Resources

• Online: ABLE INFORM: With a modem and telecommunications software package, computer users can call this electronic bulletin board service 24-hours a day to search the database directly, to leave/receive messages in the conference areas or to download ABLEDATA fact sheets. Computer dial 301-589-3563 (1200 to 9600 baud, N-8-1). There are no subscriptions fees; cost is based on the phone call from the user's station to the ABLEDATA office.

• IBM CD-ROM: ABLEDATA is now available on CD-ROM for use on IBM personal computers, and compatible with Windows™ and DOS formats. Prompts and pop-up windows permit even novice computer users to search the database by product name, company or product type. Electronic images of many products can be displayed on the screen using the “Picture” option. Yearly subscriptions (2 CDs per year for $50) are available beginning in the Spring of 1994.

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Alynne Landers, M.I.M., is a program specialist at ABLEDATA. ABLEDATA is funded by the National Institute of Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, contract no. HN92026001 and managed by Macro International Inc.
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Judy Heumann, Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS), U.S. Department of Education, was interviewed by Exceptional Parent in December 1993. An activist and policy-maker, Heumann worked on Section 504 of the Rehabilitation Act and its reauthorization, the Individuals with Disabilities Education Act, the Americans with Disabilities Act and federal policy guidance governing the provision of personal assistance services to individuals with significant disabilities. She was the first wheelchair rider to be hired by the New York City public schools. Heumann was also co-founder and vice president of the World Institute on Disability, a public policy/research/training organization. This is the second part of our interview with Heumann; Part One appeared in February 1994.

In 1973, I went out to California to attend graduate school because I needed a masters degree to go on in teaching. While I was going to school for my masters in public health and administration and planning, I got involved with the country's first independent living center—the Center for Independent Living in Berkeley.

Going to California was the beginning of another part of my life. I had left my whole family back in New York. I was never really happy in California; I liked the work, but I missed New York. It was a valuable experience for me, however, because it was a smaller, more progressive community. I could use what I had learned in New York to do some very exciting work in California.

After about seven years, I left California and came to Washington where I worked for Senator Harrison Williams for about a year and a half. Among other things, I worked on the Education for All Handicapped Children Act. After that, I went back to California and worked for the State Department of Rehabilitation. And I worked for the State Rehabilitation Agency for about eight months. I went from rehab client to rehab worker. I have been involved in many different activities over the years. I think this has given me a broad base of experience for my job at OSERS.

The role of parents

I have a lot of respect for the role that parents can play. Back when I was working at the Berkeley Center, I helped set up a number of programs that involved parents in independent living. At that time, there was a lot of disagreement among disabled adults about parental involvement. Many people felt that parents of children with disabilities tended to be overprotective. Rather than helping, they were part of the problem. I did not agree. I felt that parents needed education just like anyone else. If we could reach parents early enough, they could be very influential not only in the lives of their children, but in the disability rights movement itself.

Ultimately, I think it is important that parents see their children with disabilities simply as children. Interactions with the medical community frequently cause parents to have difficulty recognizing that their child with a disability is just like a child without a disability. Their child with a disability needs the same kind of love and support and direction. I think it is very important that parents have high expectations for their children. I also think it is important for them to ensure that their kids are being taught academic skills and independent living skills from an early age.
Challenges at OSERS

My position here is very challenging because it involves coordinating the three components of OSERS—Special Education, Rehabilitation and the National Institute on Disability Rehabilitation and Research. These three elements together allow me to work with staff and constituency groups around the country to set up systems that will enable children and adults with disabilities to receive appropriate services and become integrated members of their communities with the ability to obtain competitive employment.

This is one area where my background helps me. I have broad experience working with many different constituency groups. That enables me to be sensitive in addressing the needs of diverse groups—from the perspectives of both disability and culture.

At OSERS, I have a staff of more than 100 people and a budget of roughly $5 billion dollars. OSERS has the legal obligation to monitor special education around the United States.

I see my responsibilities here as being multiple. One is simply getting OSERS to work, getting the three components to work together and develop effective plans. An equally important responsibility is to work with groups around the country to help them recognize the important role that they need to play in helping us to shape our agenda.

I want to get people to work more effectively together—regular education and special education; employers and rehabilitation agencies; parents, children and adults with disabilities. My work in OSERS is part of an overall civil rights agenda that the disability community has been involved in for many years. For the last 12 years under the previous administrations, OSERS, the Department of Education and the government as a whole was not allowed to be at its best. I believe that many of the problems states are now facing came about because previous administrations did not provide appropriate technical assistance and other support. They didn’t monitor states in a way that would allow them to understand that we can provide technical assistance and support, but that we also expect them to live up to the letter and spirit of the law.
Right now we are beginning the process for reauthorization of the Individuals with Disabilities Education Act (IDEA). We are seeking the input of organizations and individuals on various issues within the IDEA. We want to know people’s concerns, and we would like them to make recommendations for changes. Basically, we believe that the IDEA is a very solid piece of legislation. The types of changes that we will consider will make the law even stronger.

Diversity issues

I bring two important characteristics to this job—I am disabled and I am a woman. I think when we look at statistics, we find that disabled girls and women fare worse than disabled boys and men, who fare worse than non-disabled boys, non-disabled men, non-disabled girls and non-disabled women.

I hope that one of the messages that I provide is that disabled girls can grow up and be powerful disabled women. Parents need to do everything they can to wipe out sex bias against girls with disabilities in the same way we are working on that issue for non-disabled girls.

I also feel a strong responsibility to work on issues affecting minority children and adults. I think that Congress has given us very clear directives to provide more effective services and assure better outcomes throughout the entire population. I have a very strong commitment to making this happen. I think that OSERS staff members are learning how to work more effectively with groups outside the government. And I think outside groups are learning how to work with us.

There is a big move in this country for diversity—being sensitive to racial and cultural differences, making sure that boys and girls are treated equally. But often in the case of children and adults with disabilities, we’re not appropriately reflected in textbooks or in the media. When we show up in books or on television, we are treated as special. Personally, I don’t like the word “special.” All children are special! It is important that people with disabilities are reflected more accurately in children’s literature. That’s not just something that disabled children need to see; non-disabled children need to see it too. We need to help children accept the fact that people with disabilities are becoming a larger and more influential part of society.

Looking Forward

During my tenure as Assistant Secretary, OSERS will aggressively and collaboratively work to create a society in which all disabled people can obtain the knowledge and skills necessary to achieve the goals they set for themselves. This vision can lead us into the 21st century in a way that builds on our past accomplishments, embraces the spirit and intent of our statutes and regulations, focuses our strategic planning process and drives the work we do each day. I believe it also moves us toward the society President Clinton envisioned when he pledged to work for “inclusion not exclusion, independence not dependence, and empowerment not paternalism.” I look forward to working with all of you in this important effort.
Rachel, Say ‘Hi’
by Paul J. Karch

"Rachel, look who’s here—Daddy. Say, ‘Hi’ to Daddy."

"Hi, Rachel. Good morning."

"Rachel, say, ‘Hi’ to Daddy."

She doesn’t say it. She never says it in the morning, although she occasionally does at other times. She’s clearly excited to see me still here. I can tell she’s excited because she’s dancing around on her toes with her elbows straight out, waving her forearms in the air, like she was trying to shake water off them. She looks sweet in her pajamas and her excitement. But that dancing and hand shaking is one of the things kids do when they make fun of kids who have retardation.

I don’t usually think of Rachel as looking or acting as though she has a disability. Maybe I just don’t notice, because she’s Rachel. When she was a baby and swollen from her seizure medicine, my wife and I told each other she was beautiful and we saw that she was. Now, it hurts to look at those pictures, because her flesh looks like it’s trying to burst out of her skin and her eyes are listless. Of course, now she really is beautiful.

“Rachel, are you ready to eat breakfast? Say, ‘Hi’ to Daddy.”

She doesn’t say it. She doesn’t look at me either. She does look at me sometimes. She takes my head in her hands and looks directly into my eyes without holding anything back. People who aren’t used to her can’t take it. It’s the kind of searching look that lovers and long-separated parents and children give each other in novels and movies, a warm, lively look that makes you feel special and glad to be alive, but so intense and searching that after a while, you are afraid that you can’t give her what she is looking for.

For a long time, she wouldn’t look in people’s faces. It was those eyes that first made us wonder if something was wrong with our baby. Then, for a time, she was willing to look into dogs’ faces, but not people’s. By the time we got a dog for her to look at, she was more interested in people.

“Rachel, keep the cottage cheese on the spoon. Have you said, ‘Hi’ to your daddy yet?”

She doesn’t say it. The cottage cheese is falling off the spoon because she is turning her arm back and forth to admire the morning sun and shadows moving across it. She likes that game, one of her private games that we can recognize, but can’t share. It makes her smile. She smiles her secret smile, the expression that makes you think she has just thought of a mischievous trick, but she won’t tell anybody until she’s played it.

We have a picture of her first real smile. I am holding her in the shower during the summer she turned one. I can see that picture in my mind at any time. That smile brought the sun through the dark clouds for us. We had worked hard to help her, but we didn’t know if we had the strength of character to love and live with a child who never smiled. Some people do. God didn’t require that of us. That day, she smiled and we cried.
Now, she smiles a lot, most often if you tickle her or if she’s jumping on her trampoline, riding her tricycle or doing something else that involves “major sensory input,” as her therapists say. She also smiles sometimes when I come home from work and when she hears a funny noise that she likes, like the pig grunting, “Touche,” in *Beauty and the Beast*. But she doesn’t smile much at things that make most kids smile, like playing peek-a-boo.

“Rachel, would you like some Crunch?”

“Cwunch, peese.”

She can talk. She likes to use her language for a purpose. She was the star of “meaningful communication” when she was in the special education preschool class for kids with autism. When Rachel “talks,” you know she is trying to tell you something, even if most of the time you don’t know what. We wonder if there are other ways to help her converse that don’t rely on precise control of small, working parts, like a tongue and lips. We offer her those other channels, but Rachel seems to prefer battling it out with the spoken word. If she says something often enough and takes the incomprehending listener by the hand to the place or object, we feel like we understand what she’s trying to tell us. But there are still plenty of times when she repeats herself with enthusiasm and a strong desire to let us know and we just don’t get it. Eventually, she sighs and moves on.

*Fathers’ Voices* is a regular feature of *Exceptional Parent* magazine. This column, coordinated by James May, Project Director of the National Fathers’ Network, focuses on fathers’ experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers’ Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers’ Network, The Merrywood School, 26120 N.E. Eighth Street, Bellevue, WA 98004, (206) 747-4004 or (206) 842-1354. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with the National Center for Family-Centered Care, a program of the Association for the Care of Children’s Health, Bethesda, MD.

Some parents of children with disabilities grieve continually for the loss of the normal child who might have been. I don’t feel quite that way. Rachel is the child she is, and I don’t think much about who she might have been. But when she sighs and gives up because I don’t understand, then I grieve.

“Rachel, calm down and use your words. Use your quiet voice.”

Of course, she doesn’t always give up when she isn’t understood; sometimes she has a tantrum. It’s often hard to figure out what sets her off, and it’s always hard to decide what to do next. Colleagues and friends who don’t know Rachel tend to say things like, “Well, I’ve got a 15-year-old in my house who still has tantrums.” It is not the same. Having thought about this at length in an objective, scientific manner while my blood is racing, my ears are pounding, and my hair is being pulled out of my head, I conclude that there is a fundamental difference between a “regular” child’s tantrum caused by hunger, fatigue or a fine sense of dramatic manipulation and Rachel’s tantrums caused by her rage at the world’s failure to understand her or explain to her why she can’t have what she wants. Then again, maybe it’s just a two-year-old’s tantrum in a seven-year-old body.

“Rachel, Daddy is leaving. Can you say ‘Bye-bye Daddy?’”

She doesn’t say it. She doesn’t really even look up when I leave, although I’m told that she sometimes runs around the house shouting, “Daddy! Daddy!” after I’ve gone. Some friends and acquaintances think we’re heroes for “all we’ve done” for Rachel. Others would rather not think about it at all. I don’t feel like a hero, because I didn’t volunteer for this job. Most of the time, I’m not sad about Rachel because she learns, loves and is often happy. But some imes, in the morning as I prepare to leave for work, I hope that she will say “Hi, Daddy.”

Paul J. Karch is a lawyer and the father of three children: Rachel, seven; Lydia, five; and Charlie, two. Paul and his family live in Appleton, Wisconsin, where he works in the legal department of Appleton Papers. He enjoys spending time with his family, bicycling and reading. Rachel was born with a chromosomal abnormality and has a severe cognitive disability. Rachel and Lydia attend Janet Berry School in Appleton, a school that promotes the full inclusion of all children.
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Brain Differences in Autism

by Margaret Bauman

My research colleague, Dr. Thomas Kemper, and I have been studying the anatomy of the brain in autism. We began these studies in the summer of 1983, and reported our initial findings at the meeting of the American Academy of Neurology in the spring of 1984. Since then, we have studied a total of six cases in detail.

**Method**

Our research involves the examination of human autopsy material. This material has been very generously donated by the families of children and young adults with autism who have died as the result of illness or injury. It is essential that we use human brains for this research because, at this time, there is no experimental animal model that could be utilized.

For the purpose of comparison, each autistic brain is matched with a "control"—the brain of a non-autistic person who was the same sex and age. We study each brain by cutting it into approximately 4000 thin slices, or "sections," cut from front to back. Each brain is examined, section by section and area by area. We use a special microscope that allows us to put the same sections of the autistic brain and the normal brain side by side in the same field of view and at the same magnification. Of course, this is a very tedious and time-consuming process. However, it is probably the best way to survey an entire brain, especially when the findings may be subtle and difficult to spot, as has been the case in some portions of the autistic brain. In fact, without this methodology, we probably would not have been able to identify some of the unique anatomical differences in autistic brains.

**Limbic System Abnormalities**

One abnormality that we have found has been in a part of the brain known as the limbic system. The limbic system includes a number of brain areas that are connected to each other by neuronal circuits. The limbic system appears to play a significant role in human learning, emotion, behavior, and memory. In autistic brains, the nerve cells of the limbic system are smaller and more numerous than those found in normal controls. In this respect, the autistic limbic system is like that of a younger child. This might mean that the development of the limbic system is stunted in individuals with autism.

With regard to memory, there is evidence that we have at least two types of memory systems that are involved in learning. The first type is called "habit" memory. We use this kind of memory to learn skills—tying our shoes, catching a ball, riding a bicycle. The "habit" memory system is believed to reside in areas that we have found to be anatomically normal in autistic brains.
The second memory system is called “representational” memory. This kind of memory is involved in organizing sensory input—what we see, hear and feel—generalizing and integrating information gained from sensory input to think and reason. The “representational” memory system is believed to depend on parts of the limbic system. Limbic system abnormalities, such as those found in autistic brains, could lead to a disturbance in the processing of sensory information. This, in turn, could lead to the disordered thinking, social interaction and language that is characteristic of infantile autism.

**Cerebellar Abnormalities**

We have also found abnormalities in the cerebellum and cerebellar circuits of the autistic brain. The types of abnormalities that we have found indicate that, whatever the cause, the damage to the brain occurred prenatally, before thirty weeks gestation.

**Future Plans**

I believe that we have identified the most obvious structural abnormalities, but we will continue to look at new brains and re-examine our older material. We have been able to create a “library” of slides to go back to as new research questions arise. For example, if we observe a previously unrecognized abnormality in a new case, we can go back and re-examine our previous cases to see if the abnormality is unique to this new case, or if it is present in all of the autistic brains but had been previously overlooked.

We are also interested in neurotransmitter function in autism. Now that we know the location of structural abnormalities, the next step will be to investigate the neurochemical profile of these same areas. We have the technology to do this. We also have the necessary brain material from autistic and normal individuals. All we need now is money!

The potential for this type of study could be enormous. If we are able to identify one or more neurochemical abnormalities, this might give us a chemical “marker” for autism. This marker could be used in diagnosis—prenatally or postnatally. Identification of a chemical abnormality could also lead to more directed medical intervention and treatment. I don’t know if we will be able to “cure” autism, but we should be able to improve function and the quality of life significantly. That would be a truly exciting outcome!
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**Exceptional Parent** 71

4 March
For years, I had been aware of the efforts of some parents and advocates to close all institutions for people with mental retardation by moving their residents into group homes in the community. While waiting at the hospital one day for my daughter, Erin, to come out of major surgery, I was struck by something very odd about this movement.

In the weeks before Erin's surgery, my wife Valorie and I had received tremendous support from friends and acquaintances. We had been forced to make a difficult decision. Without a spinal operation, Erin could face painful, even life-threatening organ damage in the years to come. On the other hand, the operation itself was risky—there was a 20 percent chance she wouldn't make it through surgery and recovery.

After much consultation and deliberation, we decided to go ahead with the surgery. No one questioned our decision or, more importantly, that it was ours to make. Everyone seemed to share in our anxiety as the day of the operation—coincidentally, Erin's eighteenth birthday—approached.

Why, I wondered, weren't we getting this kind of support from the disability community on our decision about where Erin would be living by the end of the year if she survived the surgery?

**Warring camps**

Erin has cerebral palsy. She can't walk, she's blind, and her brain has developed only to the level of a one-year-old. She wears diapers and needs to be fed, bathed, dressed and groomed. Valorie had been providing her with this care for the last 18 years and needed relief. It was time for Erin to leave home.

As I learned, we parents of children with mental retardation are divided into warring camps on the issue of residential care. One camp, composed mostly of people with higher functioning kids, thinks it is most important that their children are included in all aspects of family and community life. They promote placement in a community living arrangement (CLA).

The objectives of CLA advocates extend far beyond securing the best living environment for their own children. Their mission is to change the attitude of society as a whole, so that their children and others like them can lead as "normal" a life as possible. In their view, institutions symbolize unenlightened public policy.

I remember listening silently at one organization meeting as a pro-community parent explained the importance of including our children in all aspects of family life. While he talked, all I could think about was the indigestion we had experienced when we tried bringing Erin with us to a restaurant. And I'll never forget my disbelief on hearing an officer of that group speculate seriously with me about Erin's vocational potential, when she had never even met her.

The folks in the other camp, usually those with the lowest functioning children...
children, put a higher value on the care itself, and favor centralized care in a traditional setting such as a state residential center (SRC). Their children are those with severe or profound retardation, often accompanied by complicated medical conditions or physical disabilities. They have little or no concept of community, no vocational potential and no chance of living anything remotely resembling a “normal life.”

These parents feel that a community residence would not provide their children with the necessary level of care, attention and protection. They deeply resent the anti-institutional bias of the pro-community activists, and lash out in a similar fashion, finding fault wherever they can with group-home living.

One official, at an SRC parent association meeting, related stories of people in group homes becoming injured and seriously ill due to neglect. In a later conversation, she implied that abuse was not uncommon in community residences, and advised that my daughter would be much safer in an institutional setting. It was ironic. We did not find the critical help and support we needed to make the decision about where Erin would live from other parents or from disability advocates. Instead, we found an unlikely ally in our search for answers—the much-maligned State Developmental Disabilities Administration.

Staff of the Developmental Disabilities Administration arranged for us to tour residential facilities in different areas so we could see what was available. We visited several group homes and toured the day activity centers run by each. We also visited an SRC to see for ourselves how institutional care compared with

An unlikely ally

There is much about this infighting that should bother all parents and advocates. The combatants have allowed ideology to bury their compassion—they are ignoring the shared understanding that comes from common experiences of raising children with disabilities. They have stopped respecting each other. But they are also failing to provide needed information and support to parents for whom the best choice is not obvious.

The combatants have allowed ideology to bury their compassion—they are ignoring the shared understanding that comes from common experiences of raising children with disabilities.
that provided in the community-based residences.

What we saw on these tours surprised us. We found the SRC to be clean, quiet and well-staffed with courteous people. Many of the residents had greater medical needs than Erin. All appeared to be receiving good care.

We especially liked one community facility because of the tenderness which characterized the care administered. We toured other community care facilities, however, where administrators seemed more concerned with the progressiveness of their programs than the quality of their care. And we immediately ruled out one CLA with a large day activity center that reminded us of a factory.

Respect for the choices of others

After careful consideration, Valorie and I decided that we wanted Erin to live in the group home with the caretakers whose tenderness had so impressed us. We know that it won't matter to Erin where she gets that care; but as long as she remains relatively healthy, her family is more comfortable with her living in an environment like the one in which she grew up. In the end, it was that simple.

Meanwhile, we are glad for having learned about the quality of our state's institutional system. We will always be grateful for the professionalism of the state personnel who made sure we had enough information to make our decision, then stood back and let us decide.

I don't know how it was that we parents and advocates let our common concern for the well-being of our children turn into a civil war on this issue. For the sake of our children, however, we need to become a united community again. For the sake of good public policy, we need to recognize that there are important differences among our children which may require a different type and level of care. Above all, we need to grant other parents proper motives and good reasons for making the choices they do. The burden we bear is heavy enough without the weight of judgments of others.
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- **Giordano, Gerald**—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 x 10), 26 tables, $58.75.

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Andrea & Jamie

Seven-year-old Jamie and Andrea Freedman live in Randallstown, MD with their parents, Mona and Jay Freedman. Andrea has language and learning disabilities. Both girls attend Randallstown Elementary School where Jamie is in second grade, and Andrea is in first grade. Mona, coordinator of the Family Support Network within Maryland's Infants and Toddlers Part H Program, wrote about her experiences with early intervention in "Perspectives on Early Intervention" (February 1994).
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**Gone Fishin’**

Fishing Has No Boundaries is a non-profit organization which promotes access to the outdoors for individuals with disabilities through annual fishing events. The organization also works with various governmental agencies to enhance accessibility to lakes and rivers.

Event participants are welcomed regardless of age, sex or disability. By working with volunteers at the events, participants build confidence and find that there are many ways to experience the great outdoors. Events offer a unique experience to individuals who otherwise may not have such an opportunity.

The next event is scheduled for May 20-22, 1994 in Hayward, WI. June events will be held in Eagle River, WI, Thermopolis, WY, Pierre, SD, and Hemidji, MN.

For more information, contact Fishing Has No Boundaries, P.O. Box 175, Hayward, WI 54843, (800) 243-3462 or (715) 634-3185.

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**Senate Adopts Dole Amendment to GOALS 2000 Bill**

The Senate has adopted Senator Robert Dole’s (R-Kansas) amendment to the GOALS 2000: Education America Act Bill. Dole’s amendment calls for a study of how well children with disabilities are served by the bill.

The GOALS 2000 Bill provides states and localities with technical and financial support for education reform initiatives. The bill authorizes $400 million in federal grants to promote improved teacher training, increase parental involvement, and use federal funds flexibly.

In a statement made following Senate acceptance of his amendment, Senator Dole stated, “I am concerned that students with disabilities will miss the bus when it comes to school reform. Although I do not intend or expect this study to rewrite GOALS 2000, we must be sure that goals, standards and assessments work for students with disabilities, not against them by promoting their exclusion.”

“...I know that the bill contains many references to students with disabilities, and I commend the Committee on Labor and Human Resources for its strong report language in this regard. But neither bill or report language can make up in one fell swoop for a decade of neglect.”

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**New Support Groups**

- A new support group is being formed for those interested in Stickler Syndrome. Contact Jennifer Purvis, 2123 Royal Oaks, Dallas, TX 75253, (214) 286-5638.
- A support group has been formed for parents of children with Chromosome 6 disorders. For more information contact Spotlight 6, c/o Valerie Wiggins, 2617 Red Toad Road, Rising Sun, MD 21911.
- Cockayne Syndrome (CS), also known as Cachetic dwarfism, is characterized by failure to thrive, photosensitivity, retinopathy and/or cataracts, hearing loss and microcephaly. Facial characteristics include a pinched face, projecting jaw, malformed ears, beaked nose and sunken eyes. Not all children with CS have every trait. For more information, contact Share & Care, c/o Teresa Wall, P.O. Box 552, Stanleytown, VA 24168, (703) 629-2369 or (800) 484-7601 security code 2468.

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**Publications**

- **Hope Through Research: Cerebral Palsy** is a new brochure published by the National Institute of Neurological Disorders and Stroke (NINDS). Free copies can be obtained by contacting NINDS at 9000 Rockville Pike, Bldg 31, Room 8A-16, Bethesda, MD 20892, (800) 352-9424.
- **Parent Support Networks, A Workbook for Creating Successful Community Support Groups** provides information on starting and running successful support groups. The workbook may be obtained at no charge from the Maine Parent Federation, P.O. Box 2067, Augusta, ME 04338-2067, (207) 582-2504.
- **Resources the Disabled Can Use to Acquire and Fund Computers** is a free publication that includes sources for grants, programs, services and technology-related assistance. For a copy, send a long, self-addressed, stamped envelope to “Free Computer Report,” Twin Peaks Press, P.O. Box 129, Vancouver, WA 98666.

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**Inclusion Awards**

Each September, we honor education programs via our Annual Inclusion Awards. Now is the time to nominate programs that provide fine educational and social opportunities for children with disabilities, help peers welcome children with disabilities and invite active parent participation. Please mail your nominations (500 words or less, plus pictures whenever possible) to: Inclusion Awards, Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146.
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After this hard winter, we are all looking forward to summer fun. Two articles, “All in the Family” by Kate Divine McAnaney and “An Exceptional Visit to Disney” by David and Susan Brooks recount the vacation experiences of two families. Our directory of “Travel Resources” also can help families make plans.

Many parents will find valuable ideas for coping with homework in “Listening to Learn” by Elizabeth C. Mayer. Mayer's story is a wonderful example of the creativity of parents in finding ways to help children learn.

Devoted readers tell us that they appreciate and identify with articles written by other parents of children with disabilities. At the same time, many have commented on the underlying sadness of many of these stories. “Sense of Humor Required,” by Lynn Kimball Fay, is a story that will remind us of some of the lighter moments of our everyday life with children. We hope this article will encourage other readers to share humorous moments with us.

The debate on health care reform continues. We join with the National Parent Network on Disabilities (see Networking) in urging readers to continue to write to our leaders in Washington.

Role Models

We have received many favorable comments about our new regular department, “Role Models.” This month, we feature Jason Kingsley and Mitchell Levitz, authors of Count Us In: Growing Up with Down Syndrome. We caught up with Jason and Mitchell at a Boston television station where they had just completed another interview as part of their book tour. These young men speak with authority for themselves and for people with disabilities as they challenge stereotypes and misconceptions about people with Down syndrome—some of ours were challenged by this interview.

Inclusion

Although inclusion is appealing as an educational concept, its actual achievements have been the focus of considerable media attention and debate. I invited Edwin Martin, a long-time member of our Editorial Advisory Board, to write a guest editorial on this topic. Eminently qualified to speak out on this important issue, Dr. Martin served from 1966 until 1981—under four Presidents—as the leading government advocate and spokesperson for children with disabilities and their families.

New Products Page

Beginning with this issue, Exceptional Parent will include a monthly “New Products” department prepared by ABLEDATA, a respected, independent organization. Our goal is to present a wide range of innovative products for children with disabilities.

Welcome, Aisle 17!

Since 1985, when Apple Computer established its Worldwide Disabilities Solutions Group under the direction of Alan J. Brightman, Ph.D., Apple has been a leader in technology accessibility for children and adults with disabilities. In 1987, Apple collaborated with the Disabled Children’s Computer Group of Berkeley, California to create the Foundation for Technology Access (FTA) and establish the Alliance for Technology Access (ATA), a nationwide network of community-based assistive technology resource centers (see “ATA Directory,” January 1994). Now, with input from children and adults with disabilities, parents and professionals, Apple has created “Aisle 17,” a mail-order disability solutions store dedicated to computing without boundaries. “Aisle 17” is the first one-stop source for bundled computer solutions designed specifically for children and adults with disabilities.

Photos and drawings

Thanks to the many readers who have already sent wonderful snapshots and children's art. We are having a hard time choosing photos and drawings to use—but we are having lots of fun. Keep the photos and artwork coming.
Shop ’til you drop. The phone.

1-800-755-0601*.

The Apple Computer Disability Solutions Store.
Steps Toward Adulthood
I was delighted to see the October cover of my son Jonathan with Kevin McHale of the Boston Celtics. I also want to share with you the next steps Jonathan has taken toward adulthood since his bar mitzvah.

After a year of volunteering at the North Shore Jewish Community Center, helping as an aide in a tot gym class and cleaning Nautilus equipment in the health center, Jonathan just landed his first paid job. He started work at Star Market. He's not nervous, but I am, as I have been with each new challenge he has ever taken. I don't know if he's ready, but I doubt my mother thought I was ready for my first job either. Star Market is another of a long line of community representatives who have given Jonathan the chance to be all that he can. He's been working for a month now. He pays taxes and contributes to the United Way.

I want to let your readers know that volunteer experiences are very important. On the application for the job at Star Market, there was a space to indicate volunteer work as well as paid employment. At only 14, Jon already had a pretty impressive resume.

As I reread Jon's bar mitzvah speech that was reprinted in October's issue, I remembered the first time he appeared in Exceptional Parent. He was two years old, and I had written an article called "Silence versus Signing." In that article, I shared my struggles with the issues of Jonathan's lack of speech and the use of sign language. I don't know where the years have gone, but Exceptional Parent has been with us throughout, and I want to say thanks.

J.S., Massachusetts

"Inclusion"—Not Appropriate for All
I am writing out of great concern about the current trend of "inclusion" for all children with special needs. I am the mother of two sons with severe disabilities; they have a degenerative neurological condition called Batten disease. My sons have attended several different schools in the past five years, based on their educational needs. At age four, Ian and Joey began receiving services to address their developmental delays and need for intensive speech therapy. When the progress of the disease caused them to lose their sight, they attended the Maryland School for the Blind. We transferred them to their current school when they became totally physically dependent and unable to swallow, and developed a seizure disorder.

Clearly, our family has seen many sides of the special education system. Having a full range of available educational options allowed Ian and Joey to obtain the best education possible based on their ever-changing needs. This made a big difference in the quality of their lives.

The restriction of "options"—caused by the movement to "include" all children—will be detrimental for some children with special needs. The loss of small class size and close teacher-child relationships will result in less accurate assessment of a child's needs. Many children with severe disabilities have no more than nonverbal cues to communicate their readiness to learn a new task or just to interact. Without a close, intimate relationship, cues will be missed, and opportunities will be lost.

I am pleased that my children participate in some activities at the local ele-
mentary school and in the community. We have had no difficulty providing our sons with many opportunities for socialization. The care and education they receive from their teachers and the nursing staff in a small classroom could not be duplicated in a regular classroom.

"Inclusion" should be one of a variety of educational options for children with special needs. Current state and federal law requires school districts to provide a full continuum of special education placements—including separate schools. In fact, separate programming provides the most appropriate education for many children with special needs. The loss of options in the special education continuum of services will compromise our children’s futures.

R.J., Maryland

EDITOR’S NOTE: This issue of Exceptional Parent includes a thought-provoking guest editorial by Edwin Martin dealing with the topic of inclusion. See page 39.

Article on Myoelectric Prostheses Misleading

I was saddened and dismayed to read your article, New Technology for Artificial Arms (November/December 1993). If an article so filled with mis-statements, over-statements and demonstrably false statements appeared in a supermarket tabloid, it would come as no surprise. But, to have it appear in a magazine written for parents of children with disabilities is inexcusable. Parents look to Exceptional Parent for accurate, factual information, not fallacious hyperbole.

Saying that "...myoelectric prostheses come close to imitating the function of normal human arms and hands" is like saying that a 25-watt light bulb comes close to imitating the function of the sun. In the first paragraph your article says that Eden "grasps the wooden spoon firmly with both hands," but the photograph clearly shows that she has no grasp with her prosthesis!

Professionals in the field of pediatric prosthetics acknowledge that the overwhelming majority of upper-extremity child amputees will abandon their prosthesis by the time they are in their teens. No scientific study has ever been done, however, to determine if those who continue to wear a prosthesis into maturity enjoy any benefits—functional, social or financial—over those who do not. More importantly, no scientific study has ever compared the emotional health of the two groups. Prostheses are recommended based on an assumed need and assumed benefits, rather than on the basis of any body of scientific knowledge.

The most important factor contributing to a child amputee growing into a happy productive adult is a healthy positive self-image, but the factor most stressed in promoting the myoelectric prosthesis is its ability to conceal the missing limb. This emphasis on concealment teaches the child that a missing limb is a repulsive thing that must be hidden in order to fit into society. What a wonderful thing to teach a child!

The sensory functions of the human hand are far more important than its manipulative ability. I believe that this is the reason most arm amputees find that their stumps or their feet are far more functional than the best prosthesis available.

In the 20 years that my wife and I have been involved in the amputee sup-
port movement, it has been our privi-
lege to know many amputees, not as
patients but as friends. It is my impres-
sion that the happiest and most suc-
cessful arm amputees are those who
have discarded prosthetic devices and
no longer feel a need to hide their limb
deficit. Am I right? We’ll never know
until the child prosthetics industry
starts dealing in scientific evidence
instead of assumptions.

Until this happy day arrives, I would
hope that Exceptional Parent will try
to offer parents information
that has some scientific
foundation. This type of arti-
cle would be more credible
if an adult could be found to
describe the benefits of a
prosthesis rather than tour-
ting the accomplishments of
a two-year-old.

B.B., Florida

EDITOR’S NOTE: We discussed
this letter with resource per-
sons at the Rehabilitation
Institute of Michigan (RIM)
who helped prepare New
Technology for Artificial
Arms. The RIM clinic phi-
losophy is that while a child
with one arm and hand will be able to
use substitution patterns and accom-
modations to accomplish almost every
activity they encounter, these activi-
ties can be performed more efficiently
with the use of a prosthesis. Clinic
staff encourage the development of a
child’s positive self-image both with
and without a prosthesis.

Professionals at RIM agree about
the need for research, but note that
recent changes in prosthetic options,
fitting techniques and training tech-
niques make long-term studies
difficult. Nonetheless, the Institute
for Rehabilitation and Research
(TIRR) in Houston, Texas, currently
is in the process of surveying all
upper-limb amputees in the United
States to determine prosthetic wear
and use patterns. Preliminary
results show that only fifteen percent
of children and seven percent of
adults do not wear a prosthesis. Of
those that do, 60 percent of children
and 70 percent of adults report wear-
ing their prostheses more than half
their waking hours. This prelimi-
nary survey data contradicts the let-
ter-writer’s statement that “…the
overwhelming majority of child
amputees will abandon their pros-
thesis by the time they are in their
teens.”

A Hidden Disability
We receive Exceptional Parent in our
office—I work for a neonatologist. I
shared Treatments for Attention
Deficit Hyperactivity Disorder (Sep-
tember 1993 book excerpt) with my
daughter who has an eight-and-a-half-
year-old son with Attention Deficit
Disorder (ADD). It was very helpful.
Please run more articles about this
problem. We particularly need sugges-
tions on helping other family mem-
ers to be sensitive to a “hidden
disability” like ADD. Relatives who
are not faced with the challenge of an
ADD child say things like, “That child
doesn’t have a place for fathers outside the tradi-
tional boundaries of accept-
able male behavior. I do not
mean to paint with broad
strokes here because
fathers increasingly are
changing their roles. But for
the most part, men feel iso-
lated and removed.

Mr. May’s column encour-
eged me to act—I called
him, asked for information
and became a part of the
National Father’s Network.
I have stepped up my
efforts to develop a father’s
work as the group in the region where
I work.

Please continue to provide space in
your magazine for Fathers’ Voices.
There are many fathers out here that
want and need to hear about the ways
in which they can take on positive roles
for their children.

C.L., Connecticut

Keep Up the Good Work!
A brief note to compliment you and
your staff on your marvelous magazine.
Over the past several years, the quality
has continued to improve, and the vari-
ety of topics covered makes each issue
very informative and enjoyable.

My only criticism is that so very
much of your magazine is dedicated to
advertisements for equipment for per-
sons with physical limitations. As the
parent of a child with Down syndrome
who—thank God—does not have phys-
ical limitations, I would love to see
more articles and information directed
towards other areas—recreational,
vocational, medical and educational, to
ame a few. I look forward to your new
departments and encourage you to
keep up the good work!

S.R., Washington
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Encephalocele and Meckel Syndrome
I'm looking for information on encephalocele and Meckel syndrome. My daughter was born with an occipital encephalocele. I would like to find out the outcome of children born with this defect.

T.L.B., Tennessee

Daycare Dilemma
I am the parent of a seven-year-old girl who is hydrocephalic and developmentally delayed. After her birth we faced extreme difficulty in finding child care. I went back to school to pursue a career in nursing with the long-term goal of developing a local daycare center for children with special needs. Luckily, our daughter does not have any special medical needs, and we were able to find a local daycare program that was willing to accept her.

Now, due to our daughter's increasing size and complete dependence on others for everyday needs, we are having difficulty with our current daycare setting. Because of this, I have become highly aware of the problems faced by parents of children with special needs. With this in mind, I have decided to seriously look into what I need to do to fulfill my original goal of developing daycare for children with special needs.

At this point, I'm not sure what to do next and would like information on what is already available. If you have a child attending a specialized daycare center, I would like information on services provided and your likes and dislikes. If possible, I would like to get addresses of other places in the country that I may contact for guidance.

P.R., Louisiana

Good Books for Parents
I am a librarian working on building our library's collection of books and videos for parents of exceptional children. My primary concern is finding books that deal with the everyday challenges of parenting a child with physical or developmental disabilities or a child with a chronic illness. I am also interested in finding books written for parents of children who experience repeated or extended hospitalization to manage their medical conditions.

I will continue to note the titles mentioned in Exceptional Parent magazine but would also appreciate suggestions on other current, in-print materials suitable for parents—not medical professionals.

J.K., Oregon

Two Children with Down Syndrome
I am a teacher, and I work with a family who has two children. Both children have Down syndrome. They have a little girl who is two years old and a newborn son. This family is interested in hearing from another family who has two biological children with Down syndrome.

P.M., Minnesota

Benign Congenital Hypotonia
My two-year-old son, Matthew, has been "diagnosed" with benign congenital hypotonia. For a long time, doctors suspected hypotonic cerebral palsy. Gradually, his muscle tone has improved, and he is now walking. He has fine and gross motor delays and feeding problems. He is unable to eat table foods and is very small for his age. He also is delayed in his speech.

Matthew receives weekly occupational and physical therapy. During the last two years, I have felt very alone. Outwardly, my son looks like a perfectly normal one-year-old. He is hard for friends and family to understand. I would like to hear from other parents of a child with similar problems. I am also interested in hearing about any long-term problems associated with hypotonia. I understand it is associated with learning disabilities.

S.C., Virginia

Nail-Patella Syndrome
My son, Ian, has nail-patella syndrome, an easily diagnosed, but rare genetic condition characterized by nail dysplasia, bone deformities and sometimes, kidney failure. Ian is the first we know of in our families to have this. He has a full-blown case of nail-patella which is unusual. My doctors and I have been unsuccessful in finding another person or family that has or is a carrier of this syndrome.

The information we have on nail-patella syndrome seems to be quite dated. We are looking for up-to-date information on this condition. We would also like to find another individual or family with this syndrome.

C.M.T., New York

Norrie Disease and Cataplexy
We are the parents of two boys—Bobby, who is three years old, and Matthew, who is nine months old. They have a very rare, genetic condition called Norrie disease that always results in total blindness. In addition to the visual problems, both boys have physical and mental disabilities. They also have a 25 percent chance of losing their hearing.

After our nine-month-old was born, he appeared to be having seizures like our older son. After having tests run, we now know why the seizure medication did not work. They do not have seizures at all; they have a sleep disorder called cataplexy. We are looking for other parents who have a child with either Norrie disease or cataplexy.

Please write.

B.F. & S.F., Washington
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Epidermal Nevus Syndrome and Lipomas

My two-year-old son has been diagnosed with epidermal nevus syndrome. The best description I can give is that raised, wart-like skin lesions cover the right side of his body. Application of a compound made with glycolic acid helps prevent thickening of the lesions which can cause infection when they become open. Complicating this skin condition are lipomas—fatty tumors—which continue to reappear despite two surgeries for removal of the larger ones on both sides of his body. On his trunk and arm, the skin lesions are in a line-type of design; on his leg, they just about cover the entire limb up through his buttocks. The right side of his body is much larger and longer than the left, the leg being the most prominent. In fact, his right leg is about three times the size of his left.

I am desperately seeking other parents or physicians who have knowledge of this disorder and can offer guidance as we go through future surgical procedures dealing with removal of the lipomas and/or skin lesions.

L.D., New York

Spastic Paraparesis

Our two-year-old son, Bryan, was diagnosed with spastic paraparesis when we first noticed unusual leg movements at about six months of age. Bryan’s father also has this condition, so doctors believe that it is due to autosomal dominant inheritance.

Bryan, like his dad, is intelligent and managing his disability well. While developmental motor skills involving Bryan’s legs are delayed, he uses his arms and hands well and is at age level in other developmental areas. He is a determined, active, happy two-year-old who is eager to learn and explore. When asked to do tasks requiring gross-motor movement, Bryan can clearly express his dislike of these tasks.

We would like to talk with families who share experiences similar to ours and who are considering various treatment options. We are also interested in sources of information or other resources we might use to learn more about spastic paraparesis.

R.T., Pennsylvania

Bleeding During Seizures

My two-and-a-half-year-old daughter, Brianna, has Aicardi syndrome, right parietal schizencephaly and infantile spasms that are uncontrolled. But here is the problem: When she seizures, blood comes from her mouth and sometimes her nose. This has been occurring for about one year, but has worsened in the last six months. Has anyone ever heard of this? The bleeding does not occur at any other time. She has been seen and tested by her neurologist, gastroenterologist, oto-laryngologist and hematologist. None of these doctors could find a reason for the bleeding.

I would appreciate hearing from anyone who may have heard of this or who has another idea. I would also like to correspond with parents of a child with Brianna’s diagnoses.

J.W., Pennsylvania

Ischemic Strokes

After a normal pregnancy and birth, our daughter, Tricia, was born seemingly healthy. Although she was somewhat behind in meeting developmental milestones, her pediatrician was not alarmed until her 12-month checkup. Then, she was referred to a specialist who diagnosed developmental delay and prescribed physical therapy. At 14 months, Tricia suffered an ischemic stroke on the right side of the brain. It was caused by the occlusion of the right middle internal carotid artery. Extensive testing—including MRIs and an arteriogram—revealed no cause for the occlusion. Doctors decided that the artery had been malformed from birth and said that no more strokes were likely to occur.

At 16 months, Tricia suffered a second stroke on the left side of the brain. A week later, she suffered two more strokes, again on the left side. Now 17 months old, Tricia is essentially paralyzed and is fed through a nasogastric tube. Further tests, including a muscle biopsy, revealed nothing unusual other than some abnormal levels of amino acids and enzymes. Her doctors now think that she may have Moyamoya disease, although her characteristics do not really fit this diagnosis. The doctors can not tell us if Tricia will have more strokes.

We would like to hear from anyone else with a child who has suffered multiple ischemic strokes. We would also like to hear from any experts who have information that might help us. We believe that time may be running out for our little girl.

B.S. & T.S., Virginia

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Circle #36
Single Parent With Disabilities

P.D. (September 1993) is a single parent of a child with autism and other developmental delays. She also has disabilities of her own. She wrote of her feelings of isolation and her hope of finding “friendship and/or support.”

When I saw your letter, I realized we are “neighbors.” I am from Ohio too. I felt that I had to write and offer to be—well, whatever you want—a listener or a friend. The more we moms stick together, the more powerful we’ll be, and the stronger we’ll feel.

When I talk about my son to my friends with “regular” kids, I see their eyes glaze over. They just can’t understand even though they want to. I think having a child with disabilities just magnifies all our normal emotions about parenthood. Our sorrow at our child’s unrealized potential hits harder and sooner; our guilt at our inadequacies is much stronger and more often nags at us. And if our joy at the accomplishments of our child is sweeter, the joy is always tempered by the sorrow of knowing what a “regular” kid of that age would be accomplishing.

My David is almost six. He has cognitive and developmental delays and almost no speech. He’s still in preschool, but we are approaching the time when he’ll hit the school system. He has one younger sister who does not have disabilities. Wouldn’t you know it—she is one of those compliant children, and it’s so hard not to put too much pressure on her to “be good.” I know it’s not fair, but I can only handle one kid acting up at a time.

Call or write anytime. I don’t work personal care. She has a great deal of needs extensive assistance for personal care. She has a great deal of difficulty writing, but as a one-finger typist, finds typing equally frustrating. N.T. wanted to hear about the college experiences of people with needs similar to those of her daughter. She also wanted information about colleges with good support services for students with disabilities.

Undiagnosed

W.J.R. & T.R. (November/December 1993) were looking for a child who is similar to their 11-month-old son, Dakota. Dakota is developmentally delayed and has dysmorphic features which include slightly protruding, wide-spaced eyes; low-set ears; nose with flattened bridge; high palate and simian-creased left palm. His heart has an atrial ventricular valve dysplasia with a possible mild AV-valve stenosis. Extensive medical and genetic testing has failed to yield a diagnosis.

Our 13-month-old daughter, Meghan, was diagnosed at birth with a rare syndrome called cri du chat. Many of your son’s features seem to resemble those of cri du chat. Like Dakota, Meghan has a flattened nasal bridge, low-set ears, low muscle tone, slow growth and smaller head size. She has a high pitched cry and, like Dakota, is developmentally delayed. Many children with cri du chat syndrome have simian-creased palms. Meghan also has a small hole in her heart.

Cri du chat syndrome is caused by the loss of genetic material from the short arm of the fifth chromosome. When the geneticist showed us Meghan’s chromosome study, we could not even see the tip that had broken off, because it was so small. This could be easy to miss if the doctor does not know what to look for.

P.R. & J.R., New Jersey

□ Your letter caught my attention because my nearly four-year-old daughter, Elena, also falls into that void of undiagnosed children. As I was reading your description of Dakota, I couldn’t help but compare his development to Elena at a similar age and think, “Gee, he’s doing great!” At 11 months, Elena’s developmental level was measured in weeks instead of months. She was nearly completely corticaly blind, not at all alert and not a bit social. She went through a battery of tests comparable to Dakota’s, and our family situation was exactly as you describe your own.

I spent more than a year dragging Elena from one neurology clinic to another, and from one EEG appointment to another. I read everything I could get my hands on that dealt with pediatric development, cerebral palsy, autism, mental retardation and anything else you could imagine, looking for a slot into which she might fit. But she didn’t fit. Her “diagnosis” remains “developmental delay of unknown etiology.”

I felt compelled to urge you not to drive yourself nuts looking for this elusive diagnosis or label for Dakota. In the end—with or without a diagnosis—he’s just a kid. He’s your kid. By now, he’s just over a year old. He eats well. He’s alert, happy and social; a’ the needs all the love and affection you can give him. He doesn’t need to be dragged around for test after test, or to have conversation made about his facial features. As long as the tests to date have indicated no operable physical condition, what is the benefit of continued testing? Wouldn’t you all benefit more if you spent that time, energy and money on things that can actually enhance your lives?

I don’t mean to sound harsh, for I did the same thing as you. And I discovered that Elena’s just a kid. She’s in a fabulous program at the United Cerebral Palsy Developmental Center. She’s starting to walk with a walker. She’s seeing better and starting to get around a room pretty well to get the toys she wants. She’s finger feeding herself, and she’s a very content, pleasant kid—a kid with no diagnosis, and no label, and it doesn’t make a bit of difference.

I hope you can hear what I’m trying to communicate. I’m not sure whether I would have been able to at that stage or not. But if not now, then maybe soon. I would be glad to offer any help I can.

Z.G., North Carolina

College With a Personal Attendant

N.T. (February 1993) is the mother of a 15-year-old daughter who is an honor student and wants to attend college. Her daughter has cerebral palsy and uses a motorized wheelchair. She needs extensive assistance for personal care. She has a great deal of difficulty writing, but as a one-finger typist, finds typing equally frustrating. N.T. wanted to hear about the college experiences of people with needs similar to those of her daughter. She also wanted information about colleges with good support services for students with disabilities.

I’ve worked with people with cerebral palsy for many years. I am also the
mother of a three-year-old boy with a disability. I want to start by congratulating you on the wonderful job you’ve done as parents. Your daughter’s motivation to go to college is an excellent predictor that she will go on to have a productive life. Too many kids grow up believing that all kinds of things aren’t possible because of their disability.

There is incredible technology available that has the potential to help your daughter in college. There are computer systems that are voice-activated rather than keyboard-driven. Your daughter might be able to use alternative devices to operate computers such as a joystick or a scanner with some sort of switch. You can get alternative keyboards, adapt standard keyboards to change key locations or change the length of time a key may be pressed.

You might start by calling the United Cerebral Palsy Association at 1-800-872-5827. Ask to speak to a referral person or to their resource person on rehabilitation technology. Your daughter should have an assistive technology assessment to determine the technology that would best fit her needs. Many large rehabilitation hospitals perform such assessments.

You should also call your state’s Office of Vocational Rehabilitation (VR). They should get involved with your daughter before she leaves high school. I have known my state’s VR office to fund the purchase of computers and other assistive technology, pay college tuition and pay for a personal care attendant for some college students.

Yes, your daughter can go to college. I know many people who don’t write who have done so. I know one man with cerebral palsy who graduated with a business degree, works for one of the largest corporations in Pittsburgh and has started a printing business on the side. He does not write or speak. He has the use of only one finger.

Edinboro University, near Erie, Pennsylvania, has been accessible for years. They have many students with disabilities and excellent support services. Perhaps it would be worth a visit. Seeing people with all kinds of disabilities in a college setting undoubtedly would bolster your daughter’s confidence.

S.G., Pennsylvania


If I am a clinical social worker at Children’s Hospital of Pittsburgh, and I read Exceptional Parent religiously. I am also a proud 1982 graduate of Ball State University in Muncie, Indiana. Ball State has earned national recognition for meeting the needs of students with disabilities. I was a personal care attendant for a fellow student during my freshman year. You can learn more about my alma mater by writing or calling Richard Harris, Director of Disabled Student Development, Student Center 307, Ball State University, Muncie, IN 47306, (317) 285-5293.

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Jason Kingsley and Mitchell Levitz

Young authors challenge stereotypes and misconceptions

Jason Kingsley is a high school senior and former associate board member of the National Down Syndrome Congress. He has acted in films and on television, and currently lives in Chappaqua, New York. Mitchell Levitz graduated from high school in 1991. He is active in politics, has worked for two state assembly members, and presently lives and works in Peekskill, New York.


Mitchell: I think that all people can succeed if there are opportunities out there for them. It is very important for children to get the education that they need. Second, it is important to be in the community by having social activities and making friendships. Once people get to know us, then people will be very accepting of us.

Both me and Jason are in regular education and special education—we have a combination of both. I want to see more people with disabilities included in regular education. They are capable of going to a regular school with other students. They can learn the same as anyone else. Some people with disabilities take longer to learn than other individuals, but no one should be discriminated against. A very long time ago, there were many cases of discrimination, misconception and stereotyping—but that was in the past.

Jason: I took courses like math, science, and history. I was placed with people with mild disabilities, in what is called special education. But, like Mitchell said about inclusion, I do have other courses that are not special education—like gym and typing. Also, I am in the drama club.

Teasing

Mitchell: Sometimes, people will put you down or tease you because of your disability. Me and Jason try to encourage other students not to do that. First, they hurt our feelings. Second, it is not appropriate behavior because it is not right to make fun of someone with a disability or a different race. We are all individuals. We all have rights and no one should bother those rights.

When I was in school, I wanted to be part of the popular gang, to be in the crowd. There is peer pressure. People would take advantage of me because of my disability. They thought they could get away with it, and back then, they did get away with it. And now I'm here telling people, "Hey, this not right and you better stop it."

Jason: When I was in middle school, there was a lot of teasing. I didn't like the teasing. People teased me because they thought that teasing was cool. I was treated unfairly. The principal took me to suspension one time. I didn't think that I did something wrong.
Another kid did something wrong—he was trying to tease me—but I got suspended. I got into high school—that was when I was a freshman and there was less teasing than middle school. Now that I'm a senior, I truly believe that people are believing in me, trying to be very supportive. A strategy that I used to deal with the teasing was that I talked to the dean or principal or my teacher. And I talked to my parents, my grandparents and my friend, Mitchell Levitz—that's why we say "friends forever!" I also go to a psychologist once a week. He's teaching me how to think on my own. I don't need him anymore because I can solve problems on my own from now on.

Mitchell: Yes, I remember when Jason was having problems in school, and he would ask me for advice on how to handle a situation. I gave him lots of advice.

I indicated to him that he had to talk to the right people, that he needed to speak up in order to handle his problems. My situation was different because I went to school with my two sisters. They were very supportive and very understanding. They helped me solve my problems.

Hopes and Dreams

Mitchell: I would like to tell parents that they should give us a chance to be ourselves and to make decisions on our own. It is understandable that parents can be overprotective. Sometimes our parents feel protective of both me and Jason.

Jason: I also would like parents to learn to let go of their children, give us the same opportunities parents had as children.

Mitchell: We have some limits—like driving. Driving is a strong responsibility. You need to learn all of the technical skills to drive. It is very difficult because it takes us longer to learn. That is part of our disability. A person who drives needs to make quick judgments. That is something that is very difficult for me. My parents have told me that there are some judgments I make that are not that good.

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**EXCEPTIONAL PARENT / APRIL 1994**
The other thing I want to mention is that I always dreamed of having a child of my own. I know that it is irregular for a person who has Down syndrome to father a child, but I want to have the same lifestyle as everyone else.

Some people thought we would not be able to write a book. We have proven them wrong. We are trying to erase all the negative attitudes that people had about Down syndrome.

Jason: Not everyone has the same hopes and dreams, but we are heading toward the same goal—Independence.

I am a senior now. I have passed all my courses to get a regular diploma. I am going to graduate this June. We are thinking of a graduation party and all that stuff. And from there, we are looking at post-secondary colleges. Later, I am going to get a business and live on my own. I dream to be a father with kids, but we will get into that when the time comes.

Mitchell: I graduated in 1991 with a regular diploma. I am currently working at the Chamber of Commerce in Peekskill, New York. Recently, I interviewed for a new position—coordinator of consumer empowerment for Westchester County ARC. I will be filling that position next month. I will be speaking to schools, going out to the job sites and helping to organize fund-raisers. In time, I might decide to run for public office.

I am independent now—living in a house by myself which is nearby my parents. I was in a program to get ready to live fully independent. They taught me many different kinds of skills—how to cook, shop, do my laundry, finances or whatever. Since September, I have been living by myself. I felt very mature and very strong to make this decision to live independently.
Unlocking Doors

Mitchell: What is unique about our book is that it's in conversational form. And even though there are many other books written about Down syndrome, there has never been a book written by two young men who have Down syndrome. Some people thought we would not be able to write a book. We have proven them wrong. We are trying to erase all the negative attitudes that people had about Down syndrome.

Jason: This book is about misconceptions and stereotyping. We hope people with disabilities will be accepted in the community.

Strangers can become our friends. We have seen some strangers during our book tour. They say, “Hey! I know these guys from seeing them on CNN.” So are these people really strangers? People say, “Oh, I saw you on TV, and good luck with your book.” People are becoming aware and becoming our friends.

Mitchell: I would like to add that it is a positive influence on society if they show people like us on television talking about Down syndrome. Let me give you one example—the television show Life Goes On. That show has shown that we have the same capabilities as everyone else. It really makes me feel good knowing that people understand how we feel.

My message is that people with disabilities want to be accepted. They want to have opportunities for life. I just want to erase all the negative attitudes in society.

Jason: My message is that people with disabilities have hopes, dreams, goals and feelings—the same as everyone else. I want to use an analogy: There used to be locked doors on the "museum of life." But with "the key of opportunities," people with disabilities can open up those doors for many possibilities. Each room has a new adventure. And now, people are coming into the museum. They should be coming in, because we don’t want any limits on expectations for us. We have to have high expectations. One of the rooms in my museum is going to be about higher expectations for parents and for children.
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It's family vacation time again. Time to make plans—Where shall we go? What shall we do? Who will join us?

A friend calls. We've been on vacation with her family before. She wants us to go camping with them. It sounds like fun. I consider the place she suggests and wonder aloud, "Are there any pathways that will be paved or smooth enough for our son's wheelchair to safely cruise along? Will the campground have an area flat enough for him to maneuver without assistance? Can he get to the marina so he can fish?"

For our family, these are the types of questions that we think about before we go anywhere. Such concerns seem normal to me. I'm not distressed or particularly frustrated by them, so I'm surprised when my friend perceives my questions differently. She heaves a deep sigh as if to say, "What a burden for you!" Then she proceeds with a suggestion that stuns me—"Have you ever thought about not taking Mahlon? Maybe leaving him somewhere...?"

I want to laugh. Leave him? Where? On the roadside? At home alone?

At the same time, I want to cry because it's so hard to get people to understand that Mahlon is family. I want to shout at her—as if that would make her understand more easily. "A family vacation without part of the family? Are you kidding? He's our child! He likes to be with us and do the things we do. He likes to camp and fish and ride in the boat. He likes to gather with everyone around the campfire to sing and listen to jokes."

Misjudging my silence as consensus, my friend plunges forward to explain that it would be good for us to do some things without our son to hold us back. It would relieve our burden, free us from the obligation to tend to his needs.

Whoa—now I'm insulted! As if my 16 years as the parent of a child with special needs hasn't taught me that I have to take care of myself. I do take time for myself! I write, read, go to the movies, indulge in long phone calls, have lunch with friends and spend time alone with my husband. My husband and I also focus some exclusive attention on each of our children, according to their interests and abilities.

Who does she think she is? I can appreciate my friend's concern, but not her insensitivity. Rather than answer her unintentional affront with one of my own, I make an excuse to end the conversation. I tell her I'll think about it.

Defining "Family"

In reality, I don't need to give my friend's suggestion a moment's consideration. I have a very definite sense of what "family" means to me. In my definition, it includes both of my children. But I need to think about how to explain that to her. I want her to understand what it is like to be the parent of a child with special needs. I want her to know that it's like being the parent of any child and that the child with special needs is an important part of the family unit.

I appreciate it when friends are concerned about me and my life as an exceptional parent. I feel supported when they acknowledge that I'm doing a great job with my son. I always listen to their suggestions and try to hear them without becoming too defensive. I know from experience that some very useful suggestions come my way. Once, after telling someone that I had to get up nearly every night to turn Mahlon over, the person said, "You know, I wonder if you could screw a towel bar onto the wall beside his bed so he could pull himself over?" I immediately recognized that suggestion as a jewel. I went home and did it, and it worked! I wish I could think up all the good ideas by myself, but I have to admit that I can't. Sometimes, the obvious is difficult to see, so I try to keep an open mind when someone makes a suggestion. I constantly sort the useful from the ridiculous,
the helpful from the insulting and the supportive from the insensitive.

My friend's suggestion that we exclude Mahlon because he has cerebral palsy and uses a wheelchair is easily categorized as ridiculous, insulting and insensitive. Would she also suggest excluding a child who has obnoxious habits? I have been on group outings where I had to endure other people's children who were far more troublesome than the relatively

simple logistical problems posed by my son's wheelchair.

**Every Family has Limitations**

I try to put my hurt feelings aside. I tell myself that my friend's suggestion arose from her lack of experience rather than any malicious intent. I realize that she is looking at my life from the outside and imagining herself in my place. The tasks, the special preparations and the efforts that I have come to take for granted seem overwhelming to her. Or maybe she can't imagine herself in my position because it's unsettling and uncomfortable for her to look at my life.

I want to tell I was uncomfortable at first, too. I didn't think I would be any good at this kind of parenting either, but I've learned along the way. When I chose to become a mother, I decided that I was willing to take any child I got. Since then, I have asked myself what I would have done if I had known before he was born that Mahlon would have special needs. I don't have an answer. I really don't know what decision I would have made, so I don't judge anyone else's decisions on that issue. It's too easy to moralize about someone else's life when you're not in their shoes.

I do know that when my son arrived prematurely and managed to survive despite his low birth weight and immature lungs, I was hooked. I didn't care what special needs this little fellow would have—I loved him. I was his mother!

As time passed and his needs became obvious, my feelings about him didn't change. He didn't "become a burden" or "create an obligation." He was still just my child. I never even considered not helping him in every way I could. I didn't even think about not including him in my life. He was family.

Certainly, there have been frustrating times, annoying situations to deal with and overwhelming tasks to accomplish. But we plod along, one step at a time, trying to find humor in our experiences. Yes, our life is limited in some ways, but so what! Every family lives within some limitations—economic, occupational, geographical or even self-imposed. The fact that our son uses a wheelchair is just a fact of life.

Our family can't enter every building through the front door, but we've sometimes found it far more interesting to enter through the back. When we toured the White House, my son was able to enter through the kitchen and ride in the President's eleva-
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Family vacation: (from left) Kate, Mahlon, Michael and Patrick at Multnomah Falls, Oregon.

Willing to Make Things Work
How can I explain to my friend that I love my son just as much as she loves hers? How can I make her see that what she perceives as a burden, I see as a loving commitment? How can I convey that she is the one who doesn't know how to live with disabilities, not I? It's family vacation time, but I don't think we will go camping this year. I think we'll try something more dramatic—like traveling by train through Europe. Maybe, by seeing that, my friend will realize that we are willing to make things work. We are a family who enjoys traveling and sharing experiences. Where we go, when we go, and how we go will always be affected by the fact that one family member is in a wheelchair, but one thing is certain—as long as our children want to travel with us, we will go on family vacations with the entire family.

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Before our son was diagnosed with autism, we had a timetable for life's important vacation rites. We had planned trips to the circus, visits to the zoo, tours of museums and, of course, that pilgrimage to America's middle-class Mecca—Disney World. As far as the Disney trip was concerned, we had agreed to wait until our two children, five-year-old Stephanie and four-year-old Peter, were old enough to appreciate and remember all the rides.

Peter's diagnosis resulted in many changes for our family, but our vacation plans remained the same. Our family vacations have become experiments in disability-access planning and tests of our son's emerging abilities. As we mastered short visits to relatives and day trips to petting zoos, we knew the true challenge was still ahead—we wanted to make a trip to Disney World and live to tell about it.

This article is the story of our trip. We hope other exceptional families will be able to benefit from our experiences. It wasn't a perfect vacation, but it was very rewarding for all of us.

**Logistics and Planning**

A lot was involved in taking a four-year-old child with autism on a tour of Orlando's major tourist attractions. Our first step was to make an honest assessment of our son's abilities and needs. Despite his autism, Peter is generally a well-behaved child. He has some speech and is toilet-trained. Unlike some children with autism, he is not distressed by changes in his routine or environment. However, he does engage in some self-stimulatory behavior that is quite noticeable, and appears quite odd to most passersby. He also has occasional tantrums. Since autism is not a physically "obvious" disability, my wife and I were concerned about other people's reactions to Peter's occasional odd behaviors and apparent inability to understand speech. More worrisome was Peter's absolute lack of patience. Throwing him into the "endless" lines of one of the world's most popular resorts was a frightening prospect.

In speaking to another family of a child with autism, we learned that the Disney organization is very accommodating toward people with all sorts of disabilities. We called Disney, and after several transfers to the wrong department, finally reached Disabled Customer Services.

Our first question had to do with Disney's policy toward "non-obvious" disabilities such as autism. As we had hoped, the Disney representative was helpful and understanding. She explained that a "special assistance pass" was available. This pass could be used to obtain preferential access to many attractions. The customer service representative asked only that we use the pass with discretion—we should wait if the lines weren't long and our child was handling the situation calmly. Our special assistance pass and related brochures on accessibility to the Disney resorts arrived in the mail within a week.
Off to Disney!

One of the benefits of frequent flying is the nonchalant attitude you get when boarding an airplane. Though not a frequent flyer, Peter took the trip in stride. In fact, his enthusiasm and engagement surprised us. He peered out the window intently during the flight, quietly watching the world from above the clouds.

The only problem we encountered that day occurred with a long wait for a rental car at the Orlando airport. After 10 minutes in line, Peter began to scream and writhe on the floor—behavior that might go unnoticed in a two-year-old, but we got more than a few stares. We managed to treat the tantrum as “just-your-normal-everyday-kid-throwing-a-fit” and finally got our car. We arrived at the hotel, jumped in the pool and tried to plan our next day’s activities.

Revenge of the Flying Dumbos

We decided to tackle the Magic Kingdom first. We approached the parking lot and paid our four dollars. We could see the top of Cinderella’s Castle over the tops of the distant trees. Squeals came from the back seat as we pulled into an empty parking space. Since it was mid-November, the parking lot was not crowded, and we were able to park quite close to the entrance. We applauded our good fortune, boarded the Magic Tram and set off on our adventure.

Stephanie found the monorail thrilling, and her excitement was contagious. By the time we had arrived at the Magic Kingdom rail station, Peter began to bounce, hopping up and down in anticipation of what lay ahead. We began by boarding an old-fashioned car for a ride down Main Street USA to Cinderella’s Castle.

“Rella, Rella!” Peter shouted as we got out of the car and admired the scene from a favorite fairy tale. His eyes lit up with joy as he walked up the staircase.

My wife and I exchanged glowing glances of self-approval, as if to say silently, “Yes, we really did make the right decision to bring Pete.” Of course, that was before we saw the Flying Dumbo ride.

Peter spotted it first. “Dumbo! Dumbo!,” he cried as he pulled eagerly against my grip. Peter had always enjoyed the movie Dumbo, and seeing his favorite story come to life was almost too much to bear.

“Dumbo! Dumbo!,” he yelled. Stephanie wanted no part of this “kiddie” ride and towed Susan to the merry-go-round. Peter and I got in line for the Flying Dumbos.

The only problem was that Susan had taken the special assistance pass and left me stranded with a very excited and impatient four-year-old who could not understand why he had to wait.

His screaming, kicking, yelling and crying went beyond normal tantrums. When that didn’t persuade me to put him on the ride immediately, he began the repetitive sing-song sounds he makes to calm himself. I finally noticed the stares as other parents watched this odd display. “Watch the kicking,” a woman said, not to me but to her daughter.

Another 30 minutes of kicking and whining passed before we boarded Dumbo for our 90-second joy ride. “Timmy Mouse! Timmy Mouse!,” Peter shrieked as he spotted Dumbo’s diminutive friend perched above the mirrored ball in the center of the ride. Round and round we spun, up and down, flying as Dumbo does in the movie. The ride was much too short.

New Survival Tactics

After the “Dumbo Incident,” Susan and I agreed to stick together and use the special assistance pass whenever necessary. We also decided to make advance plans by scouting out each ride first—Where is the special entrance? Can we go “in” the “out” door? Are the lines too long? Is the ride worth the effort?

With our new survival tactics, we spent the rest of the day wandering happily through the Kingdom, enjoying the park like any other “unexceptional” family.

Peter’s favorite rides were very fast and very physical. He had little interest in movies or live shows like the Country Bear Jamboree, but he loved Thunderbird 2000. His other favorite was The Haunted Mansion. He repeatedly told us that the “people were dead.”

We met Uncle Scrooge when he was doing an autograph session next to the Crystal Palace. Peter was exuberant and twelve other children between 1 and 6 were equally enthusiastic. Our Tigger costumes were a hit, and they all wanted to play with our four-year-old. (He was the only one there with a walker.)

Unexceptional Orlando

The Orlando/Orange County Convention and Visitors Bureau can offer recommendations and tips for accessible travel, as well as general information about area attractions. They can be reached at (407) 834-5871.

Walt Disney World has an excellent Guidebook For Guests With Disabilities. To get a copy, call (407) 824-4321, voice or (407) 827-5141, TDD. For information on accessible Disney accommodations, call (407) 934-7639, voice or (407) 945-5880, TDD.

Universal Studios Florida has prepared a thorough Studio Guide For Guests With Disabilities. For a copy, call (407) 363-8000, voice or (407) 363-8265, TDD.

SeaWorld features wheelchair seating at all facilities, as well as wheelchair rentals. For further accessibility information, call (407) 351-3600, voice or (407) 363-5617, TDD.
Mountain Railroad, Flight to Mars and Peter Pan’s Flight. He had less interest in slow moving rides like It’s a Small World or Pirates of the Caribbean.

With the help of the special assistance pass, our trip was very enjoyable. Perhaps the most difficult challenge was getting Peter to “transition” from one good experience to another.

Should You Go?

Despite the challenges, we plan to return to Disney World again in a few years with Peter and Stephanie. Access for children with developmental disabilities was good-to-excellent, and we feel that the experience was a good one for Peter.

Despite the lack of obvious physical disabilities, Peter was never denied access to the special entrance of any ride. Most of our Disney hosts were accommodating and unquestioning of the legitimacy of our pass, although a few had never seen one and studied it carefully. Everyone treated us with respect and courtesy.

We also had good experiences at EPCOT and Disney/MGM Studios, except that both kids found EPCOT to be much too “slow”—with the exception of Met Life’s Body Wars, Norway’s Maelstrom log flume ride and GE’s fireworks and light show.

Traveling during the off season is the only way to go. The normal spring and summer crowds are difficult for most families to handle, and would be impossible for most families with special needs. Though the park is only open until 7 p.m. during fall and winter seasons, you can still pack a lot into a day by giving an early start.

Before you make the trip, weigh the pros and cons in terms of your family’s special needs. The normal hassles of any family vacation are magnified by the special problems associated with your child’s disability.

The hassles are often worth it, however. The stress fades as you look back on the fun moments. Your children who don’t have disabilities will have a vacation experience like those of most of their friends. Your child with a disability will receive respectful accommodation of his or her special needs. And parents will create singularly unique family memories.

David and Susan Brooks live in Morris Plains, New Jersey, with their two children, Stephanie and Peter. David is a marketing communications manager. Susan, a former business systems analyst, is an active member of the parents association at Peter’s school, The Developmental Learning Center in Chatham, New Jersey.
Travel Resources

The following government offices can offer referrals and information about accessible services, accommodations, attractions and tourist destinations in each state (USA) or province (Canada).

ALABAMA
Dept of Tourism
401 Adams Ave, Ste 126
PO Box 4309
Montgomery, AL 36103-4309
(800) 252-2362
(800) 548-2547, TDD
(205) 242-4169
(205) 242-4177

ALASKA
Alaska Division of Tourism
PO Box 11801
Juneau, AK 99811-0801
(907) 465-2010

ARIZONA
Office of Tourism
1100 W Washington
Phoenix, AZ 85007
(800) 842-2857
(602) 542-8687

ARKANSAS
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Little Rock, AR 72201
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(303) 640-3056

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(907) 465-2010

CALIFORNIA
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(205) 242-4169
(205) 242-4177

COLORADO
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(800) 722-8191, TDD

CONNECTICUT
Dept of Economic Development
100 Church St
Hartford, CT 06103
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(800) 533-1891
(800) 487-4877

DELWARE
Dept of Natural Resources & Environmental Control
PO Box 20000
Dover, DE 19903
(800) 487-4877

DISTRICT OF COLUMBIA
Convention and Visitor Bureaus
1212 New York Ave NW
Washington, DC 20005
(202) 857-1697
(202) 857-1825
(202) 778-2685

FLORIDA
Division of Tourism
125 W Van Buren
Tallahassee, FL 32399-2000
(800) 847-1462
(800) 847-1462
(800) 566-9493

GEORGIA
Dept of Industry, Trade
and Tourism
PO Box 1776
Atlanta, GA 30301
(800) 847-4842
(800) 847-4842
(800) 566-9493

HAWAII
Hawaii Visitors Bureau
2270 Kalakaua Ave
Honolulu, HI 96815
(800) 257-2939 (recording)
(800) 257-2939
(800) 566-9493

IDAHO
Dept of Commerce
PO Box 83720
Boise, ID 83720-0093
(208) 334-2470

ILLINOIS
Central Illinois Tourism Council
629 E Washington
Springfield, IL 62701
(800) 822-0292
(217) 735-2258

INDIANA
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One N Capitol, Ste 700
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(317) 232-5977, TDD
(317) 232-8860

KANSAS
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Topeka, KS 66603-4309
(800) 252-6727
(913) 296-3487, TDD

KENTUCKY
Dept of Travel Development
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Frankfort, KY 40601
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(800) 235-2358, TDD

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(617) 727-3201

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Michigan Travel Bureau
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Lansing, MI 48909
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(313) 722-8191, TDD

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(314) 751-4133

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Helena, MT 59602
(800) 847-4866
(406) 444-2978, TDD

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Las Vegas, NV 89150
(702) 471-5497

NEW HAMPSHIRE
State Office of Tourism
PO Box 2300
Concord, NH 03302
(603) 271-2665

NEW JERSEY
Dept of Transportation
PO Box 4309
Burlington, NJ 08016
(800) 332-8388, TDD

NEW MEXICO
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(505) 474-4116

NEW YORK
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Rutland, VT 05702
(800) 252-6579

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Columbus, OH 43268
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(614) 845-8844
(614) 462-4951, TDD

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1115 Commercial St NE
Salem, OR 97301-1001
(503) 378-6305

PENNSYLVANIA
Dept of Tourism
PO Box 4231
Harrisburg, PA 17120
(800) 487-4877
(800) 533-9595

PUERTO RICO
Division of Tourism
PO Box 4231
San Juan, PR 00905
(809) 721-0001

RHODE ISLAND
Rhode Island Convention and Visitors Bureau
1000 Memorial Blvd
Providence, RI 02903
(800) 556-2484
(401) 777-2601

SOUTH CAROLINA
Dept of Transportation
PO Box 200
Columbia, SC 29020
(803) 349-3333

SOUTH DAKOTA
Dept of Tourism
PO Box 2301
Sioux Falls, SD 57104
(800) 252-6579

TENNESSEE
Tennessee Tourism Division
PO Box 23170
Nashville, TN 37202-3170
(615) 741-0611
(615) 741-0611

TEXAS
Division of Tourism
PO Box 4231
Austin, TX 78766
(800) 533-9595
(800) 533-9595

UTAH
Division of Tourism
PO Box 1776
Salt Lake City, UT 84111
(800) 252-6579

VIRGIN ISLANDS
Division of Tourism
PO Box 1776
St Thomas, VI 00801
(800) 252-6579

WASHINGTON
State Commission on Tourism
PO Box 4231
Olympia, WA 98507
(800) 252-6579

WEST VIRGINIA
Division of Tourism
PO Box 4231
Charleston, WV 25330
(800) 252-6579

WISCONSIN
Division of Tourism
PO Box 4231
Madison, WI 53702
(800) 252-6579

WYOMING
Division of Tourism
PO Box 4231
Cheyenne, WY 82002
(800) 252-6579

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Association for the Care of Children’s Health
29th Annual Conference
May 22-25, 1994
Westin Harbour Castle Hotel  Toronto, Canada

Conference Highlights:

Sunday, May 22
Opening of Exhibit Hall followed by Celebrating Parent/Professional Partnerships Reception

Monday, May 23
Opening Plenary — Commemorating Victoria Day in Canada "Health Status of Children in the Industrialized World: Reforming Health Care"

Tuesday, May 24
4th Annual ACCH Corporate Breakfast and Plenary — "Macaroni at Midnight"

Wednesday, May 25
4th Annual Brazelton Lecture: with introductory remarks by Dr. T. Berry Brazelton: "Dreams, Schemes, and Flying Machines: The Children’s Hospital’s Vision, Strategy, and Perspective for Family-Centered Services"

President’s Luncheon — "Top Hat and Tales in Your Tool Box: Storytelling as a ‘Power’ Tool Anyone Can Use"

Closing Plenary: "Tools for Pediatric Health Care in the ’90s and BEYOND: Connecting with the Spiritual Aspects of Our Work" with dramatization of "The Goop-Ooze Story of Creation"

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Travel Council
Council Hall, Capitol Hill
Salt Lake City, UT 84114
(801) 538-1030

**VERMONT**
Division of Vocational Rehabilitation
103 S Main St
Waterbury, VT 05671-2303
(802) 241-2186, VTDD

**WASHINGTON**
Dept. of Commerce and Economic Development
Tourism and Travel Division
RSVP Volunteers
P.O. Box 42500
Olympia, WA 98504-2500
(206) 566-2768

**WEST VIRGINIA**
Division of Tourism, Parks and Recreation
State Capitol Complex
Bldg 6, Rim B564
Charleston, WV 25305
(800) 225-5982
(304) 348-0200

**WISCONSIN**
Wisconsin Travel Information Ctr
P.O. Box 7606
Madison, WI 53707-7606
(608) 266-2161

**WYOMING**
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1-25 at College Dr
Cheyenne, WY 82002
(800) 225-5956

**CANADA**

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3rd Fl, Commerce Bldg
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(800) 961-8888
(403) 427-4313

**ONTARIO**
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800 Tour de la Victoria
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Montreal, Quebec H3C 2W3
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**NOVA SCOTIA**
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(800) 341-6096, USA
(902) 424-5014

**BRITISH COLUMBIA**
Ministry of Tourism
The Parliament Bldgs
in British Columbia
Victoria, BC V8V 1X4
(800) 663-6000

**MANITOBA**
Travel Manitoba
155 Carlton St, 7th Fl
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(204) 945-3777

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It was an idyllic fall afternoon in Orlando in 1983. Life was good; God was in his heaven. Even the humidity was miraculously low. Then fate's fickle finger dropped the proverbial fly into the complacent ointment of our life. Our first child, Joshua, was diagnosed with Down syndrome. This same day—Black Monday—my husband, Dick, was laid off from his job as construction manager for a Florida-based firm.

Despite our conviction that the world had ended, the sun spitefully rose the next day and plopped us into the turbulent white-caps of readjustment. We began wildly treading water until, at last, we managed to bump up against a life-raft—half drowned, but definitely better swimmers. It took two years. If I seem to be talking in philosophic clichés, it is because we examined them all during the first few years of Josh's life.

Dick's new position took us from Orlando, to Nashville, to Indianapolis, then home to Romeo, Michigan, all within four years. Our travels also took us through many early intervention programs and parents' groups—all with diverse views on special education.

The opportunity to see so many different parental reactions and adjustments to having a child with a disability helped us chart our own course. We were not destined to become activists and advocates. Though we thank God that such people exist, we felt that if our entire family life revolved around Josh's "syndrome," we would be accentuating his differences rather than treating him like any other family member. We wanted as normal a life as possible. And we had added two more children—with their own needs—to our family. So, "life as usual" became our philosophy. Along with this perspective came a finely developed sense of humor. In fact, humor became a requisite for survival at our house. I believe our attitude resulted from a total acceptance of Josh. God made him as he is, so don't tell me God has no sense of humor!

Working to include Josh in school, religious and community programs has provided us with enough material for a sitcom. Many times, however, people have seen only tragedy in our experiences with Josh. In all honesty, I have to admit that Josh's antics were not always humorous at the time. But in retrospect, not only are Josh's escapades funny, we also delight in his cleverness. And we are never bored!

Josh's transgressions began to form a pattern over the years, so I have categorized them. They include errors of interior decoration, life and limb, hide and seek, fashion, etiquette and academic enlightenment.

**Interior Design**

Josh has always had an interest in interior design. "Trash-and-go" is his basic modus operandi, but he has
been known to use some unusual, creative art supplies. The only episode that can be mentioned here, however, resulted when old Dad fell asleep on the couch while Josh used some green stencil paint to great advantage. When it was all over, Josh looked like the Jolly Green Gremlin and his “country green” world included a three-foot diameter splotch on the carpet, and free-expression finger prints on curtains, chairs and even Great-Grandma’s hand-made quilt!

**Life and Limb**

Josh’s mistakes in this category definitely were not funny at the time. But after the fact, we had to laugh. At the same time, we made mental notes to prevent a recurrence. We remember the time Josh managed to open the car door just as Dad wheeled around a corner. A horrified Dad completed the turn with one hand firmly attached to Josh’s drawers.

Then there was the time three-year-old Josh suddenly vanished from the Montessori school. After an exhaustive search of the building, the teachers saw Josh standing outside, grinning impishly at them through the front window and waiting for them to give chase.

I’ll always remember the morning when I tiptoed out to get the paper in my pajamas... in January... in Michigan. Just as my fingers brushed the newspaper, I heard the door close—or rather lock—behind me! Once again, Josh gave me that infuriating grin through the front window but refused to let me in even though he knew full-well how to do it. Always resourceful, I managed to find a brick to use on the back-door window. Inside the back door was a landing before a full flight of stairs. Unfortunately, due to my anxiety, I underestimated my strength—the brick and the glass both made the bottom of the stairway.

**Etiquette**

Josh’s manners can be extraordinary—in all senses of the word. His teachers will never forget the time he talked them into letting him sit down on the toilet while they made the mistake of standing in front of him. Or the time he sneaked up next to Uncle Rick at the dinner table, gave him a big hug, and then snatched the last piece of steak off his plate. Or the time he dropped that piece of chocolate cake into his dad’s water glass.

Then there was the time Grandpa took Josh and brother John to pick sister Hilary up from Sunday school. It was a lazy Sunday morning; Grandma and Grandpa were baby-sitting. Hilary was the only one to attend this Sunday. Sunday school started at 9:15 a.m., and Grandpa was supposed to pick her up before the 10:30 a.m. church service. When Hilary failed to come out of the church at the appointed time, Grandpa and the boys went in to investigate. Unfamiliar with the layout of our church, Grandpa—unshaven and, needless to say, inappropriately dressed—was quite a sight as he chased Josh down the center aisle of the church in the middle of the Sunday service!

Our favorite incident in the etiquette category, however, has to be one that occurred at Josh’s public school Christmas pageant. He was seven years old and in the second-grade language-delayed program. We were very surprised that Josh stayed with his class on stage even though he spied us sitting in the audience. We watched with pride as he expertly played a bell in one song and a tambourine in another. For the last piece, the kids sang “Good Saint Nick.” At one point in the carefully choreographed number, all the kids stretched out their arms in unison. Right on cue, Josh stretched his arms out as well—only along the way, he wiped his nose along the full length of his
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sleeve. We were amazed at how politely the audience ignored it.

**Hide and Seek**

In this category, Josh hides, and I seek. He particularly loves to throw things—crusts of bread behind the couch, my car keys out the tiniest of holes in the screen or laminated flashcards down the toilet. A little less amusing are the times he throws his glasses or shoes out the school bus window—something he still enjoys.

Perhaps the most memorable incident occurred when he accompanied his grandfather fishing and threw Granddad's $300 downrigger (a weight made of cast iron) off the fishing boat. Unfortunately, it was not attached to the line at the time.

**Fashion**

Josh has always had what one might term a sense of freedom when it comes to making a fashion statement. As far as Josh is concerned, the very best clothes are no clothes, and you never know when Josh may streak a dinner party. Sometimes he likes to wear his little brother's shirt, and that's all. He also gets very attached to certain clothes and will tear the house apart until he finds them—even if it means pulling out all the wet clothes from the washer and putting on the treasured garment, sopping wet!

Most distinctive, however—and I know the neighbors will agree—are the times when Josh races through the neighborhood... naked... in the winter... with his mother, in various stages of disarray, wading madly through snow drifts in pursuit. By the way, we have many special locks on all the doors—all of which Josh has learned to negotiate with the aid of a chair.

**Academic Enlightenment**

This is my favorite category since it is here that Josh displays the most ingenuity, creativity and initiative. I know I will never remember all the incidents that belong in this section, but several come to mind immediately.

Even when Josh had virtually no language skills, he knew, of course, how to say "no!" It was always expressed emphatically and with intense satisfaction. He pronounced it, however, like the Hollywood version of a German soldier—"Nein!"

During this same period in Josh's life, we worked intensely on the development of expressive language skills. At the time, his vocabulary consisted of about six words. To our dismay, every time Grandma came to visit, she reinforced one rather off-color word. "Sh-t!"—said with such intensity and shameless enthusiasm that Josh never failed to notice—was one of her favorite expressions, and quickly became one of his. We spent many months, particularly in public, pretending he had said something else. "Sure Josh," we'd say, "Sit down if you want to!"

When Josh was about four, he finally learned to count to twenty. We were really proud of him. All those hours of hard work had finally paid off. He could read those numbers in any order, and counting was one of his favorite pastimes.

One night, all our friends had gathered in our home for a formal holiday dinner party. It had been a pleasant evening. The kids had cooperated, and chaos had been kept to a minimum. As we enjoyed a final cup of coffee around the big harvest table, Josh climbed up on my lap and gave me one of his big, sloppy kisses. As a lull in the conversation occurred, Josh pointed at my chest. "One! Two!" he counted proudly, and loudly. When the laughter subsided, and all eyes were wiped dry, my husband sweetly remarked that not only was Josh extraordinarily brilliant, but his eyesight must be much better than we had previously assumed! All in all, I couldn't be too upset. Hey, the kid was learning!

Lynn Kimball Fay is a freelance writer who has been published in Lady's Circle, Country Almanac and Byline. She represents Romeo Community Schools on the Macomb Intermediate School District Special Education Parent Advisory Committee. Josh is now 10 years old, and is fully included in a second-grade classroom at his neighborhood school.
#17 Positioning Aid Chair™

Back To Basics

This Special Purpose chair's design originates from textbook seating principles that have been used and proven effective by therapists worldwide. These principles, combined with our in-house rehab and design/ergonomic expertise, produce our unique Positioning Aid Chair™ (PAC).

The PAC can be used for a variety of purposes (e.g., as a feeding/speech chair, floor sitter, classroom seating, etc.). Depending on the accessories used it can provide exceptionally comfortable full-body support for children with mild to severe central nervous system and neuromuscular disorders.

The child size PAC is approximately 17" wide by 24" deep, 30-42" high. It is principally made out of laminated hardwood and plastics. It's average weight is 38 pounds. Included with each basic unit are the following: (1) Removable height and depth adjustable seat, (2) Mobile base with locking swivel casters, (3) Removable height and depth adjustable foot rest with foot positioning straps, (4) 45° hip and chest control belts, (5) Removable depth adjustable, leg wedge or pneum, (6) Washable slip covers over high-density foam padding for the thoracic, lumbar, arm, and seat pads.

Features Follow ... Function

The basic PAC provides a variety of features that make this chair truly unique with respect to the posture support and utility it can provide. (A) An open back design allows for easy access by attendants and allows for better fit. (B) Hook-ladder height adjustment makes changing from table to floor height, storage and/or travel a simple task (see inset). (C) All back/chest, head and neck support pads are mounted on a central column with arms that are adjustable in height, depth and angle. (D) Provides the all-important firm 90° seat back to seat pan angle while the entire seat is tilted back 105° to the floor. (E) Optional accessories are available including: Trays of various types, Tray easels, Communication covers, Head, neck, and shoulder supports, Belt cushions, "H" shaped chest supports, Individual foot positions, "S" shaped lateral chest supports, Storage/ventilator bins. (** = not shown)

Effective Benefits

Some of the PAC's consistently reported benefits include:
- It's tilt and angle which allows for the use of gravity to help maintain a more functional posture
- The non-institutional looking design
- Adaptability to children with a wide variety of postural problems
- Improvement of eye/hand coordination, verbal and other skills
- Reduced visual/postural imbalance, fatigue and stress
- Convenient room to room movement of chair
- Allows for the use of existing tables having a table to floor clearance of 19"-31" or can be used at floor level
- Individual body part support without customization

At present the PAC is available in one size only. The 9 month to 5 year old model accommodates most children 16" to 43" in total body length (standing height) 6-1/2" to 11" wide and up to 68 lbs. in weight.

The Bottom Line . . .

It works therapeutically. It's comparatively easier to adapt to different individuals, and activity settings. Plus it does all of this without looking like "ANOTHER" strange piece of equipment!

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- Hearing/Sight Impairment
- Mental Retardation
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Circle #27

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- Special Olympics
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- Physical & Occupational Therapy
- Speech Therapy
- Music, Art & Computers
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Fax: (617) 826-6474

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Executive Director
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Circle #75
INCLUSION: Rhetoric and Reality
by Edwin W. Martin

A basic premise of P.L. 94-142, the Education for All Handicapped Children Act—now the Individuals with Disabilities Education Act (IDEA)—was that all children were entitled to an "appropriate" education. Judging appropriateness was to be an individual matter for each child and would be determined by an individual education planning process that would include parental participation. Decisions on placement could not be made solely on the basis of type of disability. When this issue actually arose, the government required that placement decisions involve multiple factors and be made on a child-by-child basis.

Another key premise was that children with disabilities be educated with non-disabled children—again, when appropriate. Congress, and the experts on whom they relied, did not expect that such placements would be appropriate for all; they also mandated that a range of placements be made available—resource rooms, special classes, special schools, hospitals or home tutoring.

Some would eliminate this individual placement process and educate all children in regular classrooms. They believe that all children would benefit from such placements and that schools can be made to deliver all necessary services. Others would go further; they would do away completely with the concept of "special education," replacing it with an improved regular education system.

Speaking with colleagues across the nation, I find that almost none agree with this position. While the Congress will study this issue carefully, I do not sense that they currently see a need for such change. IDEA does encourage inclusion, and the law should be implemented toward that end if it can be shown that the child benefits from inclusion—if inclusion is "appropriate."

Measuring Outcomes
Some inclusion advocates do not want the burden of demonstrating child benefit. That inclusion will be beneficial is an article of faith—not an issue for evaluation. At the same time, there is an equal burden on all who would offer other alternatives; we, too, must provide evidence of child benefit.

Unfortunately, educational systems—both regular and special education—have failed to provide even common-sense outcome measures. How many children go on to post-secondary training or college or get jobs? What type of jobs do they get, and how long do they hold them? Do graduates of special education programs live independently, have social relationships, feel positively about themselves?

My perspective on inclusion, and my recommendations for improving the education of children with disabilities, is closely linked to the measurement of "outcomes." As a parent, wouldn't you like to know how many graduates of a given special education or regular education program are employed or in post-secondary programs? While statistics cannot predict outcomes for any particular child, knowledge of a program's overall record would allow parents to consider the probability for success. Such information is not generally available. Instead, programs offer anecdotes that report the successes of specific children.

Is the Present System Working?
We have very little information about the value of special education programs, and the information we have
raises serious questions. The most comprehensive available data come from a study of about 8,000 high school students with various disabilities (Wagner, 1992, 1993). Conducted over a five-year period, the study provides information about post-secondary education, employment and other post-school outcomes for some of the study participants. I will present some illustrative data from this massive study to help me make some points:

1. The present system, while working well for many, has many shortcomings, and the status quo does not seem acceptable. For example, 60 percent of all special education students failed at least one regular-education high school course during their four-year or shorter enrollment (see Table I). The data indicate that children who fail classes are more likely to drop out of school, and common sense tells us they are likely to feel less self-confident. In fact, more than one-third of students with learning disabilities drop out or leave school prior to graduation.

2. Children with disabilities who attend regular secondary schools do not receive a wide array of special services like therapies, life skills training or personal counseling. Fifty-three percent of students with disabilities received none of these services. Only 14 percent received personal counseling. Even among children identified as emotionally or behaviorally disturbed, only about one-third received counseling.

3. Only 16 percent of youth with disabilities out of school for three to five years attend any two- or four-year college, and most of these attend two-year colleges (see Table II). Almost four times as many non-disabled youth attend college. Only four percent of youth with learning disabilities attend four-year colleges—fewer graduate. Highest enrollment in four-year college programs are found among students with visual and hearing impairments.

4. The data raise the question of whether high school programs are aimed at the right outcomes. Sixty percent of high school students with learning disabilities report that they wish to be competitively employed after graduation; only 28 percent plan to attend college. However, they are enrolled in programs with a very different emphasis—about 90 percent of their coursework is in regular academic courses.

Where can we go from here?

My goal is to raise questions—not only about our current programs but about inclusion proposals and other future programming.

• To me, the data indicate that the prospects for inclusion are not encouraging—at least not now. These statistics suggest that the current system needs considerable improvement—more intensive programming and more services to children already mainstreamed. Even for children with learning disabilities—currently, the most frequently mainstreamed—the outcome data show high failure and drop-out rates; this suggests that the widespread assumption that such children are only “mildly disabled” is false. For further inclusion efforts to work, even more services and resources will be needed. Research and pilot programs must be focused on delivering positive results and identifying costs.

• The rate of failure in regular education programs has not been addressed sufficiently. Children who fail in their coursework are not being "appropri-

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Table I: Percentage of Youth With Disabilities Failing at Least One Regular Education High School Course*

<table>
<thead>
<tr>
<th>Disability</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability</td>
<td>65.1</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>77.4</td>
</tr>
<tr>
<td>Speech Impairment</td>
<td>56.4</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>48.5</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>53.5</td>
</tr>
<tr>
<td>Hard of Hearing</td>
<td>54.2</td>
</tr>
<tr>
<td>Deaf</td>
<td>44.1</td>
</tr>
<tr>
<td>Orthopedic Impairment</td>
<td>6.7</td>
</tr>
<tr>
<td>Other Health Impairment</td>
<td>65.7</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>50.0</td>
</tr>
<tr>
<td>All Conditions</td>
<td>62.2</td>
</tr>
</tbody>
</table>

*Adapted from Youth in Transition: Trends in Post-School Outcomes, SRI International, Menlo Park, CA.
Table II: Attendance at Post-Secondary Schools by Youth With Disabilities*

<table>
<thead>
<tr>
<th>Disability</th>
<th>Vocational School</th>
<th>2-year College</th>
<th>4-year College</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning Disability</td>
<td>19.0</td>
<td>13.7</td>
<td>4.4</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>15.4</td>
<td>10.1</td>
<td>4.2</td>
</tr>
<tr>
<td>Speech Impairment</td>
<td>16.4</td>
<td>25.4</td>
<td>13.3</td>
</tr>
<tr>
<td>Mental Retardation</td>
<td>9.6</td>
<td>3.6</td>
<td>-</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>15.6</td>
<td>27.5</td>
<td>33.4</td>
</tr>
<tr>
<td>Hard of Hearing</td>
<td>16.0</td>
<td>40.4</td>
<td>15.7</td>
</tr>
<tr>
<td>Deaf</td>
<td>22.5</td>
<td>33.2</td>
<td>22.1</td>
</tr>
<tr>
<td>Orthopedic Impairment</td>
<td>12.6</td>
<td>32.3</td>
<td>12.9</td>
</tr>
<tr>
<td>Other Health Impairment</td>
<td>33.9</td>
<td>28.4</td>
<td>21.9</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>0.7</td>
<td>7.9</td>
<td>2.2</td>
</tr>
<tr>
<td>Deaf/Blind</td>
<td>13.4</td>
<td>8.9</td>
<td>6.9</td>
</tr>
<tr>
<td>All Conditions</td>
<td>15.9</td>
<td>11.8</td>
<td>4.2</td>
</tr>
</tbody>
</table>

*Adapted from Youth in Transition: Trends in Post-School Outcomes, SRI International, Menlo Park, CA.

Adaptively served. It is no victory for integration to enroll children in regular classes, and then have two-thirds fail at least one course.

- Deaf students—who are more likely to be educated in separate settings—are among those most likely to go to college. Many variables may be involved here, including the fact that the federal government supports two higher education programs for the deaf. Other data, however, also demonstrate considerable post-secondary success in schooling and employment by graduates of special schools (Rogan & Hartman, 1990; Liebert, et. al., 1990). My point is not to suggest more special schooling. Rather, we can study successful special programs to determine the factors accounting for their success, and whether those factors may be found or created in other settings.

- We have little information about the success of current programs, and we are unlikely to have evidence that new strategies are as good or better. This leaves us arguing philosophies and beliefs, not facts.

- The current systems are not working as well as we wish. Regular education admits that it is not doing a good job serving children with learning problems associated with poverty, immigration, minority status and language differences. Nothing suggests that it will do a better job educating children with disabilities. The status quo in special education is equally unacceptable.

We need to measure and demonstrate improvement.

We should not eliminate alternatives that succeed. We should not simply adopt sweeping “inclusion” policies, however philosophically attractive, because children are likely to be hurt when sufficient services are not provided.
We need a major, federally-funded demonstration program that will allow new models to be evaluated. The federal government has followed this strategy successfully with early childhood education. When federally-funded model programs, research, training grants and media development demonstrated that such programs were worthwhile, a policy of making early childhood programs universally available was adopted. A similar effort with regard to elementary and secondary education for children with disabilities could be equally successful.

Most importantly, neither parents nor professionals should accept rhetoric in place of data. Parents must insist on options, alternatives and a realistic say in how their children are educated while significant outcome data is accumulated to provide parents with informed choices.

References:
At Chrysler Corporation, we receive a lot of letters from satisfied customers. While we appreciate all of them, none are more important to us than the ones from people who are facing, or whose loved ones are facing, physical challenges every day—including the challenge of remaining mobile in an automotive world.

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Circle 295
It's those last few months before your child is born that the dreams go into high gear. You imagine the engineer, ballerina or lawyer your child will grow up to be. As the delivery date draws near, these thoughts gather momentum, fed by parents, friends and co-workers, until you almost expect to see your child born 18 years old, highly educated and physically attractive.

It's humbling how dreams that build up over so many years can blow away like so much air from a balloon. In the time it takes for a doctor to say, "Oh no," dreams can turn to nightmares and hopes to fears. Long-held thoughts of perfection melt away into short-term prayers and frantic thoughts: Will the baby be all right? What will we tell our parents? How did this happen? Why us? In a matter of moments, you have traded bar exams for brain scans, ballet shoes for blood tests, rock-solid normality for ground-breaking lunacy.

I watched helplessly as my baby was poked and prodded by strangers who did not have the time to answer my questions or allay my fears. I coped with a day-to-day roller coaster ride of good news, then bad; hopeful signs, then puzzling questions. I found myself unable to dream, unable to see past the next doctor's visit or test—each time hoping that someone would be able to determine what was wrong or what would happen in the future. Instead, my frustration deepened as each test revealed only the need for more. Worse still, no prognosis for the future was forthcoming—everyone finally said that only time would tell.

Very slowly, I realized that I would never know exactly what was going to happen until it did. At first, I was angry; I wanted answers. But it dawned on me one day that I was really no different than any other father. No doctor or specialist can tell any of us how bright or physically capable our children are going to be. The most that all parents can do is to make the best of what is given to us. This new realization liberated my wife and me. We began to look toward the future again, and started doing things that would give us and our child choices.

New Dreams
I began to dream again. These were not the same dreams as before, but they were just as important. I dreamed of my daughter's first steps, and when they came, no parent was ever prouder. My wife and I dreamed of including her in a regular classroom at school, and after many battles, her first regular education teacher assured us that this was where she belonged.

I continue to dream of the future, of my daughter working, building meaningful relationships, and accomplishing great things for herself and others. I
At the park: John Cox enjoys an afternoon outing with two-year-old Kristina.

I know that she will never be a lawyer, doctor or ballerina, yet I dream about what she can become, cherishing each step she takes along the way.

All children are a gift to their parents, grandparents, teachers and everyone who comes into contact with them. And they all teach us something that we would not have learned without them. For me, it was to slow down so I could take pleasure in the details of my children’s lives. I learned to take an active part in all my children’s activities and cherish each of their accomplishments. I am richer for the experience of having a child with a disability. I would not wish it away.

A few years ago, I wondered what my daughter would have been like if she had not been born with a disability. I grieved for the loss of my “normal” life, somehow assuming that the one I had embarked on would not be as fulfilling. I don’t think that way anymore. I am proud of my daughter’s accomplishments, and like any father, I am looking forward to future accomplishments as well. I should not have worried as much as I did. Looking back, I see now that few others have been as blessed as I.

Fathers’s Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father’s Network, focuses on fathers’ experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers’ Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers’ Network, The Merrymood School, 16120 N.E. Eighth St., Bellevue WA 98008, (206) 282-1334. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children’s Health, Bethesda, MD.
Helping any child with homework can be difficult, but parents of children with learning disabilities experience additional frustration because traditional study techniques are often ineffective. These parents need to use many strategies to help their children. Through trial and error, I discovered some techniques that have helped my son become a more successful student. They also have made my life as a parent easier.

The label “learning disability” is an umbrella term that is used to describe many types of learning problems. Some of the techniques that worked for my child may not be as helpful to others. However, these tactics can be tried by any child and parent.

My 10-year-old son, Eliot, has weaknesses in both visual and auditory processing. He is also highly distractible. I reasoned that involving his eyes and ears in the learning process would allow him to assimilate more information, block unrelated distractions and improve his concentration.

Two years ago, we began experimenting with ways we might use a tape recorder to help him learn. We began with social studies, a subject where the sheer difficulty of reading an assignment left little time or energy for comprehension. His difficulties were reflected by extremely poor performance on weekly quizzes. I made audio tapes of each chapter in the textbook; he listened to them while reading along in the text. His comprehension and recall improved immediately and measurably—his score on the weekly quiz jumped to 100 percent! While this accomplishment was not always repeated, the following weeks showed that the dramatic improvement was not transitory. I began looking for other ways to use this “double-sensory” approach.

At this point, Eliot uses a tape recorder in almost every subject. Many of the techniques we use give him control over his own studying. This is an important bonus because it fosters independence and self-confidence and at the same time, frees me from some of the tasks of a home tutor. The greatest benefit is his growing sense of mastery and success.

Spelling

In a world of computers and “spell-checker” programs, some people consider spelling skills unimportant. But until spelling tests are abolished in school, Eliot is required to take one each week. Eliot already had a history of frustration and discouragement to overcome since he was often asked to spell words that he couldn’t read. I wanted to make him feel that the effort he puts into studying his spelling list is worthwhile. I also wanted to foster his sense of being able to master this difficult task and, with effort, the next task as well.

The first step in studying for his weekly spelling test is for Eliot to read the words aloud to me. Once he can read them fluently, pronounce them correctly and understand their meanings, he makes an audio tape of the list, reading and spelling each word aloud. Over successive nights, he listens to the tape, writing each word as he hears himself spell it. This reinforces the word through three channels—auditory (he hears it), visual (he sees the word as he writes it) and motor (he writes the word). Usually, going through the list twice each night is enough.

After three nightly practice sessions, I give Eliot a “spelling test.” If he is having trouble with only a few words, he makes a new tape of the words he missed. Sometimes, if the words are particularly difficult, he
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also listens to the tape before falling asleep or while he is getting dressed in the morning.

**Math**

We used a similar technique when it was time to memorize multiplication tables. Eliot wrote the tables correctly in sentence form (e.g. “two times two equals four”). Then, he read them onto the audio tape. He practiced by listening to the tape and writing the examples as he heard them, mastering one table at a time.

**Social Studies**

The typical social studies curriculum requires that students read and digest the text, answer questions relating to the material and memorize facts—awesome tasks for some children! We have developed techniques that help Eliot perform all of these tasks.

First, we get or make a cassette recording of the social studies text so he can listen to the tapes while reading. Many textbooks—especially for grades five and higher—are available on tape through Recording for the Blind (20 Roszel Road, Princeton, NJ 08450, 609/452-0606). For a one-time fee of $37.50, a child who has a “print disability” becomes eligible to receive needed textbooks on tape. If no cassette exists, I make one. I found that it took less time than I would have imagined and certainly was worth the time invested.

Because Eliot has fine-motor problems, he finds writing time consuming and difficult. Now he often begins by answering homework questions directly onto a cassette tape. Once his ideas are refined and he is satisfied with his answers, he transcribes them, either writing longhand or using a word processor.

Eliot finds it helpful to make a study sheet of all the facts he needs to memorize for a unit or chapter test. He reads this information onto an audio tape. As he reads over his study sheet again, he listens to the audio track at the same time.

**Recreational Reading**

One important thing we can do for our children is to encourage them to become readers. This is an especially daunting task for parents and teachers of children with learning disabilities. These children view reading as hard, even painful work. The material they can read tends to be written below their intellectual and emotional levels and is not likely to be interesting enough to engage them.

Books on tape can solve this problem. Many pre-recorded fiction and nonfiction works are available on cassette. When used in conjunction with the printed book, the child is able to hear the text while following the printed word. This type of reading becomes enjoyable because the audio track helps the child glide over difficult words and passages. Recorded books expose my son to literature on his intellectual level, let him have the same reading experience as his peers and increase his familiarity with literature of all types.

Novels, poetry, biographies and mysteries are available on cassette. Cassettes are available for free loan at most public libraries and can be purchased at most bookstores. We also have found several sources for renting books at reasonable rates—Recorded Books (800/638-1304) and Books on Tape (800/626-3333).

In addition, a person who has a disability that prevents the use of standard printed materials may be eligible to receive services from a free books-on-tape program administered by the Library of Congress. The National Library Service for the Blind and Physically Handicapped (NLS) supplies a special tape player and bi-monthly catalog describing a wide range of recorded books that are delivered and returned by postage-free mail. Eliot and I go through the catalogs together and he chooses titles which are age-appropriate but too difficult for him to read without assistance. When we receive a tape, we borrow the corresponding book from our local public library.

Applications for the NLS program are available at some public libraries or can be obtained by calling the Library of Congress at (800) 424-8567. For a person who has a learning disability to receive NLS services, a doctor’s signature is required.

Since Eliot started with this program, his interest in reading has increased. Rather than becoming dependent on tapes, he is starting to read more on his own. Some nights he reads, or reads and listens for half an hour or more—just for the pleasure of it! Nothing is more thrilling for me than when we are able to discuss a book he is reading or has just finished!

**Use Your Imagination!**

The tape recorder has other uses also. Tapes of old radio shows like The Lone Ranger and Fibber McGee and Molly are an enjoyable way to improve auditory comprehension. These tapes are available at most public libraries, some record stores and through mail-order companies such as Adventures in Cassettes (800/328-0108). When Eliot is working on a task that does not have a listening component, we’ve found that tapes of classical music provide a sort of “white noise” that blocks more distracting household noises.

The study methods and techniques for recreational reading described here work in our house, and I hope they will be helpful to you as well. Feel free to experi-
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For information and assistance, contact National Referral Services
1-800-345-1292

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The people around him started spinning around and around in crazy circles. Jesse struggled desperately to find a familiar face among the swirling images, but everything looked distorted and strange. To Jesse, it felt like the whole world had turned upside-down. In reality, he was lost in a seizure.

For Jesse, seizures were an unavoidable part of living with multiple disabilities. At times, his reactions were so severe that he would bruise himself. After years of searching for a place where their son could get the help he needed to learn and grow, Jesse’s parents found Heartspring.

At Heartspring, seizure management plays an integral part in the individualized programs we develop for each child who experiences seizures. Medication is the focus of seizure management. Heartspring strives to treat the whole child focusing not only on medical requirements, but also his educational needs. Therefore, a program may include occupational, physical and speech-language therapies, vocational training and other programs to help children learn to live independent, active lives.

Thirteen months after Jesse enrolled at Heartspring, his seizures were reduced from twice a day to less than once a month. He learned to participate freely in class, but also play a tuba and even enjoy riding a merry-go-round. His parents credit Heartspring with the balance their son has found.

For more information on the individualized programs we provide for children with multiple disabilities including seizures, call Heartspring.

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Elizabeth Mayer is a library media specialist in an elementary school in the Syosset Central School District on Long Island, New York, where she has worked with children with learning difficulties. She is married and has two sons.

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"I'm flying" by Arsenia Levie, West Hartford, CT
Department of Education Upholds Right to Privacy

A South Dakota family recently prevailed on a complaint filed with the U.S. Department of Education alleging a violation of the rights granted to students and their parents under the Family Educational Rights and Privacy Act (FERPA). The parents of a special education student charged that the family's privacy had been breached when the local school board disclosed financial information about their son's individualized education plan (IEP) to the media and general public without their written consent.

The family charged that since July 1991, the school board repeatedly violated their privacy rights by including personal details about their son in meeting minutes published in local newspapers. The minutes included the parents' names, the name and tuition rate of the child's out-of-state school, and the amounts of reimbursement payments made to the parents for travel expenses. In addition, board members made statements to the press and in a public meeting attended by more than 80 people, discussing confidential aspects of the child's IEP, including identifying information.

After the disclosures, many residents of the community blamed a long-planned property tax increase on the high cost of this child's education. The turbulent public reaction resulted in numerous stories about the controversy that appeared in the media across the state, while many members of the community ostracized and badgered the child's parents. Finally, the family filed a complaint with the U.S. Department of Education, alleging a violation of their FERPA rights.

Support Groups

• A new support group has been formed for families affected by Alagille Syndrome, a rare condition characterized by too few bile ducts in the liver. An informational brochure and quarterly newsletter is available. Contact: Alagille Syndrome Alliance, 10630 SW Garden Park Pl., Tigard, OR 97223, (503) 569-6217.

• The X-Linked Myotubular Myopathy Resource Group provides support and promotes the exchange of information among families and medical professionals. For more information, contact Pam and Gary Scoggin, 2413 Quaker Dr., Texas City, TX 77590, (409) 945-8569.

• A new support group has been formed for people affected by Incontinentia Pigmenti, a genetic disease of the skin, hair and teeth. For more information, contact Colleen Kidder, L.P. Support Network, 34029 Elm, Wayne, MI 48184, (313) 729-7912.

For information about FERPA:

• Your Child's School Records: Questions & Answers About a Set of Rights for Parents and Students is a booklet available from the Children's Defense Fund, P.O. Box 90500, Washington, DC 20090-0500, cost: $3.75.


• Accesshower is a barrierfree, good-looking, easy-to-do, 1-day, no-plumber project. It's an affordable bathtub replacement. And more—you can even take it with you when you move.

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• Von Hippel-Lindau (VHL) disease is a genetic condition that causes tumors in the eyes, brain, spinal cord, kidneys and adrenal glands. It often goes undiagnosed, or is misdiagnosed as cancer. For more information, contact the VHL Family Alliance at their new toll-free number—(800) 767-4845—or at 171 Clinton Road, Brookline, MA 02146, (617) 232-5946.

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Cycling

Cycles come with one, two, three and four wheels. Some require a bent-over rider position; some allow leaning back in a recumbent position. Some cycles are hand powered; some are leg powered. Some cycles—tandem cycles—allow two or more people to cycle together. Bikes and trikes are made for the beach, the mountains and all terrains in between. Children and teens with physical, sensory or cognitive disabilities can use cycles for transportation and recreation.

Types of Cycles

**Modified Leg-Powered Cycles:**
A number of accessories—described in detail in ABLEDATA Fact Sheet #19—allow commercially available leg-powered bicycles and tricycles to be adapted for various physical limitations. Supports, belts and backrests can be employed by individuals with the use of one arm.

People with limited hand grip or strength can use hand and wrist straps connected to the handlebars, or vertical hand grips, to help them maintain contact with the cycle’s steering components. An adult three-wheeled cycle may be an alternative to the traditional bicycle for persons with poor balance but otherwise good leg strength and trunk control.

**Hand Cycles:** Hand-powered cycles have made cycling accessible to individuals who do not have the leg strength to use traditional leg-powered cycles. Hand-powered cycles are available in numerous designs with various features. Some require the rider to pedal with the arms; others are propelled by pushing and pulling a handlebar lever.

**Tandem Cycles:** Tandem cycles are designed to carry two or more cyclists, with each cyclist contributing to the cycle’s propulsion. Most tandem cycles are leg powered, but a few allow one cyclist to use leg power while the second uses hand power. Tandems come in bicycle-style models with two or more wheels configured in a line, and in tricycle-style three-wheel models. Tandem cycles are especially appropriate for riders who are visually impaired since they can rely on a sighted navigator to steer the bike.

Special Accessories

The traditional two- or three-wheeled cycle is powered by the rider’s legs, and steered by the rider’s hands. Braking may either be accomplished by use of hand brakes or back pedaling with the legs.

- **“Strap-in” Accessories:** For individuals who are lacking in trunk control or balance, there are a number of accessories—for use with both leg-powered and hand cycles—that can help them ride.

Please note, however, that most involve strapping the rider to the cycling equipment. Should the cycle tip over, the rider may not have the opportunity or arm strength to break the fall or to fall clear.

Appropriate supervision should be given to riders using one or more of these "strap-in" accessories.

- **Pedal Attachments:** Foot pedal attachments keep a rider’s feet on the pedals. The device generally takes the form of a platform or sandal that is secured to the cycle pedal and has velcro or buckle straps that go over the rider’s foot.

- **Torso/Back Supports:** For individuals with poor balance or marginal trunk control, torso or back supports may allow them to ride a three-wheeled cycle. Torso supports provide a full-body lateral support system. Back supports provide a high backrest, but do not prevent the rider from leaning from side to side as do torso supports.

- **Hip Pads and Harnesses:** Hip pads

continued on page 65
The New England Center for Autism is dedicated to providing the most caring, comprehensive, and innovative education available today to children with autism and mental retardation.

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Circle 179

RIFTON UNIVERSAL CHAIR FRAME
The model K84 Universal Chair Frame is a modular seating system and torso support that can be used with conventional chairs and toilets. It features padded trunk supports, forearm prompts, handholds and rubber feet for stability. Rifton Equipment, Rifton, NY 12471-0901.

Circle 180

SCAN IT--SWITCH IT
Teach horizontal and vertical scanning using a single switch or TouchWindow with this control switch training program game. Up to four can play on five levels of difficulty. Target object boxes can be displayed large or small. Players' names may be entered and record keeping is available. For use on Apple IIGS and Macintosh; a version for IBM and IBM-compatibles is in development. UCLA/LAUSD Microcomputer Project, Los Angeles, CA 90024.

Circle 181

WALKERTALKER™
Kids and teens on the go who use alternative speech devices: don't carry your communication board—wear it! The WalkerTalker is a speech output communication device housed in a waist belt. The communication board can be removed from its pocket for use, then returned to keep the hands free. The unit weighs only two pounds. Prentke Romich Company, Wooster, OH 44691.

Circle 182

KID-E-PLUS™
The Kid-E-Plus is a tilt-in-space mobility base and modular positioning system adjustable enough to accommodate growing children from infants to preteens. This stroller-like seating system disassembles for easier transport. A sun shade, pneumatic tires and anti-tippers are all standard equipment. Positioning accessories include an adjustable tray, head rests, hip supports, foot straps, lateral supports and an abduction block. Kid-Kart, Inc., Belgrade, MT 59714.

Circle 183

THE BOBCAT
It goes up and down, it tilts in space and reclines, and it disassembles! It's the Bobcat! This powered wheelchair alternative is designed to allow kids to have face-to-face conversations with friends, play and maneuver about the classroom or house. Standard features include a powered elevating seat, self-jacking facility, front wheel drive, variable top speed to four mph, reduced or full speed in reverse, a warning sound in reverse at half-speed, joystick control and factory programmable electronics. The optional standing frame is interchangeable with the seat. Advanced Rehabilitative Technologies, Mason, MI 48854.

Circle 184

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8655 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3318, (800) 227-0216, V/TDD, (301) 588-9284, V/TDD or (301) 587-1967, FAX.
Hill Reception—An “Unequaled Success”

By Connie Hawkins

On Tuesday night, January 25, 1994, 500 parents and advocates for individuals with disabilities gathered and asked the congressional leadership to listen to our issues. The event was the first National Parent Network on Disabilities Congressional Reception to Honor Parents of Children with Disabilities; the issues included health care reform, family support, education reform and the reauthorization of the Individuals with Disabilities Education Act.

Twelve senators, thirty members of the House of Representatives and staff members from twenty additional Congressional offices attended the two-hour reception at the Senate Hart Office Building. Parent leaders from across the country had an opportunity to meet with legislators from their home states and other Congressional leaders to discuss disability-related topics.

Speakers included Senator Tom Harkin (D-IA), Senator Paul Wellstone (D-MN), Representative Major R. Owens (D-NY) and Maria Cuprill. Senator Harkin—Chairperson of the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education; and the Senate Labor and Human Resources Subcommittee on Disability Policy—addressed many issues of importance to parents. In his remarks, Senator Harkin emphasized family support and pledged to introduce family support legislation. He told the audience that he is aware of the need for family support because his mother and father were parents of a child with a disability. Senator Harkin has a brother who is deaf.

Senator Wellstone provided information on health care reform. He stressed that comprehensive reform of our health care system must include the needs of individuals with disabilities.

Representative Owens, Chairperson of the House Select Education and Civil Rights Subcommittee, reemphasized her commitment to services for underserved and underrepresented families.

Patricia McGill Smith, Executive Director of the National Parent Network on Disabilities, termed the congressional reception an “unequaled success.” She said, “Parents had the opportunity to let the congressional leadership hear real issues from real families. And legislators listened.”

NPND 1994 Annual Awards

The recipients of the NPND 1994 Awards are a distinguished group of leaders in disability and media:

- The Kingsley Family of Chappaqua, New York, received the Leadership on Behalf of Families award. Emily, Charles and Jason Kingsley are credited with a wide range of projects, including the work Emily did to promote children with disabilities on Sesame Street and Jason’s new book, written with Mitchell Levitz (see page XX).
- Christine Davis, Executive Director of the Parents’ Union for Public Schools in Philadelphia, received the Exemplary Service to NPND award for her outstanding work as a founding member. She has served as NPND treasurer for the past four years.

NPND honors Heumann:

(left to right) Pam Steneberg, NPND secretary; Diana Cuthbertson, NPND President and Judith Heumann, Assistant Secretary for the Office of Special Education and Rehabilitative Services, U.S. Department of Education.
Rep. Major Owens (NY) enjoys the celebration with (from left) Diana Cuthbertson, NPND President; Marcia Oyred, Staff Director of the House Select Education and Civil Rights Subcommittee and Patricia Smith, NPND Executive Director.

- Judith Hellmann, Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education, was presented an award for Outstanding Educational Advocacy for her work on behalf of students with disabilities. From her winning lawsuit against New York City that enabled her to teach to her involvement in writing Public Law 94-142—(now the Individuals with Disabilities Education Act), Judy has dedicated her life to bettering the lives of people with disabilities.

- Joseph P. Shapiro, staff reporter for U. S. News and World Report, was presented the Outstanding Individual Contribution in the Media award for his extraordinary reporting about people with disabilities. His book, No Pity, and his investigative report on special education entitled “Separate and Unequal” are just two examples of his fine work.

- U. S. News and World Report received the Exemplary Leadership in Reporting on Disability Issues award for its ongoing coverage of issues regarding people with disabilities, especially the article “Mothers of Invention.”

- Dr. Vince Hutchins, longtime leader at the Maternal and Child Health Bureau, received an award for Outstanding Service in Health Care and Family Issues, and cited for his dedicated service in recognizing “family-centered” as the key adjective for describing services to children with disabilities.
Camp Loyaltown provides a safe, fun-filled, enthusiastic & stimulating summer recreational vacation for mildly & moderately developmentally disabled children and young adults. Nestled in the Catskill Mts. at Hunter, NY, we offer classes in music, dance, drama, ceramics, wood working, sewing, cooking, swimming, athletics and team sports, recreation, crafts and nature.

Contact: Paul Cullen
Camp Loyaltown AHRC
189 Wheatley Rd.
Brookville, NY 11545
(516) 626-1007 x444

INDIVIDUAL DAY & RESIDENTIAL PROGRAMS for children and adults with special needs including dev. disabilities, autism, head injury.

- A continuum of educational, vocational & community living options.
- Complete clinical support services.
- Outpatient evaluation and remediation services.
- Neuropsychological testing.
- Vacation opportunities
- Programs in NJ and Maine.

Contact: Bancroft
Hopkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347

1993 BLUE RIBBON WINNER
Brehm Preparatory School is a Midwest boarding school designed to meet the academic, social, and emotional requirements of adolescents, age 12-21, with learning disabilities. Brehm offers specialized academic instruction, Orton training, speech and language therapy, and social skills guidance. Certified staff, family atmosphere. NCA accredited.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
[618] 457-0371

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS.
A co-ed residential camp for the:
- Learning Disabled. ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state. 2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

“MAXIMIZING INDIVIDUAL POTENTIAL”
- Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, challenging behaviors, and developmental disabilities.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-0000
THE LEARNING CLINIC
Country School and Residence enrolling children of all ages in a year-round program of specialized treatment for attention deficit and learning disability.
• small, selective and personal
• rural setting, pastures and animals
• tutorials in all subjects
• young apprentice program
• wilderness trips

The Learning Clinic, Inc.
P.O. Box 324
Brooklyn, CT 06234
(203) 928-5274
(203) 774-7471

RESPITE SERVICES provides short term residential care for children, adolescents and adults with disabilities. Respite Services gives a weekend break, vacation or help in times of illness or other crisis. Summer camp sessions are also available. Family style care and welcome in a country setting.

Contact: John & Pat Ryan
Respite Services
611 14th Street
S. Gibson, PA 18842
(717) 756-2870 Fax

SHEVET ACHIM in conjunction with YACHAD/NCSY is a new & exciting summer program in an Israeli Kibbutz. This four week program is designed specifically for high functioning Jewish young adults with developmental disabilities. Located in Kibbutz Ein Zurim, central Israel. Sabbath and Kosher dietary laws observed.

SHEVET ACHIM
63-67 108th Street
Forest Hills, New York 11375
(718) 997-1111 New York
(212) 651-5122 Los Angeles
(512) 764-1019 Chicago

TALL PINE CAMP. Co-ed mountain camping for children and adults with MR. Programs and activities based on individual abilities. Prof. staff, full-time nurses. Self-care & social skills emphasized. Academics, incl. computer programming. Recreational activities including: swimming, crafts, boating, equestrian prog., etc. 2, 3, 6 wk. sessions available.

Contact: Ron & Cammie Fydt
Tall Pine Camp
111 Tall Pine Circle
Tellisco Plains, TN 37885
(615) 261-2329 (615) 562-3350

Free Product & Service Information
A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE Information about products and services seen in Exceptional Parent!

How to use this service:
1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in Exceptional Parent!

Directory of Advertisers

Books, Audio/Video & Educational Material

Conferences

Assistive Technology '94
A full day conference with over 100 exhibits of assistive technology equipment and services for people of all ages and with any kind of disability. Come see low- and high-tech equipment for use at work, in school, at home, and in recreation. Workshops and seminars on new technologies, advocacy, funding, and more. Registration fee $10 in advance, $15 at the door. For registration form and more information, call the Massachusetts Assistive Technology Partnership at (617) 735-7620 (Voice) or (617) 735-7301 (TDD).

Videotapes

Interaka Video Sign Language Course
Illustrates 1200 signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free brochure, $19.95 (plus $4.50 shipping and handling). Contact: Attainment Company, P.O. Box 930160, Verona, WI 53593. Call (800) 333-6867.

Travel

Travelin' Talk
Network newsletter, and directory for all travelers with disabilities. The only resource travelers should need to plan trips, discover free accessibility, or find help in case of difficulties away from home. International. Huge. Friendly. Inexpensive. Free brochures and copy of newsletter. Send SASE to Travelin' Talk, P.O. Box 3534, Chaska, MN 55318, (612) 552-6670.
# FREE PRODUCT & SERVICE INFORMATION

**A. Are you a subscriber to Exceptional Parent?**
- [ ] Yes
- [ ] No (If no, please see the subscription card in this issue.)

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**B. Annual Household Income (include all family members)**
- [ ] Less than $30,000
- [ ] $30,001 - $40,000
- [ ] $40,001 - $50,000
- [ ] Over $50,000

**C. Do you live in a(n):**
- [ ] Home
- [ ] Apartment
- [ ] Own
- [ ] Rent

**D. In all, how many automobiles do you and others in your household own or lease?**
- [ ] One
- [ ] Two
- [ ] Three or more

**E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):**
- [ ] one month
- [ ] nine months
- [ ] three months
- [ ] one year

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**Issue Date: April 30, 1994**

**Expiration Date: July 31, 1994**

**Circle #**

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Superior Quality

Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day and residential programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources.

There are five programs for women (from semi-independent to highly structured) including one specifically designed for mature women. A new community-based program for men is now available.

- Life skills and vocational training
- Employment opportunities at Martha Lloyd and in the Troy community
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmentally disabled adults.

For Information Call
(717) 297-2185
or write Martha Lloyd Community Services
190 West Main St. Troy, PA 16657

Circle number 175


Just A Few Reasons Why You Must Try The Ultimate In Cloth Diapers from the Friendly Earth Co.

★ Sizes newborn to adult ★

No pins or diaper covers needed. Plus, they're ultra absorbent so no extra padding is necessary.

Best of all, our diapers mean incredible savings for you because they're washable and can be used for years. Plus, they're environmentally friendly.

Order Your Sample Today
Call and order your sample diaper today. If you're not 100% satisfied, simply return it within 30 days for a full refund.

The Village offers residents single or double rooms in very attractive modern homes or apartments. The Village is a Model, Supportive Community.

For Information Call
(1-800-358-2128)

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P.O. Box 378
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(503) 383-7109
Enjoy cycling with the whole family. We offer customized bicycle trailers adapted to carry children & adults with special needs.

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HARD Manufacturing Co., Inc.
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(800) 829-2476
The #1 manufacturer sets the standard for safety in today's cribs. 210 models are available. HARD will adapt products to meet your special requirement.

Equipment Dealers
Atlantic Rehab., Inc.
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Williamston, MA 02292-9055
(617) 894-0009

Atlantic Rehab. specializes in Pediatric Mobility and Seating, Sales and Service. Call for more information.

Dowd Rental & Sales
138 Main Street
Buffalo, NY 14202
(716) 683-8183
Dowd has been serving the area since 1930. For personal service and quality equipment and further information call Dowd Rental & Sales, Inc.

Loyal LeFland Supply Co., Inc.
6702 E. 11th St.
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(918) 335-0631
Custom seating. Check Marc certified repaired. Authorized Check Marc Repair Center. We carry most products & advertised in this mail-in.

Rehabco
1513 Oldstead Ave.
Bryan, OH 43506
(718) 829-3800
45 years at New York's oldest & largest Rehab. dealer. Experts in children's mobility & seating. Full time therapist for evaluations at our new facility. Ask for our 295 page Technology Guide. Call us or write today for more information.

A Models for Mobility, Supportive Community.

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available. A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages will help you make the right decision.

For more information call
(617) 293-5461

THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available. A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages will help you make the right decision.

For more information call
(617) 293-5461
Each person is a unique individual with God-given potential to live a personally satisfying, productive life. At St. Coletta's, we not only believe this, but we act on our belief. Each of our students and adult residents receives the kind of personal attention they might expect to receive from their own family. Their education, home life, recreation and leisure activities, vocational training and employment are planned to make the most of their individual interests and abilities. We are a caring community where each of us shares a loving concern for one another. In a world where love is sometimes in short supply, we have it in abundance.

St. Coletta School, founded in 1904, offers a year-round academic residential program for children and young adults (ages 6-25) with mental retardation. Special services include personal and vocational counseling, socialization skills, personal living skills, transitional home living, speech and language development, music and art, adaptive physical education and swimming, and physical and occupational therapy.

Our Alverno ICF/MR program provides superior quality care for adult residents in a pleasant, attractive setting. Wholesome meals, attentive staff, and stimulating activities are among the things which make Alverno of special interest to families seeking comprehensive care.

Other St. Coletta programs include habilitation/vocational training, employment opportunities for adult workers, and community transitional group homes. For further information, contact the Admissions Office at (414) 674-4330.
ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, and rehabilitation professionals.

Mark your Calendar to attend ABILITIES EXPO in a city near you:

**ABILITIES EXPO EAST**
Edison, NJ  
Raritan Expo Center  
April 15-17, 1994

**ABILITIES EXPO WEST**
Anaheim, CA  
Anaheim Convention Center  
May 20-22, 1994

Opportunities to try and buy on the Show floor

One giant marketplace of products and services for People with Disabilities, Seniors, and Health Care Professionals. See and try: Vans, Lifts, Wheelchairs, Exercisers, Computers, 3-Wheel Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

**Longest running show of its kind in the U.S.**

Emphasizing a more independent and rewarding life for People with Disabilities. Come and explore a huge, fully accessible "shopping center" full of products and technologies. Attend workshops and visit the computer center, geared to your needs and interests.

For more information on attending please call 203/256-4700.

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**SAVE ONE DOLLAR**

Save ONE DOLLAR on a single admission, regularly $4 when you present this coupon. Children under 12 are free. Name and address must be completed to validate coupon.

Name ____________________________

Address ____________________________

City ___________________ State ______ Zip ______

Telephone (_____ ) ______-__________

New Jersey — Produced by Expocon Management Associates, Inc. and RCW Productions Inc. — California —

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for lateral waist support and shoulder and leg harnesses may be added to a torso or a back support.

**Modified Seats and Seat Accessories** may be used to provide extra support or maintain knee abduction. Pressure sores—from extended periods of sitting on an insufficiently padded seat—may be another concern. Most standard seats—even on adapted cycles—do not have proper pressure relief seats. However, many will accommodate a wheelchair seat cushion. Another option for pressure relief during long bike rides may be the Jay Protector™ manufactured by Jay Medical of Boulder, CO. The Jay Protector is a minimally-sized fluid/foam cushion for children and adults that straps around the user's legs and waist to stay in place regardless of the user's movements.

**Adapted Handlebars and Handlebar Accessories**

**Protective Helmets:** As with all sports equipment and in all recreational activities, safety is of the utmost importance. Protective helmets are recommended for all riders, and required by law for children.

**Cycling continued from page 52**

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**Did I Hear You Say Help?**

☐ Are you looking for appropriate services for yourself, your family member or client?

☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

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PLANNING FOR THE FUTURE
Providing Meaningful Life for a Child with a Disability after Your Death
Mark Russell

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Answers to Questions Parents Often Ask
Jay Schleicher

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Mark Russell

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COPING WITH CEREBRAL PALSY
Answers to Questions Parents Often Ask
Jay Schleicher

Provides answers to more than 300 questions that have been carefully researched.
P0037P0 $24.00
Hi! My name is Lindsay. I have two sisters. One is named Lauren and the other is named Jana. Jana is seven years old. Jana has a disability. She has a syndrome called Rubinstein-Taybi. Jana learns slowly and grows slowly. Her face is small and her nose is flat. But that doesn't bother me at all; I still love her.

The thing that does bother me is when people make fun of me for having a sister with a disability. I don't know why it bothers me though.

My sister might look sweet and friendly, but if you have to live with her she's a big, fat pain! What I mean is that when I'm not around or nobody is watching her, Jana will go into my room and mess it all up. It's a real big mess. The worst part about it is that my mom makes me clean it up—not Jana. My mom says Jana doesn't understand. Yeah, right!

Jana goes to Coventry Elementary School. She has a special class. This year Jana gets to spend one hour a day with the regular kindergarten class. I'm proud of her!

Jana's favorite things are corn, ketchup, horses, swimming, McDonald's, basketball, hula hoops and smiling.

I wish that people would accept my sister the way she is.

Lindsay Golden—now 11 years old and in fifth grade—lives with her family in Yorktown, Virginia, and attends Mount Vernon Elementary school. Her father, Mike, is an F-16 pilot and squadron commander for the 4525 Combat Applications Squadron at Langley Air Force Base. Lindsay's mother, Julie, has a teaching degree, owns her own business and is in training to become a child advocate for children with special needs.

Lauren is ten and a fourth grader. Jana, now eight years old, is included in a first grade classroom at Dare Elementary school.
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Parenting Your Child With A Disability

Recreation

Stefano Cargnel—Becoming A Contender
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- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance in addition to the amount you receive from the Mobility Motoring Program.

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So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You’ll discover that Mobility Motoring is your kind of reward!

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The wonderful stories and pictures in this issue demonstrate how children with disabilities are becoming active in a wide range of exciting recreational and leisure activities. Many of these activities will become lifelong pastimes that will continue to enrich their everyday lives. Not too many years ago, some parents and professionals might have said that it was unrealistic to expect children with disabilities to participate in some of these activities. Often, so much attention was focused on "therapeutic" activities that children and parents did not learn to enjoy recreational pastimes.

Gardening, fishing, drama, track and field, fitness! The worlds of children and adults with disabilities are widening because parents like Duane Blaska ("A Father’s Gift") and Roger Bossley ("Peter’s Garden") share the activities they love with their children. As 16-year-old Stef Cargnel ("Becoming a Contender"), a wheelchair track and field athlete and basketball player, so eloquently explains, sometimes, a parent’s encouragement makes all the difference.

Traveling

Now that our difficult winter is finally history, I am traveling and meeting many wonderful readers—both parents and professionals. In April, I flew to Germany to work with early intervention professionals serving Armed Forces families stationed in Europe. I also met with parents and children at the Abilities Expo in New Jersey, at the Frank Porter Graham Child Development Center in Chapel Hill, North Carolina and at the International Parent-to-Parent Conference in Asheville, North Carolina. In May, I will be speaking each day at the Abilities Expo in Anaheim, California and, in August, at the Abilities Expo in Chicago. I look forward to meeting our readers and getting valuable feedback and inspiration at every stop.

Thank you, Ann Landers

Long-time readers know that without the glowing comments about Exceptional Parent that have appeared in Ann Landers’ widely read columns since 1973, this magazine would not have survived the ’70s. On April 19, Exceptional Parent was praised once again by America’s most widely-read columnist. We always appreciate this recognition—as a result, we know that we will hear from parents from throughout the world who had not previously been aware of the magazine.

Health Care Reform

Several months ago, we urged readers to write to the President and to Congressional representatives regarding concerns about health care reform. Because of the urgency of this issue, we even urged readers to have their children write. We are interested in copies of children’s letters as well as any responses they may have received.

Educational Program Award

In past years, each September’s educational theme issue has included an award to an exemplary educational program. First, it was called the “Mainstreaming Award,” then, the “Inclusion Award.” Although we are advocates of inclusion when it includes necessary supportive services for children and teachers, more importantly, we promote good educational choices for parents. For this reason, the award undergoes another name change. This year, it will be called the Exceptional Parent Annual Educational Program Award.

We invite nominations for this year’s award. Programs will be judged on criteria such as attention to the needs of the whole child—academic, social and recreational; parental participation; teacher support and community participation. Entries should explain, in 500 words or less, how the nominated program meets these criteria. We also encourage you to send pictures. Send nominations to Exceptional Parent Annual Educational Program Award, 209 Harvard St., Ste. 303, Brookline, MA 02146. Deadline for entries is July 1, 1994.
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The Need for Balance

I'm the parent of a nine-year-old boy who is deaf and has additional disabilities. He was a preemie who was hospitalized for his first five months. I've been an appreciative reader of Exceptional Parent since he was a toddler.

I'm writing now because I am troubled by something in the February 1994 issue. You printed a response letter from a parent who wrote with unequivocal enthusiasm about her son's experience with a cochlear implant. It was the only letter published in response to an October 1993 Search letter asking for pros and cons on the subject.

I'm sure you are aware of the controversy about cochlear implants. There is much concern that parents will have unrealistic expectations of their postimplanted children, that they will forego the use of sign language in favor of speech therapy and that children will feel enormous pressure to validate their parents' decision to proceed with this new, experimental procedure. Indeed, the procedure has been so recently approved for use in children that it would not surprise me if you did not have a parent willing to write and say, "Don't do it. We did and it was a terrible mistake." At what point would a parent come to that conclusion—three years later? Five?

There hasn't been enough time—although studies citing the incidence of medical complications make one wonder if some parents may be questioning their decision on that basis alone. Some people predict that children who have cochlear implants will be socially isolated. They may not be able to communicate effectively with hearing people nor have the sign language skills to be part of the deaf community. Indeed, some members of the deaf community have likened cochlear implantation to genocide.

It is good to read of a child for whom the implant has worked so well, but hundreds, if not thousands of parents of deaf children will see that letter in Exceptional Parent and assume that it will work the same way for their child. Statistics do not support that conclusion, and I'm disappointed that you let the letter run alone.

I know that many of the medical procedures discussed in the magazine have their proponents and detractors, and that you can't always devote space to a full debate. However, I think this is one time you should have stepped into with an editor's qualifying comment, or withheld the letter until you also could have published one that answered C.N.'s request for the downside of cochlear implants. Otherwise, keep up the good work!

B.B.M., Massachusetts

Editor's Note: We appreciate your thoughtful letter. Responses to 'Search' letters do not always reflect both pros and cons of a controversial issue, but letters published in 'Respond' are always representative of those received and forwarded. Responses that come down on one side of an issue often inspire other readers to write letters that differ by a previously expressed viewpoint—just as you have done. This type of thoughtful, ongoing dialogue informs everyone. Balance happens over time—even if both sides are not presented in the same issue of the magazine.

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all aspects of childrearing. As the deaf parent of a deaf child, I have developed a great deal of respect for the many hearing parents of deaf children I have met over the years. I have seen these parents become adept at sifting through conflicting recommendations regarding amplification, communication and education to make decisions that are best for their individual children. I do not believe that most parents will assume that what has worked for one child will necessarily work for theirs as well.—K.S.

Magazine is Less Useful

I agree with the letter from C.O. of Washington (February 1994) that your magazine is generally less useful to me than it was even a year ago. I miss the regular feature, Family Life, and the additional articles by parents for parents. Advocacy is important—but it's not for everyone. The current emphasis seems to be on telling parents what they should do—the magazine talks at us rather than letting parents share with each other. Unlike C.O., I wouldn't say that Exceptional Parent has become a scholarly journal, but it's become a newsletter for the politically active parents, rather than a forum for all parents.

The first sign of this unresponsiveness to the needs and desires of the parents was when you declared that all parents writing letters would be identified only by initials and state—even if they wanted to give their full names and addresses. This lack of trust in parents' ability to decide whether we want to risk being "known" bothered me, and others. I remember the letters about it at the time, and I don't recall any parent who was glad to be forced to be anonymous or to go through your offices for communication. I don't like paternalism; I don't like this we-experts-know-best attitude. And the changes in the magazine since then have all been in the same direction.

The worst of it is that real parental empowerment goes by the board when advocacy results in increased control of our children by the bureaucracy. Advocacy organizations want all our children in public schools, so that they'll have the numbers to make an effect. But many of our children will do better in non-public schools that can be much more flexible. We do not yet know enough about how best to educate and rear every child who has a disability—but some bureaucrats are eager to throw a standard IEP at a nonstandard child and then blame the parents if the kid fails. Those of us with strong reservations about the public school system find ourselves at odds not only with the education system, but also with the kind of parent that Exceptional Parent now seems to represent.

I wish this magazine would return a little power to the ordinary parent and treat us like grownups. Let us have the option of using our full names and addresses when we write. Print more articles by parents. Let parents do reviews of books they've found helpful rather than just printing excerpts of books you think are important. Encourage diversity in ideas—we do not yet know what will be best for any given child, let alone any group of children. There is no one right way to parent a child with mental retardation, autism or spina bifida. Any one of
your readers might have a unique approach that may help another parent or spark a new line of research. Focusing on government policy is the wrong priority; our children—each individual child—should be the top priority.

I will continue to subscribe, but I wish you hadn’t taken the turn you’ve taken.

E.M., Texas

EDITOR'S NOTE: We appreciate your letter and hope you—and other readers—will continue to be specific in letting us know what you like or dislike about the magazine. We make an effort to be responsive to suggestions.

The policy of using initials of letter-writers rather than full names was announced in 1989. Current editorial staff members agree that it is time to re-evaluate this practice; we would like input from readers on this issue. Currently, we are leaning toward a change in policy that would allow letter-writers to choose between using their full name and state, initials and state or “name withheld upon request.”

We are not comfortable with a blanket policy of identifying letter-writers with full addresses. This practice could leave people vulnerable to unwanted solicitations or harassment. Even if these potential problems were not a concern, we would still want to handle the forwarding of initial responses to SEARCH letters, because this process allows us to choose a representative cross-section of letters for publication in RESPOND. It also gives us another avenue of insight into our readers’ interests and concerns; the “school bus” response letters published in this issue are a good example. (See page 42.) At the same time, we also are thinking about places where full addresses may be appropriate—if we were to start a pen pal page, for example.

Brain Differences in Autism

I am the president of a parent-run self-help and advocacy group for children’s mental health; I have three children with special needs. I was very excited to see Margaret Bauman’s article “Brain Differences in Autism” (March 1994). Two of my children—ages four and eighteen—have autism. Finally, someone has said that this disease begins with brain development before birth! I needed to know that there is proof of what we, as parents, have always believed. Thank you!

B.M., Louisiana

Thank You

Thank you for continuing to publish a magazine that provides me with a sense of connection and a feeling of support. I look forward to receiving your magazine each month and often cry while reading it. I cry from profound sorrow when I read of the many other people who are facing such incredible obstacles in their children’s lives, and I cry tears of joy when I read of their successes. And sometimes I cry just because I realize that there are people out there who truly understand what it is like to raise and to love a child the world does not consider “perfect.”

S.G., Hawaii

You Asked DynaVox To Do Even More...
Accessible Camps
HEL-P-P-P-PPP! I am a single, adoptive mom to nine children, ages 12-25. One of my youngest, Abigail, is a 13-year-old who has cerebral palsy—primarily affecting her lower trunk and uses a wheelchair. Illiterate when adopted from Korea five years ago, today she is fully mainstreamed in a regular seventh grade class and is a strong student. The problem? She is poorly socialized compared to her peers because of her relative lack of ongoing, informal give and take with friends. She spends most of her time with the family, often in the house. I try to provide socialization opportunities for her, but since I also work full-time, Abby's opportunities to "be a regular seventh grader" are limited.

A residential or "sleep-away" camp would be of enormous help in meeting this very real need. However, I have run up against a brick wall in locating a camp that is fully accessible and both willing to deal with Abby's wheelchair and assume the responsibility of a child who is physically challenged. Abby is fully independent when given enough lead time to meet all of her needs—it's just that most things take her longer, physically, than others. She can use a walker to travel short distances and to make transitions; she gets around on her own but always welcomes a helpful "push" of her chair. She loves the water but does not swim on her own and needs help to get in and out of a pool.

We live just down the road from a camp that is well-known for its programs for children and young adults with disabilities. However, Abby's needs are really not well met there, because her interests and intellectual skills are age-appropriate even though her body does not work well for her. She desperately needs a chance to be with other young teens in a relaxed, fun-filled setting where accommodations can be made for her physical limitations. Any ideas? I simply don't know where to turn!

C.P., New Jersey

Editor's Note: Many camps have "counselor-in-training" programs for teenagers. You might want to explore the possibility of your daughter participating in such a program at the camp near your home.

G-Tube with Internal Disk
My two-year-old son had a severe hypoxic incident at birth. He has been diagnosed with hypoxic eschamaphaloplastic encephalopathy, cerebral palsy, an uncontrollable seizure disorder and extreme lack of physical growth and development. He also displays a great deal of inconsolable irritability. He arches his back and thrashes to an extent health professionals have not seen in other children.

He had a G-tube insertion recently, but, due to his arching and thrashing movements, the tube pulled out of the stomach and ended up between the stomach and the skin. Resulting complications led to its removal. We can feed him very little orally—this results in dehydration and constipation. Feeding also requires many hours each day. His gastrointestinal specialist has recommended a G-tube with a disk inside the stomach. The disk would prevent unintentional removal of the tube, but its placement is a more complicated procedure and precludes the use of a button.

Some caregivers have related stories of irradiation associated with severe arching and the disk, and one doubted that any tube would stay in place with our child. I wonder if an improvement in the ease of his care would be worth an increase in his irritability. We would like to avoid the heartbreak of another hospitalization that could result in a net gain of zero when yet another tube fails to stay in place. On the other hand, the benefits of his G-tube were clear during the short time that it was working. I would be interested in hearing from anyone with a similar experience. We have a third child on the way, so care issues are taking on a new urgency.

R.H., Vermont

Prader-Willi Syndrome with Normal DNA Test
Our three-year-old daughter has been diagnosed with Prader-Willi syndrome. However, no chromosomal deletion or genetic abnormalities show up on DNA probe testing. It is hard to accept this diagnosis when the tests come back negative.

She has severe hypotonia and some of the facial features seen in Prader-Willi. She receives occupational and physical therapy. She has a hard time articulating words; she also bumps into things and falls quite often.

I want to talk to other parents of children with Prader-Willi, especially children with negative DNA tests. I want to know what their lives are like, how the children do in school and what to expect in the future.

C.M., Minnesota

Editor's Note: You can contact the Prader-Willi Syndrome Association (PWSA) at 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144, (800) 926-4797. PWSA publishes an informative newsletter for parents.

Rhizotomy
Our three-year-old daughter has spastic quadriplegic cerebral palsy. She is non-ambulatory and does not crawl. Her trunk control is poor, and she can sit unsupported only to a very limited extent—on the floor in a ring-sitting position. Her upper extremities are sig-
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nificantly involved as well. She is verbal and of normal intelligence.

Her neurologist has recommended rhizotomy surgery. We’ve done a lot of research about the procedure, but can’t seem to make up our minds. We’d appreciate hearing from parents of children who also have a diagnosis of spastic quadriplegia and who have had rhizotomies. We’d like to hear about any results—good, bad or in-between.

C.S., New York

Chondrodysplasia Punctata
Our daughter, now almost three years of age, has been diagnosed as having Chondrodysplasia Punctata, also known as Conradi-Hunermann syndrome. This condition is characterized by a broad, flat nose; a short neck; coarse, sparse hair and growth deficiencies. Her doctors told us there was no one else in the United States with this syndrome—imagine our surprise when we came across it in a very old Search letter from your magazine. We would like this family or others to get in touch with us. We are very anxious to talk to other families who have dealt with this condition.

E.H. & V.H., New Mexico

Bilateral Aniridia
I am the mother of a bright, beautiful 21-month-old daughter who was born with bilateral aniridia, a rare birth defect involving absence of the iris. Katie’s diagnosis also includes foveal and macular hypoplasia, optic nerve hypoplasia, nystagmus, congenital cataracts, hyperopia, strabismus and amblyopia. People with aniridia are considered to be at high risk for glaucoma. Katie’s intraocular pressures appear stable and within the normal range.

We have no familial history of aniridia and genetic screening has determined that Katie’s chromosomes are normal, so this is thought to be a new genetic mutation or rare autosomal recessive. Katie has no other identified systemic abnormalities and so far, has tested negative for Wilm’s tumors. She has some vision which she uses remarkably well. She has not shown any developmental delays.

Because aniridia is so rare, we have had a difficult time researching current articles on the subject and finding ophthalmologists who have a broad base of experience with the condition. I am interested in locating other people with aniridia, or other parents of children with this condition. Perhaps we could form a support group to disseminate information on treatments and knowledgeable specialists. I am particularly interested in contacting people with aniridia who have had cataract surgery or experience with intraocular or contact lenses with a painted, fixed iris.

I am also interested in locating people with aniridia or other abnormalities of the eye in which there was a maternal history of penicillin or penicillin derivatives (i.e. ampicillin, amoxicillin) being used during the first 10 weeks of pregnancy. I know of four or five other non-familial aniridia cases involving mothers who had been given penicillin derivatives before the eighth week of pregnancy—the time when a child’s eyes are forming. I wonder if there are more such cases.

S.G., Hawaii

Ritalin and Autism
I am the parent of a four-year-old son with autism. He is also somewhat hyperactive and has a short attention span. He attends a specialized preschool program for three hours every morning. The doctor who diagnosed my son’s autism suggested a small dose—2.5-5 mg—of Ritalin on school days only to help control my son’s distractibility and improve his concentration.

I cannot find much information or research on Ritalin being used by persons with autism and would appreciate hearing from anyone with experience in this area. I am interested in knowing whether the medication was effective and whether any negative side effects were observed.

L.S., Illinois

Cerebral Arteriovenous Malformation
My seven-year-old son was recently diagnosed with a cerebral arteriovenous malformation (AVM). He has neurological problems including poor fine and gross motor skills and very slow speech. He is in the second grade and makes good grades but has trouble writing because he has an “intention tremor”—a tremor that intensifies when he attempts to perform a coordinated movement. The tremor also makes dressing difficult because he can’t work buttons, zippers or snaps. He has trouble opening containers and feeding himself. He drools, chokes on liquids and bites his tongue, lips and cheeks.

After reviewing his MRI and angiogram films, several doctors say that the AVM is too large to treat without significant risk of causing permanent neurological deficits. But one doctor is willing to do embolization therapy—a risky procedure in which he would insert a microcatheter into an artery and inject a substance that causes clotting. The doctor tells us that he cannot cure our son, but hopes to slow the progression of his symptoms.

We feel that embolization may be our son’s only hope, but we aren’t completely sure it’s worth the risk. We have been told that his symptoms will continue to get worse, but no one will say for certain what his prognosis would be without treatment. Is there someone out there who has a child with an AVM who could share their story with us?

P.H., West Virginia

Umbilical Cord Sampling
We are the parents of a two-year-old son who was diagnosed shortly after birth with Neonatal Alloimmune Thrombocytopenia (NAIT). This was the result of PLA2 antibodies. Our son suffered cerebral hemorrhage as a result of a low platelet count at birth. The platelet issue was resolved within 30 days but the hemorrhage was quite large and left our son with a vision impairment and cerebral palsy.

My husband and I want to have another child. Specialists tell us that another pregnancy will involve similar risks but they are confident that they can deliver a healthy baby with careful fetal monitoring and drug therapy. Fetal monitoring will be done by umbilical cord sampling. We are interested in talking to anyone who has had experience with umbilical cord sampling. We are also anxious to speak to parents who have had a child with NAIT, especially parents who have had subsequent pregnancies.

M.L. & T.L., Maryland
Wide Shoes

D.M.G. (September 1993) was looking for a source of wide dress shoes for her 30-year-old daughter who has Down syndrome.

Finding extra-wide shoes in small sizes is practically impossible! My daughter has feet of two different sizes—one is an extra, extra-wide ladies' size five, the other is an extra wide eight-and-a-half. In addition to having a wide foot, my daughter's difficulty in finding shoes that fit is compounded by her leg braces.

I looked everywhere before finding a shoe company that carries just the right shoes for our kids—P.W. Minor and Sons, 3 Treadeasy Ave., P.O. Box 678, Batavia, NY 14021-0678, (716) 343-1500. They will custom order mixed-size pairs. They will modify the sole to make it flat instead of wedged. In addition to making wide sizes, they also manufacture many different styles of "extra-depth" shoes that accommodate even the largest braces.

M.S., California

My son also needs wide shoes. I get them from Mason Shoe Manufacturing Company, Chippewa Falls, WI 54774-1905. They carry shoes in widths AA–EEEE and have a catalog with a variety of styles. Their shoes come in women's sizes 4–12 and men's sizes 5–15.

M.B., Missouri

EDITOR'S NOTE: Starlight Footwear (21537 Kapok Circle, Boca Raton, FL 33433, 800/557-4637) is another source of wide shoes in a variety of styles. See their ad on page 7.

Rasmussen Syndrome

S.K.J. (February 1994) is the mother of a nine-year-old who was recently diagnosed with Rasmussen syndrome. In hopes of learning more about her daughter's prognosis, she was looking for other families who have dealt with this condition.

I am the mother of a 14-year-old girl who was diagnosed with Rasmussen syndrome at five years of age. At age seven, she underwent a radical hemispherectomy—the removal of the diseased part of the brain. In Beth's case, the entire left side of her brain was removed. Since leaving the hospital, she has not had one seizure, nor has she taken any medication. Prior to her surgery, she was losing the function of her right hand and had a progressively worsening limp. Her speech and intellectual functioning were deteriorating.

It took two years for Beth to fully recover from the surgery, but now she is a bright, beautiful, happy eighth grader who receives minimal resource help in school. She bowls on a team, swims and is like any "normal" child. Beth would be most willing to talk to you if you would like to see how she is doing.

K.U., Connecticut

Three Kids, Three Disabilities

P.G. (February 1994) is the mother of three very young children with three different disabilities. After genetic testing failed to explain why all her children had disabilities, P.G. hoped some readers might have insight on the question. She also wanted "copier" advice from parents in similar situations.

I also have three children with different problems, though they do not seem to be as involved as your children's. I can't give you any "words of wisdom" about why your children have such different problems; all I can say is that many things happen for which we never know the reason. Let me encourage you by saying that your children are still very young and things generally get easier as they age. Under the best of circumstances, it can be very trying to have a three-and-a-half-year-old, a 19-month-old and a newborn.

My eldest child is 12 years old and has had asthma since he was less than a year old. When he was younger, his asthma was frequently out of control. Searching for the right physician and educating myself about the disease made a profound difference for him. If you do not already take your son to an asthma specialist, I would encourage you to do so. It has been my experience that pediatricians are usually not aggressive enough in asthma treatment.

A good allergist/asthma specialist really knows how to attack this disease and get results. My son still misses more school and activities than a "normal" child, but things have improved greatly.

My middle child is nine and has a learning disability (LD). As a result of this, he is fairly fragile emotionally—or maybe that has more to do with being the middle child. I also have educated myself about LD, because it is a disability that requires a parent to be assertive in order to get an appropriate school program. It is not too soon for you to begin learning about the special education programs in your school system— as if you already don't have enough to do! Educators use a whole different language when it comes to educating our kids; you must also learn to negotiate the huge bureaucratic maze. Other parents who have already "been there" can be particularly helpful.

My youngest child is five and has ocular albinism, a type of albinism that primarily affects the eyes with only slight skin and hair involvement. She is visually impaired, but not legally blind. We just learned that she, too, has asthma, though we don't believe her condition is as bad as her brother's. I know what you mean about the constant stress of doctors, therapists and bills. Support from other parents of children with disabilities has been crucial for me. Our local parent-to-parent group's motto—"If your child has special needs, so do you"—is very true. It's incredibly important to remember to take care of yourself so you will be better able to help your little ones. I hope you have someone available to give you a break once in a while. Being a full-time mother or father is exhausting; we all need some time off occasionally.

I hope you will reach out to other parents in your area for support. It seems that parents of children with disabilities are nearly always willing to do whatever they can to help another parent survive this roller coaster ride. The following organizations can provide a wealth of information relevant to your children's disabilities and have great newsletters:

- National Organization for Albinism and Hypopigmentation, 1530 Locust St., #29, Philadelphia, PA 19102-4415;
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We have much in common—while our children's disabilities are not the same, our lives probably are. I also have had three children with disabilities. My daughter died at age 12 from a rare form of bone-related cancer. That was in 1989, when my two boys were babies. During Emily's two-year illness, both boys were born and eventually diagnosed with disabilities. I remember having two children in the hospital at once and worrying about the third. I remember feeling like an overstretched rubber band and wondering how much longer I could take it all. I felt resentful of parents whose biggest "problem" was that their kid hated having his hair shampooed or that he needed tubes for ear infections. I lost some of my compassion for these people and that really bothered me. I developed defenses against my kids' pain. Sometimes, I felt that if I really started crying, I might never stop, so I tried not to cry. Bad idea!

For a while, I fell into a trap of trying to meet every single need that my family had. It took time to learn that I couldn't do it. I learned to make a list of priorities and to place my husband and me on that list. I learned to very clearly define my needs and then communicate them. Have you ever met those people who ask if there anything they can do? I began answering those questions with very practical responses, like "Wow, I am so glad you asked that. Do you think you could come over and walk my dog the next time one of my kids is hospitalized?" or "You know, I was just praying that somebody could help my son practice feeding himself once in a while. Would you like to come over next Tuesday morning and see how we're working with him?" When you very specifically outline what you need, all those well-meaning folks either get lost forever or you uncover some very talented people who are on your kids' sides.

I like talking about my kids, so I'll do that for a minute if you don't mind. As I said, Emily died five years ago. Besides having cancer, she also was hearing impaired. She was wonderful, and we were so fortunate to have her. She taught us so much about faith, obedience and love.

Patrick is our seven-year-old. He has the biggest disability of the three kids—Angelman syndrome. He is severely developmentally delayed in all areas and basically non-verbal. He has seizures, a sleeping disorder, fine- and gross-motor deficits and eyes of two different strengths. He has a very affectionate and happy nature and is the love of my life. He is working on feeding and dressing skills and is able to do some pre-school level work on the computer. He walks pretty well, but uses a stroller when we go places. I don't think he is capable of anger.

Jaron, our five-year-old son, was born with eye cancer and lost an eye at one week of age. He is hearing impaired, but has good vision in his remaining eye. Jaron is very entertaining and always is doing something funny. He came up with the idea of starting his own "business" last April; he now earns $5 a month dragging the neighbors' empty trash cans into their backyards on garbage day. We are home-schoolers, so I teach both boys myself. It is the best decision I ever made, but it is not for everybody.

The other thing I wanted to address is the young ages of your kids. At this point in their lives, your life is very intense. Please be encouraged that although it may seem this phase will go on forever, it really does change. Believe it or not, you do get time to catch your breath and even relax eventually. You'll get through it somehow. Really!

B.M., New York

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"Birthday" by Alex Blum

Circle # 36
College With a Personal Attendant

N.T. (February 1993) is the mother of a 15-year-old daughter who is an honors student and wants to attend college. Her daughter has cerebral palsy and uses a motorized wheelchair. She needs extensive assistance for personal care. She has a great deal of difficulty writing, but as a one-finger typist, finds typing equally frustrating. N.T. wanted to hear about the college experiences of people with needs similar to those of her daughter. She also wanted information about colleges with good support services for students with disabilities.

Our daughter is capable of writing, but has required a personal care attendant throughout her college career. Since she first enrolled in college in 1987, we understand that many universities and colleges have taken significant strides toward establishing the necessary programs and offices to meet the needs of their students with disabilities.

Our daughter chose to attend the University of Pennsylvania for her undergraduate work. While Penn did not have an organized program for students with disabilities, the school agreed to provide our daughter with whatever support she required, including building accessibility and assistance in obtaining attendant care. However, some tense moments occurred relating to our ability to find the necessary personal care attendant services. Our daughter requires turning during the night, and we relied on her roommates for this aspect of her care. Penn lived up to its commitments and our daughter enjoyed four happy years there.

Currently, our daughter is a Ph.D. candidate at the University of California Berkeley (UCB). UCB has one of the best programs for students with physical disabilities. It has a dormitory manned 24 hours a day by individuals capable of providing care; it also provides a service that enables its students to find personal care attendants for their respective needs.

M.B. & M.B., Pennsylvania

Prudence K. Tweed and her son, Jason, inspired by their own search for a college that met their educational goals and personal care requirements, compiled Colleges That Enable: A Guide to Support Services Offered to Physically Disabled Students on 401 U. S. Campuses (Park Avenue Press, 1989). This book may be helpful. J.K., New York

EDITOR'S NOTE: The book can be ordered from Colleges that Enable, Inc. (P.O. Box 6585, Wyomissing, PA 19610, 610/376-1551). Suggested, tax-deductible donation is $15.00.

Niki from California—

We received your pen pal letter to J.A., but you did not include a return address for her to write back to you. Please send your address to EXCEPTIONAL PARENT so we can forward it, along with your letter, to J.A.
FAMILIAR FACES

Brian Michael Sullivan of Sarasota, Florida, 16 months old, is described by his mother, Laura, as having "mischief in his eyes." Despite visits to geneticists and other specialists, Brian remains undiagnosed. Laura hopes that all the doctors who wrote about Brian's "dysmorphic features" will see this picture and begin to appreciate this boy with the "million dollar smile."

Eight-year-old Rodrigo (left) and five-year-old Jorge Nevares live in Guaynabo, Puerto Rico. Jorge has cerebral palsy. The boys' mother, Carolina, writes that she is looking forward to seeing pictures of other readers' families—"it's a great way for us to share part of our lives with each other."

Three-year-old Brittanne Jade McClain (right) chats with her friend, Ben, while waiting for the school bus. Brittanne's grandmother, Gloria Reeves, who sent us this picture, wants everyone to know how proud she is of her daughter, Lori—Brittanne's mother. Lori is a full-time college student and according to her mom, a truly "exceptional parent." Lori and Brittanne live in Long Beach, California.

This picture of the Mercado brothers of Fort Bragg, North Carolina—14-year-old John, Jr. (left) and 11-year-old Danny—was taken on Thanksgiving Day, 1993. Danny has multiple disabilities. Danny's mother, Denise, feels that this picture demonstrates the love between the brothers. The family also includes dad, John Sr., and 13-year-old sister Haelan.

Heather and Kyle Brandon stop off at the fountain for a drink of water. Heather has CHARGE syndrome; Kyle is her twin brother. The pair, who live in Castro Valley, California, were four years old when this picture was taken.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
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Circle #25

Circle #26

342
A Father's Gift

David's outings with Dad encourage fun and learning

By Joan K. Blaska

David raced into the house and announced to everyone who would listen, "We caught 19 sunnies and on the way home, I saw three deer!" A couple weeks later, David rushed into the kitchen and shouted, "My team won by one touchdown. I gotta go call Dad—he owes me a quarter!"

These may sound like typical scenes in the lives of children who spend time participating in recreational activities with their parents. But David is our 26-year-old son who has mental retardation and attention deficit hyperactivity disorder. When he was younger and living at home, we privately called him the "white tornado," because he moved so fast. Today, he lives in a group home with three other young men.

Even though David has a developmental delay and some challenging behaviors, his father included him, whenever possible, in his own favorite activities—watching sporting events, fishing and hunting. Over the years, this meant taking David on hundreds of "scouting trips" to find good fishing and hunting spots.

Our family has always enjoyed watching sporting events. David began by watching parts of televised games with his dad; as he gained more control of his behavior, he progressed to attending some of the games. Sometimes, our family would even wager quarters on which team would be the winner. With all this exposure to team sports, one of the first songs David tried to sing was the national anthem! He didn’t know the words but tried to sing the melody. He knew that the first strains of the Star-Spangled Banner meant that the game was about to begin! Today, he turns up the sound and loudly sings along as best he can.

David’s favorite sports are hockey, baseball and football. He attends many games, and has budgeted his money to buy jerseys to wear when his teams play. He also collects trading cards which has helped him learn the names of many players. With help from his high school teachers, David learned to read scores on the Sports page and check the schedule of upcoming games. Today, whenever we’re not sure of a game time or don’t know which teams are playing, we call David.

David Blaska shares a warm moment with his father, Duane.

David. In return, he often calls to report a score or to let us know who won the quarter—and it’s usually him!

Over the years, David’s inclusion in recreational activities increased as he gained more control of his behavior. For example, his first hunting outings began as rides in the car, looking at ducks in the ponds and making a game out of naming them. Later, he went along on hunting trips that often involved three generations of our family’s men. David was not allowed to carry or use a gun, but he enjoyed roaming alongside Dad as they tried to scare up a grouse or pheasant. On these outings,
David learned the rules of hunting safety and the names of various birds and wild animals.

As a very small boy, David would go out in the boat and fish with his dad. Often, it was just the two of them. David learned to sit still in the boat and enjoy moving across the water. He also learned to bait his hook, cast out his line without messing up the reel, set the line and sometimes, pull in a fish.

On fishing trips, David learned to identify and name many common fish. When he got older, he learned to steer the boat with Dad sitting by his side. The first time I watched David drive the boat, I saw a wonderful look of delight on his face. Tears came to my eyes as I thought of the benefits David had reaped through my husband’s patience and willingness to include and teach him.

Over the years, there were times when David and his Dad would return early from an outing that hadn’t gone well because of David’s challenging behaviors. But this never stopped Dad from trying again.

David proudly displays the “catch of the day.”

David’s outings with Dad have resulted in many unanticipated benefits. At our house, David feels like he is one of us. While he is aware of his limitations, he feels accepted because we have emphasized what he can do. By including him in recreational activities, David’s father helped him develop interests that are appropriate for a man; more importantly, these activities have given David lots to talk about!

When David meets someone, he might ask, “Did you see the game—who won?” or “Did you know they traded the catcher?” This small talk is socially appropriate and has helped other people accept David. Sometimes, people don’t know what to say to a person with a disability. But all of our family members and friends have lots to talk about with David because of his interests and involvement in these leisure-time activities.

Parents have the opportunity to expose their children to a variety of activities that they may enjoy participating in as adults. Keep in mind that recreational activities are not limited to sports. What do you like to do during your free time? Allow your child to choose among your hobbies and participate in the ones that he or she enjoys. For example, David doesn’t like to watch golf on television. But sometimes he is happy to walk along in the woods and find lost balls, which he then sells to the rest of us!

Persons with disabilities often lack the skills for leisure activities. As parents, it’s important to remember that while our children’s disabilities result in varying levels of potential and interest, they all have the capability to participate in some way. We need to ask ourselves, “Am I including my child in activities that I do which are fun and may help prepare my child for the future?”

Through many outings, David’s father gave him the priceless gift of time—time to be together, to share and to learn. Because of this gift, David has learned to talk about and enjoy a number of leisure activities. This happened because David’s father was willing to share an even greater gift—the gift of love.

Joan K. Blaska, Ph.D., is an associate professor in the Department of Child & Family Studies at St. Cloud State University, St. Cloud, Minnesota. Dr. Blaska trains professionals to work with young children with disabilities and their families. She frequently speaks to parent groups about the joys and challenges of raising children with disabilities.
Chris and the entire staff at Aisle 17 have talked to lots of people just like you. They're friendly, they're knowledgeable, they're ready to help.
My eight-year-old son, Peter, has always spent most of the day with me when I am home. Since much of my free time is spent in the garden, Peter developed a great deal of curiosity about what I was doing. His younger brother, Benjamin, spent time exploring the garden while I worked. However, Peter, who is blind, hesitated to follow, knowing that he would be likely to stumble over the ground and smash some plants.

I initially agreed that the garden should be off-limits and encouraged Peter to "stay out of the way." Then, I reconsidered—since he was so curious, maybe this would be the ideal time to let him learn something about botany and how plants grow. I started thinking about ways to include my son in one of my favorite pastimes.

**Planning Peter's Garden**

I set aside a 12-square-foot area of the garden for Peter's use and decided on crops that would be easy for him to plant, weed, harvest and even sell. Large or bushy plants with large seeds seemed like a good choice. That first year, we put in Indian corn, miniature pumpkins and gourds.

I knew that the planting and maintenance of his garden plot would be much more clear and meaningful if Peter was involved in the planning process. Peter raised a number of questions during our planning sessions. Many of his questions were very visual. He wondered how big his pumpkins would grow, how much space each plant would need and whether the plants would grow upright or sprawl. We discussed the garden plan in detail—the location of each row, the reasons for choosing these locations and the amount of space between each plant.

**Planting**

Peter and I worked together to till the garden so it would be smooth enough for him to keep his balance in the area. Then, we strung kite string to mark each row.

Peter planted his pumpkins and gourds in mounds, or hills, directly beneath the string. He counted out six seeds to a hill—later to be thinned out to three plants per mound—and covered them with soil. Then, he used a four-foot section of sapling to measure out the right amount of space between each just-planted hill and the next.

Peter planted corn the same way, by using the string for a guide and a small stick for a measure. He planted kernels of seed corn under the string, about six inches apart.

**Garden Maintenance**

A clawed garden tool and good mulch—such as leaf mulch or clean straw—will be the only tools a child will need for most small gardens. Simply have the child remove the mulch in one small area.
Gardening is for Everyone!

Adaptations can make gardening more accessible to children and teens with various disabilities.

Some children with visual, motor or intellectual disabilities may have difficulty planting a garden. This task can be made easier by the use of seed tapes which eliminate the need to count out seeds and measure the distance between them.

**Raised beds and containers** are adaptations that may be useful for wheelchair users and others who can't easily stoop. These containers bring the gardening surface up to the level of a standard table. Raised beds and containers come in various sizes and materials and are available for indoor or outdoor use. A helpful, free publication—Gardening in Raised Beds and Containers for the Elderly and Physically Handicapped—is available from the People-Plant Council, Office of Consumer Horticulture, Virginia Tech University, Blacksburg, VA 24061-0327.

**Equipment**

Many types of gardening equipment have been adapted; other, commercially-available products also have useful features.

**Specialty handle tools** solve a number of problems. **Extended handle lengths** make gardening easier for children who have difficulties bending or kneeling, or who work a ground-level garden from a wheelchair. Individuals with limited manual dexterity and grip may use these tools by strapping the handle to their forearm. **Normal or extra-short handle lengths** are beneficial for gardeners working a raised-bed garden from a wheelchair. **Enlarged-grip handles** assist individuals with limited manual dexterity and grip strength. **Lightweight-handle tools** may be easier to carry and use than traditional metal-handle tools. And **rubber-grip handles** are often easier for any child to grasp.

**Gardening stools and knee pads** are designed to alleviate pain or discomfort associated with bending, stooping, kneeling and getting up from the ground. Additionally, some stools have built-up frames which can help a child get into and out of a kneeling position.

Many commercially-available products also have helpful features—hose nozzles now come with a "lock-on" feature; ride-on lawnmowers have hand controls; many pruning and trimming tools are now motorized and made of lighter-weight materials. Check local hardware or garden stores.

Handle padding can always be added to help the youngest gardeners grasp tools. Sets of commercially-made, plastic toy tools may be appropriate for the small hands of beginning horticulturists. However, a set of "real" tools for children is offered by Smith & Hawken.

**Resources**

- The **American Horticultural Therapy Association** (AHTA) promotes the use of horticulture as a therapeutic, rehabilitative activity. It operates a national employment project for persons with disabilities, sponsors continuing education programs and publishes reports and periodicals. **American Horticultural Therapy Association**, 362A Christopher Ave., Gaithersburg, MD 20879, (301) 948-3010.

- **ABLEDATA**, an assistive technology and adaptive communications database, can provide a list of adapted garden tool manufacturers and products. **ABLEDATA**, 8456 Colesville Rd., Suite 885, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TDD).

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Gardening turned out to be an activity we could enjoy together—from initial planning stages to end product.

And weeds were sprouting. When the plants were large enough, I showed Peter what pumpkin and gourd plants felt like at the stem—fuzzy and somewhat prickly. Now he could easily differentiate them from the weeds. We waited until the corn plants were fairly thick at the base; then, Peter also was able to distinguish them from the weeds he pulled out from around their thick stalks.

**Crops for Kids**

Not every variety of plant is a good choice for a child with a visual impairment or other disability, but there are plenty of good ones from which to choose. Besides the plants I chose for Peter's first garden, other good crops include the bush varieties of string beans, potatoes, peppers, tomatoes, beets and various herbs and flowers.

Bushy string beans have uniformly large beans that ripen at the same time. These are easy for a child to harvest and less prone to insect infestation—and who wants to touch bugs while picking beans? Pepper plants are not too difficult for children to plant and will live even if they are not planted in the most delicate fashion. Tomatoes, too, if planted deeply enough, will survive a child's sometimes
imperfect handling. Both peppers and tomatoes can be staked to allow children with visual and muscular impairments to locate the plants, weed around them and pick their fruits. Again, mulching these plants will reduce the need for weeding.

Seed potatoes are another good crop for children. Potatoes can be planted at ground level and covered in heavy soil or planted three inches deep in loam. If the plants are mulched with leaves, they will need little weeding. Peter and I planted seed potatoes in his second garden; in the fall, we dug them up. I taught him to follow the stem with his hands to search for spuds. Most spuds will be found on the roots very close to the stem.

Beets are another root crop to raise and weed—they are hardy biennials that are a good choice for longer-term gardens. They can be mulched after the plants are three inches tall.

Children enjoy growing mint plants. Mints have square stems which make them easy to distinguish from weeds. They do best when lightly mulched and planted in moist places. Mints come in many different varieties with smells from chocolate to apple to lemon—an exciting crop for a child with a visual impairment. Older children may wish to grow other herbs such as dill or fennel; enterprising youngsters can even find a market for them.

Easily-grown flowers include marigolds and sunflowers. Marigolds grow quickly and are extremely hardy. For a child with a visual impairment, they have an odor that makes them easily distinguishable from weeds. If mulched, sunflowers of the Sunspot variety grow quickly to a height of two feet and produce large 10-inch flowers. Their seeds will attract goldfinches in the late summer.

Marketing

Many garden products can be easily marketed. Gourds, miniature pumpkins and miniature Indian corn find ready buyers at flea markets, garage sales or craft fairs in late August through October. All of my children, including Peter, have had experience selling these and other crops.

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Peter (right) and brother Benjamin plant seed potatoes.

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Peter uses a stick to measure the correct distance between seedings.

Indian corn should be sold with the husks on—peeled back and dried one week prior to sale. Pumpkins should be picked when the stem is starting to dry and the surface is not easily scratched by a fingernail.

Gourds are easier to sell when they are dried—this means waiting until the next season—and scrubbed to a natural color or painted. The American Gourd Society (Box 274, Mount Gilead, OH 43338, 419/362-6446) has free information packets on various types of gourds; they also sell gourd seeds. **Benefits of Gardening**

I am glad I rethought my initial reluctance to include Peter in gardening activities. His gardening experiences have led to an increased enjoyment of the outdoors and greater knowledge of plants and plant growth. More than that, however, gardening turned out to be an activity we could enjoy together—from initial planning stages to end product.

Roger Bossley is a retired agriculture teacher, freelance writer and speaker who lives in Northeastern Ohio. He and his wife, Susan, have six children, including three adopted children with special needs. The family recently returned from living in the Ukraine for five months where they helped Crimean Tatars reestablish agriculture-based villages after the fall of communism.
Camerer, M. C. Gore—A PARENT’S GUIDE TO COPING WITH ADOLESCENT FRIENDSHIPS: The Three Musketeer Phenomenon. ‘94, 186 pp. (7 x 10), 1 ill.


Giordano, Gerald—DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION. ‘93, 320 pp. (7 x 10), 85 ill., 26 tables. $58.75.

Brigance, Albert H. & Charles H. Hargis—EDUCATIONAL ASSESSMENT: Insuring That All Students Succeed in School. ‘93, 182 pp. (7 x 10), 4 ill., $38.75.

Jones, Carroll J.—CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS. ‘93, 174 pp. (7 x 10), $36.75.

Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists. ‘93, 382 pp. (7 x 10), 32 ill., 8 tables, $73.75.

Jones, Carroll J.—CASE STUDIES OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered. ‘92, 236 pp. (7 x 10), $47.75.


Jones, Carroll J.—SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted. ‘92, 218 pp. (7 x 10), $37.75.


Cipani, Ennio—A GUIDE TO DEVELOPING LANGUAGE COMPETENCE IN PRESCHOOL CHILDREN WITH SEVERE AND MODERATE HANDICAPS. ‘91, 268 pp. (7 x 10), 6 ill., 22 tables, $52.75.


Blanco, Ralph F. & David F. Bogacki—PRESCRIPTIONS FOR CHILDREN WITH LEARNING AND ADJUSTMENT PROBLEMS: A Consultant’s Desk Reference. (3rd Ed.) ‘88, 264 pp. (7 x 10), $33.00.


Holley, Shelby—A PRACTICAL PARENT’S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES. ‘94, 276 pp., 13 ill., 1 table.


Jones, Carroll J.—CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted. ‘93, 272 pp. (7 x 10), $51.75.

Kass, Corrine E. & Cleborne D. Maddux—A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice. ‘93, 222 pp. (7 x 10), 3 ill., $45.75.

Vaughan, C. Edwin—THE STRUGGLE OF BLIND PEOPLE FOR SELF-DETERMINATION: The Dependency-Rehabilitation Conflict: Empowerment in the Blindness Community. ‘93, 256 pp. (7 x 10), 3 ill., $41.00.

Durán, Elva—VOCA TIONAL TRAINING AND EMPLOYMENT OF THE MODERATELY AND SEVERELY HANDICAPPED AND AUTISTIC ADOLESCENT WITH PARTICULAR EMPHASIS TO BILINGUAL SPECIAL EDUCATION. ‘92, 182 pp. (7 x 10), 21 ill., $37.75.

Jones, Carroll J.—ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered. ‘92, 294 pp. (7 x 10), 7 tables, $50.50.

Lombana, Judy H.—GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed. ‘92, 198 pp. (7 x 10), 1 table, $45.75.


Fadely, Jack L. & Virginia N. Hosler—ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS. ‘92, 292 pp. (7 x 10), $49.75.

Hughes, Barry K.—PARENTING A CHILD WITH TRAUMATIC BRAIN INJURY. ‘90, 111 pp. (7 x 10), 3 ill., $28.50.

Durán, Elva—TEACHING THE MODERATELY AND SEVERELY HANDICAPPED STUDENT AND AUTISTIC ADOLESCENT: With Particular Attention to Bilingual Special Education. ‘88, 250 pp. (7 x 10), 5 ill., 3 tables, $45.50.


Tuttle, Dean W.—SELF-ESTEEM AND ADJUSTING WITH BLINDNESS: The Process of Responding to Life's Demands. ‘84, 336 pp., 13 ill., $44.00.

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Stefano Cargnel—
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Stefano Cargnel is a 16-year-old high school sophomore who lives in Carlstadt, New Jersey. Stef, who has spina bifida, is a wheelchair athlete who is nationally ranked in track and field. He is also an avid basketball player. We asked him to write an article for EXCEPTIONAL PARENT about his involvement in athletics.

I am very active in sports—wheelchair sports, that is. But I wasn’t always so athletic; I used to hang around the house after school with nothing to do. At the time, I didn’t feel I had any choice. “What can a handicapped kid do with his time other than school, television and homework?” I would ask myself. I had always wanted to play sports, but where? With whom? It was obvious that I couldn’t participate in “normal” sports like football or Little League. The more I thought about what I was missing, the worse I felt and the madder I got.

Of course, peer pressure didn’t exactly help. My classmates constantly reminded me of what I could not do; this only added to my problems. It seemed that I was always getting into trouble for fighting. If someone challenged me, I accepted. Fighting was a way to blow off steam. It really began to get out of hand, however, and I spent a lot of time in the principal’s office. I wasn’t a bad kid; I just couldn’t handle the frustration anymore. Everyone was concerned—my teachers, my principal and especially my parents—but no one knew what to do.

My mother’s answer changed my life...
Then, one winter day in 1989, my mother came home from a spina bifida meeting with a big smile on her face. I asked why she was smiling, not realizing that her answer would change my life forever.

She said that a man named Andy Chasanoff, who coached a wheelchair track and field team at the Children’s Specialized Hospital in Mountainside, New Jersey, had come to the meeting to give a presentation about the program. The word “wheelchair” made me cringe; I had never used a wheelchair in my life! Still, I thought, “why not?”—at the rate I was going, it was worth a try.

I will never forget the first practice I attended. I was scared to death and didn’t have a clue about what to say or do. When people asked me questions, I just nodded or gave a one-word answer. Andy introduced himself and tried to explain the program. I just sat there like a dead weight and listened.
Then, Andy asked me if I wanted to try out a wheelchair he had. After pondering for a minute, I agreed. He went into a room, unlocked a storage closet and rolled out an odd-looking black and yellow wheelchair. I didn't know what to do—sit in it or run! I must admit that it took some coaching, but finally, I sat down. It felt strange and uncomfortable; I sat there totally still and silent. Everyone looked at me as if waiting for a response, and I began to hesitantly push the wheels back and forth in place.

"Hey, this isn't so bad!"

Slowly, everything seemed to become less scary. By that point, I had made up my mind to come back, even though I didn't know what would lie ahead.

**Junior Nationals**

My first year was extremely difficult. Being new to sports, I had no idea of what to expect, so I just took things as they came. I wasn't very good, and I knew it. No matter what I did, I got blown off the track. In field, I placed well—only because there was very little competition in my age division.

I heard all the other athletes buzzing about something called the Junior National Championships. I knew only that this was the meet where the best of the best showed their stuff. The coach told me that the Nationals are held in a different state every year and participants must qualify to compete. The qualifying concept intrigued me. It brought out a desire to improve, and I started to work harder.

In my first season on the team, I qualified for the Nationals. I was in a daze. For the first time in a long time, I was proud of what I had accomplished.

I knew I would not win at my first Nationals, but I didn't care—I just wanted to do my best. I met new people, made friends and learned more and more every day. For the first time in my life, I felt accepted for who I was.

In my second season, I qualified for Nationals again. By now I was developing a comfort zone for competition and the pressures it brought. I was becoming a true athlete.

**Becoming a Contender**

By my third year, I was beginning to develop physically. Finally, I could make a muscle and actually see a bulge appear on my arm. At fourteen, I had grown into a leadership role because I had become the oldest person on my team. Now, I was competing on a higher level. I had gone from a puny kid to a well-built athlete who could compete seriously. I wasn't what is considered "elite," but I was holding my own. I was beginning to get noticed by other athletes and coaches—not just as an athlete, but also as a person. For the first time, I felt popular. It was great! My confidence soared. I don't think it was cockiness; for once, I just believed in myself.

I knew that the National Championships that year would be a whole new ball game. I could barely sleep the night before we left for Orlando, Florida. I arrived at the airport feeling like a million dollars. Everyone was buzzing with excitement. The plane touched down an hour or so later, and the minute I saw the palm trees, I smiled—I knew that this year would be different and special.

The first few days in Orlando were devoted to relaxation and pleasure. We visited Disney World, M.G.M. Studios and Epcot Center. But once competition began, I was all business. I had made a mental game plan to handle each race and throwing event. With my newfound seriousness, I fared better than ever before. I finished seventh in javelin and placed in the top ten in shot put and discus. Although I did not qualify for track finals, I placed within the top ten in all my divisional races. I had finally broken through. I was a contender.
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by Ayala Manolson, M.Sc., CCC

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The Turning Point

When Stefano was eight or nine years old, he went through a very difficult period. He had a lot of energy and nowhere to vent it. He dreamed of playing football and basketball, but he was very limited in what he could do using his leg braces. His father and I had focused on his learning to walk and being mainstreamed into public schools. Stefano was very frustrated and angry.

Wheelchair sports was the turning point in our lives. Once Stef got started, there was no stopping him. Racing provided him with freedom and speed, taught him about being part of a team and returned the motivation he had lost.

Over the next few years, Stef became self-confident, gained a healthy sense of competition and was given the opportunity to travel to national competitions. He also became involved with a group of adults who played wheelchair basketball for Kessler Institute—there are no junior teams in New Jersey. While he's had some great role models in both sports, I have to give him a lot of credit for his perseverance with basketball. He continued to practice every week—as the "baby" among much older, experienced men—literally, getting "creamed" at times. It definitely was a school of hard knocks.

Stef has won many medals and awards, but none made me prouder than the huge trophy he won in 1992. It was the Tri-State area "Coaches' Award" given to the competitor who had demonstrated the most improvement, growth and development in racing and team spirit during the previous year.

Wheelchair sports has been the best thing to happen in Stef's life. I hope that his story will encourage you and your children, maybe even recruit some wheelchair athletes of the future. No, not every kid who uses a chair will be able to become—or even want to become—an athlete, but there is something out there for him or her to excel in and be proud of, something that will build self-esteem and character.

Stef is now the oldest member of the "Lightning Wheels" track and field team. His young teammates look up to him for guidance and friendship. He truly has become a role model for them, as well as many others.

—Lisa Cargnel
Discussing strategy: Stefano confers with coach Andy Chasanoff at a recent practice.

It has been two years and two more Nationals since Orlando. I am now highly ranked nationally in both track and field.

Wheelchair Basketball
The same year I began track and field, I started playing wheelchair basketball. I asked my grammar school advisor if there were any teams in the area; she said she would look into it. About a week later, she told me about a recreational team that was funded by the Kessler Institute. I figured I would give it a try.

The following Monday, I went to my first practice. Boy, was it tough! I was this little kid who could barely reach the rim from the foul line, and here I was playing with a bunch of men who, it seemed, could hit shots from anywhere! It was a real learning experience.

Now, five years later, I blend right in with those guys I used to think were the wheelchair equivalents of Michael Jordan. Looking back, I think the challenge of playing with adults as a kid made me a better player.

Practice and Determination
Beyond the physical advantages sports have given me, they also have equipped me with a better outlook on life and given me confidence to achieve whatever I strive for. Before sports, I could barely hold a football, never mind throw it, and I would never have had the nerve to ask a girl out on a date. Now, these things are just basic parts of my new life.

Getting involved in sports, on any level, can be an essential stepping stone in life. My involvement in sports has changed me for the better. I feel that everyone—both able-bodied and disabled—should make sports a part of their lives. All you need are practice and determination. These two qualities alone can make or break an athlete. With this in mind, I suggest that all those interested in wheelchair sports give it a try.
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The Arts and Disability

by Sally Dorothy Bailey

The arts can greatly enhance every aspect of our lives: learning, work, play, relationships and identity formation. In fact, because they are so basic and so life-affirming, the arts often open up new avenues for stimulation, communication and growth. If this is true for people who don’t have disabilities, it is equally so for people who do have them.

Disabilities—whether physical, cognitive or emotional—cause a great deal of frustration in the lives of those who have them... The arts break through barriers and limitations. They offer participants many possibilities and options for successful expression of feelings and ideas. Difficulty on one level of perception or communication does not negate enjoyment or participation on another... For example, someone who has difficulty expressing herself in words because of a speech disorder or learning disability may be able to express herself through pantomime or dance. A student who can’t write about something that happened to her might be able to act it out or sing about it...

If an individual can experience success, be valued for her ideas and have her feelings validated, her self-confidence and self-esteem begin to grow. When attitudes about the self change, obstacles become surmountable...

Making friends and sharing experiences creates a sense of belonging to the community, of having the right to exist and enjoy life alongside everyone else. To be acknowledged for artistic creations leads to the desire to contribute more—to the self, family, friends and community...

Specific Skills Which Drama Develops

Each art form helps student artists develop specific skills. A look at some of the skills that drama enhances will show how participation in theater arts might benefit a person who has a disability.

Listening: Directions to games must be listened to in order to play. Stories must be heard before they can be acted out. While acting out a scene, each actor must listen to the other actors in order to know when to say her line and what to say...

Eye Contact: Many children who have cognitive disabilities or low self-esteem have difficulty making eye contact with others. Eye contact is part of listening and receiving information from others. It is also part of sharing information with others about what you are thinking and feeling. Being able to make eye contact with another person enhances trust as well as communication.

There are many drama games that stress eye contact and therefore

Performers, as well as audiences, enjoy musical theatre productions.
develop the ability to use it on stage and in real life...

**Awareness of the Body in Space:** Some people need a lot of "personal space" and some need just a little. If someone breaks the boundaries of your personal space without your permission, you probably will feel threatened. Sometimes students are aware of their own personal space, but not of the fact that others have it as well.

Awareness of personal space is a cultural concept that is taught non-verbally. Children normally learn it through observing their parents as they interact within the family and in the world at large. Children who have special needs sometimes miss out on a lot of information that is taught non-verbally because their attention is occupied with other emotional, physical or information-processing concerns. This lack of awareness of body and personal space boundaries can lead to personal misunderstandings and fights...

Shape-shifting or transformation exercises stress changing your physical self into other animals or objects, both large and small, and moving in different ways. Slow motion/fast motion exercises can create the awareness of how your body moves through space and at which speeds you have more or less control.

Once a student understands how her body inhabits the space around her, she can begin to learn how her body interacts with other bodies in space. Many movement games teach spatial relationships. Others teach how to touch appropriately and in a non-aggressive manner.

**Physical Expressiveness:** Guessing games and transformation games require students to use their bodies in different ways to communicate an idea to others. Pantomime necessitates that students imitate an action as clearly as possible. Creating a character different from oneself encourages expressing emotions in different ways and exploring how other people move and express themselves.

**Facial Expressiveness:** For humans, the face carries more emotional information than any other part. In fact, communication begins with the face... Working with facial expressiveness in drama class develops ease and appropriateness of expression as well as the ability to interpret the meaning of facial expressions in others.

**Verbal Expressiveness:** The most obvious way drama can enhance verbal expressiveness is by training students to speak clearly and understandably. Through improvisation, students can learn to translate thoughts and emotions into words... Expressing how a character in a fictional context feels can provide a student with enough emotional distance to be able to sort through her own feelings and choose appropriate words...

**Focus and Concentration:** Focus and concentration are crucial for an actor to develop in order to create an exciting performance on stage... Focusing on drama games and activities, which are of short duration, but which create intense, enjoyable feelings, a student begins to learn how to focus her attention. The immediate positive feedback from her body, her emotions, the teacher and her fellow students reinforces focused behavior and encourages her to pay attention to what is going on in the classroom.

**Flexibility and Problem Solving Skills:** Many children with special needs, in trying to cope with physical, relational or educational situations that seem to be out of their control, can become very tight and rigid in the choices they are willing to make. They stop taking risks and limit themselves to a narrow range of behavior that may or may not be appropriate to the current moment.

For example, a child who has difficulty controlling her body movements because of cerebral palsy could develop an inflexible need to always be in control of every interpersonal interaction. Things have to go her way or no way at all. If she can't call the shots, she might whine, complain, protest, have a temper tantrum or refuse to participate. Obviously, these are not productive coping strategies. No one can always control other people's behavior or choices...

In drama class, students have the opportunity to try out different roles and behaviors in a safe situation. Different strategies for solving a problem can be acted...
out and the pros and cons of each evaluated and discussed. Changing points of view on a situation through role reversal often helps students open up their personal perspective on a specific problem or on their general orientation toward themselves and others. Just the experience of standing in another's shoes for a little while teaches flexibility and opens up the possibility that other choices do exist and might be considered.

**Social Interaction:** Sometimes children who have special needs have poor group interaction skills because they don't have enough opportunities to practice them...

A wide variety of group experiences are available for students in a drama classroom. The entire class might act out something together in a parallel fashion, expressing different versions of the same idea side by side without interacting. The teacher might lead the group in a transformation game where everyone changes from elephants to monkeys to thorn bushes. The whole group might play an interactive game... Individuals can take turns getting up in front of the group and pantomiming different activities or singing a song. Partners can work together on games and exercises. Small groups can invent an improvisational scene or play a game in which they have to work together to solve a problem. In each type of group experience, students have the opportunity to make positive contact with other students, to give and take ideas, to resolve conflicts and to make friends.

**Self-Esteem:** Because they are different from other children in their neighborhood or school and because they may not succeed in academic and social settings—the two main arenas of childhood—children with disabilities may not feel good about themselves.

Drama is a self-esteem builder. Through dramatic experiences in class and in performances, children can share the creative, vulnerable, and absolutely unique aspects of themselves with others. They can explore who they are, experience success, and begin to feel proud of themselves.

Sally Dorothy Bailey, R.D.T., is an established playwright, director and drama therapist with an M.F.A. degree from Trinity University. She is director of the Special Needs Program at the Bethesda Academy of Performing Arts in Bethesda, Maryland—a program she established in 1988. Her work at BAPA includes teaching special needs classes and directing three barrier-free performing companies for individuals with and without disabilities.
The Sky is the Limit

by Debbie Meyer

It all started six years ago with an ad in the paper—"Wanted: Drama Teacher." My educational theatre program was at a standstill at the time, and I was looking for something to do. The position, however, turned out to be a bit more than I had anticipated. The Baltimore County Department of Recreation was looking for someone to teach a theatre program for 12 young adults with developmental disabilities.

Could I do it? Well, I had a degree in theatre arts, and I also had a degree in psychology. This might be a way to combine both interests. Sure, why not?

As I began thinking about the task, I became more excited about the challenge. I needed to create a way for anyone, regardless of their ability or disability, to participate in and develop a love of theatre. Since musical theatre was my first love, I wanted to find a way to share this experience with my students.

Creating a musical theatre program for individuals with multiple disabilities would not be simple. Some people were non-verbal and I wondered how to include them. Then, I came up with the idea of having actors and actresses sing along with recorded voices. This allowed everyone to participate.

Choreography development was another challenge—some people were not too steady on their feet; others used wheelchairs. The choreography had to be exciting enough to maintain audience interest, but simple enough to avoid frustration on the part of the performers.

As we continued to rehearse, previously hidden talents were uncovered. We all worked hard to create costumes and scenery. I learned to be flexible. Every director begins a project with a certain vision, but

William Lundy and Anita Jacksits perform in a "Sky is the Limit" production.

William began his involvement with theatre as a student in the first musical theatre program. He is now active in integrated community theatre productions.

knows that the show develops according to the talents of the cast.

Finally, it was "opening night." We performed our show for friends and family. It was a huge extravaganza, and no one was left untouched by the experience.

Such a marvelous experience was bound to grow. With the support of Baltimore County Department of Recreation and Parks, the program expanded and won numerous honors and awards. One day, my boss asked if I was interested in starting an integrated theatre program for people with and without disabilities. Once more I said, "Sure, why not!"

That was the beginning of "The Sky is the Limit" Community Theatre. Housed in a 700-seat auditorium, "The Sky is the Limit" now performs two large-production, family musicals every year. It also sponsors five 20-week musical theatre programs, a tap program, a six-week integrated summer performing arts camp for children and performing arts classes for children. People with disabilities are encouraged to participate in all programs and performances.

For some, community theatre has become a "family affair." Cathy Steffen had always loved the theatre, but when her third child, Ryan, was diagnosed with developmental disabilities and autism, she thought her perform-

From left, Tom Sawyer (Brookes Evans), Becky Thatcher (Sarah Collier), and Huck Finn (Tommy Lewis) do some exploring in this scene from the community theatre production of "Tom Sawyer." In addition to her community theatre involvement, Sarah, who has Charcot-Marie-Tooth disease, is beginning her second year as a "goodwill ambassador" for Maryland's Muscular Dystrophy Association.
ing days were over. When Cathy saw an announce-ment about “The Sky is the Limit” in her local paper, she knew it was the answer to her prayers. Not only does she perform in all of our shows, but so do her children, Sarah, Jenny and, of course, Ryan—he played Little Jack Horner in our production of Babes in Toyland last year.

Of course, none of our programs would be successful without the commitment of our wonderful staff and volunteers. Parental involvement has also been crucial. These programs would not exist without the courage and support of many people.

Anyone with a love of the arts can start a program like ours. We keep growing and growing—your program can too. Give it a try. After all, the sky is the limit!

Debbie Meyer is Director of Therapeutic Creative Arts for the Baltimore County Department of Recreation and Parks. She lives in Baltimore, Maryland with her husband, Frank, and their four-year-old son, Hank.
Meeting the Challenge
by Debra Corwith-Frieden

The President's Council on Physical Fitness and Sports (PCPFS) was established by President Dwight Eisenhower in 1956. It was one of the first steps in a national campaign to help American youth "shape up." In 1958, I was one of the program's first eager participants. I remember pushing myself to perform the required number of sit-ups and chin-ups in hopes of earning the coveted Presidential Physical Fitness Award. My sister, Marcia, who has developmental disabilities, was not given an opportunity to participate in this—or any—fitness program.

Much has changed since 1958. Today, PCPFS sports and physical fitness programs are open to people of all ages, including individuals with special needs.

**Presidential Sports Awards**

The Presidential Sports Award program was developed by PCPFS in 1972 and is administered by the Amateur Athletic Union (AAU/Presidential Sports Awards, P.O. Box 68207, Indianapolis, IN 46268-0207). The program's purpose is to encourage physical activity and exercise for people of all ages—anyone over the age of six may earn an award. Awards are available for almost every imaginable sport or fitness activity.

Participants in the program keep track of their activity on a "fitness log." Fitness logs and qualifying standards for each sport can be obtained from the AAU. Adaptations to qualifying standards may be made for individual disabilities. When qualifying standards have been met, send the log and $6.00 per award back to AAU. An award packet consists of a certificate of achievement from President Clinton, letter of congratulations from the chairman of PCPFS, embroidered emblem or blazer patch, sports bag identification tag and shoe pocket which can be used to hold identification, money, keys or other small items.

Family members who participate in the program and earn awards together receive a special Family Fitness Award. Christine Spain, Director of Research, Planning and Special Projects at PCPFS, says that earning a Family Fitness Award can be a fun activity for parents to share with their children. It can promote family togetherness while introducing children to fitness activities.

**The President's Challenge**

Under the guidance of physical educators and youth leaders, young people ages 6 to 17 can earn one of three Youth Physical Fitness Awards. To earn an award, students must participate in five tests: 1) Curl-ups: a measure of abdominal strength and endurance; 2) Shuttle Run: a measure of speed and coordination; 3) One-Mile Run/Walk: a measure of heart/lung endurance; 4) Pull-ups: a measure of upper body strength and endurance and 5) V-Sit Reach: a measure of flexibility. A child's level of performance on these five tests determines the award he or she will receive—the Presidential Physical Fitness Award, the National Fitness Award or the Participant Physical Fitness Award.

Students with physical disabilities can earn Presidential Youth Fitness Awards through the use of modified award criteria. PCPFS allows modifications to or substitutions for any of the five tests in order to accommodate an individual child's disability. The instructor may use his or her discretion in deciding whether the child has qualified at a Presidential, National or Participant award level.

**Program Benefits**

In 1991, after eight years of teaching swimming to students with mental retardation, I became a classroom teacher of students with multiple handicaps. My experience with the Presidential Fitness Mile Lap Swim for Special Populations (see sidebar) had shown me that fitness award programs could pay off in many ways. Along with
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This method of assessment has worked well for children with autism, mental retardation, behavior disorders, cerebral palsy, seizure disorders, hearing and/or vision impairments, and developmental delays. All assessments are conducted in a caring residential school atmosphere by professionals who have chosen to work with children with multiple disabilities.

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The Presidential Fitness Mile Lap
Swim for Special Populations

The Presidential Fitness Mile Lap Swim for Special Populations is a unique component of the AAU/Presidential Sports Awards. This program allows children 10 or older who have multiple disabilities to earn a Presidential Sports Award by swimming a minimum of one mile (5,280 feet) within 80 hours during a four-month period. Children and teens with no prior swimming experience have successfully earned this award.

Interested people can implement this program in their communities by scheduling training times at a community pool facility, obtaining local sponsorship and recruiting volunteer coaches. Local newspapers can help spread the word.

An informative brochure has more information on the program and suggestions for implementing the program in local communities. Contact Debra Corwith-Frieden, 3539 Ada Vista, Uniontown, OH 44685, (216) 699-8956.

improved physical condition, I had seen my swimming students develop motivation, self-confidence and pride in their accomplishments. I promised myself that I would give each of my students the opportunity to earn a Presidential Youth Fitness Award. Our school’s physical and occupational therapists worked with me and another teacher to modify each fitness test for individual students. Then, we recruited a classroom of fourth grade students to help our students train.
We established various training stations in the school gym and trained four times a week. Integrated groups of six children rotated from one exercise station to the next. The fourth-graders demonstrated each exercise and gave hands-on assistance as needed.

This program reaped a number of benefits. Special needs students gained the expected physical benefits of a program of regular exercise; they also gained new social acceptance. Within months, a new spirit of unity and openness came about as the integration that began in the gym spread throughout the school. Regular-education students spent lunch and recess times with students who had disabilities. In the hallways, students with disabilities were greeted by name, verbally or through sign language. Classroom exchanges took place.

**Fond Memories**

For one fourth-grader and her brother, the program had special meaning. Ruth’s mother wrote, “My son, Andy, had many severe disabilities. Even though he never spoke a word in his fifteen years of life, he conveyed volumes in body language. It was so heartwarming to watch his reactions to the fourth graders helping with this program.

“Andy’s sister, Ruth, was the only fourth-grader to be able to claim a sibling with special needs. Though dealing with disabilities was not new to her, she learned that her brother’s challenges were not the same as the others in the class—each person had his or her own special package of abilities. It was wonderful to have her come home each day and share the triumphs of her brother and his classmates. I will never forget the day of the awards ceremony when Ruth pushed Andy’s wheelchair up to the front of the room so that he could receive his award. It was a picture that will never be erased from my mind, because it was one of the last things they did together. Andy passed away several weeks later. All of his fourth grade friends still think of him fondly as an honorary member of the class of 2000.”

**For more information...**

For further information on any PCPFS program, contact: The President’s Council on Physical Fitness and Sports, 701 Pennsylvania Ave., NW, Suite 250, Washington, DC 20004, (202) 272-3427.

Debra Corwith-Frieden lives in Uniontown, Ohio, with her husband and two children. Currently, she is a supervisor at the HELP Foundation, an agency that provides supported living services to adults with disabili-
Riding the Bus

It's hard to predict the reaction a given search letter will bring, but we were astounded by the deluge of mail—and the outpouring of opinion and emotion—elicited by a question about the pros and cons of riding the school bus (February 1994). Clearly, this issue hit a nerve with many readers. Some of them share their thoughts here.

Joy Dillman:

Your letter really pushed a button with me. I have experience in just about every angle of this issue and am delighted that you have voiced this question. While I know of no studies on this topic, I can speak from my own observations and experiences.

I am the mother of an 18-year-old son. Dave had infantile spasms and developmental delays beginning at eight months. He attended a parent-infant program starting at 15 months and various special education programs through second grade and was totally mainstreamed thereafter. Dave had some autistic characteristics as a preschooler and continues to have some social difficulties. We have transported him ourselves, used school buses and utilized car pools during all his school years.

I also am a professional. Currently, I am the educational specialist and center director of an early childhood intervention program. Our program provides limited transportation services, primarily to children whose parents have no means of coming in for services.

As a parent, I much preferred to transport my son. It seems that the most meaningful communication I have had with any of my children occurred while in the car. These were, and still are, precious times—the phone doesn't ring, chores aren't calling and the enticements of TV and Nintendo aren't present.

When Dave was small, the car provided a major context for learning language. He learned the letters of the alphabet—"M" for McDonald's, "K" for K-Mart—and began to read by observing billboards and street signs. He learned about colors, sizes and the concept of same and different. He learned action verbs and adjectives as we talked about the things we saw along the way. As he got older, we played math games by making stories about topics he liked. When we didn't feel like talking, we listened to tapes of classic children's stories, rhymes and songs. Because he had a very short attention span and tended to be anxious and obsessed about certain thoughts, he needed a lot of structure. We used our time in the car to go over the day's schedule and review the rules he needed to remember before school. Immediately after school, he was ready to talk about what went on during the day. During the ride home, he talked more than at any other time of the day.

When my son was in preschool, I usually accompanied him to his classroom each morning. This gave me contact with his teacher and other parents. I felt good that I knew what was going on at school. I also made some great friends—both his teachers and other parents. I didn't realize how important this was until he began riding the bus, and I missed it so much. But because I had gone back to work, riding the bus, at least part of the time, became a necessity.

I was never pressured to utilize bus transportation, but I have worked with other professionals who did pressure families. They felt that riding the bus was an important part of learning to separate from parents and

Joy Dillman and son Dave celebrate his 17th birthday.
to become independent and responsible. They believed that riding the bus aided social development. Some teachers may prefer that children ride the bus because it gives them an additional measure of control over their time with the child. They may not wish to be distracted by parents coming and going and prefer that the children arrive together rather than individually. Part of their agenda may be to break down the overprotection that they feel the parents have for their child.

While transportation is a needed service and a godsend to some families, no one should be pressured to use it. To some children, the bus ride can be very disorganizing and overstimulating. Transportation decisions should be based on the best interests of the child and the family.

Joy Dillman lives in Round Rock, Texas with her husband, Ken, and their children, Dave and Mary. Dave is a senior at Brentwood Christian High School and plans to attend Abilene Christian University in the fall. Joy is director of the PRIDE (Parents' Resources for Infant Development Enrichment) Program in West Williamson County, Texas. Her career is a direct result of being a parent participant in early intervention programs.

Debbie Johnson:
I have a six-year-old son with autism, and I take him to school each day. At times, his teachers have stressed the "need" for Joshua to ride the bus, but they never gave any solid reasons as to its benefits.

I have found that the time we spend together each morning and afternoon is some of our best quality time. We share a prayer together before we leave in the morning, and, as we travel, I constantly feed him verbal information. I talk about everything from the things we see outside to our plans for the night or weekend. Joshua learns a lot during this time. I also have the benefit of daily teacher-parent contact. I get firsthand information about his progress and am able to give my input regarding his educational program.

I also get to know the other students and see how my son is relating to them. Just last week, I had the privilege of seeing my son and another boy hug each other—on their own, without any prompting. If Joshua rode the bus, I never would have seen that. It means a lot to parents like us to know that our children have friends.

My advice to you is this: if your child wants to ride the bus, let him ride it—but on his time frame, not the teacher’s. Pushing a child too fast can do more harm than good and if your way of doing things is working for you and your child, why change just because the professionals tell you to? You have more credentials than they have; you are the parent.

Debbie Johnson lives in Suffolk, Virginia with her husband and son. She works part-time as a real estate title searcher.

Norene Parker
My 20-year-old son, Mike, has multiple disabilities. I have been driving a special education school bus for the last 10 years. I first began driving Mike’s bus when it became increasingly difficult to make adequate day care arrangements for him. I discovered that I loved driving the bus, so I have continued. During the course of my day, I transport children as young as 18 months and as old as 21 years.

Yes, your seven-year-old probably should be riding the bus just as his classmates do. As crazy as it may sound, it is an integral part of the school day. It's a chance for the kids to socialize and make friends outside their immediate classrooms. It fosters independence and self-reliance. Students use this time to grumble about teachers and homework and to exchange ideas on topics not usually discussed in school—video games, the opposite sex, sports and...
other subjects. Your son would feel like he was more a part of the school program if he arrived and departed just as the other students do. This may be a boost to his self-esteem. Being made to feel different may be more distressing than he realizes and may hurt the feelings of some of his classmates. Usually, being picked up by a parent is a special treat.

Yes, the teachers may prefer that your son ride the bus for other reasons that they are not discussing. Do you always arrive on time? Are you anxious to chat with them while they are trying to get other students to their buses? Do you keep them talking after the buses have left, preventing them from getting home to their own families? Do you expect a detailed report of your son's day each afternoon? There could be many reasons that the teachers would prefer not to see a parent twice a day, but most likely, they simply know that your child will mature faster if he takes some small steps toward independence. Don't worry—in 10 years of transporting several hundred students, I have yet to find one that didn't absolutely love riding the bus!

Norene Parker lives in Ellicott City, Maryland, with her husband, Mike, and two sons—Mike, Jr. and Billy. For the past ten years, Norene and her husband have led a Boy Scout troop for boys with disabilities—Mike, Jr. earned the rank of Eagle Scout in 1992. Norene drives Howard County Bus Number 77.

Lynn Cahill:
Our son is also seven years old and mildly autistic. He began school four years ago. Placing David into a special program that would benefit him didn't bother me—we all want the best for our children. However, I worried about putting my young son on a bus. I was very apprehensive, but my husband encouraged me to give it a try.

David's first day of school arrived. The bus stopped in front of our house and its doors opened. I waited for the tantrum and tears to begin. To my surprise, David got on the bus, took a seat and never looked back. For me, the decision to let David ride the bus was one of the most difficult ones I ever had to make. But for David, the bus signaled the beginning of a new adventure, and he enjoyed every minute of it.

Riding the bus has helped David gain a sense of independence and self-esteem. He gets very excited when he sees the bus because this is part of his very structured day—and he desperately needs structure. He even looks for the bus to come on weekends. His bus rides also make him feel like part of his school community because it is something that he shares with his peers.

We don't know the preference of David's teachers, but we do know that driving our son to school would not work for us. He would expect us to stay, and he
David Cahill enjoys his summer vacation.

would balk at getting out of the car. An upheaval like this in the morning would affect his actions for the rest of the day.

Whatever your decision is, however, it should be honored and respected by all involved. We strongly feel that parents know what is best for their child.

Lynn Cahill lives in Chicago, Illinois, with her husband, Paul, and three sons. She does volunteer work for her local PTA and Cub Scouts.

Kathy Andrus:

When our three-year-old daughter, Kate, who was blind and had a congenital heart problem, began preschool in our public school system, we were strongly urged to put her on a school bus. Since the school was only a mile and a half from our house, we really didn't see the need for her to ride a bus. She often rode to school on the back of my bicycle, or I transported her back and forth in the car. Since Kate was the youngest of our five daughters, we found this time in the car or on the bike to be a special time to share together.

Throughout my daughter's preschool years, teachers and administrators continued to nag me to put her on the bus. One administrator actually told me that I was depriving her of a valuable educational experience! Neither my husband nor I ever had to ride a school bus until we accompanied our children on school field trips. We found it to be pretty low on the scale of "valuable educational experiences!" Preschool children were strapped into their seats—one child per seat—and "quiet" was enforced. We never gave into the pressure to put Kate on the bus during her preschool years, but we often felt bullied and intimidated by professionals who felt that we were not doing the right thing for our child.

When Kate began elementary school on the other side of our vast county, she began riding the bus. For the first two years, her ride was about an hour long each way with only two other children on the bus. The
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Ten-year-old Kate Andres (front) with older sisters (clockwise from top left) Molly, Margaret, Robin and Beth.

Kathy Andres lives in Alexandria, Virginia, with her husband, Nick, and four daughters. She has an M.S. in Child Development and does volunteer work with various family support groups in Fairfax County, Virginia.
Crying Can Make You a Better Man
by Hogan Hilling

Many men have a difficult time expressing their feelings—especially when it comes to crying. Like most men, from the time I was a young boy, I was taught not to cry. I was told that crying was a feminine characteristic, a sign of weakness. I knew that if I cried without having a very good reason, I would be subjected to teasing and name-calling. While growing up, there were many times I wanted to cry, but I was afraid of what my male peers would think and say about me. As it turned out, I had to wait until I was 38 years old before I finally realized that it was all right to cry.

One day, early in our marriage, before our children were born, I arrived home to find my wife, Tina, in the living room sobbing. "Why are you crying?" I asked as I tried to console her.

"I don't know," she replied.

"What do you mean you don't know? How can I help if I don't know why you're crying?"

"I don't know, honey! I just feel like crying."

"That's ridiculous! You have to be crying for a reason. C'mon! What is it?"

"I don't know!" Tina answered.

I became very frustrated. I expected to come home to a happy wife, a clean house, a nice dinner and maybe, a little romance. Instead I was met by a crying wife who had no reasonable explanation for her actions. I despaired of ever understanding women!

One evening last year, I went through my usual bedtime ritual of going into my sons' rooms to kiss them good night as they slept. This was a special time each day when I felt as though I could stop the hands of time to cherish the privilege and honor of being a father. After I kissed Wesley, a warm feeling came over me that touched my heart like never before. His beautiful face, glowing in the dark night, brought tears to my eyes. I sat motionless on the edge of his bed, crying my eyes out.

Ten minutes later, my face still wet with tears, I walked to the master bedroom. I got into bed next to Tina, looking for comfort. She held me in her arms as I let out the biggest cry of my life. I was crying so loud that I thought the neighbors might hear. I put a pillow over my head to muffle the sound.

I cried for what must have been close to 30 minutes. Like a good wife, Tina did her best to console me. Then, it was time to for her to ask the infamous question, "Hogan, why are you crying?"

Guess what my answer was. That's right—"I don't know!"

When I look back to the first time I asked my wife that question, I can see how insensitive I was because...
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**Hogan Hilling with sons Grant (left), Wesley (right) and Matthew.**

of my frustration with her inability to answer. And although I didn’t have an answer for her that evening, the next day I understood my reasons for crying. Crying helped me release all the tension, anxiety and frustration that had been building up inside me. It felt great to relieve myself, in a nondestructive way, of all the hurt and pain I was feeling. I also realized that I could never love another human being as much as I loved my children that night.

Crying is a wonderful, intimate experience that I recommend to any man. It’s an experience men ought to learn to accept and share with their families. By coming to terms with my own need to cry, I now have a much better understanding of other people’s feelings. Most importantly, it has strengthened and enhanced the relationship I have with my wife and children.

Put the macho stuff on hold for a while, guys. Find the strength within yourself to open up your heart and give yourself permission to cry, cry, cry for whatever reason. You’ll be a better man because of it.

Fathers’s Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father’s Network, focuses on fathers’ experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers’ Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers’ Network, The Merrywood School, 16120 N.E. Eighth St., Bellevue WA 98006, (206) 747-4004; fax: (206) 747-1069. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children’s Health, Bethesda, MD.
From Rage to Reform: What Parents Say About Advocacy
by Judith A. Mayer

We got on those committees because we were desperate for change. We have desperate crisis-oriented kids. We have to have change."

Although her child has a serious emotional/behavioral disorder, this mother, like many other parents of children with disabilities and chronic illnesses, has

managed to overcome stigma and resistance from professionals and the public to become an advocate.

"Not only are our children stigmatized—so are we!"

Anger progresses to rage. Parents become angry at professionals who blame them for "poor parenting" and will not listen to what they have to say about caring for their children. They are upset with the policies of educational and mental health systems that do not meet their children's needs.

Listening to Parents
I began listening to parents—first, as a parent of children with special emotional needs, then, as an associate with the Research and Training Center on Family Support and Children's Mental Health in Portland, Oregon. The Research and Training Center staff interviewed parents from across the United States, individually and in groups, about their advocacy experiences. Common themes were woven through their personal stories of parenting and advocating for children with emotional and behavioral disorders.

Parents are the first to realize that "something is different" about their child. This realization produces a variety of emotions—fear, guilt, shame, loss and grief. Parents spoke of the barriers to finding support and services:

• Blame: Parents are blamed for their child's disability—"Blame either keeps us from getting involved, or makes us so angry that we get involved just to prove them [professionals] wrong."

• Stress: "Some days it is just exhausting to be with my child."

• Stigma: "It is the stigma of mental illness. You're not going to say to anyone, 'My child is driving me crazy.'"

• Lack of understanding: Professionals do not understand—"We were stereotyped as emotionally disturbed parents who had to be tolerated."

• Lack of services: Educational and mental health services are often unavailable and/or inappropriate—"Programs need to be designed for the needs of the children and the parents rather than for the needs of the bureaucracy."

• Lack of knowledge about resources: "We didn't know what help was available to us. Professionals did not know either."

These parents knew that in order to make a better life for their child and family, they needed to overcome these barriers. Most started by contacting another parent who led them to a support group.

Help and Hope
Parents found that an invitation to join a support group was the most helpful ingredient on the road from anger.
to advocacy. Parents who could not find a support group started one. Support groups provide a safe place to vent anger at both professionals and a service system that does not understand or meet the needs of their children.

Parents shared other factors that allowed them to overcome barriers:
- **Other parents:** "Parents need special time to just be with other parents... to share strength together."
- **Learning about resources and services:** "I wanted to be informed about how I could help... These parents took the time to talk to me about my fears and anxieties. They said, ‘You need to start looking for services and be your child’s best advocate.’"
- **A professional mentor:** "A good professional is a gift."
- **Success in getting services:** "You begin to change things for your own child. Then you think, ‘Maybe I can do this for more kids.’ That’s how I started as an advocate."

**From Personal To Public Advocacy**

"Personal advocacy" occurs when a family overcomes barriers and successfully makes changes in a child’s life. This experience often provides a springboard to move into public advocacy for other children. This transition from personal to public advocacy brings about needed improvements in services for children— "When you start putting ideas together you can make a difference. This time it will help my kid; next time it will help another kid."

Parents who are not successful in finding services for their child can also become public advocates— "Our involvement has evolved from being so overwhelmingly angry at a system that couldn’t serve our child to deciding that we could vent our anger in a way that will change services—perhaps not in time for our child, but maybe other parents and other children will not have to suffer..."

More than any other emotion, anger serves as the driving force for change. Dealing with personal anger and seeing it as a positive force for change has proven effective for parent advocates.

**Advocacy Has Benefits—and Costs**

Parents have found that joining with other parents brings benefits to themselves as well as to their child and other children.

"What’s kept me going is being armed with so much information that I can share with so many other parents."

"...my advocacy brings about change that improves services not only for my kid, but also for kids across the state."

"Being able to change the system does something for my self esteem. I feel good about myself when I talk with other people who are struggling with the same issues."

Public and private advocacy ends isolation by providing opportunities to share experiences with other parents without blame or judgment. Parents assist each other in identifying needed services and accessing or advocating for these services. By helping others, parents feel valued for their experience and expertise.

Parents also begin to work with professionals to bring about attitudinal and system changes. Collaborating with professionals, they provide a unique perspective on the child and the disability.

But advocacy also has its costs: being both parent and advocate for one’s child takes considerable time and commitment. Moving into public advocacy requires even greater commitment and may lead to greater frustrations.

"...as a parent on a committee, I am expected to answer for every parent."

"...it’s so hard to sit at meetings and listen. I can’t decide if I want to scream or cry."

"You have to fight a system that’s unbelievable, and you get tired. We all need a break sometimes."

"I feel hopeless sometimes when I don’t see that what I’ve said or done has made any difference."

"I feel intimidated by professionals."

"Professionals ask me questions but they never really listen."

"I have contributed to a lot of groups and have barely even gotten a ‘thank you.’"

Although public advocacy has many difficulties, parents stay involved to bring children the services that will give them a brighter future. Many parents view their involvement as integral to the role of being a parent.

**A Family Affair**

A decision to move into public advocacy needs to be made by the entire family. Families need to decide on the extent of their involvement.

Public advocacy can involve time away from home; this places heavier responsibilities on other family members. Sometimes families just need to pull back and “recharge their batteries.” When a child is doing well, parents may want simply to enjoy time together. A family may need to take a break.

Often, advocacy involves talking about private family experiences—"It is hard to make a career of your child’s disability; you keep living those events over and over." A parent who is beginning to consider public advocacy needs to think about respecting the privacy of the child and family. They also should contemplate how, or whether other family members, including the child with a disability, should become involved—"Children whose lives are emotionally disordered need the advocacy of those who parent them."
They cannot do it themselves. As they grow older, it is the task of parents and professionals to help them learn how to advocate for themselves.

Words of Wisdom

Parents who advocate for improved services in education and children's mental health learn by trial and error. They continue because they see changes and because they believe in the power of parents. These parents advocate with compassion, strength and hope—"Our role switched from one of saying, 'well, we just happen to be parents,' to... 'we have expertise that nobody else has.'"

Parents who have "been there" offer this advice:
• Make decisions about public advocacy as a family.
• Define the roles family members will play in advocacy.
• Join with other parents in advocacy. Decide on the issues to be addressed; present a united front.
• Have a coach or mentor—usually a professional—to keep parents informed about system issues and politics.
• Have a team of parents available to serve on boards and other committees. Know the board you will serve on. Know your role on the board, the time commitment required and the provisions that have been made to reimburse you for expenses.

Advocacy Works

"What I gained a long time ago from other people, I can give away now. It's my gift to all parents."

The process of working through anger, hurt and frustration with other parents can lead to reforms in education and mental health services for children. The parents in this story found hope for the future by using anger as a force for change. A parent is a child's best advocate; you can make a difference.

Judith A. Mayer, MSW, is Project Coordinator for an integrated service center in a local high school. She is the parent of two teenagers who have special needs.

The Research and Training Center on Family Support and Children's Mental Health provides information to families of children with serious emotional disorders, as well as professionals and other interested persons. The National Clearinghouse on Family Support and Children's Mental Health includes a rational toll-free telephone service, a computerized data bank, a series of information sheets on children who have emotional disabilities and their families, a state-by-state resource file and a family resource coordinator. Contact: The National Clearinghouse on Family Support and Children's Mental Health, Portland State University, PO Box 751, Portland, Oregon 97207-0751, (800) 628-1696.

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We believe that all children, no matter how severely disabled, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.
Racing Wheelchairs for Children

By Alyyne Landers

Wheelchair racing is fun, recreational, therapeutic and highly competitive. Adults don't have all the fun, though—kids, too, are tearing up the tracks. Within the junior class, the girls are as tough as the guys—the 1992 and 1993 Sports 'n Spokes Junior Athletes of the Year, Shannon Morrissey and LeeAnn Shannon, are racing champions.

As with all sports and recreational activities, safety considerations should be foremost. It is advisable that a protective helmet be worn at all times while racing.

From the standard wheelchair to today's state-of-the-art models, the racing chair has gone through many changes: its seat angle has been raised to provide better sitting stability; the seat itself has been lowered; the two widespread front casters have been replaced by one large tire, and the front housing, connecting the front wheel to the frame, has been extended to create an open V-shaped form or a single bar, an "I" or "T" frame. Today's aerodynamic chairs have a lower center of gravity, provide a more stable seat for the racer and are incredibly fast.

Racing Wheelchair Components

Scaled down to proportionate size, children's racing wheelchairs have the same design as those for adults. Seats come as variations on one of two forms. The first looks like a standard wheelchair seat but with a shorter depth and a fabric strap which attaches to either side of the seat frame to go over or in front of the knees. This is sometimes referred to as a traditional seating position.

The second style is the bucket seat that supports the lower legs from the knees to the ankles. This seat keeps the legs in a tucked position under the racer's torso, resulting in the "kneeling" racing position.

Frames are generally tubular and made of chromemoly, graphite or other lightweight composite materials. The more aerodynamic V-shaped frame consists of one or more sets of bars that connect to a center bar or the front wheel housing from each side of the seat. This style is designed for advanced racers who have the flexibility to transfer over side bars and assume a kneeling position.

Rear wheels usually measure 24 or 26 inches; front wheels are 16 or 20 inches for children and youth. Some models have a "fender" running over the top portion of the rear tires to prevent chafing on the inside of a racer's arms. Handrims, or pushrims, on the rear wheels range from 13 to 16 inches; the optimum diameter is determined by what is most comfortable for the individual racer.

A variety of footplates have been developed for various abilities and preferences. A fixed platform may be best for children who have difficulty transferring or strapping in their feet. For others, a simple foot strap may be sufficient.

Handbrakes are located near the front wheel casing on the center frame bar, along with a track compensator or steering system. The steering system may provide the ability to "lock-in" a steering position such as a constant turn or straightaway so the racer may concentrate more on propulsion than steering.

Quickie Shadow Racer, Quickie Designs/Shadow Products, Kent, WA.

Accessories

While standard equipment will get your child to the finish line, there are many available accessories to help racers do it more efficiently. Push-gloves help to protect the hands and may give better traction for each push. Safety lights may be added for higher evening visibility, and water bottles or drinking sys-
Gems can help a racer keep cool. Tool kits are handy for dealing with minor mishaps, and cordless computers assist in race training. Side guards, which protect a racer's clothing from entering the spokes of the rear wheels, may be standard or optional equipment.

As far as appropriate racing wear is concerned, anything goes! For recreational racing, anything comfortable will do—however, clothing should not be too loose or include belts or scarves which might tangle in the rear wheels. Competition racing outfits are colorful and diverse. Form-fitting body suits are becoming the norm in competitions worldwide. Shoes, however, are more often than not left on the sidelines. For reduced weight and wind resistance, most racers wear only socks or go barefooted during workouts or competitions.

**Competitions**

Young racers can pit their abilities and equipment against one another and the clock at local, regional, national and international competitions. Children are allowed to compete in marathons along with adults, but there are also many events specifically for children that are held in conjunction with adult events. For kids only, the Junior National Wheelchair Championships are held annually in the United States; comparable events are held in many foreign countries.

More information on competitive events is available from: National Handicapped Sports (Rockville, MD, 301/217-0960), Wheelchair Sports, USA (Colorado Springs, CO, 719/574-1150) and International Wheelchair Road Racers Club (Stamford, CT, 203/967-2231).

Alynne Landers, M.I.M., is a Program Specialist at ABLEDATA, the government-funded project which maintains the assistive technology database by the same name. The database lists more than 19,000 products for persons with physical, cognitive and/or sensory disabilities. The project is managed by Macro International Inc. for the National Institute on Disability and Rehabilitation Research (contract no. HN92026001).

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RECREATION

Resources

The following national organizations sponsor recreational events and/or provide information about recreation programs for people with disabilities. Groups listed in the general recreation category can provide information and referrals for a number of recreational activities, including many for which there is no national organization.

RECREATION (GENERAL)

American Athletic Association of the Deaf
3607 Washington Blvd, Ste 4
Ogden, UT 84403-1737
(801) 393-6710 (Voice)
(801) 393-7916 (TTY)
(801) 393-2263 (FAX)
all ages, deaf and hard of hearing; referrals to local groups, annual children's sports festival

Boy Scouts of America Scouting for the Handicapped Service
1325 W Walnut Hill Ln
Irving, TX 75038
(214) 580-2000
referrals to local troops

Canadian Wheelchair Sports Association
1600 James Naismith Dr
Gloucester, ON CANADA K1B 5N4
(613) 748-5685
(613) 748-5722 (FAX)
all ages; referrals to local groups, national programs

Girl Scouts of the USA Services for Girls with Disabilities
420 5th Ave
New York, NY 10018
(212) 852-8000
(212) 852-6515
referrals to local troops, training for scout leaders

International Center on Special Recreation
c/o John Nesbitt
362 Koser Ave
Iowa City, IA 52246-3038
(319) 337-7578
all ages, all disabilities; referrals to local groups, information on recreational activities

National Handicapped Sports
451 Hungerford Dr, Ste 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0968 (FAX)
ages 5 and older, all physical and developmental disabilities; referrals to local groups, parent advocacy training

National Sports Center for the Disabled
PO Box 36
Winter Park, CO 80482
(303) 726-5514
(302) 892-5823 (FAX)
all ages, all disabilities; referrals to local groups, national programs

U.S. Association for Blind Athletes. Photo: Eric Horan.

National Sports Center for the Disabled
PO Box 36
Winter Park, CO 80482
(303) 726-5514
(302) 892-5823 (FAX)

Wheelchair Sports, USA (National Wheelchair Athletic Association)
3595 E Fountain Blvd, Ste L1
Colorado Springs, CO 80910
(719) 574-1150
ages 5 and older, all physical and developmental disabilities; referrals to local groups, national office for various sports

US Association for Blind Athletes
33 N Institute St
Colorado Springs, CO 80903
(719) 630-0422
all ages; local, national and international sports events

US Cerebral Palsy Athletic Association
500 S Ervay St, Ste 352B
Dallas, TX 75220
(214) 352-4100
ages 6 and older, cerebral palsy and related conditions; referrals to local groups

Basketball

National Wheelchair Basketball Association
c/o Stan Labanowich
Univ of Kentucky

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American Water Ski Association
c/o Phil Martin
Adaptive Aquatics
PO Box 21
Jackson, AL 36561
(205) 826-3001
(205) 826-8332 (FAX)
all ages, all disabilities; referrals, information

Canadian Wheelchair Sports Association
Committee for Sailors with Disabilities
1600 James Naismith Dr
Gloucester, ON
Canada K1B 5N4
(613) 748-5685
(613) 748-5722 (FAX)
all ages, all disabilities; referrals to local groups

US Wheelchair Swimming
C/o Larry Quintiliani
229 Miller St
Middleboro, MA 02346
(508) 946-1964
ages 7 and older; referrals to local groups, recreational and competitive swim programs

HORSEBACK RIDING
North American Riding for the Handicapped Association
PO Box 33150
Denver, CO 80233
(303) 269-1421
(303) 452-1212
all ages, all disabilities; referrals to local groups

PERFORMING ARTS
Association for Theatre and Disability
c/o Access Theatre
527 Garden St
Santa Barbara, CA 93101
(805) 564-2063
(805) 564-2142
(805) 564-0054 (TTY)
al ages, all disabilities; referrals to local groups

Road Racing
International Wheelchair Road Racers Club
c/o Joseph M. Dowling
30 Marano Ln
Stamford, CT 06902
(203) 967-2231
(203) 327-7959 (FAX)
al ages; referrals to local groups

SKIING
Canadian Association for Disabled Skiing
Box 307
Kimberley, BC
Canada V1A 2Y9
(604) 427-7112
(604) 427-7115 (FAX)
al ages, all disabilities; referrals to local groups, information

Softball
National Wheelchair Softball Association
c/o Jon Speake
1616 Todd Ct,
Hastings, MN 55033
ages 7 and older; referrals to local groups, annual camp, national and local tournaments

10933 Johnson Ave S
Bloomington, MN 55437
(612) 750-3973
teenagers with mobility impairments; referrals to local teams

The Bonfils-Stanton Winter Park Outdoor Center in Winter Park, Colorado, provides a universally-accessible trail system for hiking, camping and fishing to participants in summer programs sponsored by the National Sports Center for the Disabled. Photo: Jeff Stine.

Skating
Canadian Wheelchair Sports Association
Committee for Sailors with Disabilities
1600 James Naismith Dr
Gloucester, ON
Canada K1B 5N4
(613) 748-5685
(613) 748-5722 (FAX)
all ages, all disabilities; referrals to local groups

The Bonfils-Stanton Winter Park Outdoor Center in Winter Park, Colorado, provides a universally-accessible trail system for hiking, camping and fishing to participants in summer programs sponsored by the National Sports Center for the Disabled. Photo: Jeff Stine.

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Contact: Nathan Anderson
Children's Care Hospital & School
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Sioux Falls, SD 57105-2498
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This spring and summer, Special Olympics state games will be conducted by all 51 state chapters. Prior to state games, athletes will compete in local or area competitions that will take place in more than 1,500 sites around the country. Athletes will compete in such sports as swimming, softball, running, equestrian events and bowling. For more information on Special Olympics events in your area, contact your state's chapter (Phone numbers listed are for voice only).

More than 450,000 athletes will take part in Special Olympics competitions this year; some will have the opportunity to represent Team USA at the 1995 Special Olympics World Summer Games in New Haven, Connecticut. For more information on the World Summer Games, contact: Special Olympics International Headquarters, 1350 New York Ave, NW, Ste 500, Washington, DC 20005-4709, (202) 628-3630, Voice only.

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Continued on page 64

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Exceptional Parent

120 State Street
Hackensack, NJ 07601
Phone: (800) E-PARENT (372-7368)
Fax: (201) 489-1240

Vice President Advertising Sales
KERRY J. CANNON

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(201) 680-8355 Fax

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(708) 416-0793 Fax

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(714) 366-9289 Fax

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(206) 858-7576 Fax

Ad Traffic Manager
STEFANIE FERRANTE
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(617) 427-0901 Fax

HPA International Consumer Magazine
### Free Product & Service Information

**A. Are you a subscriber to Exceptional Parent?**
- Yes
- No (If no, please see the subscription card in this issue.)

**Name**

**Occupation/Title**

**Company/Association**

**Address**

**City**

**State**

**Zip**

**Phone**

**Fax**

### B. Annual Household Income (include all family members)

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<thead>
<tr>
<th>Income Range</th>
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### C. Do you live in a(n): (Circle)

- 7 Home 8 Own 9 Rent
- 10 Apartment 11 Own 12 Rent

### D. In all, how many automobiles do you and others in your household own or lease?

- 13 One 14 Two 15 Three or more

### E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

- 16 one month
- 17 three months
- 18 nine months
- 19 one year

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**FREE PRODUCT & SERVICE INFORMATION**

**A. Are you a subscriber to Exceptional Parent?**
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- 17 three months
- 18 nine months
- 19 one year

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**Issue Date:** May 31, 1994

**Expiration Date:** August 31, 1994
Ross' Bibs
Haco, Inc.
PO Box 5642, Asheville, NC 28813
(704) 274-0075
These Bibs were originally made for
your son, Ross, by his Aunt Catherine. Now we can make them for
your special child. They are made
of machine washable, long lasting,
heavy duty vinyl. The large child size
is $13.95. The teenage/small adult
size is $15.95; plus $2.00 shipping.
Other sizes available, please call for
more information.

Bibs


equipment Dealers

American Discount Medical
Spring Savings on ALL Strollers—
Equipment and Supplies Discounted
to 50%. Call 800-877-9100. Free
brochure.

Home Medical Equipment Co.
2137 Fowler Street
Ft. Myers, FL 33901
(800) 226-0404
Custom wheelchairs and seating for
pediatric to geriatric. On-site repair
center. Rental of most medical
equipment and vans.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Watertown, MA 02274-9055
(617) 894-0069
Atlantic Rehab. specializes in
Pediatric Mobility and Seating. Sales
and Service. Please call for
more information.

New Hampshire

Advent Medical/Ride-Away
51 Wentworth Ave.
Londonberry, NH 03053
(603) 437-4444
Advent Medical specializes in all
types of rehabilitation & mobility
equipment for your child. Nurse &
therapist on staff for any positioning
issues. Dealers of all major brands
of equipment. Skilled technicians,
24 hour everyday service. Huge list
of references available.

New York

Rehabco
1513 Oldsted Ave.
Bronx, NY 10462
(718) 929-3800
45 years as New York's oldest and
best Rel. ab. dealer. Experts in chil-
dren's mobility & custom seating.
Full time therapist for evaluations
at our new facility. Ask for our 295
page Technology Guide. Please call
or write us 7 days a week for more
information and quality service.

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Consumer Care Products, Inc.
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

To place an ad, please contact:
Barbara Nastro
EXCEPTIONAL PARENT
(201) 880-4874
Fax: (211) 680-8355

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(614) 224-1060
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35-75 lbs. $51.95/cs (60), Free
Delivery. Also—Depend, Serenity,
other items. Manufacturer's
coupons accepted.
Free Catalog!

Incon Products Company
509 West 9th Street
S. Sioux City, NE 68776
Fax (402) 494-1744
We carry a full-line of reusable dia-
pers and pull over plastic pants.
Available in all sizes. Write for more
information and FREE brochure.

Mobility

Blue Sky Cycle Carts
PO Box 5788
Bend, OR 97708
(503) 383-7109
Enjoy cycling with the whole family.
We offer customized bicycle trailers
adapted to carry children & adults
with special needs.

Blue Sky Cycle Carts

Monitoring Systems

Care Electronics
5741 Araphoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCare Systems notify care-
givers when they wanderer leaves
home. Locate them up to ONE MILE
away. FREE catalog!

Sign Language

Evergreen Sign Language Gifts
PO Box 20003
Alexandria, VA 22310
(703) 893-3755 Cal/Fax
Unique Sign Language Gifts for spe-
cial friends; say "I Love You." Good
fund-raisers too! Jewelry, Stationery,
Clothing, FREE Brochure.

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2603 Johnson Rd., Suite 2B
Waitsfield, VT 05673
(802) 847-2545
FREE Sign Language Course!
"ASL 101" with a Sign Language
expert. 4 lesson video, 82 min.
FREE catalog!

For more information and FREE
catalogs contact Keepers Care Systems
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Books, Audio/Video

Interax Video Sign Language
Course
Interax Video Sign Language
Course illustrates 1200+ signs based
on ASL. Six videos with 8.5 hrs.
Graphics provide reference of
equivalent English word.
Free Brochure! $199 (+$4.50 s&h). Interax Training, Inc.,
PO Box 473106, Garland,
TX 75047-3106, (800) 242-5583.

Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all
publishers about disabilities.
Comprehensive resources for
parents, children & professionals.
Special Needs Project, 3463
State Street, Santa Barbara,
CA 93105, (800) 333-6867.

Free Book Catalog:
The 1994 Special Needs Collection
features a collection of valuable
books for parents on Down
syndrome, CP, Autism, Tourette
syndrome, Mental Retardation,
Special Education and more.
Woodbine House Contact: 5615
Fishers Lane, Rockville, MD
20852, (301) 843-7323.

Publications

Hydrocephalus News/Notes
Published quarterly for individuals/
families & professionals who spe-
cialize in their care. Highlights:
medical/technical articles, human
interest stories, great resources! A. Liakos, Editor, HNN, 1870
Green Oak Circle, Lawrenceville,
GA 30243. $25 year.

Books, Audio/Video

& Educational Material

Videotapes

Interax Video Sign Language
Course
Illustrates 1200+ signs based
on ASL. Six videos with 8.5 hrs.
Graphics provide reference of
equivalent English word.
Free Brochure! $199 (+$4.50 s&h). Interax Training, Inc.,
PO Box 473106, Garland,
TX 75047-3106, (800) 242-5583.

Books for Parents

& Professionals

Turtle Books
Provide a bridge of understanding
for your children with disabilities,
their siblings & friends. Send for a
FREE Turtle Book brochure to
Jason & Nordic Publishers, PO
Box 441, Hollidaysburg, PA
16648. Cal (814) 696-2290 or
FAX (814) 996-4250.

Crib & Youth Beds

HARD Manufacturing
230 Gridle Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard
for safety in hospitals. 216 colorfu
models available. HARD will adapt
products to meet your special
requirement.

Let them know
you saw their ad in
EXCEPTIONAL PARENT!
### Van Conversion Dealers

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<thead>
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<th>State</th>
<th>Name</th>
<th>Address</th>
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<tbody>
<tr>
<td>Connecticut</td>
<td>Drive-Master, Inc.</td>
<td>9 Spielman Road, Fairfield, NJ</td>
<td>(201) 808-9709</td>
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<td>C &amp; C Ford - Mercury</td>
<td>5th &amp; Monroe Streets, Sturgis, KY</td>
<td>(800) 332-6696</td>
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<td>Ride-Away Corp.</td>
<td>51 Wentworth Ave., Londonberry, NH</td>
<td>(603) 427-4444</td>
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<td>Arcola Mobility</td>
<td>51 Kao Road, Carlstadt, NJ</td>
<td>(201) 507-8500/(800) ARCOLA-1</td>
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<td>Forward Motions</td>
<td>214 Valley Street, Dayton, OH</td>
<td>(513) 222-5001</td>
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<td>Arcola Mobility</td>
<td>51 Kao Road, Carlstadt, NJ</td>
<td>(201) 507-8500/(800) ARCOLA-1</td>
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<td>Drive-Master, Inc.</td>
<td>9 Spielman Road, Fairfield, NJ</td>
<td>(201) 808-9709</td>
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<td>Florida</td>
<td>Ocean Conversion &amp; Mobility, Inc.</td>
<td>750 East Sample Road, Bldg. 8/117</td>
<td>Pompano Beach, FL 33064</td>
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<td>BEAT THE HEAT!</td>
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### CORN ASSOCIATES

**Child Care/ the education connection**

An uniquely qualified firm and leading advisor to corporate human resource management personnel. Corn Associates is foremost a diversified pool of professional talent and academic practitioners who become the corporation's personal child care planners and providers.

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- Personnel level advisor to corporate leadership on current educational trends

For more information write or call:

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Phone: (201) 996-0720
Friends Who Care

The National Easter Seal Society's Friends Who Care disability awareness program was introduced in 20,000 elementary schools nationwide in the fall of 1990. By providing materials that help children better understand what it means to have a disability, this award-winning program teaches them to accept and include people with disabilities in their everyday lives.

Friends Who Care has been featured on NBC's Today Show and in USA Today, Child Magazine, Weekly Reader and local publications nationwide. The teaching materials and public service advertisements have won nine national awards.

The curriculum kit includes a pre-and post-program attitude survey, a 16-page teacher's guide with information and classroom activities designed to provoke hands-on experiences for children, five activity worksheets, a 45-minute video to augment the activities, guest speaker guidelines, five campaign posters and 50 bookmarks with tips on disability etiquette.

To order, send a $25.00 check or money order (includes postage/handling) to: National Easter Seal Society, Friends Who Care, 230 West Monroe St., Suite 1900, Chicago, IL 60603. For further information, call (312) 726-6200.

Camp for Kids with Vents

The PA Vent Camp is designed to provide a camp experience, free of charge, for medically stable children who are ventilator-dependent. This year's session will be held June 25-Jul 1 at Camp Harmony Hall in Middletown, PA. The camp is staffed by a team of health care professionals and community volunteers. Applications are still being accepted from children between the ages of three and 19, between 6:00 a.m. and 9:00 p.m. For more information, contact PA Vent Camp, P.O. Box 60443, Harrisburg, PA 17106, (717) 671-0226.

Support Groups

- The Autism and Sensory Impairments Network maintains a database of families with a member who has autism and/or hearing or vision impairment, and professionals who have an interest and/or experience with this combination of disabilities. For more information, contact Dolores and Alan Bartel, 7510 Oceanfront Ave., Virginia Beach, VA 23451, (804) 428-9036.
- A new support group is being formed for the families of children affected by Rasmussen syndrome. For more information, contact Al and Lynn Miller, 8353 Lethbridge Rd., Millersville, MD 21108, (410) 987-5221.
- A support group is being formed for the parents of children with Opitz-Frias syndrome, also known as Opitz-G syndrome or BBB syndrome. Major indications of this syndrome are extensive swallowing problems and hypospadia in boys or imperforate anus in girls. For more information, contact William and Janet Wharton, P.O. Box 616, Grand Lake, CO 80447, (303) 627-8836.
- A new network is being formed for parents of children with opsoclonus-myoclonus syndrome. For more information, contact Connie Quinn, 725 North St., Jim Thorpe, PA 18229.
- A support group has been formed for parents of children with Aarskog syndrome. The group, formed by the mother of two children affected by the syndrome, offers information and a newsletter. Contact Shannon Caranci, 62 Robin Hill Lane, Levittown, PA 19055-1411.
- A parent advocacy group, the FRAXA Research Foundation, has been formed by parents of children with fragile X syndrome. For more information, contact FRAXA Research Foundation, P.O. Box 935, Newburyport, MA 01950, (508) 462-1990.
- Forward Face, a support group for people and families with craniofacial disorders, publishes a quarterly newsletter that offers helpful, inspiring articles by parents, children and professionals. A membership to Forward Face, which includes a subscription to the newsletter, costs $15. Contact Forward Face, 317 East 34th St., New York, NY 10016, (800) 422-3223.

Publications

- Iceberg is a quarterly newsletter dealing with fetal alcohol syndrome (FAS) and fetal alcohol effect (FAE). It is available from FAS Information Service, P.O. Box 9597, Seattle, WA 98145-2597, and costs $10/year for families; $20/year for professionals (prepaid subscriptions only).
- Two free booklets can help pre-college and college-age students with disabilities make decisions about attending college and choosing a career. The booklets, Find Your Future and You're in Charge, are available from the American Association for the Advancement of Science, 1333 H St., NW, Washington, DC 20005, (800) 222-7809, VFTY; (202) 371-9849, fax. Ask for AAAS publications 94-12S and 94-13S.
- Developing Social Skills: Issues for Adolescents with Chronic Illnesses and Disabilities is a bibliography of programs and materials that are available to help adolescents deal with relationships. A companion to this bibliography, dealing with self esteem, will soon be available. Cost is $6.00, available from University of Minnesota—NYCD, Box 721, University of Minnesota, Minneapolis, MN 55455, (612) 625-2625.
- Understanding Neurofibromatosis: An Introduction for Patients and Parents is available from the organization Neurofibromatosis, Inc., Mid-Atlantic, 885 Annapolis Rd., Ste. 110, Lanham, MD 20706-2924, (301) 577-8884. Single copies are free.
- Bone Marrow Transplants: A Book of Basics for Patients is a 157-page book written by bone marrow transplant patients with the help of medical specialists. The book is designed to augment the information provided to patients and to translate medical terminology into lay language. Cost is $5.00; available from BMT Newsletter, 1885 Spruce Ave., Highland Park, IL 60035, (708) 831-1913.
NEW PRODUCTS

LET'S GO TO THE CIRCUS
Animals, clowns, jugglers and language development? Yes! This program for the Apple II GS or IBM computer combines large, colorful graphics with more than 75 vocabulary words and 20 pairs of opposites. This program is accessible with a keyboard, touch screen, single switch or mouse, and utilizes high quality speech to provide auditory reinforcement to visual learning.

Laureate Learning Systems, Inc., Winooski, VT 05404-1898
Circle # 192

WOODCRAFT CREATIONS ADAPTABLE HOBBYHORSE
The age-old classic hobbyhorse meets present day accessibility needs in this recreational and therapeutic toy. Hand-crafted of hardwoods, a stately steed with bridle and saddle sits atop a wide, reinforced rocking platform. A removable adapter frame developed for a child with severe disabilities fits over the horse and secures to the platform. The child can rock back and forth and exercise the legs and arms while being supported on all sides.

Woodcraft Creations, Salem, MO 65560
Circle # 193

FORMBOARD WITH A BRAIN
Microprocessor-controlled, extra-large shapes, angled play surface and tactile, auditory and visual feedback all in one product! This versatile activity board can be used for recreational play or entertaining therapy to teach cause and effect, fine motor skills, hand-eye coordination, spatial concepts and more. Sequencing activities can also be programmed. Correctly-performed activities are rewarded with internal tones, small vibrations, music and lights or moving toys when connected to the unit.

Enabling Devices, a division of Toys For Special Children, Hastings-on-Hudson, NY 10706
Circle # 194

THE MULTISENSORY CURRICULUM™
For children with traumatic head injury, cognitive disabilities and visual or auditory limitations, this curriculum encompasses 30 interactive programs. Colorful graphics, enlarged screen print, and computer sound create a multisensory interface for readers and nonreaders learning vocabulary, sentence making, grammar and math objectives. Users can navigate through the lessons using a Touch Window, single switch, keyboard or mouse.

Creative Learning, Inc., Nevada City, CA 95959-2617
Circle # 195

TALKING SCREEN
This dynamic, voice output communication system is the first color, programmable, pictographic display system featuring graphics, Mayer-Johnson PCS symbols, clip-art, the ability to create or modify symbols and environmental control capabilities. Talking Screen is easy to personalize for the user and also features auditory scanning for low vision users and display options from one to thirty-two symbols per screen.

Words +, Inc., Palmdale, CA 93550
Circle # 196

BEGINNING ASL VIDEOCOURSE
This award-winning videocassette collection features the Bravo family—a deaf father, hearing mother and two deaf children. Each video focuses on a different set of vocabulary associated with such topics as doctors' visits, shopping, banking, school and getting a job. Each video includes notes on deaf culture and ASL grammar. Recommended for joint viewing and learning by parents and their children.

Sign Enhancers, Salem, OR 97304
Circle # 197

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, VTID, (301) 588-0284, VTDD or (301) 587-1967, FAX.
You can order any of the books listed here with the coupon below or by calling (800) 535-1910
THIRD PARTY BILLING FOR SPECIAL EDUCATION: Panacea or Mirage?  
Joy J. Rogers  
The use of third party billing to cope with escalating special education costs, especially those not directly educational.  
BLOG600D  $27.95

WORKING TOGETHER: Workplace Culture, Supported Employment and Persons with Disabilities  
David Hagner  
Assisting individuals to achieve meaningful careers.  
BLOG600D  $24.95

DISABILITY, PHYSICAL  

COPING WITH CEREBRAL PALSY: Answers to Questions Parents Often Ask  
Jay Schlesinger  
Provides answers to more than 300 questions that have been carefully researched.  
PEG037PD  $24.00

INJURY  

INJURED MIND, SHATTERED DREAMS: Brian's Survival from a Severe Head Injury  
Janet Miller Rife  
Recovery and victory a family can achieve through caring.  
BLOG607D  $17.95

MENTAL RETARDATION  

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Hello. My name is Carlo. I have a brother named James. I am lucky to have him as a brother because I know what it's like having a brother with a disability.

My brother is four years old. He attends school at Meadowwood—it is a good school. I attend school at Caravel and I like it a lot. James started walking at the age of two and a half. He is working on talking.

My brother likes Kidsongs movies and books. My brother likes to eat; he will eat any piece of food you give to him, ha, ha, ha. When people call my brother retarded I don't care, nor do I listen to them. I don't believe that there is any label that can be put on my brother or anyone else's. We are all alike in this world, and we are all different, too. I love my brother James.

Carlo and James live in Hockessin, Delaware, with their parents Bob and Donna Aviles and their new little sister, Estella Grace. Carlo is a fourth grader at Caravel Academy in Bear, Delaware. James, who has Coffin-Lowry syndrome, now attends kindergarten at Forest Oak Elementary School in Newark, Delaware. Both boys enjoy basketball, baseball and wrestling.
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Nathan remembers a brother and a friend.
At the end of April, I joined more than 1,100 parents in Asheville, North Carolina for the International Parent-to-Parent Conference. Entitled “Weaving the Future From the Fabric of our Past,” this meeting was an exciting opportunity to experience the energy and passion of many fantastic, activist parents from all over the United States and other countries. It was wonderful to witness this tremendous display of “parent power,” and to be in the company of such a large group of people who are so dedicated to making life better for all children and their families. The next International Parent-to-Parent Conference will be in Albuquerque, New Mexico, March 29–April 1, 1996; save those dates!

In May, at the Abilities Expo in Anaheim, California, I had another opportunity to meet parents, families and many of our fine advertisers. During the same weekend, I was able to stop by a meeting of the Fiesta Educativa in Los Angeles to learn about the activities of Hispanic parents and professionals. On the way home, I enjoyed an informative visit to the Utah Parent Center in Salt Lake City.

I look forward to meeting midwestern parents at the Abilities Expo in Chicago in August. All of us at Exceptional Parent appreciate the helpful feedback and suggestions—and even the few complaints—we hear from our readers at these meetings.

Words from the White House
In this issue, we are honored to feature an article by Carol Rasco, Domestic Policy Advisor to President Clinton. Having a parent advocate like Mrs. Rasco in the White House is important for all parents. As she reminds us, even though we may lack direct access to the White House, all of us need to continue our individual efforts on health care reform by contacting congressional representatives.

Learning about telecommunications
Thanks to our talented assistant editor, Kim Schive, this issue brings us into the modern age of telecommunications!

To gather information about how parents are using telecommunications, Kim went online and posted a few brief requests for people to share their experiences. The response was incredible! More than 300 parents, professionals, and adults and children with disabilities responded with wonderful examples of how the power of telecommunications has enabled them to meet friends with similar concerns, learn more about helping children and families, even get help with the diagnosis of children who have rare disorders. Kim heard about a variety of ways that parents are using this technology—from weekly, online, support group meetings to online contacts with adults who have disabilities, allowing parents a glimpse into their children’s future.

Kim had hoped to respond personally to everyone who shared their stories, however, she also had to get this issue out on time! We both want to extend our deepest appreciation to all those individuals who shared their experiences—your personal stories are reflected in this issue.

I am proud to announce that my personal telecommunications phobia has been cured! In addition to Kim’s contribution, I credit my cure to the articles by Peter Green (“Getting Started with Telecommunications”) and Bill McGarry (“Cruising the Internet”) and most of all, to the beautiful letters—“electronic mail,” actually—we received from parents everywhere. I am very excited about the vast potential this technology provides for sharing our compassion and knowledge with each other.

Just after the Abilities Expo in Anaheim, I met with the Worldwide Disabilities Solutions Group at Apple Computer in Cupertino, California to discuss our plans for collaboration between Exceptional Parent and Apple’s new online service, eWorld (see page 30). Look for more information on these exciting developments in the July issue.
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Feeling “Different”
I am the parent of an eight-year-old daughter with Down syndrome. Her level of retardation is very mild. She is enjoying second grade in an inclusion program in Falls Church, Virginia. This year, however, she has become more aware that she is “different” from the other children and that she learns more slowly. She wants so desperately to be included and accepted.

The children and staff have been very loving, patient and supportive; but, we all are seeing a lot more acting out and inappropriate behavior. We are seeking new approaches to handle discipline in an appropriate manner while helping her to maintain her self-esteem and get in touch with her emotions.

E.M., Virginia

Skeletal Anomalies
Our three-year-old daughter, Amanda, was born with significant skeletal anomalies. Her legs are normal to the knees which she can bend. From each of Amanda’s knees extend a three-toed foot with sole turned inward. Three of Amanda’s fingers on her right hand are webbed—two will be surgically separated. She also has a heart condition—hypertrophic cardiomyopathy with asymmetric septal hypertrophy—but this has been managed well throughout her life.

We have received many medical opinions about Amanda’s legs. Recommendations have included splinting, partial amputation with prosthesis use and other surgeries. We have not yet found an option with which we are comfortable.

Amanda is very bright, busy and inquisitive; her disability has not impeded her development in other areas. We have never seen or heard of any children similar to Amanda, but as we consider medical options and plan her education, we would be grateful for the opportunity to correspond with other families facing similar choices. We would also welcome referrals to resources for additional information.

D.D., Pennsylvania

DiGeorge Syndrome
We are the parents of a three-year-old boy who has DiGeorge syndrome. We would welcome correspondence from other parents of children with this syndrome, as well as professionals or organizations who may have current medical information on this condition.

T.A. & J.A., Colorado

Teeth Grinding
Our nine-year-old daughter, Nicole, has been diagnosed with pervasive developmental disorder, autism and bi-polar disorder. I sometimes wonder if these diagnoses are correct. Nicole is non-verbal but can answer questions by pointing to word cards with no physical assistance.

I am writing in regard to Nicole’s habit of grinding her teeth. This is something she would do off and on in the past; now, she does it constantly. The dentist said that the teeth in her jaw are quite worn. He acts as though there’s nothing that can be done. Nicole grinds her teeth so hard at times, I’m afraid they may actually crack. She has several permanent teeth and I don’t see how they can last a lifetime under these circumstances. I’d appreciate any helpful suggestions.

A.T., South Carolina

Robinow Syndrome
Our three-year-old son, Zachary, was born with Hirschsprung disease and hydronephrosis of the kidneys. At six days of age, he underwent surgery for an ileostomy and urostomies. At two months of age, he began having seizures, now controlled by medication. His pinkie fingers and toes are not fully developed—the nails are just dots. He functions at a three- to six-month-old level. He doesn’t have total head control, but can roll all over the house and hold a bottle. He will eat soft baby food but cannot chew.

Because of his physical features—widely spaced eyes, low-set ears, high palate, seizures, short stubby fingers and toes, flattened facial features, microepenis, undescended testes and simian creases—Zach has been diagnosed with Robinow syndrome. We do not know what his future will be like because his doctors have yet to find another child with the same combination of problems as our son.

My husband and I love our son dearly and are hoping to find someone who has a child with similar problems. We would also be glad to receive and share information on caring for an ileostomy and urostomies.

J.L., Michigan

Vomiting Problem
Our one-year-old son, Jimmy, was born with meconium aspiration and a grade IV brain hemorrhage. He has cerebral palsy, a seizure disorder, cortical blindness, temperature instability, diabetes insipidus and a poor suck/gag reflex, for which he is fed exclusively through a Bard G-button.

At six weeks of age, before Jimmy was released from the hospital, surgery was done to insert a gastrostomy feeding tube and to perform a Nissen procedure to prevent reflux. At three months of age, the G-tube was replaced by a Bard G-button. Around this time, Jimmy began vomiting following some of his feeds. We tried to find a pattern for these episodes, but they seemed to occur randomly. Since this time, the amount of formula we have been able to give Jimmy without provoking vomiting has decreased from six to two ounces.
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per feed. Consequently, he has had trouble gaining weight, even though we try to feed him every couple hours using a high-calorie, concentrated formula.

We have tried a variety of anti-reflux and stomach medicine—including Zantac, Bethanecol, Cispide and Reglan—without much success. Upper gastrointestinal and milk scans show some reflux. A pH probe test will be done soon. Additional surgery on his Nissen is also a possibility.

We would like to know if anyone has encountered similar feeding problems under these circumstances.

J.K. & T.K, Virginia

Panic Attacks?

Our six-year-old son, Davis, has Coffin-Lowry syndrome. Cognitively, he is at a two-year-old level. He had sensory defensiveness as an infant, but has overcome much of that. Due to scoliosis, he has an awkward gait and poor coordination, but he gets around just fine.

At age four, he had three bad falls during a two-week period. He became afraid of walking, started falling for no apparent reason and, eventually, stopped walking unaided entirely. That lasted for about three months.

The same thing has happened twice since then, each time about a year apart.

He has what looks like a seizure—his body goes rigid and pulls into a fetal position with his head thrown back. His normal self-protection mechanisms fail, and he falls—always landing on the right side of his forehead. He appears terrified. Between episodes, he will have months of normal physical activity.

We have not been able to find a physiological cause for the behavior.

Seizures have been ruled out and these episodes appear unrelated to his syndrome. His neurologist thinks he has an abnormally high level of background anxiety that manifests itself in "panic attacks" when he becomes overloaded with unpredictable sensory input. Currently, we are experimenting with a medication.

I am interested in corresponding with anyone who is familiar with this problem, knows its cause or has had success with medications or behavior modification techniques to overcome a similar problem. The neurologist is interested in whether sensory defensiveness in infancy may be related to higher anxiety levels, panic attacks and compulsive behavior in older children and adults.

M.I., Washington

Ring Chromosome 22

We are the proud parents of a 12-year-old boy who was diagnosed with ring chromosome 22 at age five. We have been unable to find much information about this disorder and would like to be in touch with other families and/or professionals who have experience with this syndrome.

T.W. & D.D.W, Washington

Scoliosis

My 13-year-old daughter was born at 27 weeks weighing two pounds, eleven ounces. She suffered a brain hemorrhage and was diagnosed with bronchopulmonary dysplasia, a seizure disorder, profound physical and mental retardation and spastic quadriplegia. A few years ago, she was also diagnosed with scoliosis. Now, the doctor has said she needs immediate surgery, because the scoliosis has progressed to more than 50 percent.

I would like to hear from any parent with a child who has had scoliosis and/or surgery for this condition. I would also like to hear from any parent who has a 13-year-old with disabilities similar to my daughter's—how do you handle everyday things like feeding, clothing, toys, school, social events and the fear that your child will become too big for you to care for properly? I know I am asking a lot, but I need some help and advice to deal with the upcoming years.

D.R., New York

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At every stage of the Learning Center curriculum and throughout the rest of the Berkshire Meadows programs we work with each young person to improve his or her ability to communicate. For most of these young people, there has been no incentive to communicate: their basic needs have been provided for, in one way or another, and they have in any event been unable to express needs or wants in ways that other people understand. So the first task is to motivate communication, which we do by offering choices - of toy, snack, drink, etc. By using pleasurable choices and consequences, we provide even greater incentive to the child to break through his or her passivity.

Total and Augmentative Communication

In general, the staff use Total Communication with all our students – that is, we use a combination of sign language, facial expressions and words. However, for many of our students, using normal sign language is not feasible, so we develop individual augmentative communication skills. We teach the use of mechanisms such as object displays, switch-operated scanning devices and VOCAs (voice output communication aids) ranging from simple, pre-programmed devices to sophisticated computers with speech synthesizers. Once a system of communication has been established, we ensure that family members and all staff are trained to understand it, so that the student is spared the repeated frustration of not being understood.

Concomitant with learning to communicate is the ability to impact one’s own life. For the youngsters at Berkshire Meadows, this is a primary step toward psychological development and emotional wellbeing.

For more information, please contact: Mrs. Gail Charpentier, Executive Director
Berkshire Meadows
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(413) 528-2523

Circle # 6
Transporting Two Non-Ambulatory Children

D.H. (February 1994) has three boys, two of which have multiple disabilities and are non-ambulatory. She was looking for a portable, adjustable means of transporting both boys simultaneously.

Soon after we found out that we were expecting another child, we realized that it would be impossible for one person to transport a 20-month-old child with cerebral palsy and a newborn. Nobody seemed able to offer assistance on this particular problem.

While there are many double strollers available, none are designed to accommodate a child with even a minor disability. Our solution was to take a conventional double stroller and modify it (see photo) so that it could provide the support our 20-month-old child required, and also transport our new baby.

We started with a Grayco double stroller and Fisher Price bicycle seat. The stroller was not quite large enough to allow the bike seat to slip into it, so we sawed off the front bumper bar and extended it with a custom-bent piece of electrical conduit. This allowed the bike seat to be placed in the stroller.

The bike seat also required modifications. First, there were side rails that needed to be removed to allow the seat to slide easily in and out of the stroller. Second, we needed a way to secure Alexander's feet. We attached straps to wooden blocks that were screwed into the bike seat's plastic foot protectors. The third modification was a bit more involved. Alexander's lack of complete head control meant that he would need a padded head support. To accomplish this, we heated and bent a piece of one-quarter inch-thick Plexiglas, bolted it to the bike seat, padded it and covered it with fabric. Last, we added a strap to secure the bike seat in the stroller. The stroller folds down with the bike seat inside so it is easy to handle and fits in an ordinary car trunk.

These modifications were not as difficult and extensive as they sound—the difficult part was figuring out how to make the changes, not actually making them. Alexander is now 30 months old and Amy is 10 months. Additional modifications to the bike seat have been required to accommodate Alexander's growth. Soon, we will have to figure out how to accommodate the growth of both children, so we would welcome ideas. One ready-made product that holds some promise is the Runabout™ (Runabout/USA, Inc., 9025 S.W. 15th, Aloha, OR 97007, 503/649-7922). Runabout "Baby Karts" are fully adjustable, can accommodate from one to three children and also use bicycle seats. However, the Runabout is more difficult to handle and transport than a stroller and carries a higher price also.

D.S., Wisconsin

Celiac Sprue

S.L.W. (March 1994) wanted to correspond with other parents of children who have celiac sprue, a digestive condition which prevents the digestion of gluten-containing products.

My son, now 23 years old, has been on a gluten-free diet since he was 11 months old. He was diagnosed with celiac sprue after suffering from symptoms for five months. After a few days on the diet, his diarrhea stopped.

Here are three sources of more information than you'll know what to do with:

- Celiac Sprue Assn.–USA, P.O. Box 31700, Omaha, NE 68131-0706.
- ENER-G Foods Inc., P.O. Box 84487, Seattle, WA 98124-5787. (Mail order food products. Sometimes you can find the brand "ENER-G" in large health food stores.)
- Gluten Intolerance Group, P.O. Box 23053, Seattle, WA 98102-0353.

Don't forget to always read labels. Also, write to food companies and ask for a list of their gluten-free products.

L.R.H., New York

School Districts With Full Inclusion in New England

J.H. (March 1994) was planning a move to New England and wanted assistance in finding inclusive school districts.

Each state has a Planning Council on Developmental Disabilities. These Councils are an excellent source of information on inclusion and many other topics. You may contact the Planning Council in your state and ask for information about various New England states, or you may contact those states' Councils directly. The numbers would be available through directory assistance; a state's Planning Council is usually in the state capital and/or the largest city.

K.R., Illinois

Lennox-Gastaut Syndrome

D.S. & J.S. (March 1994) have a 22-month-old son who has seizures and autistic symptoms; doctors say he has Lennox-Gastaut syndrome. "We are searching for parents of a similar child," they wrote, "or anyone with a suggestion as to how I could simply get my beautiful son to look into my eyes. It is hard not knowing how to get through to him."

You are practically describing my little girl! Amy seemed perfectly normal for her first two years, then her pediatrician began to wonder why she wasn't speaking as she should. She was a happy child, just rather aloof. At three years of age she received her first diagnosis—mild cerebral palsy—because the neurologist didn't know what was wrong!

Last year, after five frustrating years of neurological testing, she received what we believe is a correct diagnosis of epilepsy. She is now on a combination of drugs that we hope will control her seizures. She has been diagnosed with Lennox-Gastaut syndrome.

Amy remains unable to perform even basic functional living skills. Her teeth are almost flat from grinding in her sleep and constant chewing. She mostly avoids eye contact. She is only partially verbal, does not communicate any desires and is extremely hyperactive.
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get a copy of the magazine that helps you parent your child with a disability times a year.
Now, to give you something encouraging after all that! Amy has always been aloof, but loves attention when it's forced on her. Love and hug and tickle your child as much as possible, even if he doesn't seem to understand. Treat him as if you don't notice that he's squirming and trying to avoid you. We have always tried to treat Amy as he's squirming and trying to avoid you. We have always tried to treat Amy as normally as possible, even when she's literally kicking us in the head! Her aloofness is just a part of her and we try to ignore it as much as possible.

At times it's extremely difficult to love this child, but the dividends, when she loves back, are tremendous. Every night I put her to bed and say to her "Amy, Mama loves you. Can you say "I love Mommy"? Only once in nine years did she respond "I love..." but that one time has kept me going for many years. She never tries to kiss or hug me, but she can't stand to have me out of her sight—"I take this as her way of saying, "I love you Mommy and never want you to leave me." I may be deluding myself, but it's my delusion and I need it!

Actually, she loves on her daddy more than anyone else. She will hug his neck and offer her forehead for a kiss. She will sit on his lap for a moment and say "good morning" to him. Of course, he loves all this attention and is proud to have it directed only at him! But it has taken years to get to this point.

My best advice is to just love your son with all your heart and keep giving him affection no matter what. Hold his chin and make him look into your eyes—even if it's only for five seconds a day. We have been doing this with Amy all along; each year it seems to get easier to reciprocate. Her love of her family is obvious, even if it's disjointed.

My only other advice is to find the best neurologist you can. If you don't feel completely comfortable with the one you have, or if you question his commitment to your son's care, find another one. I've been through four of them and only now have one who's willing to pay attention and try the things I feel will be most helpful. Also, do your homework and find out all you can about each thing they tell you, no matter how discouraging it may be. Your son can't speak for himself. He's depending on you to make sure the doctors are doing right by him. They're only human too!

M.E., Texas

☐ I know what you are feeling—"Look at me. Please just look at me! I love you more than I could ever say." As I write this, I can hear my sons upstairs babbling together. They are both so beautiful, so special and so different. Our older son has blonde hair and autism; our younger son has brown hair and an attitude. They have their own ways of relating to each other that are fun to watch and hear.

The best advice I can give you is to look for other ways to know that your child is "connecting." My son sometimes looks directly at me, sometimes looks out of the corner of his eye and sometimes looks just over my head toward my hair. I know my son senses things differently than everyone else. He is sensitive to different food textures and noises. He won't wear overalls because of the straps on his shoulders.

Try to find ways to tell when your child is paying attention to you. It's not easy, but there may be some. It's hard to tell what's being taken in by someone who has no way of telling you. We have a wonderful speech therapist who has helped us find other ways for our son to communicate. We tried sign language, but that didn't seem to help. We use lots of pictures, and our son has a touch talker with pictures on it. He can point to a picture of juice, and the box says "I want juice." It's hard for us to think that our son may never talk, but we feel great knowing that we have given him other ways to communicate.

All behavior is communication. When my son is whining and driving me up a wall, as any kid can, I look at what's going on around him. We feel lucky that he communicates his needs so well—if he wants to go outside, he whines near the back door; comes to us, grabs our hands and takes us to the back door; or brings us his coat. He doesn't always look at us or talk, but he does communicate. (I know, it doesn't take away the hurt, does it?!) I don't want to give you some quick psychology lesson or sound as though I've fully accepted everything with my son—I just know what you're going through and want to help you change your expectations.

K.S., Illinois

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Circle #34
Laughter Helps!
Reading what other parents write about their everyday life really helps me cope. That is why I really enjoyed the April 1994 issue which featured quite a few articles from parents. I especially enjoyed the feature Sense of Humor Required. I laughed while I was reading!

This article reminded me of some of my own experiences that were not so funny when they happened, but seem humorous now—like the day my six-year-old daughter, who has autism, went to the park with her father to see the ducks. A short time later, they came home... soaking wet and muddy from head to toe. She had jumped right into the lake, and Dad had jumped in after her. I was horrified at the time, but now, remembering her sheepish expression makes me laugh. Maybe you could start a regular column where parents could write about some of their funny experiences.

PC., New York

Editor's Note: Great idea! We enjoyed your story and would love to hear from others.

If you could peek in my mailbox...
I know you know how you enhance the lives of those with special needs with every issue. Still, you would be amazed if you could peek in my mailbox, or listen in on my recent phone calls. Since you mentioned The Myelin Messenger newsletter (for families with children with insufficient myelin, c/o Ruth Anderson, HC-29, Box 868, Stable Lane, Prescott, AZ 86301-7435), parents have been calling and writing daily. They are so grateful to Exceptional Parent for printing information that allowed them finally to connect with other parents who are dealing with this rare disorder. Several have called with tears of joy because they are so glad to find out they are no longer alone.

For two families, that happened to be the first issue of Exceptional Parent they had ever seen. They saw it in a doctor's office, and were so grateful they had picked it up. Two other families each had two children with this disorder, but had never made contact with other, similar families. Another two parents who wrote were physicians who themselves had children with this disorder.

I have heard from many other families—in Alaska, Nova Scotia, Florida, California and everywhere in between. I have had a firsthand look at the phenomenal, positive impact Exceptional Parent magazine is making on families; we are all very thankful!

R.A., Arizona

Viewpoints on Inclusion
I am writing in response to Dr. Edwin Martin's guest editorial, Inclusion: Rhetoric and Reality (April 1994). As our parent group struggles to implement inclusive practices in our school district, it is a shock to have Dr. Martin stating that "the prospects for inclusion are not encouraging." Why would any parent want to give up a child's birthright to belong? Sure, inclusion involves risk, but we are enjoying educational benefits for our children today that were earned by parents who took risks in the past. Now, it is our turn to make a difference for the children of today and tomorrow.

The studies that Dr. Martin cites involved students who did not have an opportunity for an "inclusive" educat-
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P.A.D., Pennsylvania

□ As a parent of an 18-month-old who has Down syndrome, the title of Dr. Martin’s guest editorial intrigued me. I was disappointed. Martin writes, “Neither parents nor professionals should accept rhetoric in the place of data.” He should have followed his own advice.

Martin cites data on the percentage of youth with disabilities failing at least one regular education high school course. These data could be interpreted in many different ways. Advocates of inclusion might say that this reinforces their claim that regular education should be strengthened to meet the needs of students with disabilities. Others might conclude that this points to a failure of mainstreaming. In any case, Martin needs a great deal more data and detail to support his conclusion that “…the data indicate that the prospects for inclusion are not encouraging.”

As a history teacher, I can testify to the extraordinary impact of inclusion on the lives and academic performance of my many special education students. Martin is right in calling for long-term studies of “outcomes.” But parents like me will not wait for the findings of such studies before they demand what most see as the most empowering education for their children — inclusion.

I was disappointed in Exceptional Parent for making this a “guest editorial” without comment or response, thereby giving it the Exceptional Parent imprimatur.

J.H., California

□ I really do not have any interest in knowing how many graduates of a program are employed or in post-secondary programs. This will not tell me anything about the future of my child. I am much more interested in how teachers and administrators view children with disabilities. Are they inclusive or exclusive? Do they see my child, or do they see his disability? These are the truly important questions.

Martin attempts to make a case for collecting more data. His article, however, provides a perfect example of how data can be misused. For example, he cites the percentage of youth with disabilities who fail at least one regular education high school course. But he never provides comparable numbers for students who do not have a disability. This reminds me of the data once used to “prove” that having a child with a disability led to marital strife and discord — fifty percent of such marriages ended in divorce! What one was never told was that the divorce rate was identical for couples who did not have a child with a disability. Likewise, I suspect that a similar percentage of youth without disabilities fail at least one high school course.
Martin also attempts to correlate segregated education with a higher rate of college attendance by using the example of children who are deaf. But such children may also have a lower rate of cognitive disabilities. That factor could have more to do with their rate of college attendance than the fact that they are more often educated in segregated settings. And what does college attendance have to do with being accepted in the community?

As a parent who has worked hard over the last nine years to include my child in the community, I am willing to say that inclusion is a necessary piece of life's puzzle. I work with many families who don't need data to tell you the difference inclusion has made in their lives. I believe that spending money on evaluating federally-funded demonstration projects is a waste of time. Let's put money into providing the supports needed to make inclusion successful.

Families must be involved in including their children in their community, and school is often the place to begin. My son receives some services outside the regular classroom but is seen by all his classmates as just another kid. Josh plays on local sports teams, participates in the annual talent show and knows more people in our town than me. I believe these things are the true indicators of what Josh's life will be like in the future—not whether or not he attends college.

I agree with Dr. Martin that inclusion practices need to be continually reviewed. I believe that support and training of regular and special educators is the real issue. I look forward to reading more from parents on this subject in future issues.

S.M., West Virginia

Dr. Martin replies: I appreciate the chance to reply to the thoughtful letters concerning my guest editorial. Each raises concerns about my views, fearing incorrectly, that I oppose "inclusion" in principle. The letters elicit feelings of compassion and support from me—I applaud the hope and dreams of these parents and wish them and their children well.

My goal in writing the editorial was to elicit thought and to caution readers that inclusion, as implemented, will almost certainly be of uneven quality. Almost five million children and hundreds of thousands of teachers will be involved; no broad-scale, tested preparation and teacher training has yet been demonstrated. Past efforts toward education reform, including parts of IDEA (P.L. 94-142), have floundered for these very reasons, leaving parents and professionals frustrated and disillusioned. Testable reform is needed; the support of teachers and funding sources must also be established.

Further, since school systems have not kept careful records of the "outcomes" of students in special education, many problems in the system are only now becoming obvious. The statistics I cited were intended to make that point, to provide guidance for the future.

As a government official, I felt it was a victory that the overwhelming number of children with learning disabilities were receiving at least some of their education in regular classrooms. I did not know, nor did anyone else, that two out of three children were failing one of those classes. Continued on page 53.
FAMILIAR FACES

Seven-year-old Sydney Greer Hinks enjoys swimming, nurses and riding the school bus. Sydney, who has autism and epilepsy, lives in Katy, Texas with her mom, Nancy; dad, Alan and dog, Kanga. Sydney is in first grade at Cimarron Elementary School.

Horseback riding is one of six-year-old Cory Powell’s favorite activities. Cory, pictured here with his dad, Billy, "has lots of experience with horses." Last year, he rode with a group called "Horses Helping Handicapped." Cory, who lives in Port St. Lucie, Florida, has cerebral palsy.

Chocolate cake is always welcome at the household of Dakota Josef Rizzo. Dakota, seen here celebrating his first birthday, is developmentally delayed. In hopes of finding a diagnosis for Dakota, his parents, William and Tracy, published a SEARCH letter in EXCEPTIONAL PARENT last year; they say that although Dakota remains undiagnosed, their SEARCH letter has resulted in many new friends.

Two-year-old Alexandra Sellitti of Sayville, New York, flashes a charming grin. Alexandra, who was born with myelomeningocele and hydrocephalus, was recuperating from hip surgery—her seventh operation in two years—when this photo was taken at Easter, 1994. "She remained her usual happy self through the whole thing," says her mother, Rosemary. "She’s a real trooper and we are all very proud of her."

Ryan Lutak, 11, of Fords, New Jersey, finds his wheelchair surrounded by classmates from the Matthew Jago School in Sewaren, New York, during a fun-filled field trip to the Statue of Liberty. Front row (from left): Jackie, Heather; back row: Megan, Stephanie, Steven, Louis, Ryan, Daniel and Michael. Ryan has spina bifida.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers’ Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child’s full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
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Carrie Miller
Harvard student-athlete talks about growing up deaf

Carrie Miller, 19, has been deaf since a bout with spinal meningitis at the age of 15 months. Carrie, who has been swimming competitively since the age of nine, is a two-time participant in the World Games for the Deaf. At the 1993 World Games in Bulgaria, she won an unprecedented 10 medals—nine golds and a bronze. Next fall, Carrie will enter her junior year at Harvard University where she is a top swimmer and student, majoring in environmental sciences and public policy. Exceptional Parent caught up with Carrie in April, during an hour's free time between a meeting with Harvard swim coach Maura Scalise and a marine science seminar.

After I recovered from spinal meningitis, my parents did not realize that I was deaf. I wasn't diagnosed until the end of the following summer. At that time, my father was almost finished with graduate school at the University of Pennsylvania. My parents started looking at schools for the deaf in areas where my dad had job offers. My father accepted a teaching job at the University of Delaware because my parents were impressed with the parent-infant program at the Sterck School. I think I would have been frustrated by low expectations if I had stayed at the deaf school. I'm sure none of those teachers ever expected me to attend Harvard.

Delaware's state school for the deaf, Sterck's program used the philosophy of "total communication." My parents had looked at, and decided against, schools with strictly oral programs. They wanted me to talk, but they believed that I needed sign language also.

When I started first grade, my parents wanted me to be mainstreamed all day with an interpreter. At the deaf school, I had been put in classes with kids who were three or four years older than me because I was doing so well. My parents wanted me to spend more time with kids my own age; I would also be going to school with a few hearing friends from my neighborhood who knew some sign language—back then, my speech wasn't as intelligible as it is now, so my friends had to know sign language to understand what I was saying.

I had already been mainstreamed for half-days in kindergarten and the school for the deaf thought that arrangement should continue. They wanted me to take social studies and English classes at the deaf school. My parents refused to sign the IEP; they even brought a lawyer to the IEP meeting. Finally, the school backed down.

Although I was mainstreamed for all my academic subjects, I still received services from the school for the
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deaf. I would go back to the deaf school for auditory training and speech therapy. In seventh and eighth grade, my parents noticed that I was feeling isolated from my deaf friends. So, they arranged for me to take a few classes at the deaf school—classes that were not educationally important like shop and cooking.

After eighth grade, my father got a job at the US Naval Academy, and we moved to Annapolis, Maryland. One other deaf girl attended my high school there, but she was very oral and her mother did not want her to learn sign language because she thought the girl would lose her ability to speak. Of course, I could sign and speak, and while her daughter was struggling to keep up with regular classes, I was in honors classes with an interpreter. When this girl’s mother found out that I was doing better than her daughter, she decided to let her daughter learn sign language and get an interpreter. The girl eventually ended up in honors classes with me.

**Mainstreaming**

In general, I'm happy that I was mainstreamed. A lot of deaf people are surprised that I didn't go to a deaf school. I think I would have been frustrated by low expectations if I had stayed at the deaf school. I'm sure none of those teachers ever expected me to attend Harvard.

On the other hand, I did attend the school for the deaf for some classes, and I had deaf friends while growing up. Especially during early adolescence, the time I spent with other deaf kids helped me to get through that rough period in my life. Even if a deaf child is mainstreamed, I think it is important that deaf people are around at crucial times while he or she is growing up. You need to have the right balance between a child's educational needs, social needs and development of a strong identity.

**Communication**

When I was young, my parents emphasized using Signing Exact English (SEE), so I would learn English grammar. Once I had a good grasp of the grammar, we stopped signing all the word endings—"-ing," "-ed," "-s" and so forth. In elementary school, a lot of my interpreters would want to use American Sign Language (ASL). But my parents said, "Look, ASL is going to be around for the rest of her life. Right now, we want Carrie to learn English!"

I feel that this approach really did help me learn English. Without already having a good grasp of English grammar, I would not have been able to understand written English as well. My parents also emphasized speech therapy. As a result, I speak pretty well. People can understand me. My speech is not perfect, but I can have conversations with my hearing classmates.

**Swimming**

I started swimming when I was about seven years old. My house was one block from the neighborhood pool, so I saw a lot of the older kids swimming and decided I wanted to swim too. My first swimming teacher lived in my neighborhood; she also taught at the deaf school and could sign. At first, I just swam during the summer, but I was enjoying it so much that I joined a team at the YMCA when I was about nine. After my family moved to Annapolis, I trained with the Navy Junior Swim Club and the Retrievers Aquatic Club in Baltimore.

My father had an Italian friend whose brother was deaf and had gone to the World Games for the Deaf in 1981. So my father decided to get more information about the Games. In 1985, I was still too young to compete; in 1989, my dad and I decided to go to Florida for the tryouts. And I made the team! The Games were held in New Zealand. I was fourteen years old at the time and beat many of the veteran swimmers. Of course, I was very excited.

In New Zealand, my performance surprised everyone. But in 1993, when I went to the World Games in Bulgaria, everyone knew who I was. I was under a lot of pressure to maintain my reputation. I won nine...
golds and one bronze. The bronze came in the fifty-meter freestyle. I could have done better in that race, but because Bulgaria is a very poor country, they didn’t have a flashing-light system to alert swimmers to the start of a race; instead they used flags. The fifty free is a short race, so the start is crucial. I got off to a slow start, so I lost the race before it began.

In competitions, when I was a kid, they usually announced the start of a race into a microphone. My father or mother would stand behind me and tap me on the shoulder when it was time to start—usually, it was my mom, because she had a faster reaction time than my dad. Or, if I were doing the back stroke, they would stand in front of me and tell me to go. But, of course, I was always a late starter.

Now, many pools have a strobe-light signaler that comes with the timing system for competitions. I don’t think Harvard had one before I arrived, but the coach ordered it immediately when she knew I was coming. When we travel to other schools, we always call ahead to make sure that the school has a strobe ready to use. With a strobe light to signal the beginning of a race, I am a very fast starter. In fact, I normally go out first because light travels faster than sound—I react to the light; the hearing swimmers react to the buzzer. Since I’m such a fast starter, my coach likes to put me in the first position on the relay.

I am having a great time swimming at Harvard. Before college, I sometimes had problems with some of my teammates—usually boys. They tended to pick on me. I decided that if anything like that happened to me in college, I would refuse to swim. Now, I am enjoying being a member of a swim team for the very first time in my life. For example, I have an interpreter at practices, something I never had before. When I was younger, my parents didn’t think I needed an interpreter at practices. They felt that I needed to learn how to communicate with hearing people, you know, like in the “real world.” I do things on my own with hearing friends without interpreters, but having an interpreter at practices really makes a difference.

It has helped a lot in communication with my coach and with other swimmers, and I feel more like I am part of the team.

Avoid low expectations

I would like to tell parents to make sure that their children are not limited by low expectations. Parental support is extremely important. There are a lot of bright deaf kids out there, but if the parents aren’t behind them, their educational supports will fall through and they will never reach their full potential.

When I was young, my parents really benefited from meeting and talking with parents of older deaf children. For example, one summer, they went to a “Family Learning Vacation” (FLV) at Gallaudet University. This was before my brother was born. Since I was deaf, my parents were not sure if they should have another child; they didn’t know if it would work out to have a deaf child and a younger, hearing sibling. Through meeting other parents at the FLV, my parents were able to see that it had worked out fine for others.

Other parents helped my parents a lot; now my parents help others. When I was growing up, my father became involved with the board of directors of the American Society of Deaf Children. He was the president of the PTA at the deaf school. Almost every year, the teachers at the deaf school would ask my parents to come in to talk to parents of new students about what it was like to have a deaf child. Even now, my first parent-infant teacher continues to refer parents of newly-diagnosed deaf children to my parents.

It is really important for parents of deaf children to know that they are not alone, and to know that their kids will be okay. Parents shouldn’t think, “Oh my God, my kid is deaf! What a terrible thing!” Deaf kids can have good lives and contribute a lot to society.
Kate’s Song

These pages feature the pictures and words of artist Michelle White. Michelle has used her considerable artistic talents to chronicle the life of her daughter Kate, who has Down syndrome. If a picture is worth a thousand words, these images speak volumes.

Birth Cry
Kate was born on November 1, 1989. I had refused to have an amniocentesis, so we did not know before Kate was born that she had Down syndrome. I don’t regret my decision.

The Promise
Katie was a planned pregnancy. Both my husband and I believed that God wanted us to have a third child. It was very hard to understand when Kate was born with Down syndrome. After the grief and the tears, we came to peace with God and recognized Kate as a blessing, hence this drawing’s title.
Bubbles
Kate delights in blowing bubbles. We first worked with her on blowing bubbles as part of her speech therapy; it was intended to help her mouth muscles develop. Now that she has the hang of it, she will sit for a long time and blow bubbles. It's pure joy to watch her.

Dad and Kate
Dad loves to toss Katie around and rough-house with her. She loves it, too.

John and Kate
In many ways, Johnny and Kate are typical siblings—one minute they are playing together nicely; the next minute, John teases Kate and the tears flow. Kate's limitations have been difficult for John to understand, because he is an exceptionally bright child.
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See What I Can Do

I will never forget Katie's first checkup with her pediatrician. She was two weeks old and had severe hypotonia. Dr. Robinson picked her up, and we both watched her legs, arms and head dangle like those of a rag doll. Then, the doctor said, "She probably won't walk until she is four." This is Katie at two and a half, one month after she walked unassisted for the first time.

Michelle White lives in Holtwood, Pennsylvania with her husband, John, and children, Christin, 14; Johnny, 10 and Kate, 4. John is sales manager for WDAC Christian Radio in Lancaster. Kate attends the S. June Smith Center for children with developmental delays and a regular preschool program at Noah's Ark. Michelle has won numerous awards for her paintings, drawings and sculptures. Her recent works celebrate the human form and Christianity, and convey her belief in the sacredness and beauty of life. Michelle combines showings of her artwork on slides with speaking performances and music; she also does portraits. For more information, write to her at Hidden Hills Studio, 624 Hilldale Road, Holtwood, PA 17532.
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1-800-600-7808, 1-800-755-0601 (TTY). The Apple Computer Disability Solutions Store.

*Chris and the entire staff at Aisle 17 have talked to lots of people just like you. They're friendly, they're knowledgeable, they're ready to help.
few months ago, looking ahead to this special, telecommunications theme issue, and hoping to put a "human face" on the technology, I set out on the "information super-highway" looking for parents of children with disabilities. I got online and posted a few public invitations for parents to share their experiences with readers of Exceptional Parent.

To say simply that the response amazed me would be an understatement. The sheer numbers took me by surprise—more than 300 pieces of electronic mail ("e-mail") flooded my online mailbox. I was even less prepared for the incredible power and emotion of the stories these letters told... or for the words parents used to describe others they knew only through printed text on a computer screen—words like close friends, family and community.

**Information and Support**

For many parents of children with disabilities, telecommunications may provide their first contacts with other families in similar circumstances. Patti is the mother of an adolescent daughter only recently diagnosed with Rett syndrome, a rare disorder affecting only girls. Doctors had considered her child autistic, but information Patti obtained from other parents on Prodigy's Medical Support Bulletin Board led her to suspect the Rett diagnosis, which was later confirmed. Patti credits her online friends for more than information, however—"When our daughter entered puberty, she went through a severe behavioral and physical regression. Without the sup-
AOL AUTISM "CHAT" GROUP

Thursday nights at the Dixon household in Hingham, Massachusetts can get a bit hectic. Bob and Lee try to eat an early dinner, wash the dishes promptly and hustle the kids off to bed. After setting the VCR to tape Seinfeld, they are ready to attend their weekly support group for parents of children with autism. Settling into chairs in front of the computer, they sign on to America Online (AOL) and head for the “Equal Access Café,” an “online chat room” in AOL’s disAbilities Forum.

Joining Bob and Lee Dixon online each week are parents from all over the country. Joy Brown of Mason City, Iowa will be there. So will Ann Gibbons from Maryland, Diane Woodward from Louisiana, Fred and Susan Moore from North Carolina and many others. Tonight, conversation among the 22 parents in the “café” touches easily on a variety of topics—one child’s upcoming IEP meeting, a new book that another parent has just read, an embarrassing incident with an impatient child who did not want to wait in line at a fast food restaurant. This last anecdote leads to a flood of others; it seems that almost everyone present has been embarrassed in a restaurant at least once by a child—and not always a child with autism!

Bob (screen name, JBob74) and Lee (Margsmom) remember the first time they joined the Thursday night chat—“At the beginning, we just sat back and listened, fascinated that all the people behind the screen names seemed to know each other, and that the conversation was not unlike that which friends might have across the kitchen table. The subject was autism, but these people could laugh and cry together, talk about their families and plans for the weekend, and in between all the small talk, they could exchange valuable information about autism... We enjoyed ‘eavesdropping’ that first week, and couldn’t wait to return!”

Other regular participants share this enthusiasm. Jill (JillDJ), a busy trial attorney and the parent of four-year-old Zachary, calls the Thursday night chat “one of the highlights of the week.” Diane Woodward (Parlante) agrees, “These meetings are an invaluable resource. I just can’t emphasize that enough. ‘Comparing notes’ helps me to find out what is common among children with autism and what is unique about my child. It also helps to know I am not alone.”

Online support is not limited only to parents. Nine-year-old Caitlin Dixon (CaitTheGr8) found an online buddy in six-year-old Allison Moore (AllisonCM). Both have younger siblings with autism. The girls’ relationship began with a piece of electronic mail (e-mail) to Caitlin’s dad, Bob, from Allison’s father, Fred (AttyFred). Fred wrote that Allison, who sometimes considers younger brother Stephen “a pain,” wanted to ask Caitlin if her sister, Margaret, also “got on her nerves.” Caitlin, says her dad, “couldn’t wait to reply.” Since then, the girls have exchanged pictures of themselves (scanned into the computer and attached to e-mail), personal greetings (saved as “sound files” and attached to e-mail) and computer-generated artwork. Allison, says Fred, arrives home from school daily and says, “I need to go check my e-mail!”

Regular Thursday night chatters are unanimous in urging other parents to take the plunge into telecommunications. Joy Brown (Joyb837443) says that her experiences with telecommunications have been invaluable—“I would recommend this to anyone just for all the information that is available; the many friends you will make online is the icing on the cake!”
port we found online, we would never have been able to deal with it. I had started to resent my daughter. Actually, it had become difficult for me to summon up any feelings for her. My friends on the bulletin board helped me to understand what was happening during my daughter's regression. They helped me to reach out to her and love her. My online friends virtually gave us back our family."

Sally Wilson, the West Virginia mother of a four-year-old boy with autism, also appreciates the opportunity to speak with other parents of children with autism, especially those older than her son—"I have made a close online friend (although she lives far away) who has a six-year-old son very similar to mine. Recently, doctors suggested that it would help if I could find a parent with a high-functioning child who was about two years older than mine. Thanks to telecommunications, I could tell them, 'I already have!' I was one step ahead of the medical community. When will they catch up?"

Virginia Crimarco, a registered nurse and the mother of a nine-year-old child with phenylketonuria (PKU), is happy to provide support to parents of children younger than her own. In fact, she has been active in notifying hospitals about the online support that is available to new "PKU parents"—"Technology has made life easier for those with newly diagnosed infants. A new mom and dad, upset over a recent diagnosis, need only turn on their computer to find warm and compassionate people who have 'been there.' They never even have to leave the house!"

A Glimpse into the Future

Telecommunications also allows parents to make contact with adults who have disabilities, allowing them a glimpse into the futures of their own children. Heather RaVell Strafach is the mother of ten-month-old Will, who has albinism and is visually impaired. Although Will is very young, and the extent of his visual impairment is still unknown, Heather's online discussions with adults who are visually impaired or blind have made her more confident about his future—"In 'real life,' I don't know any people who are blind. Online, I have asked questions and learned so much. I cannot tell you how much this has meant to me!

Robert "Bear" Eshelman, an adult who is visually impaired, says he welcomes the questions of parents like Heather—"Parents of a child who is blind wouldn't think about approaching me on the street, but online they are more comfortable and willing to ask questions. Parents should know that it is okay to ask questions; most of us are glad to help. There are many people with disabilities online who have years of experience that would be useful to parents."

Benefits Outweigh Risks

Although the parents I heard from were uniformly enthusiastic about the information and support they had found online, a few mentioned some pitfalls of electronic support. Donna Getz is a member of a family who has been dealing with the effects of neurofibromatosis type II (NF2) for several generations. Her husband and father-in-law are affected; so are two of the couple's three children. Donna asserts that "I would rather give up my microwave than my online support group—and I really like my microwave." But she warns that it is easy to become overwhelmed by the sudden onslaught of support, and over-involved in the lives of your new online friends—"After feeling 'on your own' for so long, it is easy to become an 'online junkie.' You can become very involved with the people you meet there. We have become very close to people who died from NF, or as a result of NF-related surgery. It's very upsetting when that happens. No question about it."

Of course, all close human relationships involve making ourselves vulnerable; friendships forged in "cyberspace" are no different. Donna, like most others, agreed that the incredible benefits of telecommunications outweighed its minimal risks.

-K.S.
GETTING STARTED WITH TELECOMMUNICATIONS
by Peter Green

To many people, a personal computer is little more than a sophisticated typewriter with the ability to play video games. But nowadays, it may be more appropriate to think of a computer as a kind of enhanced telephone. By connecting a computer to your phone line, you can easily communicate—not only with your voice, but with pictures and written words, too.

For children with disabilities, and for their parents, this is no small achievement. When the subject is disability, communication—the sharing of questions, answers, ideas and information—isn’t usually easy. Most parents of a child with spina bifida, for example, don’t live in a community filled with other parents of children with spina bifida. Nor do most local libraries carry extensive collections of disability-related information. For parents of a child with a disability, exchanging information and meeting people in similar situations can be, at best, difficult.

Telecommunications can change all that.

An Electronic Community
In the literal sense, telecommunications refers to a bunch of wires, computer chips and telephones working together to connect computers with one another. But what telecommunications represents is nothing short of an electronic community—a place where the post office never closes, where there are ongoing seminars about every conceivable topic and where very generous libraries give away information instead of loaning it. It’s a community where people cannot see one another, so they care more about what is being said than who is doing the saying. It’s a community that you can plug into, or disengage from, whenever you choose.

Perhaps most importantly, telecommunications is a chance for everyone to present themselves as they would like to be perceived. A computer is able to level the playing field like no other tool. It doesn’t care what you look like, what you sound like or how old you are. Unless you choose to make these characteristics known, the person with whom you are communicating isn’t able to judge you based on anything other than what you have to say and how you express it.

First Things First
Especially if you are new to computers, it makes sense to learn about telecommunications from someone who has experience—a student at a nearby university, a colleague at work, another parent or a counselor at a local technology resource center.

Before jumping into the middle of any new community of people, it helps to have someone show you around town.

It also helps to have some understanding of the place you’re visiting. Who are the people in this electronic community? How does your computer help you travel there? And where is “there,” anyway? To answer these kinds of questions, the following overview describes what happens behind the scenes when you use your computer to plug into a commercial online service:

Somewhere, often in some remote part of the country, sits a big computer, packed with information. This computer—the online information service—acts as the central meeting place for people from all around the world, a place where kids and adults gather to chat and retrieve information. Of course, people don’t actually travel to this remote place to meet in the shadow of this computer. Instead, they call the computer using regular telephone lines in their homes and offices (usually, only a local phone call is required). It is through these phone lines that information—words, pictures and sounds—passes from the main computer to your personal computer, and vice versa.

Because telephone lines are naturally designed to handle voices rather than written words and pictures, you need something called a “modem” to connect to this central computer. A modem is a small computer accessory that makes it possible for all types of digital information—the form used in computerized communications—to be carried across normal phone lines.

Getting Started
You need only four things to get started:
1) A phone line;
2) A personal computer system;
3) A modem; and
4) A subscription to an online information service.
Assuming that you already have a phone line, your first challenge may be to locate a computer that you can use. If you have one at work, using it may be the most convenient and affordable solution—buying a new personal computer, with accessories, can cost from $1,000 to $3,000.

If a child with a disability will also be using the computer, accessibility is another important consideration. Your state’s Alliance for Technology Access center or assistive technology program—see directories in January 1994 Exceptional Parent—can help you come up with accessibility solutions.

Making the Connection

Once you have access to a personal computer system, you’ll need to make sure that it has a modem. Sometimes modems come with computer systems, but often they do not. So, how do you go about finding one?

First, do not feel like you must immerse yourself in modem minutiae. Consult with a friend or ask someone at your local computer store for a recommendation. Be sure to tell them three things: 1) the type of computer you have, 2) that you plan to connect to a standard online information service and 3) that you want a “14,400-baud” modem (baud is a measurement of the modem’s speed—14,400 is just about the fastest modem you can buy, and it offers the best performance for its price). You may also want to indicate a price range—most modems of this caliber cost between $150 and $250. Not surprisingly, name-brand modems usually cost a bit more, but also tend to include the useful extras like cables, software and customer support.

The last thing you’ll need is an account on an online information service. For most people, there’s no better place to start than a commercial online service like America Online, CompuServe, Delphi, eWorld, GEnie or Prodigy. Most come with user-friendly software, and all have toll-free customer-support helplines.

Some people may balk at the notion of paying for an account on a commercial online service when there are thousands of “free” online services, or “electronic bulletin boards,” in existence (see Disability-Related Electronic Bulletin Boards, page 39). And almost everyone has heard of the most famous “free” service of all—the Internet (see Cruising the Internet, page 33). But, unless you are an experienced computer user, connecting to these kinds of services can be difficult. Such services do not come with user-friendly software, so you’ll need to use the communi-
LANDON HAMLIN
E-mail: 70431.3577@CompuServe.COM

In January of 1992, my 19-month-old son, Luciano, contracted bacterial meningitis, resulting in a profound, bilateral hearing loss. My desire to find answers for my son led me to join CompuServe's Disabilities+ Forum, where I began scanning messages and searching online libraries for information. At some point, I introduced myself as a parent and indicated that I would appreciate some guidance.

The online community has provided support through networking with other parents and individuals with hearing impairments. These people have shared their experiences with me—sometimes lending a sympathetic ear, other times providing a contrasting opinion against which to weigh my own. I have found friends from as far away as Ontario, Canada and San Francisco, California who share otherwise unavailable resources. I have been informed of upcoming conferences and technological advances, sometimes even before the professionals who are involved with my son.

Shortly before I discovered this online community, a friend had loaned me What's That Pig Outdoors, the autobiography of Henry Kisor, a man who, like my son, lost his hearing to meningitis as a child. It was a tremendous thrill to find this bright and humorous man online, sharing words of wit and wisdom.

I think the most valuable aspect of my online experience is the sense of control it gives me in dealing with my son's hearing loss. Parents in our circumstances feel a tremendous need to do something positive; especially in the beginning, there is always the feeling that one is not doing enough. Telecommunications gave me the information I needed to do all that I could for my son and the confidence that came from knowing that I wasn't simply trusting his care to someone else. No other medium offers such a broad spectrum of information in such a timely manner.

Landon Hamlin lives in Apopka, Florida.
CINDY PRICE
E-mail: BXRT89C@prodigy.com

My husband and I have six children—yes, six, all ours! Our youngest son, Evan, has spina bifida, hydrocephalus and renal tubular acidosis.

I have been "hooked" on telecommunications since my older son got Prodigy for a Christmas present a little over a year and a half ago. My online "spina bifida family" has been very supportive through all the ups and downs. It is great to get online and post a note, and know that people who understand will reply. This support was especially helpful as I went through a very difficult IEP process trying to get Evan into a regular classroom. The encouragement I received from my online friends helped me to be confident that what I wanted for my child really was the best thing. It's been wonderful to share our joys, accomplishments and sorrows. It also feels good to be able to offer support to others.

Last year, all of us sent family pictures to one of the mothers in the online group; she put all the photos together in a collae and had it photocopied—in color, no less. Each person who had sent a picture received one of the "albums." It was very exciting to finally see what everyone looked like. Our group is quite diverse—it includes adults with spina bifida; college-age kids; parents with brand new babies, toddlers and teens; even a very loving grandma.

I would encourage parents who are not yet online to give it a try. If I can do it, anyone can. Many of the commercial online services are very user-friendly for those, like myself, who are not very computer literate. It is great to be able to sit at home and have your very own support group that you can attend in your spare time.

Cindy Price lives in Grover Beach, California.
Sure, Jessica Radtke likes school, but like most 8 1/2-year-olds, she loves recess. Although she's good at dodgeball and baseball, you can see she excels at tetherball. As a three-year-old, Jessica was one of the youngest children in California certified to operate a power chair. At six, Jessica was enrolled in public school and
immediately helped therapists teach other young students how to control their power wheelchairs. Jessica is currently a third grader at Centerville School. Here she demonstrates her power and agility in her Zippie P500.
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EXCEPTIONAL PARENT
Announces Forum on eWorld

Exceptional Parent magazine is collaborating with Apple Computer, Inc. to develop an exciting electronic forum on eWorld, Apple's new commercial online information service.

eWorld, which will be available this summer, is a state-of-the-art online service that uses computer graphics to make communication and information retrieval fast and easy. There are eight main buildings on the eWorld globe—E-mail Center, Newsstand, Marketplace, Arts & Leisure Pavilion, Learning Center, Computer Center, Community Center and a Business and Finance Center. Each area uses distinctive graphics and a standardized user interface to guide the subscriber around the service.

The Exceptional Parent forum will contain three main components: an interactive message area for adults and children, a fully searchable database containing resource information and a bulletin board containing a variety of helpful documents. The Exceptional Parent forum is part of a larger eWorld "Disabilities" forum which includes participation from several other organizations, including: Trace R&D Center, ABLE-DATA, Telecommunications for the Deaf, Inc., Special Needs Project, National Center on Accessible Media and Don Johnston Incorporated.

You'll learn more about eWorld—and the new Exceptional Parent forum—in upcoming issues of this magazine.
Commercial Online Information Services

**AMERICA ONLINE**
Pricing: No setup fee; $9.95/month (includes 5 free hours; $3.50 each add. hour).
Look/Feel: Graphics (requires special software)
Membership (approx.): 700,000
Disability-related information:
- disabilities forum (message boards, online chats and software libraries)
- Assistive Technology forum
- National Multiple Sclerosis Society
- United Cerebral Palsy Associations
- National Alliance for Mentally Ill
Contact: 800-827-6364

**COMPUSERVE**
Pricing: $39.95 one-time setup fee; $8.95/month for basic services; $4.80/hour or $9.60/hour (depending on modem speed) for non-basic services).
Look/Feel: Text or Graphics (requires special software)
Membership (approx.): 1.7 Million
Disability-related information:
- Disabilities+ Forum (live chats, message boards, software libraries)
- Handicapped Users Database (HUD)
Contact: 800-848-8199

**DELPHI**
Pricing: No setup fee; $10/month (includes 4 free hours; $4 each add. hour) or $19 one-time setup fee; $20/month (includes 20 free hours; $1.80 each add. hour).
$3/month add. for Internet access.
Look/Feel: Text
Membership (approx.): N/A
Disability-related information:
- Access to WIDnet managed by the World Institute on Disability (online chats, conferencing, file libraries, message boards)
Contact: 800-695-4005

**eWORLD**
Pricing: No setup fee; $8.95/month (includes 2 free hours; $4.95–7.90 each add. hour).
Look/Feel: Graphics (requires special software)
Membership (approx.): N/A (new service to be launched in Summer 1994)
Disability-related information:
- Exceptional Parent forum
- ABLEDATA, RehabData libraries
- Trace Center Information Library
- Special Needs Project Bookstore
- Telecommunications for the Deaf, Inc. forum
- Software libraries, message boards, chat rooms
- Assistive Technology Center
Contact: 800-775-4556

**GENIE**
Pricing: No setup fee; $8.95/month (includes 4 free hours; $3.00–9.50 each add. hour).
Look/Feel: Text
Membership (approx.): 300,000
Disability-related information:
- Disabilities Roundtable
Contact: 800-638-9636

**PRODIGY**
Pricing: $4.95 one-time setup fee; $14.95/month for “core” services and 5 hours of “plus” services; $3.60 each add. “plus” hour.
Look/Feel: Graphics (requires special software)
Membership (approx.): 2 Million
Disability-related information:
- Medical Support Bulletin Board (many different topics and subjects)—5 free hours per month, then $1.20/hr
- “Parenting Special Needs” Topic on Homelife Bulletin Board (a “plus” service)
Contact: 800-776-3449

**The Bottom Line: Content**
While many online services may look and even act alike, the information they offer may be quite different. Often, information from a particular organization or publisher is available only on one online service. Comparing the same two services as above, only America Online has access to information provided by Time magazine and files from the United Cerebral Palsy Associations. CompuServe, in turn, offers exclu-
EILEEN NAUSS
E-mail: NKSJ63A@prodigy.com

I am the parent of a seven-year-old boy who is deaf and has hydrocephalus. Patrick has had 17 shunt revisions over the last two years. At this point, he is doing very well. He is finishing first grade, and his first year in a mainstream classroom.

I have been active on the Prodigy "Hydro" board for 18 months. The support I have found there has been quite profound. In fact, we have become a family. The board has participants who are adults, and this is so important to me.

On the board, I can talk to people with hydrocephalus who have gone to college, married and have kids of their own. As a parent, my biggest challenge is to treat Patrick as if he were a normal child. At the same time, I need to deal with the reality that he could face yet another surgery tomorrow—our kids need functioning shunts to survive.

I feel particularly empowered by members who relate their own experiences and share their fears as well as their successes. For example, it is a wonderful thing that Patrick is able to play baseball, but I had many talks with my friends on the board about my fears related to his safety. I think it is vital that I have people to share these feelings with; after all, this really is my problem and not Patrick's. I had to consider the opinions of the adults on the board who have strong feelings about the effects of "overprotective parents." It is this kind of day-to-day support that is so important to me.

Eileen Nauss lives in LaGrange, Illinois.

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Circle # 185

Looking Ahead

What lies ahead for the rapidly-evolving field of telecommunications? In the short term, it is expected that more information (both disability-related and otherwise) will become available. Information providers including organizations, magazines, retailers and product developers are racing to explore the benefits of making their information available electronically.

Computer-based telecommunications will never replace natural, human interaction. However, at its best, this technology empowers people to expand their world—and to break their isolation—by opening new avenues of communication.

Peter Green lives in Boulder, Colorado, and is part of Apple Computer's Worldwide Disability Solutions Group. He co-authored, with Alan J. Brightman, the book INDEPENDENCE DAY: DESIGNING COMPUTER SOLUTIONS FOR INDIVIDUALS WITH DISABILITY (1990, DLM).
Cruising the Internet
by Bill McGarry

The largest electronic network in the world, the Internet, is actually a world-wide web of interconnected networks. The Internet is growing at a tremendous rate; a new network is added every ten minutes. It is nearly impossible to know how many people are connected to the Internet—some estimate that there are more than 15 million users in 140 countries.

Mailing Lists and Newsgroups
A variety of resources are available on the Internet. The most common is electronic mail or "e-mail." Almost everyone on the Internet has their own mailbox where e-mail can be sent directly. E-mail can be used for private discussions between Internet users. Internet users can also add their e-mail addresses to—"subscribe to"—any one of several thousand electronic mailing lists. Mailing lists allow subscribers to participate in ongoing discussions of almost any imaginable topic. Any message sent to a mailing list is mailed to every subscriber; individual subscribers can respond to messages or enter new messages which will, in turn, be sent to every subscriber. See sidebar for a partial list of disability-related mailing lists.

Many mailing lists also store all messages in a database at a central location. This allows users to search previous messages by using a "keyword." For example, I was recently contacted by someone who was looking for information on a program where dolphins were used in therapy with children who had mental retardation. Using the keyword "dolphin," I was able to search a database storing the last 30,000 messages posted to the Handicap Digest mailing list. Within a few minutes, an article describing this therapy program was retrieved from the archives and mailed to my electronic mailbox.

The USENET network, which is part of the Internet, also has a collection of more than 5,000 discussion groups called "newsgroups." Newsgroups store messages on a computer in a central location. Users can read and reply to the messages from their own computers. Disability-related newsgroups include Misc.handicap, alt.support.spina-bifida and alt.support.arthritis.

Alder Castanoli lives in Key West, Florida.

My four-year-old son, Christopher, was diagnosed with attention deficit disorder (ADD) early this year. At first, my wife and I were ashamed and worried to have a "hyperactive" child.

I had just received a new Macintosh computer for my birthday, so I thought I would use it to try to learn something about ADD. I joined America Online (AOL) and started to get involved in "chats" with other parents of children with ADD and other disabilities. During one of these chats, I learned about an Internet mailing list for parents of children with ADD. I found out that I could subscribe to this list through my e-mail address on AOL.

In the few short months since subscribing to the ADD-Parents mailing list, I have learned that my child is not a freak. I now know that Christopher has a medical condition that is treatable through medication and behavior modification techniques, many of which I have learned about through e-mail exchanges with other parents on the list.

The ADD-Parents list includes parents from all over the US and Canada, so we can compare notes on special education laws and practices in various locations. When we have an especially trying day with our kids, we can share our frustrations by sending e-mail to the list; often, we will get rapid return e-mail with suggestions or, just as importantly, moral support. The particular computer service each individual member of the list uses is not important—we can receive e-mail from commercial services like CompuServe, America Online, Prodigy, GEnie or any other service that provides an Internet mailing address.

I have learned how to better be a father to my son. And thanks to the parents of older children on the mailing list, I also have learned about the challenges that lie ahead. I know about the potential pitfalls of elementary school and higher education, and I am ready to deal with problems as they arise.

Alder Castanoli lives in Key West, Florida.
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Retrieving Information

Many computer sites on the Internet offer free access to file libraries of software and text files. One such site at Olivetti North America is devoted to disability-related information and has more than 1,000 programs and information files. Some of the programs are free or “shareware”—if you like the program, you pay the author directly. Available programs include a sign language tutor, programs that allow the use of a computer with one finger, word predictors and speech synthesizer drivers.

The Internet has so much available information that it can become difficult to find what you are looking for. To make it easier to find and retrieve information...
mation highway, looking for other solutions. This time, a woman answered my query, and we started correspon-
ding via e-mail. Her son had also been diagnosed with sensory integration disorder, but was now consid-
ered to have autism. We compared notes and found that our sons were very similar. Eventually, we traveled from Colorado to New Jersey to have Jason seen by the same experts who had evalu-
ated this woman's son. Just before his fourth birthday, my son was diagnosed with mild-to-moderate autism.

Two years later, this woman and I still correspond by e-mail several times a week. Besides meeting face-to-
face on the trip when Jason was evaluated, we have attended one autism conference together and we will attend another soon. This time, we will be joined by another "electronic friend" from Minnesota, also the parent of a boy with autism.

My other friends can't understand what it is like to potty train a child who has autism. They have never dealt with a four-year-old who tantrums if you drive home via a different route. They don't comprehend the constant search for new treatments and therapies. My online friends give me the day-to-day support that can only come from someone who is going through the same things.

Jean Jasinski with children, Kayla and Jason, at Disneyland.


and files, many sites now offer user-friendly utilities, including one called "Gopher" (named after the masc-
ocot of the University of Minnesota, where the program was first developed).

The Gopher program provides a single access point to the resources available on hundreds of Internet computers and presents all of the information in menu format. Instead of having to remember specific com-
mmands or recall the exact computer site where certain information is located, the Gopher program presents a menu of choices in plain English. Choosing one item on a menu may display a text file; another may get a software program from a file library, retrieve a picture, allow database searches or display another menu.

The choice is easy... A Columbia Toilet Support gives your child independence, privacy and secure support

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Handsome, durable and convenient to use!

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COLUMBIA
DISABILITY-RELATED INTERNET MAILING LISTS

The Internet offers a number of disability-related mailing lists. To participate in discussions taking place on a list, one must “subscribe” by sending a message to the list’s distribution address (see below). The message should say simply (and without punctuation):

   Subscribe LIST-NAME Your-Name

For example, to subscribe to the list for parents of children with attention deficit disorder, Alphus Jones would send a message to the distribution address, listserv@n7kbt.rain.com; his message would say:

   Subscribe ADD-PARENTS Alphus Jones

He does not have to include his e-mail address in this message; the list administrator will get that information by looking at the “From:” line that will be automatically inserted at the top of his message.

<table>
<thead>
<tr>
<th>List-Name</th>
<th>Topics of Discussion</th>
<th>Distribution Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADA-LAW</td>
<td>ADA, related legislation</td>
<td><a href="mailto:listserv@vm1.nodak.edu">listserv@vm1.nodak.edu</a></td>
</tr>
<tr>
<td>ADD-PARENTS</td>
<td>Children with ADD</td>
<td><a href="mailto:listserv@n7kbt.rain.com">listserv@n7kbt.rain.com</a></td>
</tr>
<tr>
<td>BEHAVIOR</td>
<td>Behavioral and Emotional Disorders in Children</td>
<td><a href="mailto:listserv@asuvm.inre.asu.edu">listserv@asuvm.inre.asu.edu</a></td>
</tr>
<tr>
<td>BICOMPAL</td>
<td>Matches adults with disabilities as pen-pals of kids with the same disabilities</td>
<td><a href="mailto:listserv@sjuvm.stjohns.edu">listserv@sjuvm.stjohns.edu</a></td>
</tr>
<tr>
<td>BLIND-L</td>
<td>Blindness</td>
<td><a href="mailto:listserv@uafsysb.uark.edu">listserv@uafsysb.uark.edu</a></td>
</tr>
<tr>
<td>BLINDNWS</td>
<td>“Blind News Digest”</td>
<td><a href="mailto:listserv@vm1.nodak.edu">listserv@vm1.nodak.edu</a></td>
</tr>
<tr>
<td>BRAILLE</td>
<td>Braillie</td>
<td><a href="mailto:listserv@cseam.bitnet">listserv@cseam.bitnet</a></td>
</tr>
<tr>
<td>BRAINTMR</td>
<td>Brain tumors</td>
<td><a href="mailto:listserv@mitvma.mit.edu">listserv@mitvma.mit.edu</a></td>
</tr>
<tr>
<td>COMMDis</td>
<td>Communication disorders</td>
<td><a href="mailto:listserv@rpitshym.bitnet">listserv@rpitshym.bitnet</a></td>
</tr>
<tr>
<td>CPALSy</td>
<td>Cerebral palsy</td>
<td><a href="mailto:listserv@vm1.nodak.edu">listserv@vm1.nodak.edu</a></td>
</tr>
<tr>
<td>CYSTIC-L</td>
<td>Cystic fibrosis</td>
<td><a href="mailto:listserv@yalevm.cis.yale.edu">listserv@yalevm.cis.yale.edu</a></td>
</tr>
<tr>
<td>DADVOCAT</td>
<td>Fathers of children with disabilities</td>
<td><a href="mailto:listserv@ukcc.uyk.edu">listserv@ukcc.uyk.edu</a></td>
</tr>
<tr>
<td>DOWN-SYN</td>
<td>Down syndrome</td>
<td><a href="mailto:listserv@vm1.nodak.edu">listserv@vm1.nodak.edu</a></td>
</tr>
<tr>
<td>DDFIND-L</td>
<td>Information on disabilities</td>
<td><a href="mailto:listserv@n7kbt.rain.com">listserv@n7kbt.rain.com</a></td>
</tr>
<tr>
<td>DEAF</td>
<td>Deaf online magazine</td>
<td><a href="mailto:deaf-request@clark.net">deaf-request@clark.net</a></td>
</tr>
<tr>
<td>DEAF-L</td>
<td>Deafness</td>
<td><a href="mailto:listserv@slucvmb.bitnet">listserv@slucvmb.bitnet</a></td>
</tr>
<tr>
<td>DEAFBLND</td>
<td>Deaf and Blind</td>
<td><a href="mailto:listserv@ryevm.ryerson.edu">listserv@ryevm.ryerson.edu</a></td>
</tr>
<tr>
<td>DISRES-L</td>
<td>Research and disabilities</td>
<td><a href="mailto:listserv@ubvm.bitnet">listserv@ubvm.bitnet</a></td>
</tr>
<tr>
<td>DSSHE-L</td>
<td>Students with disabilities in higher education</td>
<td><a href="mailto:immune-request@webcr.ucsd.edu">immune-request@webcr.ucsd.edu</a></td>
</tr>
<tr>
<td>IMMUNE</td>
<td>Immune disorders</td>
<td><a href="mailto:ls-list-request@east.pima.edu">ls-list-request@east.pima.edu</a></td>
</tr>
<tr>
<td>LD-LIST</td>
<td>Learning disabilities</td>
<td>(Msg should say only: “Subscribe”)</td>
</tr>
<tr>
<td>L-HCAP</td>
<td>“Handicap Digest” — general disabilities</td>
<td><a href="mailto:listserv@vm1.nodak.edu">listserv@vm1.nodak.edu</a></td>
</tr>
<tr>
<td>MD-LIST</td>
<td>Muscular dystrophy</td>
<td><a href="mailto:md-list-request@dataz.bizix.com">md-list-request@dataz.bizix.com</a></td>
</tr>
<tr>
<td>MOBILITY</td>
<td>Mobility disorders</td>
<td><a href="mailto:listserv@slucvmb.bitnet">listserv@slucvmb.bitnet</a></td>
</tr>
<tr>
<td>MRDEAF-L</td>
<td>Mental retardation with deafness</td>
<td><a href="mailto:majoro@oma.oma.com">majoro@oma.oma.com</a></td>
</tr>
<tr>
<td>RIPLIST</td>
<td>Retinitis pigmentosa</td>
<td><a href="mailto:rplist-request@iri.fr">rplist-request@iri.fr</a></td>
</tr>
<tr>
<td>STROKE-L</td>
<td>Strokes</td>
<td><a href="mailto:listserv@ukcc.uyk.edu">listserv@ukcc.uyk.edu</a></td>
</tr>
<tr>
<td>TBI-SHRT</td>
<td>Traumatic brain injury</td>
<td><a href="mailto:listserv@slucvmb.bitnet">listserv@slucvmb.bitnet</a></td>
</tr>
</tbody>
</table>

Each choice on a menu will connect you to the computer where that information is stored, no matter where in the world it may be. The location of the information will be indicated.

Depending on the system you are using for Internet access, a single text command, menu selection or mouse-click on a Gopher icon will connect you to any Internet gopher site. For example, if you were to connect to the Gopher server at the Olivetti Disability Resource Center (gopher.aid.olivetti.com), the main menu would display a number of choices including: 1. Caution! Gopher Under Construction, 2. How to Find Your Way Through this Gopher, 3. Other Disability-Related Gophers, 4. Disability Resources, 5. Medical and Health Resources, and 6. Search the GopherSpace for Special Topics. If you were to select the fifth menu item, Medical and Health Resources, the Gopher would then display a multi-page menu with nearly 200 choices including a genetic engineering database in Italy, the World Health Organization in Switzerland and biomedical resources at Yale—New Haven Hospital.

The Internet has more than 7,000 Gopher sites, with 75 to 100 new sites being added weekly. More than 12 million items are available through Gopher. The amount of available disability-related information is growing rapidly.

Getting Internet Access

How do you get access to the Internet? Most universities and many companies offer access to students and employees. Most of the major commercial online services offer at least e-mail access to the Internet; some offer access to other Internet features as well. Other options for gaining Internet access include local bulletin boards, community-sponsored networks, called “Freenets,” or commercial Internet.
providers—most charge a flat monthly fee and provide a local access number.

**Internet Resources**

These books can tell you more about the Internet:


A number of useful electronic manuals are also available on the Internet itself, or from many commercial online services and local electronic bulletin board services.

---

**Bill McGarry** is the parent of three children, 11-year-old Alexander, who has Down syndrome, Meghan, 10, and Timmy, 7. He lives in Shelton, Connecticut and works as a computer programmer at Olivetti North America. McGarry is the system operator of the Handicap News BBS (203/926-6168, 300–14,400 baud) and moderator of the Disability Forum on the National Videotex Network (NVN), a commercial online service. (For more information on NVN, call 1-800-336-9096.) Bill also moderates several Internet mailing lists and Fidonet conferences. He can be reached via e-mail at wt@bunkerafly.olivetti.com.

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**DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS**

The disability-related bulletin board services (BBSs) listed below can provide a wealth of helpful information. Use of all listed services is free, however, depending on where one lives, calling a BBS may incur long-distance telephone charges. A few bulletin boards charge fees for increased access or membership; when applicable, these fees are mentioned in the notes following each entry. Some boards chose to list voice numbers where the coordinator of the BBS, known as the system operator (sysop), can be reached for questions or comments.

These services do not provide special software, as do most major commercial online services. Instead, users must call the BBS using the communications software that comes with their modems. Users must be sure to stay within the given baud rate per second for modems (bps)—this figure is listed after the BBS modem number (i.e., “up to 9,600 bps”). This is the only aspect of the communications software that the user must configure (set) differently for various BBSs; the other modem settings are the same for all listed services—8 data bits, no parity, 1 stop bit (8-N-1). (These are the default settings for most communications software—you don’t need to understand what each means; you may not even need to change the configuration of your software from the default.)

Once connected to a BBS, users can post and read messages, upload (post) and download (receive) files and leave messages for the sysop. Certain boards are connected to larger networks, such as Internet, Fidonet or ADAnet, which allow files to be shared and messages to be posted among a large number of bulletin boards.

### ALABAMA

**ADAnet**

(205) 254-6050, up to 2,400 bps
All disabilities; many BBSs are linked to this system; many message areas; large file area for downloading; users get 30 free minutes daily; subscriptions ($40/yr) allow increased usage and unlimited downloading.

### ALASKA

**Assistive Technology of Alaska BBS**

(907) 577-1239 (in AK), up to 2,400 bps
(907) 277-1239 (out-of-state), up to 2,400 bps
(800) 536-0318 (voice)
(907) 274-0316 (voice)
Forums on specific disabilities, education, assistive technology, legislation; files for downloading.

### ARIZONA

**Tucson Prologue**

(520) 322-8014, up to 14,400 bps
General disabilities; some emphasis on blindness; Internet e-mail; Fidonet, message areas, files for downloading; local issues; most users are adults with disabilities.

### CALIFORNIA

**BayTalk**

(415) 904-6430, up to 9,600 bps
Emphasis on computer-access issues for persons with disabilities; message/area list for downloading; local issues; accessible; message areas; some Fidonet access.

**Handicap News BBS**

(203) 225-6168, up to 14,400 bps
Wide range of disabilities—50–80 conference areas; Internet e-mail/newsgroups; Fidonet, many conferences helpful to parents, local conference available, although most callers are non-local, nearly 1000 files for downloading; sysop is parent of child who has Down syndrome.

**DISTRICT OF COLUMBIA**

**ACB On-Line (American Council of the Blind)**

(202) 331-1016, up to 14,400 bps
(202) 457-5061 (voice)
Emphasis on visual impairments; files on braille literacy, resource lists, archive of ACB literature.

### ILLINOIS

**COPH 2 BBS**

(312) 436-0659, up to 2,400 bps
General disabilities; message areas, files for downloading.

### INDIANA

**The Special Needs BBS**

(219) 569-0112, up to 14,400 bps
General disabilities, some emphasis on hearing impairments; Internet e-mail, Fidonet, health care net access; message areas for parents, files/programs for downloading; sysop is parent of child who is deaf.

### LOUISIANA

**Resource Access**

(504) 897-9204, up to 2,400 bps
General disabilities; message areas, files for downloading.

### MAINE

**Maine Meeting Place BBS**

(207) 339-3845 (ME only), up to 28,800 bps
Wide range of disabilities, related issues; BBS designed to accommodate computer novices—many parents are users, Internet e-mail/
DISABILITY-RELATED
ELECTRONIC BULLETIN
BOARDS,
newsgroups; local issues; outreach
to groups/individuals who need low-cost computer equipment.

MARYLAND
Braille Inn BBS
(410) 893-8944,
up to 9,600 bps
General disabilities; files in and about braille; Fidonet.

Deaf New World BBS
(301) 587-2277,
up to 14,400 bps
TTY-compatible; thirty minutes free access dailysubscribers (varying rates)
receive more time and Internet e-mail emphasis on deafness, Fidonet; online shopping areas for deaf-related products: files for downloading.

HEX BBS
(301) 593-7357, up to 9,600 bps
TTY-compatible; general disabilities; Fidonet; message areas, files for downloading.

NFB Net (National Federation of the Blind)
(410) 752-5011, up to 14,400 bps
Emphasis on visual impairments; NFB literature, publications online, conferences for parents to discuss issues with adults who are blind; Fidonet, ADA.net; electronic books/text files for downloading.

MASSACHUSETTS
Disabled Individuals Movement for Equality Network (DIMENET)
(508) 880-5412, up to 14,400 bps
DIMENET is a coalition of Independent Living Center (ILC) BBSs working to obtain resources for online computing for all ILCs. The BBSs are based in Taunton, MA, Dayton, OH and Tulsa, OK; general disabilities, ILC related issues; Internet e-mail/newsgroups; Fidonet; files for downloading.

Mass. Commission for the Blind BBS
(617) 451-5327, up to 14,400 bps
Emphasis on visual impairments; message areas, conferences, employment info, conference info for parents; files for downloading.

EXCEPTIONAL PARENTS
TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Rueben, parent
Canoga Park, California

"It’s changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

KAREN BURKA
E-mail: ACUA16A@prodigy.com

Parenting a child with a disability is a time-consuming, all-consuming job. After you adjust to the fact of your child’s disability, you try to pick up the pieces and get back to living a “normal life.” But your life is far from normal. You spend all your free time—sick days, vacation days and personal days—going to therapy, medical specialists, IEP reviews and evaluations.

I have two children with hearing impairments. Sarah is six and has only a moderate loss, but two-and-a-half-year-old Mark is profoundly deaf. Parenting a child with special needs means that I have to do twice as much with half as much time. I work full-time to cover the additional expenses and maintain health insurance, but end up with no time left for myself.

Telecommunications gives me the opportunity to quickly make contact with people who understand my situation, my decisions, my excitement when my son says a two-word sentence for the first time or my confusion over differing medical opinions and educational philosophies. If I get depressed because Mark’s progress seems to be at a standstill, I can always find somebody out there to nudge me out of it and remind me to stay focused on those areas where he is excelling.

Besides making contact with other parents, I also get support from adults who are deaf. I can talk to deaf people through telecommunications, but would be unable to talk to them if they were standing right in front of me because I do not know American Sign Language.

Telecommunications allows people to be social again. Hectic lifestyles prevent us from going out and making contact with other parents just when we need it the most. I usually get on Prodigy late at night when the kids and my husband are asleep. Being on the board is therapeutic for me. Just reading all the messages, maybe responding to one or two, is like a catharsis.

Karen Burka with Sarah and Mark.

Karen Burka lives in Falls Church, Virginia.
James is my handsome, 14-year-old son. Our odyssey—or nightmare—began about seven years ago. One night, at a Little League baseball game, I noticed that James was not getting to the ball as quickly as usual. At the time, I didn't think much of this observation. As the months went by, however, things got more complicated. Something was wrong with my son! The tests—all those tests—what could it be? At the time, I thought the worst it could be was a brain tumor.

There was no cure! It felt like a ton of bricks had hit me. I became really angry and frustrated—what can a hard-living, tough guy do when there is nothing or no one to fight?

I went to work the next day bent on showing no signs of weakness. Then, someone asked me about our visit to the doctor. I broke down and cried—a big, macho guy crying uncontrollably.

How unmanly of me to be brought down by this! I was supposed to be the father, the strong one. Guess what—all the macho bullshit in the world is zero compared to having to tell your son he has MLD and is going to live a life of less and less until he dies at a very young age. For me, it was the end of dreams that were just dawning—there would be no more baseball games, no arriving home to be greeted by a boy who is jumping up and down and saying “let's play,” no more toy stores.

I ended my work day with a stop at the old watering hole; I got drunk while playing the role of a tough guy, but that only lasted for a little while. Reality set in at four or five the next morning when my son started screaming with pain in his legs. The pain in my heart prevailed over the pain in my head, but not by much.

The next day, I wanted to go and get drunk again, but something in my Neanderthal brain finally said, “No.” I realized it was time to get on with the job at hand—taking care of my son, getting him up in the morning, dressing him, feeding him, changing him, carrying on both sides of our conversations, learning to play with him in new ways and putting him to bed at the end of each day—always the hardest time for me. Telling interesting bedtime stories had always been difficult; now it seemed almost impossible.

But along the way, I learned to be a more caring father for both of my sons. All those “womanly traits”...
Empowering
Individuals to Share
Their God-given Gifts
with the Community

St. John's Villa, founded in 1948, is a private, Catholic, non-profit residential community providing a caring, loving environment which enhances the growth of each adult resident towards self-acceptance and respect. The Villa integrates a residential adult population with mild to severe mental retardation with outreach programs in Carroll County attempting to empower individuals to share their God-given gifts with the community. St. John's Villa, nestled in the hills of northeastern Ohio, resembles a small rural community and is located near the friendly town of Carrollton.

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- Speech and Language Development
- Physical Education and Swimming
- Case Management Services
- Leisure Activities
- Personal Living Skills
- Social and Domestic Skill Training
- Community-based Supportive Employment and Living

St. John's Villa
For Information Contact:
Sister Elaine Weber, O.S.F.
Executive Director
(216) 627-9789

Mailing Address:
P.O. Box 457
620 Roswell Rd. N.W.
Carrollton, OH 44615

I was so shocked to find within myself have helped me to survive the onslaught of emotional and physical demands leukodystrophy has thrust upon me. I must add that my older son, Brian, has benefited greatly from the United Leukodystrophy Foundation's sibling program. He has emerged as a "severely normal" 18-year-old young man. I love him very much; now, maybe more than ever.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN), or to receive their quarterly newsletter, write or call: National Fathers' Network, The Merrywood School, 16120 N.E. Eighth St., Bellevue WA 98008, (206) 747-4004; fax: (206) 747-1069. NFN is funded by a grant from the federal Maternal and Child Health Bureau and works in collaboration with National Center for Family-Centered Care, a program of the Association for the Care of Children's Health, Bethesda, MD.

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Circle # 75
Circle # 202
Circle # 178
Empowering People with Disabilities and Their Families

by Carol H. Rasco

I come to you to express my deep commitment, and that of the Administration, to the empowerment of people with disabilities.*

Those of you who work in this field—whether as volunteers, professionals or family members—boost our determination and our capacity to resolve the tremendous challenges that remain before us. Your dedication and compassion inspire us to embrace the responsibility of meeting them.

As a parent who worked exclusively in this field as a volunteer until my son was seven, and who now works as a policy-maker, I want to tell you about some of the ideas and individuals that inspire me in my daily work. Although I will focus on health care reform, our reform agenda also extends from education reform to welfare reform, from safer streets to safer transitions to adulthood for all our youth.

The White House Domestic Policy Council coordinates the efforts of the Administration, Cabinet secretaries and other federal agencies involved with the development of every aspect of our nation's domestic policy. As director of the Council's day-to-day work, I bring a strong determination that all children shall be empowered to develop to their fullest potential. To meet this crucial goal, our children need each of us to believe in them, and we as parents need the opportunities to nurture their growth.

As President Clinton recently stated, "Having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we are responding to the President's call to "craft policies of inclusion, independence and empowerment that will inspire positive changes in this country and in nations around the world."

Health care reform is an indispensable part of that mission. The President's health care plan is a dramatic advance for people with disabilities and their families.

* This article is a revised and expanded version of remarks delivered by Ms. Rasco to the Ave Governmental Affairs Seminar, held in Washington, DC, on March 21, 1994. Nonprofit and disability organizations may freely make copies of this article for their members' information.

Here's why:
- It guarantees universal coverage for all Americans, and the peace of mind of having health care that is always there.
- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or become disabled.
- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.

- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable for the self-employed and subsidized for the unemployed. As a result, no one will be uninsured, even if they or members of their family experience a disability, injury or sickness.
- It offers a nationally uniform and comprehensive benefit package—in contrast to some of the other legislative proposals—that includes a range of preventive services, doctor and hospital visits, outpatient rehabilitation, home health care, adapted durable medical equipment (including orthotic and prosthetic devices and training in their use), mental health services, and many other essential services.

Furthermore, under Senator Edward Kennedy's proposal—now in congressional committee markup—outpatient rehabilitation services would be available to those who need them to restore capacity or minimize limitations as a result of illness, injury, “disorder or other health condition.” And to maintain functioning or to prevent or minimize deterioration, rehabilitation services would be provided through a four-step process—initial evaluation and periodic oversight by a qualified rehabilitation health professional; design of a maintenance or prevention program; instructions for the patient, family members or support personnel to carry out the program; and patient reevaluations.

- It provides a major expansion of long-term care coverage by adding home- and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with dis-
abilities and their families benefiting from this new program, this coverage allows people with disabilities to live in their own homes—with their families, where appropriate—and to enjoy fuller and more satisfying lives.

- It adds significant civil rights protections for the enjoyment of health care benefits, consumer involvement in the design of the new home- and community-based services for individuals with disabilities, and health care “report cards” so that families can determine the health plan that best fits their needs and reward that plan with their membership.

The disability rights movement can play a critical role in this drive for universal coverage. On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President emphasized: “This is a battle that you may be able to lead for the rest of America... And so I ask you: Be an agent of change, an agent of empowerment. Never forget that you are carrying on your shoulders not only your cause, but ours as well. You can break through to those members of Congress. You can do it.”

From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial; then, on to lobby on Capital Hill.

Now is the time to guarantee health security for ourselves, for our children and for the generations to come. Without secure health coverage, too many of us are not free to change jobs, move to a different location or venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire a person with a disability or a person with a family member who has a disability.

These basic principles unite us. But it is our common love for our families that propels us to act.

Early in my son’s life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of essayist and poet Joseph Addison: “Everyone must have something to do, someone to love, something to hope for.”

I am constantly reminded of those words, not only for my son, Hamp, but for all the people with whom I’ve worked. In our quest to empower people, we must strive to fulfill these ends at each stage in life. In this process, we have myriad questions to ask and actions to take.

What do persons with disabilities have to do? For a young child, is a preschool program or other early intervention available? For a school-age child, is school relevant, safe and effective? Are our schools and transitional programs teaching both how to make a living and how to live? And, for adults, is there a job, day activity or voluntary service that satisfies and excites? As President Clinton said in Memphis last November: “I do not believe we can repair the basic fabric of society until people who are willing to work have work.

Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children... We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives.” Those powerful thoughts are particularly apt for our citizens with disabilities who, too often, experience high rates of unemployment and underemployment.

What do persons with disabilities have to hope for? And what do we who love them have to hope for? Linda Charlton, the mother of a two-year-old daughter with Down syndrome, recently described her goals for her Katie before a superb and productive meeting of the President’s Committee on Mental Retardation:

“First, we want her to feel loved... to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There’s even a part of us that hopes she’ll continue her education after that... I wonder if she’ll ever get married... If she doesn’t, I hope at least she has a companion to enjoy life with. And if we could, we’d like to see her remain as happy as she is today... Our Katie—who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red.”

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son was asked last year by the members of his high school graduating class to give one of the commencement addresses. I will never forget that moment, nor will Hamp. Here was the young man whom we were once told would not survive or if he passed the hurdle of his first days, would have to be institutionalized. But Hamp defied those predictions, living at home and attending school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother’s offer of help. Hamp said that this was his speech to give:

“Hello, my name is Hamp Raso. I am pleased to share with you what attending Hall High has meant to me. I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria and going out into the community with my CBI class.

“After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.

“I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.

“I want to thank Dr. Anderson and the vice principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work
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they have done on my behalf and for all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be. I really hate to leave all my friends at Hall, but I must move on. “Thank you. Good evening.”

Like Hamp, we must all move on. Great challenges lie ahead, indeed. And as you well know, they are not limited to health care reform. From the White House to your house, we must work together. We need to reassure the countless young people like Hamp across this country that they will always have health insurance, that they can have jobs and that they are an essential part of life in our communities. For surely, to be whole and part of whole communities, people deserve something to do, someone to love and something to hope for.

The leaders of the disability community are campaigning to achieve these goals and objectives. I sincerely want to thank all those leaders, including Paul Marchand and the rest of Arc’s Government Relations staff, for their hard work in fighting to bring health security to every American. In addition, I commend the 100 sister organizations united in the Consortium for Citizens with Disabilities for their steadfast support. Now, we must intensify those efforts. We must each tell our personal stories so that members of Congress have before them the human faces of health care reform. We need each of you to help seize this moment of opportunity to guarantee private insurance for all our citizens—coverage that offers choice, comprehensive benefits and freedom from unfair and exclusionary insurance practices.

I believe that a new day has dawned for America’s citizens with disabilities and for all our people. We won’t always succeed and we won’t always be able to do everything that we want. But with your energy and resolve, we can have health security now. And I can promise you this: we will never relent in our effort to give every person a chance to develop—fully. Because, at the end of Bill Clinton’s second term, at the start of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all of America, with a clear conscience and full heart—“We did our best.” And for all our children’s sakes, I want each of us to be able to look at one another and say—“We did our best.”

Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is President Clinton’s chief domestic policy adviser, coordinating the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco.
Augmentative and Alternative Communication Devices

This article will offer tips for parents about the purchase of highly-specialized augmentative and alternative communication (AAC) devices—self-contained units designed to meet the communication needs of children and adults who are unable to communicate through speech. This article will not discuss the use of general-purpose personal computers with accessories such as voice synthesizers and/or specialized software, even though such equipment can be very helpful in meeting the communication needs of some children.

**Before you buy...**

Parents should consider a number of factors when considering the purchase of an AAC device:

- **Team recommendations**—AAC equipment choices for a child should be based on a comprehensive evaluation by an experienced clinical team, usually including a speech-language pathologist, occupational therapist and physical therapist. This evaluation also should include the input of parents, classroom teachers and other professionals. Evaluations normally include an assessment of communication skills, physical abilities, intellectual abilities, and visual and auditory functioning. It also should consider the settings in which the device will be used. The child’s abilities to use different devices can also be assessed at this time.

  Parents and the team can determine the best ways for the child to access an AAC device. A child may operate an AAC device with a standard or adapted keyboard, visual or auditory scanning, standard or sip-and-puff switch, touch-screen or joystick. Again, the team should consider both the child’s current and future needs.

  Parents and the team also can consider whether a “low-tech” system like a picture and/or alphabet communication board might work better for a child in some or all situations.

- **Expandability**—A child’s language abilities and educational and social needs will probably change over time. An AAC device should have the potential to meet the child’s needs for the next few years. “Expandability” refers to the ease of adapting the device to the child’s growing communication skills.

- **Communication output**—Most children will want to communicate using both speech and print. Find out about the ease with which an AAC device can provide both speech and print, and evaluate the quality of each type of output.

  Some AAC devices can be used to operate personal computers. Ask about this capability and find out whether additional equipment is required.

- **Ease of operation**—It is important to find out how the device is programmed. “Programming” refers to customizing a device so it contains the vocabulary a specific child needs for communication. The device should be easy for key adults to program.

  Although a device may look easy to operate, be sure to talk with other users of the product—both parents and children—to find out about their experiences. Other users can discuss the device’s reliability, ease of “troubleshooting” when problems arise and vendor/manufacturer ability to repair the device quickly.

- **Portability**—Find out if the system is portable and how easily it can be positioned in reference to the user. For a child who uses a wheelchair, find out about the ease of mounting the device on the chair—as well as removing it for those times when the child sits elsewhere. Some devices are heavy, 10 pounds or more, but will need to be transported with the child.

- **Trial period**—Find out if there are a variety of similarly appropriate devices from different manufacturers. Whenever possible, have your child try each device at home, at school and in other environments where the device will be used.

**Manufacturers of AAC Devices**

AbleNet
1081 10th Ave, SE
Minneapolis, MN 55414-1312
(800) 322-0956
(612) 379-9143 (FAX)

ACS Technologies
1400 Lee Dr, Ste 3
Coraopolis, PA 15108-1205
(412) 264-2288
(412) 269-6675 (FAX)

AdapTech
ISU Research Park
2601 N Loop Dr
Ames, IA 50010
(800) 723-2783
(515) 296-9910 (FAX)

Adaptive Innovations
68 Hale Rd
E Walpole, MA 02032
(508) 660-2635
(508) 668-4134 (FAX)

Al Kalashlan
3234 S Wila Cir
W Allia, WI 53227
(414) 327-4051

Baylor Biomedical Services
2625 Elm St, Ste 102
Dallas, TX 75226
(800) 365-1890

Canon USA
One Canon Plaza
Lake Success, NY 11042
(516) 488-6700

Crestwood
6625 N Sidney Pl
Milwaukee, WI 53209-3259
(414) 352-5678
(414) 352-5679 (FAX)

Don Johnston
1000 N Rand Rd, Bldg 115
Wauconda, IL 60084-0639
(800) 999-4660
(708) 526-4177 (FAX)

Ekeg Electronics
PO Box 46199, Station ‘D’
Vancouver, BC V6J 5G5
Canada
(604) 273-4358

continued
Some manufacturers offer trial or rental periods; in some areas, there are equipment loan programs. Some manufacturers offer informative videotapes that show individuals with disabilities demonstrating the equipment’s potential. Manufacturers can also put parents in touch with other users of the devices.

**Vendor support**—AAC devices are usually purchased from a local vendor who represents a manufacturer. Find out if the vendor will:
1. come to your home and/or child’s school to assist in initial set-up;
2. come to your home and/or child’s school to provide “hands-on” training;
3. provide additional training aids to help children and parents learn at their own pace and convenience; and
4. assist with problems or repairs.

Find out from the vendor, and other customers, whether the manufacturer will provide toll-free, around-the-clock telephone support for questions and problems; repairs within a reasonable time frame; and a clear, understandable warranty with available extended coverage.

**Meet Other AAC Users**

To make contact with consumers who rely on AAC, their family members and friends, contact: Hear Our Voices, 55-301 Hanover Circle South, Birmingham, AL 35205, (205) 930-9025, (205) 934-9459 fax.

Professionals may be interested in the International Society for Augmentative and Alternative Communication (ISAAC), P.O. Box 1762, Station R, Toronto, Ontario, M4G 4A3 Canada, (905) 737-9308, (905) 737-0624, fax.

Thanks to the following for their contributions to this article:

Dick Bissegger, President, TechnoGenesis, Inc., Prescott, AZ
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Jaryn Romich, P.E., President, Prentke Romich Company, Wooster, OH
Ken Sahan, Ph.D., Marketing Manager, Sentient Systems Technology, Inc., Pittsburgh, PA

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**EXCEPTIONAL PARENT / JUNE 1994**

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continued from page 15
I am concerned less about the academic problems of these children than their “social and emotional needs,” as P.A.D. writes. No child benefits in a setting where he or she fails. Even children with severe disabilities usually know when they can’t perform as others do; it generally pains them.

S.M. reports “no interest in how many graduates are employed or in post-secondary programs.” However, a job is an essential part of inclusion in society. I am fortunate to work in a program which assists hundreds of persons with disabilities to find jobs each year. Their response to being employed cannot be understated. It brings great self-worth, dignity and independence. Education should seek, wherever appropriate, to lead to greater employment.

S.M. asks good questions about comparable data. The study I cited did not measure the failure rate of students without disabilities. It did include some related comparisons, however. The grade point average for children without disabilities is significantly higher than for children with disabilities in the same school setting (regular classes). Children with disabilities also drop out of school at significantly higher rates.

Two out of three high school students with learning disabilities failed at least one course, more frequently in their freshman and sophomore years; their dropout rates then accelerated. My point in reporting this data was to show that current efforts are inadequate—no one can wish to support a system where two out of three children experience failure.

S.M. uses the term “segregated” schools, which is why I wanted to “shake that foundation” a bit. It is overly simple to suggest that all special (read segregated) schools are bad and all integrated programs are good. It is possible to offer excellent programs or awful ones in either setting. I am not recommending a return to special schooling; in fact, only six to eight percent of all children with disabilities are in such settings. Rather, I suggested looking at successful special programs to see what we can learn in order to help the nine out of ten children in regular school-based programs succeed. Inclusion models can be successful, and we need to demonstrate that by carefully constructing and evaluating them.

To answer S.M.'s question about college attendance, college education does, in fact, correlate with successful acceptance into the community because it is correlated positively with employment, higher salaries and general independence. It is a good outcome measure, where appropriate to a given student's abilities.

Finally, I have also received personal responses to my editorial which presented additional views. In one, a father expressed concern that his school district is changing policy toward inclusion without considering the individual needs of each child or demonstrating its value. The other, from one of the nation’s leading educators, expresses support for the effort to move ahead with inclusion. He asked to reproduce the editorial’s closing admonition—“Most importantly, neither parents nor professionals should accept rhetoric in place of data.”

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Circle # 210
DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS, continued from page 44

VIBUG BBS (Visually Impaired/Blind Users Group)
(617) 767-2909, up to 14,400 bps
Emphasis on visual impairments; conferences for parents; Fidonet; files for downloading.

MICHIGAN
Blind Ambition BBS
(313) 651-4009, up to 2,400 bps
Sponsored by Leader Dogs for the Blind, Rochester Hills, MI; emphasis on visual impairments; message areas, files/programs for blind users for downloading.

MINNESOTA
Blind Services BBS
(612) 827-2294 (voice/IT11)
(612) 753-1943, up to 14,400 bps
Disability Resources Affiliates & Groups Network (DRAGNET)
(612) 642-0483, up to 2,400 bps
Wide range of disabilities; free access, user guide available for suggested $5 donation; Internet, Fidonet, ADAnet; conferences for parents, will put other groups' newsletters online for free; many non-local callers; files for downloading.

Special Needs Network BBS
(612) 866-7371, up to 14,400 bps
(612) 866-7380 (FAX)
General disabilities; Internet e-mail/newsgroups; inter-user chats; file areas for organizations to place their newsletters; message areas, files for downloading.

Missouri
Point of View
(816) 254-9116, up to 9,600 bps
General disabilities, emphasis on visual/hearing impairments; local issues; message areas, files for downloading.

SSMART BBS
(314) 781-6397, up to 9,600 bps
Forums on brain injuries, stroke, spinal cord injuries, other disabilities; forum for parents; user guide available for $5.

MISSOURI
Disability Resources Affiliates & Groups Network (DRAGNET)
(518) 885-4192, up to 16,800 bps
Disabled Individuals Movement for Equality Network (DIMENET)
(503) 777-6561, up to 14,400 bps
Emphasis on disability rights, advocacy. Files for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

NEW YORK
Access BBS
(518) 885-4192, up to 16,800 bps
General disabilities; Internet e-mail, Fidonet, ADAnet; files for downloading.

New Jersey
Disabilities Electronic Network (DEN)
(201) 342-3273, up to 14,400 bps
(201) 342-6984 (voice)
Wide range of disabilities; Fidonet, ADAnet; message areas on specific disabilities, message area for parents, files for downloading.

Microtalk BBS
(903) 832-3722, up to 2,400 bps
General disabilities, local issues, message areas, files for downloading.

Sounding Board BBS
(513) 237-8360, up to 2,400 bps
Emphasis on disabilities; message areas.

BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

OKLAHOMA
Disabled Individuals Movement for Equality Network (DIMENET)
(918) 582-3622, up to 14,400 bps
(918) 237-8360 (voice)
See DIMENET/Massachusetts.

virginia
Handiline BBS
(703) 536-4182, up to 9,600 bps
General disabilities, local issues; message areas.

West Virginia
Project Enable
(304) 759-0727, up to 9,600 bps
General disabilities; Fidonet, ADAnet; many message areas.

Oregon
The DisAbility BBS
(503) 777-6561, up to 14,400 bps
General disabilities; 42 conference/message areas—LD, AOD areas recommended for parents; Fidonet, ADAnet; files for downloading.

Pennsylvania
Sounding Board BBS
(412) 621-4604, up to 14,400 bps
Emphasis on deaf-blind, visual/hearing impairments; conferences for specific disabilities; Fidonet, files for downloading.

Texas
CCAD Online
(214) 647-5739, up to 2,400 bps
Emphasis on assistive technology, education; BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

的能力 BBS
(214) 647-5739, up to 2,400 bps
Emphasis on assistive technology, education; BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

Canada
Disability Access
(604) 856-4778 (voice)
(604) 856-3661, up to 14,400 bps
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Abilities Online
(416) 650-5411, up to 14,400 bps
(416) 650-6207 (voice)
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Disability Access
(604) 856-4778 (voice)
(604) 856-3661, up to 14,400 bps
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Ontario
Abilities Online
(416) 650-5411, up to 14,400 bps
(416) 650-6207 (voice)
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Disability Access
(604) 856-4778 (voice)
(604) 856-3661, up to 14,400 bps
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

British Columbia
TASH On-Line Disability Resources
(604) 856-3661, up to 14,400 bps
(604) 856-4778 (voice)
Wide range of disabilities, health/education issues; Fidonet, Health care net, Internet, local resources; software for preschoolers/files for downloading; will provide assistance to anyone who wants to start a BBS.

Special Needs Network BBS
(612) 866-7371, up to 14,400 bps
(612) 866-7380 (FAX)
General disabilities; Internet e-mail/newsgroups; inter-user chats; file areas for organizations to place their newsletters; message areas, files for downloading.
LEGISLATION

Family Support

Family support legislation is rapidly moving through both the House and the Senate. The House has attached the legislation to the Head Start legislation in Title II, "Community-Based Family Resource Programs," that passed a short time ago. Senator Tom Harkin (D-IA), chairperson of the Senate Appropriations Subcommittee on Labor, Health and Human Services; and the Senate Labor and Human Resources Subcommittee on Disability Policy, held hearings on family support and appeared likely to attach the legislation to the Individuals with Disabilities Education Act (IDEA) through a new "Part I." Even if attached to IDEA, the Department of Health & Human Services would be responsible for the administration of this legislation.

Crime Bill

Both the House and Senate have now passed their own versions of the "crime bill." NPND is working with both houses to insert language in the bill that will provide training to parents and family members to prevent children, youth and adults with disabilities from entering the criminal justice system. NPND also supports provisions for disability-sensitivity training of criminal justice professionals. Much interest in and agreement with these concepts has been expressed, but there are no assurances that the amendments NPND are seeking will become reality.

Reauthorization of IDEA

The Congress will be reauthorizing the Individuals with Disabilities Education Act (IDEA) within the next year. All signs point to this process heating up next fall with both the Senate and Administration aiming to have a bill fleshed out by November or December. Currently, the House is moving on a fast track. Representative Major Owens (D-New York) intends to have a bill completed this month. While a draft of the bill has yet to appear, staffers report that it will greatly strengthen, and more clearly enunciate the rights of parents.

The Administration is developing their bill with an expected publication of November or December. The Senate appears to be timing their activities to coincide with, or shortly follow the appearance of the Administration's bill. The House is urgently seeking input to IDEA.

NPND is seeking input now from parents across the country. We want to hear about changes that you feel are needed in IDEA. NPND also seeks stories about the positive outcomes that have been experienced by children who already are receiving their education through IDEA. We want to know what works, as well as what does not. Please forward all comments, input and anecdotes to NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, or call Larry Searcy or Patty Smith at (703) 684-6763 or (703) 836-1232 (FAX).

Goals 2000 Orientation Conference

Secretary of Education Richard Riley hosted a Goals 2000 orientation conference May 25-27 in Washington, DC. The purpose of the conference was to assist states in designing and eventually, submitting their initial application for funds. The conference also aimed to help states launch their planning efforts under the Goals 2000 education reform plan. Secretary Riley had asked governors and chief state school officers to send a state team, comprised of up to six members, to participate in the conference. He urged them to reach outside of state government and include team members who would reflect the full range of perspectives that will be represented on state planning panels.

ITEMS OF NOTE

Dybwad Scholarship Awards

The Rosemary F. Dybwad International Travel Scholarship Foundation has recently released guidelines to apply for one of its scholarships. The awards support travel and study abroad for anyone interested in "gaining knowledge and sharing their experiences on innovative programs that benefit persons with mental retardation." If you have interest in applying, please contact the NPND national office.

Toys "Я" Us Toy Guides

NPND, in conjunction with Toys "Я" Us, is disseminating more than 550,000 toy guides for children with disabilities. These guides contain a description of toys that classifies them by type of disability. These classifications should enable parents and other family members to better select appropriate toys for children with disabilities.

Parent Program Happenings

Patty Gerdal of Families Together has been successful in securing a $100,000 line item in the budget of the State of Kansas specifically to support Families Together in setting up a statewide Parent Assistance Program.
Family Support:
“A Reasonable Accommodation”

Family support is a combination of assistance, services or technical supports that empower families by assuring that they can control their own lives.

On May 10, 1994, Senator Tom Harkin (D-IA) held a hearing on family support legislation. Known as The Families of Children with Disabilities Support Act, this legislation would allow states to receive funds under a competitive grant process to develop or enhance statewide systems of family support. The bill is not intended to provide support for direct services to families of children with disabilities. Rather, it is designed as a "systems change" bill that will assist states and families in working together to develop systems of family support that are family-centered and family-directed, and that use existing resources more efficiently. In order to receive a grant, states would have to submit an application with specific information and assurances including:

- The designation of a lead entity in the state. This may be an office or commission of the Governor, a public agency, an established council or another appropriate office or agency;
- The establishment of a state Family Support Policy Council. The majority of Council members must be family members of children with disabilities or persons with disabilities;
- A preliminary plan, and a description of the steps that the state will take to develop a strategic plan;
- An assurance that families are actively involved in all aspects of the state program; and
- An assurance that the state will submit an annual progress report.

This hearing was viewed by NPND as critical to the introduction and eventual passage of the bill.

The hearing consisted of testimony from five people organized into two panels. Allan Bergman, director of state-federal relations of the United Cerebral Palsy Associations, provided a concise description of the need for and benefits of family-centered, family-driven support programs. He cited family support as a "reasonable accommodation" that should be provided to families to give them a level playing field in life. Parents from Illinois, Iowa and Minnesota provided "real-life" examples of the need for effective family support programs.

Families were well represented in this hearing, and Senator Harkin appeared encouraged that the "Family Support Act" was the right policy choice, and strengthened by the packed hearing room and the support it symbolized.

Home Stretch for Health Care Reform

The President's health care reform bill got a boost recently from Senator Edward Kennedy (D-MA). The Senator, in "marking-up" the President's bill, has offered some creative and very positive alternatives. Most importantly, long-term care is very much alive in this version of the bill. Additional changes to the President's bill include: the replacement of "mandatory" alliances with "voluntary" consumer purchasing cooperatives; the opportunity for everyone to participate in the Federal Employees Health Benefits Plan if they so choose; the exemption of "mom-and-pop" businesses with five or fewer employees from the employer mandate; the basing of employer subsidies on the wages of individual employees rather than on the size and average wage of the firm; the provision of additional benefits for women, children, persons with disabilities and individuals with low incomes; the provision of increased mental health and substance abuse benefits; the creation of a new self-funded insurance program for long-term nursing home care; and an increase in support for biomedical research and academic health centers. As we go to press, the NPND Legislative Committee has not yet had the opportunity to fully review the Kennedy alternative. NPND continues its support of the President's bill. The President, it should be noted, has welcomed Senator Kennedy's mark-ups to his bill.

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Parent Program Happenings

continued from page 55

Network. For further details, contact Patty Gerdel at (913) 233-4777. Let us know what is happening with parent programs in your state—we'll share it in this column.
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Call NICHCY Toll-Free!
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Publications
• A national directory of local hydrocephalus support groups is available. Cost is $1.50, available from Hydrocephalus Association, 870 Market St., San Francisco, CA 94102, (415) 776-4713.
• Swallowing Problems: A Caregiver's Manual provides guidance to family members and caregivers on how to identify swallowing problems, get help and implement a treatment plan. This free brochure is available from the American Speech-Language-Hearing Association (ASHA), 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY).
• Also available from ASHA is a free, 18-page information packet on cochlear implants. The packet provides practical information on the types of cochlear implants, who is a suitable candidate, what to expect from the evaluation process and an extensive list of resources for further information. Contact ASHA, 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY).
• Living Your Own Life is a handbook for teenagers written by young adults with disabilities or chronic illnesses. The authors share their views and experiences on managing their lives. The handbook costs $8.00. A companion volume, the Speak Up for Health Parent Handbook, helps parents pre-

• The American Brain Tumor Association provides a number of free publications for families and friends of individuals with brain tumors. Their newest publication is Alex's Journey: The Story of a Child With a Brain Tumor, a book for children ages 9-13. Contact American Brain Tumor Association, 2720 River Rd., Des Plaines, IL 60018, (800) 886-2282.
• Wide Smiles is a quarterly publication that addresses the needs of families of children born with cleft lip and palate. Subscriptions are $18/year or $34/two years. Contact Wide Smiles, P.O. Box 5153, Stockton, CA 95205-0153, (209) 942-2812.
• The National Tay-Sachs & Allied Diseases Association has recently published The Home Care Book, a guide written by and for parents caring for children with progressive neurological diseases. Contact NTSAD, 2001 Beacon St., Suite 204, Brookline, MA 02146, (617) 277-4463. Cost is $3.00 including postage/handling.
• A Heartbreaking Choice is a quarterly newsletter for parents who have interrupted a pregnancy after a prenatal diagnosis of fetal anomalies. Each issue contains articles written by parents who have faced this difficult decision, information from professionals and helpful resources. Subscriptions are $15/year for parents and $25/year for professionals. For subscriptions or a complementary issue, contact Pineapple Press, P.O. Box 56, Mullet Lake, MI 49761.
• The Child Care Careers Institute has published a handbook, Integrating Children With Special Needs Into Pre-School Settings: A Resource Handbook. Though written primarily for child care professionals, the guide also features many helpful resources for families—books for children and adults, clearinghouses, organizations, publications and videos that address special needs issues. Contact Child Care Careers Institute, 99 Bishop Richard Allen Drive, Cambridge, MA 02139. $5.00 including postage/handling.
• Hydrocephalus News & Notes is a quarterly publication for children and adults affected by hydrocephalus, their families and professionals. The newsletter provides resources, research and parent networking information for families with children who have hydrocephalus associated with spina bifida, Arnold-Chiari malformation, holoprosencephaly, lissencephaly, micro- and/or macroencephaly, Sturge-Weber syndrome, neurofibromatosis, porencephalic cysts, Dandy-Walker syndrome, encephalocele and agenesis of the corpus callosum. Subscriptions are $25/year. For subscriptions or a complementary issue, contact Ann Marie Liakos, Hydrocephalus News & Notes, 1670 Green Oak Circle, Lawrenceville, GA 30243, (404) 995-7534.
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TeleSensory Corp., Mountain View, CA 94030. Circle #209

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, VTDD, (301) 588-9234, V/TTDD or (301) 587-1967, FAX.
You can order any of the books listed here with the coupon below or by calling (800) 535-1910.

**Attention Deficit Disorder**

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I once had a brother. His name was Daniel Jordan Reiff. He died at age five and a half. He had pyruvate dehydrogenase deficiency. He was my absolute best friend.

When Daniel was two years old, he could say 50 words. Then, he got sick and lost all his words except for “Naa Naa” (his name for me), “Mama” and “Daddy.” He crawled a lot—so much that my little sister called him a “crawl boy.” I loved him a lot, even though he had a disability. Sometimes, I felt lonely because none of my friends had brothers like Daniel. He was really, really hard to take care of and it took a lot of time, but I still loved him.

After school one day, when Daniel was in the hospital with mononucleosis, my friend’s mom came and took me to the hospital. Then, my mom told me to say good-bye to Daniel because he wasn’t going to make it through this hospital stay. I said good-bye and I kissed him. At 7:20 p.m., on May 3, 1993, he died. I knew this was going to happen, but I was not ready for it. I was at my aunt’s and uncle’s house when he died.

Daniel’s funeral was on May 8. It was my idea to put lilacs in his casket because they were just blooming. I also put in a note that said how much I loved him and missed him. I was not only sad; I also was angry.

That was one long year ago. Back then, many changes were arising. We lost Daniel, and we moved from Lynnwood, Washington to Eugene, Oregon. We did not have friends or relatives in Eugene. It was a hard time for me.

Now, I am doing better. I have some good friends, and I’m seeing a counselor. I still feel a little bit of regret about moving. I mean, there’s only so much an eight-year-old can handle at one time!

Even with all of those things helping me, I still am not totally okay about Daniel dying. As I said before, he was my absolute best friend. I will never have a best friend exactly like him again. I really miss you, Daniel.
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Like the original TriStander 45, the new TriStander 58 is actually three standers in one. A unique design allows infinite adjustments between vertical, prone and supine so you need only to invest in one stander to meet all of your positioning needs. The frame is adjustable for height and what's more, the module support components come in a variety of sizes and can be ordered separately allowing you to adapt the stander to your client's individual size and shape. The new TriStander 58 accommodates individuals from 45 to 58 inches tall; TriStander 45 accommodates those 32 to 45 inches.


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October 1, 1993 - September 30, 1994

A NEW CAR, VAN OR LIGHT TRUCK ... ADAPTIVE EQUIPMENT ... AND ON-THE-SPOT CASH!
The Dangerous Yew by Sally Caroline
Sword fights with bushes and other tales of growing up with blindness.

A Date to Remember by John Gray
A young man's dream date turns into a nightmare.

The First Time by Robert Perretz-Rosales
A father reacts to his son's first seizure.

All Children Belong
A national program to promote inclusion.

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Teenagers and Young Adults

When girls and boys become teenagers and young adults—whether or not these children have disabilities—their mothers and fathers also find themselves in a new phase of their development as parents. Parents realize that they are no longer young children, and they, too, may find themselves in a new role as parents of teenagers and young adults. In current discussions of teenagers and young adults, the word “transition” comes up frequently. People talk about transitions from school to work, from home to away-from-home, from short-term social relationships to long-term commitments, from relative dependence to relative independence, from family member to family creator. Parents may also face transitions of their own as they deal with the challenges of caring for their own parents or other relatives.

For teenagers and young adults with disabilities and their parents, these transitions involve charting new territory. Because societal attitudes and opportunities are evolving rapidly, we have neither a long history from which to learn nor many experts upon whom we can call.

In this issue, three features—John Gray, A Date to Remember; John Kemp, Role Models; and a young adult panel discussion, Living the Course, included in Youth Connections—deal with social relationships. Charting the Course, also in Youth Connections, deals with the emotional aspects of transitions from youth to adulthood.

Despite many positive attitude changes, uncertainty about the future remains. This is especially true, as Elaine Greenbaum describes in Point of View, when young adults with disabilities who want to work face the peculiar disincentives that appear to be built into the system. Clearly, more changes are needed.

New Departments

Because our readers have many concerns about health care and about health insurance, this issue has the first installments of two new, regular departments on these topics. Both will respond to readers’ questions.

In Ask the Doctor, David Hirsch, M.D., a member of our Editorial Advisory Board, answers commonly-asked questions about toilet training and incontinence. In future issues, Dr. Hirsch will respond to selected readers’ questions as well as invite the participation of other experts.

Health Insurance Troubleshooter is a role that Richard Epstein assumed when he became a person with a disability. In his first article, he describes some of the complexities of dealing with health insurance companies and ways that parents can cope. Like Dr. Hirsch, Mr. Epstein encourages readers to write to him with their health insurance questions and quandaries.

Send questions for Dr. Hirsch or Mr. Epstein to Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005. Or fax questions to 617-730-8742.

Fathers

This issue includes another wonderful Fathers’ Voices article, Not For a Nickel and a Dime, by Will Cameron. It also includes The First Time, a poignant story by another father, Robert Perretz-Rosales, about a child’s first seizure. Last but not least, Lou Shaw, another father featured in this issue, has just written a fascinating adventure novel about a young man with a disability who is accused of murder.

Inclusion

All Children Belong is the first of a series of articles describing an exciting national project to promote the inclusion of children with disabilities in their local schools and communities. In September, our 22nd annual education issue will discuss inclusion from a variety of perspectives.
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Episodes of Increased Activity
My 11-year-old son has agenesis of the corpus callosum with resulting athetoid cerebral palsy and moderate mental retardation. He also has periodic episodes of highly increased motor activity, elevated heart rate, dilated pupils, abnormal respiration and increased muscle tone. His EEG is normal: blood and urine tests reveal nothing. I would like to correspond with anyone who has any information concerning these episodes.

P.B., Oklahoma

Severe Shaking
I am the mother of a five-year-old girl who has ataxic cerebral palsy. Annie cannot walk unassisted, but uses a walker with supervision. Her main form of mobility is to bunny-hop everywhere. Over the past year, Annie has developed a very severe shaking pattern that paralyzes her movements for a few minutes. Her whole body goes rigid and she shakes violently. It is not a seizure. She is aware of what is happening and will usually start to whimper as if frightened. She can make the shaking stop if you put her on the floor and let her hop very hard and fast. Sometimes the shaking starts when she is already hopping. When this happens, she becomes rigid and cannot move—almost as if she is stuck. In these cases, she usually throws herself down on the floor and rides it out. These episodes usually last several minutes; then, she is perfectly fine and goes back to her normal movement patterns.

Some clear triggers of these episodes are loud noises, being spoken to in a reprimanding tone of voice and fear of people or places. But the shaking also happens when she is perfectly relaxed and calm. Now, these episodes are becoming more frequent and interfering with daily life. They happen at school, at meal times, when walking or using the potty—just about any activity can be interrupted by a shaking spell.

The neurologists don’t know what is causing these shaking spells. Annie has been tested and does not have a degenerative disease. Does anybody out there know what’s going on with my child? If you have a child like Annie, please write to me!

S.W., Georgia

Partial Trisomy Eight
I am looking for another parent of a child with partial trisomy eight. My daughter is 16 years old. I’d love to hear from parents who could help me know more about her future.

E.F., Colorado

Darrow Syndrome
We have a 19-month-old daughter with Darrow syndrome—also called chloride-diarrhea. We have heard of only 14 cases of this in the U.S. and would like to contact other parents of children with this genetic disorder.

T.W., Ohio

Angelman Syndrome
My son, Christopher, is three years old. At age two, he started having drop attack seizures and was diagnosed with Angelman syndrome (AS). Chris is on medication to control his seizures. He is a very active child who needs one-on-one supervision at all times. Christopher’s doctors have told me that they do not know of another black child with AS. I don’t know what Chris will learn to do next or what medical problem may arise. I would like to contact other parents of children with AS. I have a lot of questions.

V.R., Ohio

Seizures
Our six-month-old daughter, Meg, has 20 to 70 seizures daily—even on four seizure medications. Doctors have been unable to diagnose her problem but believe she has a metabolic disorder. She has undergone extensive testing including CT scans, MRI, chromosome studies and metabolic studies. All but her EEG have produced normal results.

Meg is also severely hypotonic and developmentally delayed. She appears normal, but small. She never sucked or swallowed with any coordination and is now fed through a G-tube. She has a wide variety of seizures—most involve apnea. We have been told that Meg has seen the best doctors available and that they have done all they can for her. They refer to her condition as progressive and terminal. We would love to hear from parents of children with similar symptoms.

D.T. & A.T., Texas

Obsessive Compulsive Disorder
I am the parent of a 10-year-old son who has been diagnosed with obsessive compulsive disorder. He is presently on medication for this condition. He also has some learning disabilities.

I would like to hear from parents of children with the same diagnosis to compare notes.

P.P., Massachusetts

Drooling
We have an 11-year-old daughter who has cerebral palsy and is non-verbal. She has a problem with constant drooling. She is a very outgoing child and we
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Home is where the heart is, but sometimes children with multiple disabilities need special help beyond their parents and school districts. Financing multi-year private school placements can be costly too. But now a school known for its successful individualized education programs is offering an extended assessment and treatment program. That school is Heartspring.

Curt came to Heartspring not because he needed a long-term, intensive program, but because his skills had plateaued, and problematic behaviors were unmanageable. He needed a program with a fresh perspective. With Heartspring's team approach, Curt has the resources he needs: specialists in the areas of special education, audiology, physical, occupational, and speech/language therapies, pediatric development medicine, psychology, and behavior management. Together, they will address his complex needs in a comprehensive, interdisciplinary program designed to continue after he returns to his home environment.

Just think! Curt enrolled this spring, and he'll be going home before school starts this fall. When he does, a Heartspring staff member will return home with him and stay a few days to make reintegration as smooth and effective as possible.

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Necrotizing Enterocolitis
I am writing in search of others who have a child with necrotizing enterocolitis (NEC). My three-year-old daughter developed NEC at four days of age. I would appreciate any information about this condition. I am looking for information about long-term health and care.

J.M., Colorado

Cogan Syndrome
We are the parents of two children, Derek, who is almost four years old, and Sarah, who is thirteen months old. They have a very rare syndrome called Cogan II or congenital oculomotor apraxia. A child with this condition is unable to voluntarily perform the rapid eye movements called saccades and moves his head because he cannot turn his eyes quickly.

In addition to abnormal head and eye movements, both of my children have low muscle tone which has gradually improved. Derek crawled at 16 months and started walking at 25 months. He is also delayed in his speech.

Sarah is not yet crawling, pulling herself up or walking. She babbles and puts weight on her feet. Her head and eye movements are not as noticeably abnormal as her brother's. Both children are getting physical therapy and Derek is also getting speech therapy.

We would like to hear from other families who have a child or children with Cogan II syndrome. We would like to know about the problems we may face when the children get older.

D.T. & K.T., Kentucky
Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices. The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays,
by Susanne R. Hays, M.S., R.N., C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. ED 0770D

Effective Intervention For Self-Feeding Success,
by Christine A. Nelson, Ph.D., OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. ED 0780D

Massage For The Infant With Developmental Disabilities,
by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant’s individual concerns. A valued resource for every parent to assist their child’s development. ED 079DD

Near Normal Feeding For Infants With Oral-Facial Anomalies,
by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant's born with cleft lip and/or palate can be very difficult. Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies that parents can follow. ED 0800D

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Or call 1-800-535-1910

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Chondrodysplasia Punctata
B.H. & V.H. (May 1994) are parents of a three-year-old daughter who has been diagnosed with chondrodysplasia punctata, also known as Conradi-Hunermann syndrome. After doctors told them that there were no other cases of chondrodysplasia punctata in the United States, B.H. & V.H. found another child with the syndrome mentioned in a Search letter published several years ago. They hoped to contact other families who have dealt with this condition.

I felt happy when I read your letter and wanted to let you know that there is someone like your child. That's me! I'm a girl. I am eight years old. I'm in second grade. I want to tell you not to be scared. I had surgery on my eyes and my back. I'm short, but it doesn't bother me and I'm sure it won't bother your kid. I'm very smart. I can walk, but I need a lift in my shoe.

M.M., Louisiana

Chromosome Translocation
K.H. (March 1994) wanted information on her son's chromosomal abnormality, a complex translocation between chromosomes five and six.

Your letter caught my eye because my three-year-old son has an unbalanced translocation involving chromosomes four and twelve. This disorder has affected his muscle tone and connective tissues. He cannot crawl or walk; he also has a speech delay.

You may want to look into an organization called Chromosome Deletion Outreach (Box 280, Driggs, ID 83422, 208/354-8550). They maintain a directory of families who have children with various chromosomal disorders and try to match people dealing with similar conditions. Five dollars will get you on the mailing list for the newsletter; you can let them know if you would like to be part of the database for matching families.

B.G., Florida

Ischemic Strokes
B.S. and T.S. (April 1994) asked for information about conditions that would cause multiple ischemic strokes in children. Their daughter has been tentatively diagnosed with Moyamoya disease.

Our 17-year-old daughter, Beth, has Moyamoya disease. At age two, she had an ischemic stroke affecting her entire left side. A year later, she had another that affected her entire right side and her speech. At that point, she was diagnosed with Moyamoya disease. Her doctors predicted that she would not live long. About a year later, however, she had surgery to induce circulation to her brain. She didn't have another major stroke but, for years, continued to have daily "mini-strokes," transient ischemic attacks (TIAs).

In December 1992, Beth started taking 20 mg. of Cardene every day. Cardene is a calcium channel blocker that prevents the contraction of arteries and is most commonly used in heart patients. Beth has not had a TIA or migraine since she took the first pill. Now, she is alert and feeling well all the time. She has severe physical disabilities as a result of her strokes, but is a very happy teenager who loves music, malls and the telephone (she uses a TouchTalker with a speaker-phone). We feel like we have had a miracle!

T.E., Illinois

Bleeding During Seizures
J.W. (April 1994) hoped someone could give her a possible explanation for why her daughter, Brianna, bleeds from her mouth and nose when she has seizures.

I was interested to hear that your daughter has bleeding from her mouth and nose when she has seizures. Our son, Craig, is twelve and has 4p-(Wolf-Hirschhorn) syndrome. He has had seizures since he was eight months old. Several years ago, Craig began vomiting bloody material with his seizures. It was always a small amount and stopped quickly. I associated the bleeding with the medication I was giving him for the seizures. However, the medication was given by rectum with mineral oil, like a small enema, so I couldn't imagine how it was affecting his stomach.

Last February, Craig began vomiting blood with a seizure but, this time, the bleeding did not stop. He was hospitalized for a week. Doctors did an upper-gastrointestinal examination and ultrasound. These tests showed nothing except gastric reflux. After coming home, he was fine for two weeks, then began vomiting blood again—and this time, the bleeding was not seizure-induced. The gastroenterologist did a stomach gastroscopy and biopsy. He found that Craig had severe erosive esophagitis, as well as nodemal erosion, which proved positive for a bacterial infection. Craig was put on antibiotics for the infection, and began taking other medications for the gastric reflux which had caused the esophagitis in the first place.

I wanted to alert you to the possibility that your daughter has a similar condition. Craig's esophagus had been slowly eroding for years; we just didn't realize it. Apparently, the stress of the seizures caused periodic bleeding.

B.R., Vermont

Prader-Willi Syndrome
C.M. (May 1994) is the parent of a three-year-old daughter who has been diagnosed with Prader-Willi syndrome. She was looking for information about the lives of children with the same diagnosis.

There are other sources of information in addition to the Prader-Willi Syndrome Association mentioned in the Editor's Note following your Search letter. The quarterly journal Prader-Willi Perspectives (4th Holly Lane, Roslyn Heights, NY 11577, 516/358-0682) sponsors the Prader-Willi Syndrome International Information Forum, a worldwide network of parent-to-parent and parent-to-professional referrals that brings together people with similar concerns.
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The Prader-Willi Foundation (223 Main Street, Port Washington, NY 11050, 800/253-7993) is another valuable source of information. The Foundation also issues newsletters and other printed material of interest to families.

S. T., New York

Ritalin and Autism

L.S. (May 1994) is the parent of a four-year-old boy with autism. A doctor had recommended the use of Ritalin to improve her son’s concentration and decrease his distractibility. L.S. wondered whether the medication would be effective. She also wondered about possible side effects.

Our nine-year-old son, Jeffrey, has been diagnosed with autism and attention deficit hyperactivity disorder (ADHD). He has been on Ritalin for a year. Jeffrey started with a dose of 2.5 mg. a day. He now takes a 5-mg. dose three times a day.

The medication has been effective in improving Jeff’s attention and focus, especially at school. Most days are good; some are great; a few are days when it seems as if he didn’t take the medication. The only “negative” side effects have been decreased appetite and a sometimes too-intense focus on what he is doing. Of course, factors other than the medication affect Jeffrey’s focus and learning. These factors include the type and length of the activity in which he is involved, transitioning issues, the amount of encouragement he is receiving and his general health and mood. Of course, these are factors that affect all of us!

G.S. & B.S., New York

□ Our seven-year-old son is mildly autistic. When he was almost four years old, he was diagnosed with pervasive developmental disorder (PDD) and ADHD. The doctor prescribed 2.5 mg. of Ritalin twice daily. After a few weeks, we began to see frightening side effects. He began biting and scratching himself until he bled. He banged his head repeatedly. Sometimes, he would go into what we called a “robotic state.” We could not get his attention, make eye contact or obtain any response, even when we turned his favorite videotape off—he just stared into space. Then, all of a sudden, he would give out a blood-curdling scream, cry hysterically and slap his face with both hands. He also slept much more than normal, which lowered his physical activity level. We disposed of the medication and within a few days, had our son back again. We no longer have him on any type of medication. He is doing very well at school; we have learned to deal with problems as they come up.

L.C., Illinois

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G.S. & B.S., New York

I have a four-year-old son with autism. For the past year and a half, he has been taking 2.5 mg. of Ritalin a day. We asked our physician to try Ritalin with our son because we have two daughters and numerous other relatives with ADHD. We had seen autistic-like behaviors in them and thought, “If Ritalin helps them, maybe it could help our son.”

Before this, my son would not respond to noises, his name, people—

anything. He had all-consuming, self-stimulating behaviors that included running in circles while twirling his fingers in front of his eyes.

The doctor started him on a low dose (2.5 mg.) of Ritalin because of his size and age. He became able to sit and pay attention at school, at home and during therapy sessions. He started to respond when his name was called and began to follow simple commands. Self-stimulating behavior also decreased substantially—to the point where he would stop “self-stim” when told to do so.

When the doctor increased the dose to 5 mg. every morning, our son began having frequent tantrums involving screaming, crying and physical aggression. After a month—we thought this was a fair trial—we brought him back down to 2.5 mg. The tantrums subsided. Then, we tried 2.5 mg. twice a day; he responded by being very whiny and resistant to any activities that were not of his choosing. So, we went back to 2.5 mg. and a happy, loving child.

K.G., Arizona

□ Our seven-year-old son is mildly autistic. When he was almost four years old, he was diagnosed with pervasive developmental disorder (PDD) and ADHD. The doctor prescribed 2.5 mg. of Ritalin twice daily. After a few weeks, we began to see frightening side effects. He began biting and scratching himself until he bled. He banged his head repeatedly. Sometimes, he would go into what we called a “robotic state.” We could not get his attention, make eye contact or obtain any response, even when we turned his favorite videotape off—he just stared into space. Then, all of a sudden, he would give out a blood-curdling scream, cry hysterically and slap his face with both hands. He also slept much more than normal, which lowered his physical activity level. We disposed of the medication and within a few days, had our son back again. We no longer have him on any type of medication. He is doing very well at school; we have learned to deal with problems as they come up.

L.C., Illinois
Kimberly-Clark "Listens and Cares"

A letter in the September 1993 issue of Exceptional Parent magazine encouraged interested readers to write to Kimberly-Clark Corporation, the maker of PULL-UPS training pants, to ask for a larger, PULL-UPS-style product for older children.

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for discreet protection. Please pass on my thanks to your readers who were concerned enough to contact us about this product. Believe me, we listen and we care. We also welcome any comments your readers may have about our new GOODNITES™ product.

Thomas J. Falk
Group President, Infant and Child Care
Kimberly-Clark Corporation

Learning Disabilities and Inclusion

I am the parent of two children with learning disabilities and a long-time subscriber to Exceptional Parent. The timing of various articles continues to amaze me. Many times, when searching for specific information, along came my copy of Exceptional Parent with exactly the information I needed. The April 1994 issue and Dr. Edwin Martin’s guest editorial, Inclusion: Rhetoric and Reality, was one such case.

The information Dr. Martin provided is something I have been seeking. Unfortunately, many educators do not understand learning disabilities and, as a result, our children suffer. Parents Aware for Children, an advocacy group with which I am involved, has made a proposal to the local public schools to provide inservice training on learning disabilities and attention deficit disorder for regular and special education teachers during the 1994-95 school year. Dr. Martin’s article gives a good overview of the complexities of inclusion for children with learning disabilities. I know we can use this information to help children with learning disabilities succeed. Thank you for a wonderful magazine and a superb article.

J.W., New Mexico

Thank You

A recent mailing I received from the National Tuberous Sclerosis Association (NTSA) inspired me to write to you. I was surprised to learn that NTSA began as the result of a mother’s Search letter published in Exceptional Parent 20 years ago.

My husband and I are actively involved with NTSA because our four-year-old daughter has tuberous sclerosis. We are lucky because she is doing

Siegfried M. Fueschel, M.D.,
Ph.D., M.P.H., Parent, Prof. of Pediatrics, Brown Univ. School of Medicine, Providence, RI

PROCT MANN RINEHART, B.A.,
Parent, Director of Communications, Center for Children with Chronic Illness and Disability University of Minnesota, Minneapolis, MN

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Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

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Last July, our son, Peter, was born. At four months of age, we learned that he had complete absence of the left hemisphere of his cerebellum and had some brainstem damage. He may also have a profound hearing loss in one ear. Our neurologist believes that Peter probably suffered an intrauterine stroke sometime in the second trimester and that there is absolutely no relationship between his disability and our daughter's.

At almost 10 months of age, Peter also is doing remarkably well. His intellectual and fine-motor skills are on target for his age, and his gross-motor skills are progressing. His most obvious impairment is an equilibrium problem; he holds his head with his right ear "down" and looks at the world sideways. Our neurologist and many other doctors say Peter is one of a kind.

As is the case with most parents of children with disabilities, we do not know what Peter will do in the future. But I have come to realize that nobody really knows what will become of their children—whether they have disabilities or not—so I no longer worry constantly about my children's future; I just work hard with them in the present.

Thank you again for being available to parents like us!

S.D.T., Maryland

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Editor's Note: NTSA can be contacted at 8000 Corporate Dr., Ste. 120, Landover, MD 20785, (800) 225-6872.
An Excellent Resource
As a parent of a two-year-old son who has cerebral palsy, severe developmental delay, a seizure disorder and blindness, I find Exceptional Parent to be an excellent resource. Nothing is more comforting than stories of other families in similar situations. It is very discouraging to be unable to look to the future, because no one—including doctors—can predict what my son will be capable of doing.

Although a few of the articles have been difficult to read, I have forced myself to continue. I know that stories about the deaths of these beautiful children may one day hit home. These articles have made me more aware of how precious life is. I appreciate every second I have with my son. I hope more articles about coping and preparing for a child's death will appear in future issues. To the brave parents who have written these stories—I thank you and pray for you everyday. I also pray for every parent who has a child with a disability. God bless us all.

L.M.Z., New Jersey

In Defense of My Daughter
I had to write in response to Judy Horton's article, In Defense of My Daughter (March 1994), which detailed the author's method for dealing with children teasing her daughter.

My 10-year-old daughter, Josie, is hyperactive. She jumps, screams and sometimes, curses. She has a hearing aid. She also gets really close to everything because she has a visual impairment.

Over the years, through trial and error, I have developed a system that seems to work when other kids tease or, more often, just stare. If the stare is real intense and I have time, I ask, "Do you have a question about Josie?" Sometimes children beat me to it and ask, "Can she see?" or "How come she does that?"

Children's curiosity—their usual first reaction to Josie—creates a "teachable moment." I describe some of Josie's disabilities using simple language. One child reacted to my explanation by saying, "Poor thing." I said, "Don't feel sorry for her. Just be a friend."

Sometimes, kids have made rude comments about Josie or to her. Again, I first ask if they have a question about her. I try to assume that kids will behave responsibly if they have good information. So far, I haven't had to go beyond giving information in a very matter-of-fact way, always acting like disability is just one part of the normal human condition.

Incidents with my son, who is black, have also provided me with lessons in dealing with prejudice. The first time kids teased him, I lost my temper and threatened to tell their parents. However, I didn't think that solved the underlying problem. So, next time it happened, I walked up to the kid and used an idea I got from a book. I said, "Name-calling hurts feelings." To my complete amazement, the kid turned away, totally embarrassed, and left my son alone after that.

If education fails to work, however, I would endorse Horton's firmer methods! I think it is necessary to come to terms with your child's disability before one is able to help your child's peers do the same.

M.H., Hawaii

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Circle # 46
Parents of children with disabilities face an enormous number of challenges. They must cope with the physical and psychological difficulties inherent in a child's disability or condition. In addition, they must deal with school systems, government agencies, architectural barriers and a society that sometimes exhibits subtle negative attitudes or open hostility toward people with disabilities.

The inability to obtain health insurance coverage for children with disabilities can compound the frustrations of their parents. It can also lead to severe economic hardship. Even for parents who are fortunate enough to have health insurance, the struggle to obtain appropriate benefits can be overwhelming.

Parents of children with disabilities often need help dealing with health insurance. Health Insurance Troubleshooter is dedicated to providing that help by offering practical suggestions in response to questions from readers. In addition, the department will focus on general issues and changes that may occur as a result of the health care reforms being discussed on the federal level by President Clinton and congress, and by the governments of various states.

Future installments of Health Insurance Troubleshooter will discuss ways that parents can obtain health insurance for their children with disabilities, even if they have had difficulty in the past.

We will also review claim problems resulting from difficulties in communication between insurance companies and consumers. A common problem, for example, involves the situation in which an insurance company rejects a claim—for a hospital stay, the purchase of a wheelchair, x-rays, diagnostic tests or other services—by using the phrase "not medically necessary." This can be economically and emotionally distressing.

In many cases, however, "not medically necessary" simply means that the insurance company is lacking adequate paperwork to document the medical necessity of the product or service in question. In such cases, all that is required is a letter from a doctor explaining that the expense was necessary for a specific illness or condition. Insurance companies generally consider that kind of paperwork, or "documentation," to be essential, and won't pay for a claim until it's on file.

Ideally, of course, insurance companies should communicate more clearly and more effectively with consumers. In fact, they insurance companies generally try to do so. However, due to the number of legal challenges insurance companies have faced over the years, companies have become very careful in the way they phrase explanations to consumers. Unfortunately, misunderstandings are common.

One reason for the occurrence of misunderstandings between insurance companies and consumers has to do with the use of technical terms and phrases. Such terminology may be well understood in the health insurance industry but is frequently misunderstood by the general public. Furthermore, as companies have grown larger, they have come to depend on pre-written, computer-generated, rather than personal letters.

Consumers can understand insurance company behavior better by knowing how insurance companies work and what they mean by specific technical terms and phrases. This also can increase the likelihood that claims will be properly paid.

I first became involved with health insurance problems 15 years ago, when my disability—spinal arthritis—resulted in a need to use an electric wheelchair. In order to ensure that my claims were properly processed, I had to learn how my insurance company worked. A few years later, when the public school district in which I teach switched insurance companies, I was hired to help solve the insurance problems that many staff members were experiencing. Three years ago, I began to write a "Question and Answer" column on health insurance for a large newspaper.

As a result of these experiences, I have been involved in helping to solve hundreds of health insurance problems. I have had the opportunity continued on page 67
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The Dangerous Yew
And other tales of growing up with blindness
by Sally Caroline

There is, of course, nothing inherently amusing about blindness, or any other disability for that matter. Blindness imposes all sorts of frustrating limitations and complicates some of life’s most basic tasks. Still, life goes on—busy, demanding, annoying... and yes, funny. Our family members, like those of families around the world, are bound together by collective memories that have been built up over many years. My daughters, Rebecca and Melinda, are young women now, off living their own lives, but many of the funny stories that the family still retells revolve around Rebecca’s blindness.

Your Other Left

As if blindness was not disorienting enough, Rebecca also has had to cope with a slightly defective mother. Now, I don’t know exactly how one would define my disability—directional dyslexia, perhaps? It isn’t that I don’t know my right from my left; it’s just that I can’t seem to name them correctly with any consistency.

One day, when Rebecca was in third or fourth grade and no longer had “traveling vision,” she came into the living room to ask if I knew where the three-hole punch was. Either her sister or dad had used it and failed to return it to its proper place on the kitchen shelf. I glanced around, spotted it abandoned on the floor and replied, “It’s right here, on the floor about five steps to your left.”

Rebecca confidently headed off, as I suddenly realized it was to my left all right, but since she was facing me, it was to her right.

“No, no!” I exclaimed. “I meant your... uh...”—the word had deserted me—“uh... your other left.”

Becca stopped in her tracks and shot me the most incredulous of looks. Then she slowly and patiently asked, “Would that be the ‘left’ that the rest of us call ‘right,’ Mom?”

That incident proved to be a learning experience for Rebecca. Even today, if I give her directions, she takes an exploratory step or two in the direction I name and waits for me to correct myself. Wise move.

Playing “Popeye”

Rebecca had always attended public school in our small town. Over the years, as her vision deteriorated, her friends adjusted quite matter-of-factly. When she was in fifth grade, Rebecca had to have both eyes removed. They were replaced with ocular prostheses, often called “glass eyes,” though they are now made of some wonderful type of plastic. Becca, along with her classmates, took this new development in stride.

Shortly after Rebecca’s return to school, while her body and her prostheses were still adjusting to each other, she attended an all-school assembly with her class. During the assembly, Becca suddenly sneezed, and out popped one of her prostheses! The young man sitting next to her saw where it had landed, retrieved it for her, and handed it to her, saying simply, “Here’s your eye, Becky.”

“Thanks a lot,” she replied, and as unobtrusively as possible, popped it into her mouth to clean off any dust and dirt, then, replaced it in its socket. After the assembly, she went to the school nurse because she wasn’t quite sure if there was something else she should do to clean the prosthesis and avoid infection. Apparently, she explained the situation to the nurse—by this time a very good friend—by saying, “I just got through playing Popeye.”

The very idea quite discombobulated the poor woman—this was not an everyday event in the life of a small-town school nurse—and she called me in a bit of a dither. Well, we all were pretty new to this prosthesis business, but I knew enough to be able to reassure her: “As long as Becca reports no discomfort that would
indicate dirt in the socket, just rinse the eye, right in place, with some sterile saline. We'll do a thorough cleaning of the socket and prosthesis when she gets home." That nurse eventually went into a different kind of nursing and has now retired, but I still run into her around town and she always recalls "the day Rebecca played Popeye!"

**Kids Say the Darndest Things**

Kids are amazingly forthright and direct, and also wonderfully accepting once their questions have been answered. Fortunately, Rebecca has never been bothered by honest questions about her condition and has always been willing to answer them as clearly as possible. A family friend has a daughter about five years younger than Rebecca. When this little girl was about six, she evidently began to think about Rebecca's blindness in practical terms. The kids were having a snack one day when Helen turned to Rebecca and asked, "How do you find your mouth?"

This was one question Rebecca really couldn't answer—you don't need to see to find your mouth, you just do it! Finally, Rebecca said, "Well, close your eyes and take a bite of your cookie."

Helen did.

"How did you find your mouth?" Rebecca asked.

A big smile spread over Helen's face and she looked relieved. Apparently, it had bothered her quite a bit that Becca might not be able to eat without lots of trouble. "I guess it's not a problem, huh?" she said.

"Well," Becca answered, "Sometimes it's hard finding food on your plate, or making it stay on your silverware. But no, finding your mouth is not a problem." Kids think about the most interesting things and ask the best questions.

**Battling Bushes and Dogs**

Like most suburban mothers, I ran a "taxi service" throughout all the years my daughters were in school. One day I had to pick Becca up early to go to an appointment. We had worked out a system whereby I parked at the end of the drive nearest a side door. Becca would step out that door and I'd toot the horn once, so she knew I was there.

That day, she appeared on time, backpack over one shoulder, white cane in the other hand. She had to come down a short paved path and make a 90 degree turn onto the drive, a route she traveled regularly. But for some reason, this day, she made her turn a few steps early. Her cane promptly encountered a low yew bush planted beside the walk. Realizing her error, she took a small step back, but her cane had become quite thoroughly entangled in the yew's branches. She proceeding to engage in what resembled a sword fight for perhaps 30 seconds before managing to extricate her cane. This looked so funny that by this time she opened the car door, she found her mother quite collapsed with a fit of the giggles. After I'd recovered enough to explain myself, we both collapsed into another fit of the giggles and arrived at our destination still periodically chuckling. This has evermore been known in our family as the tale of *Rebecca and the Dangerous Yew*, which she bravely battled into submission with her sword-cane.

About the same time as the yew incident, Rebecca encountered another adventure involving her cane. In middle school, classes were held in two separate buildings set close together on the same lot. Rebecca would leave one class a few minutes early in order to cross to the other building ahead of the mob scene that erupted at the end-of-period bell. As she was crossing the courtyard one day, up bounded a large, playful dog who grabbed Rebecca's "stick" in his powerful jaws and tried to make off with it. A tug-of-war began. Neither side could win, but neither would back off, either. Fortunately, a couple of Rebecca's classmates chanced to look out the window and see her predicament. With the teacher's permission, three young men came running out. Two got the dog to let go of his "stick" and held him at bay, yelling, "Make a break for it, Becky!" The third boy quickly escorted Becca the rest of the way across the courtyard and into the other building. Of course, they all found this riotously funny, and that cane, now long since retired, still bears quite a number of canine tooth marks.
Laughter, the Best Medicine

Living with illness and disability is certainly no day at
the beach; over the years, our family has shed many
tears. But Rebecca came into this world with a sunny
disposition and a sense of humor that has never com-
pletely deserted her, even during the worst of times.
Her ability to laugh has saved us all. Sure, sometimes
it was a kind of “black humor,” but we’ve managed to
laugh our way through some pretty horrible things.
Nowadays, I read about current research that shows
that laughter actually can be a useful therapy. I believe
it... but, I’m glad we learned to laugh even before it
became “medically correct.”

Sally Caroline and her
husband, Peter, have
lived in Hamilton,
Massachusetts for 24
of the 27 years they
have been married.
Their daughters,
Rebecca and Melinda,
are now adults and on
their own. For many
years, Sally worked as a special education tutor.
When the grant money that funded that position ran
out, she began a new career in retail sales which she
describes as “not as challenging, but a lot of fun.”
The purpose of this handbook is to help children who learn differently and who have been failing or underachieving in school. It does this by giving enough information for an adult with no previous teaching experience to design and implement an effective remedial program. Most parents feel guilty when their children do not do well in school, and the first section is designed to help parents make realistic changes in the physical and emotional environment at home and at school. The second section gives simple objective tests that show what a child knows and what he needs to learn. It evaluates the maturity of skills in memory, visual-perception and auditory-perception, as well as skills in reading, spelling, phonics and math. The final section shows how to use test findings to determine which subjects should be taught and specific techniques for teaching them.

Holley, Shelby—A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES. '94, 308 pp., 13 ill., 1 table, $59.75.

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A Date to Remember

A young man's "dream date" turns into a nightmare.

by John Gray

I was born in 1948 and diagnosed with cerebral palsy when I was two years old. My balance was poor, but I learned to walk. I can't control my hands well. My speech is slow and slurred, but understandable. Although my physical disabilities are severe, my intelligence is not impaired.

When I was growing up, I was not allowed to attend the local public school. The school system sent a tutor to my home for two hours a day, two days a week. My parents realized that I would never receive a complete education unless I entered a state school. When I was 10 years old, I went to live in an institution. I missed my home and family terribly. Finally, when I was 15 years old, my parents took me out of the institution and fought to get me into the local high school. The teachers at school knew that I was bright, but because of my disabilities, I was not considered "college material." I got my first job, as a light-duty janitor; at age 21. I started to think about dating. This is the story of one of my first dates—one that turned out to be so embarrassing that I have never had the courage to write about it until now.

It was 1969 when I got my first job, and most people had never seen individuals with disabilities in the workforce. Even after some time, many people in my workplace continued to be uncomfortable with me.

The closest relationship I developed there was with a woman who worked in the building. Lynn and I started out by greeting each other as she would arrive for work. Eventually, our interactions escalated into teasing. Sometimes I would fall on a floor I had just waxed and after making sure I was all right, she would make a comment like, "I think that's enough wax on the floor, don't you?"

When Lynn would come into work late on a Monday morning, I would say something like, "That Monday morning hangovers can be rough, can they?"

Then the bad news came. She was going to move away in a couple of weeks. I was heartbroken. I thought, "There goes the only one who ever noticed me." Of course, I couldn't let her know how I felt, so I just continued laughing and joking with her as usual.

The Tease that Turned into a Date

Lynn's last day of work was a Friday in the middle of August. As we were preparing to leave, I had to tease her one last time. "Can I come over for a swim this weekend?" I asked.

"Sure," she replied.

"Whoa! What did she say?" Alarms were going off inside my head. "She asked for my address so she could pick me up the next day at noon. I stuttered my address at her while she grinned.

I lay awake that night thinking of ways to cope with possible problems that could arise the next day. Only when I was sure I had covered every eventuality did I allow myself to drift into a restless sleep.

The following day, Lynn arrived at 12:00 sharp. I climbed into the car, and we were off. We chatted and giggled about work-related subjects.

Then it was time to meet her parents. They smiled at me but kept shooting mournful looks at Lynn. I tried to lighten the atmosphere by telling a few jokes, but because her parents were having difficulty understanding my speech, they didn't laugh.

The afternoon started with a cookout. I knew Lynn's parents were trying not to stare at the way I handled my utensils. But I could feel them watching me. I was sure they were going to jump up, grab my silverware and start feeding me. Somehow, we survived the meal.

Fantasy Meets Reality

After lunch, Lynn asked me if I would like to go for a swim. This was a scene I had played out in my mind many times. As for many young men my age, the "pool scene" was a favorite fantasy: A beautiful young woman in a two-piece bathing suit beckons me into the pool. As I suavely slide into the water, the young woman slips into my arms and tells me how big, strong and capable I am... Oh, did I mention that in this fantasy, I look exactly like John Wayne?

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severe disability to normal human flaws, and fantasies shatter quickly. Still, I had prepared for this moment; I was wearing my bathing trunks under my pants. I found the bathroom, took off my clothes and kicked off my sneakers—I kept them tied at all times. When I came out of the bathroom, Lynn teased me about being so slow. We both laughed and hit the pool.

I don’t feel completely safe in water, but I still had a great time. We spent two hours in the pool; then, it was time to get out and get dressed.

The Nightmare Begins

This was where my nightmare began. I felt a bit nervous on my way back to the bathroom to get dressed, but I knew I had everything I needed—especially my buttonhook. I could not button anything without it, and I carried it with me all the time. Everything was going fine until I got to my pants. In all my planning, I had forgotten that these pants were a bit tight-fitting and had a small button. The buttonhole was a little bit too small for the buttonhook, but after a long struggle, I finally forced it through and latched it onto the tiny button.

Whew! At this point, I was sweating big marbles, but I thought the worst was over. Then, I tried to pull the button through the buttonhole and discovered that the buttonhook would not budge in either direction. I could not pull the button through the hole, and because the buttonhook was so taut, I could not force it to let go of the button. I knew I would not be able to zip up my fly without buttoning my pants. To make things even worse, the buttonhook was positioned so that at first glance, it looked like I was sexually aroused.

In this condition, I could hardly walk out of the bathroom to ask for help! So I pulled and pushed and tugged on the buttonhook for what seemed like hours. I had made no progress and was starting to cry. I didn’t want to do this, but it was my last option—I’d have to ask Lynn’s father for help.

From Bad to Worse

Lynn was walking back and forth in front of the bathroom door. I guess she was wondering what was taking me so long. I poked my head out and asked her to go get her father. She looked at me curiously but agreed.

A few minutes later, her father came marching into the bathroom with a very stern look on his face. I showed him the problem, and he was able to help me out. Then I made my biggest mistake of the day. In a feeble attempt to humor my way out of a bad situation, I said something like, “I bet you were a little worried about me when I asked you to meet me in

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At the wedding reception: John, 32, with new wife Linda, accepts the congratulations of his aunt, Hope King.

the bathroom. I started to giggle nervously as he stared at me, his expression unchanging. I began to hope that he had not understood a word I said.

Finally, I came out of the bathroom. Of course, by this time, I would have been happy to stay in there forever. When I entered, everyone was very quiet. I said my good-byes and climbed back into Lynn's car. She drove me home silently. I guess we were both embarrassed - she for her parents, me for myself.

I did it! I did it!

On Monday, I went back to work. Lynn was gone, but people knew I had been to her house over the weekend. As it turned out, this marked the beginning of a change in the atmosphere. I was still the butt of some jokes, but not as many. It seemed that because someone had started a relationship with me, it became all right for others to do the same.

Another good thing came out of this embarrassment. The next Saturday, I was sitting in my bedroom feeling sorry for myself. Through the open door, I could see my mother at the ironing board. She was ironing the pants that had caused me so much grief just one week ago.

Seized by a sudden impulse, I jumped up, ran into the next room and grabbed the pants. Mom was left running the iron back and forth over the bare ironing board as I slipped back into my bedroom and locked the door. I heard her walk to my door, knock on it and call my name. When I didn't respond, she left.

Three hours later, I burst out of my room yelling, "I did it! I did it!" I could now button those darn pants without using a buttonhook. To this day, I can button any pair of pants I own without assistance.

John Gray lives in North Attleboro, Massachusetts with his wife, Linda. After studying for seven years, he earned a college degree. He has recently completed a computer training program for people with severe physical disabilities and is pursuing a career in journalism.
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*Patent Nos. 4,701,163, 4,780,582, 4,685,901, 4,701,163
U.S. patents pending and foreign patents issued and pending
The First Time

A father reacts to his son's first seizure.

by Robert Perretz-Rosales

My son, Simon, struggled through a lot in his first eight years. He didn't know how to suck and was fed through a tube until he was six months old. He didn't have the strength to lift his oversized head until he was two. At three, he still couldn't move from the spot where he was left. Only after a year of intensive home therapy did he take his first step. By eight, he was running around and things were going better. Then, out of nowhere, he had a grand mal seizure.

At first, I didn't know what was happening. He said there was a buzzing sound and wanted to know what it was. I listened intently and looked around for a fly or wasp, but I didn't see anything. Since his hearing is so acute, I assumed it was some faint motor that I couldn't hear.

A little while later, he asked again about the buzzing. I told him I didn't hear anything. Then, I asked him to come to his room for a story. He had difficulty standing up—the kind of balance problem he'd had a few years earlier while learning to walk, but not recently. Finally, he stood and faced me. I could tell something was very wrong. He took a few drunken steps and just toppled over, not even trying to catch himself, like laundry falling to the floor.

My hands arrived in time to break the last of his fall. Most of his weight landed on his knees and face. I imagined a heart attack or stroke. Nothing ever scared me more.

I rolled his limp body over onto the mat he uses as a bed, and then it really began. I had never seen anyone have a full-blown seizure before, but as soon as his body became rigid, chin tucked in, face tensed as though a billion volts of electricity were being shot through him, I knew that my son was having a seizure. I knew that, but I was still afraid he was dying or that a part of him was going some place from which he would never return. It was all too strong, too powerful—my soft little son riveted by such force.

But I knew what it was—thank God, I knew that—so one of my selves stayed there, kneeling over him, talking soothing words to absent ears, stroking concrete. Frightening as it was, if I hadn't known, at least on some level, I don't think I could have stood it.

I kept telling myself that this would stop soon. I kept telling myself that it would end and that my son would be fine, maybe even better than before.

It continued for who knows how long, and then his eyes started blinking. His mouth started moving, making a sucking noise, over and over again. His eyes were in another universe. The blinking and noises were like some cartoon character imitating a slot machine gone haywire—over and over again.

Finally, he just laid there, and for a moment that was the worst—he seemed to fade away. Even though I knew better, I had to shake him and not let him go.

I knew it was just a seizure, but couldn't let him go, just in case.

He had become too pale, too drained, too empty. I lifted his arm. It flopped. I wanted him back, all of him, just like before. And although I told myself he would be fine, I didn't know if he would be.

He rolled over then. My boy rolled over, groaned and even opened his eyes. He was fine, but so tired that he went right to sleep—a good sleep, a replenishing one with a soft pillow under his head and his favorite blue fuzzy pillow Grandpa made for him in his arms. A regular,
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Simon Perretz-Rosales, age 12.

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My son has had several seizures since then, each pretty much the same. They continue for about two long minutes after which he is restless and squirmy for a while before he sleeps. He always wakes up fresh and ready-to-go after a few hours. The sight of his body being overpowered by a seizure is still hard to see, but now, at least, I know about that peaceful slumber ahead.


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John Kemp
Growing Up With Inclusion

I was born on October 10, 1949. When I was born, it was very obvious that I was missing the lower part of my arms. I did not have elbows, but the upper parts of my arms were of normal length; it's just that there was nothing at the end of the stumps. My right leg had a knee and several inches of one of the two bones below the knee with three toes on the end of that stump. My left leg ended at the knee, and I had three toes on the end of that stump.

My family has been very important to me; we are very close. I have two sisters who both are able-bodied. My older sister, Kathy, is four years older than I. My younger sister, Mary, was born eleven months after me. Three months after Mary was born, when I was 15 months old, my mother died of ovarian cancer. My dad raised us while continuing to accept jobs of greater and greater responsibility for the federal government. That meant that we moved around a bit—from Iowa, where I was born, to Minneapolis for a couple of years and then to Bismarck, North Dakota where we lived from 1952 to 1963.

School Inclusion
Early on, my dad developed the philosophy that I would live as normal a life as possible. He did not like the ideas of institutionalization or segregation. He believed that it would be best for me to stay with my family and go to regular schools. So, in 1954, when it was time for me to start kindergarten in Bismarck, he was as good an advocate as there ever has been. He told the school administrators that I would be coming and that I needed minimal assistance. He had taught me how to take care of myself in the bathroom; so they did not even have to worry about that. Basically, he just created the expectation that I was part of the community and would attend regular schools.

I got my first set of arms when I was two. They were arms without elbows—I would slide into them like a harness over my shoulders. I got legs when I was three; then, when I was four, I got my first set of arms with elbows. That meant I could learn how to feed myself and take care of myself in the bathroom. My dad tells me he taught me to walk using a set of parallel bars in the back yard in Bismarck—just back and forth, back and forth.

My dad was as good an advocate as there ever has been. He just created the expectation that I was part of the community and would attend regular schools.

I remember running up and down the block playing cowboys and Indians with my six-shooters on my hips, stuff like that. School was a great deal of fun. I have always done very well in school and enjoyed it. I once heard a blind individual talk about his view of schooling as a liberal education—there is the academic part, and
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GOODNITES™ Absorbent Underpants are specifically designed for larger children. There's nothing else like them. They're plain white with no babyish designs or colors so a child can wear them with confidence even in the daytime. GOODNITES Absorbent Underpants offer a trim, comfortable fit and are totally discreet, disappearing under clothing. Children who wear GOODNITES Absorbent Underpants feel better about themselves and that makes for better mornings for everyone.

How to make bed-wetting easier to control.

- Watch what your child drinks
- Limit liquids after dinner
- Drink water, not juice or soda
- Avoid soft drinks with caffeine
- Put child in charge of his or her own GoodNites™ Absorbent Underpants
- Support and praise will help your child

Your child will not be embarrassed by crinkling plastic noises because GOODNITES Absorbent Underpants are quiet under clothing. Children who wear GOODNITES Absorbent Underpants feel better about themselves and that makes for better mornings for everyone.

GoodNites™ Absorbent Underpants are comfortable, easy to use and provide all-night protection.

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An illustrated booklet for children on dealing with nighttime accidents. Also an informational booklet for parents describing causes of nighttime accidents and ways to help children stay dry all night.

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then there's the social part where you learn to get along with everyone else. It was the social component that I think I needed and benefited from the most. Although I did fine academically, I needed to learn how to get along with and compete with able-bodied kids. I think I benefited greatly from being integrated.

I was the only kid in school with a disability until I went to high school. Actually, my dad used this fact to "sell me" to the public schools first and then, when I was in third grade, to the Catholic school I attended. He argued that not only would I benefit from an integrated education—what we would now call an "inclusive education"—but that the other kids who came in contact with me also would benefit. They would learn that I was just another kid, that I have the characteristics of disability just as they have characteristics of wearing glasses, having brown hair, having green eyes or whatever. He was one of those cultural diversity types. He has always been a very forward-thinking guy, and he was way ahead of his time.

I also know that because of his commitment to my inclusion, my dad turned down some employment opportunities—and when I was about twelve or thirteen, a real promotion. That job would have brought him to Washington, DC, and he turned it down because they would not accept me into the regular school system in Montgomery County, Maryland. Today, Montgomery County is one of the leading school districts in the country in terms of inclusion and services for children with disabilities. In 1962, they were not so enlightened and my dad refused to accept a promotion that would have resulted in my placement in a segregated school system.

**Catholic School**

Our family is Catholic, and my dad wanted me to go to the Catholic elementary school that opened when I was in third grade. It was a block closer to our home.

Saint Anne's School let me participate in everything. For example, I got to be an altar boy. I couldn't carry things but I was the bell ringer. I'd work it out with the other altar boy: he'd do all the work and I'd ring the bell. We always managed to choreograph it and it worked out just fine.

When I got to high school, I was sitting in a freshman class when this fellow came by to talk to us about entering the priesthood. I thought that maybe that would be something that I would want to do. So I went up to him and said I would be interested. He looked at my clamps and said, "You could never be a priest because you have to have hands to touch the body and blood of Christ."

I thought, "That's a little tough. Nobody just walks up to me and gives me that kind of slap across the face!" But, that was the only time in the Catholic church that I really felt that they were discriminating against me. Otherwise, I participated in everything.

**Athletics**

I also got into athletics. In the summer, I played on a Little League baseball team and had a great time. They would just choose up sides, and we would get assigned to a team and be in a league for something like six weeks. I was always the last guy picked because I was the worst player, but they always let me play. I got to bat my regular turn and I got to play in the field. I don't remember if I ever made a hit or caught the ball. I just remember that I was always included. Even though they chose up sides on the basis of skill, they never denied me the opportunity to play.

When I was about 11 or 12 years old, I got to be a bat boy for the Minnesota Twins farm team in Bismarck. I loved it. In high school I was the student manager for the basketball, track and swimming
Kenny is an 11-year-old boy who, at one time, attended a private, special education school 45 minutes from his home. His local school district felt that this educational setting was best for him due to the severity of his disabilities. Kenny, who has Williams syndrome, has fine motor impairment, attention deficit disorder, cognitive disabilities and perceptual disabilities. At the private school, Kenny was viewed as a child with significant deficits who progressed very slowly. His social skills were considered to be inappropriate and immature, and the consensus was that he was not "ready" for a return to his home district's programs.

Kenny's parents had a different view. They believed in his academic potential since he was acquiring reading skills rapidly. They realized that he could be an employable adult, and began to worry that his education at the special school was not preparing him for the real world. When they heard about "inclusion," they felt that he would benefit from attending his neighborhood school.

By working closely with their local district team, Kenny's parents succeeded in gaining his inclusion in a first grade classroom with all necessary supports. During the last three years, he has made remarkable progress. He earns A's and B's, has been elected to the student council and has friends among his classmates. He is happy and has progressed academically at a rate similar to that of his peers. He has been truly included.

Stories like Kenny's are at the heart of a recently-announced national project known as All Children Belong (ACB). Jointly operated by the National Parent Network on Disabilities (NPND) and the Statewide Parent Advocacy Network of New Jersey, and supported by the DeWitt Wallace-Reader's Digest Fund, ACB envisions inclusion as the future for our children. Inclusion embodies the humanistic values that are expressed in the Individuals with Disabilities Education Act (IDEA) and the Americans with Disabilities Act (ADA). It means we all count; our communities cannot be whole without all of us.

ACB activities began in October 1993 and will continue until September 1996. Currently, Parent Training and Information (PTI) centers in 42 states have committed to becoming ACB operational sites.

ACB bases its activities on principles essential to the meaningful inclusion of children with disabilities in their neighborhood schools and surrounding communities:

- Inclusion is a process, not a place, service or setting.
- Children and youth with disabilities have the right to participate in the same neighborhood schools, classrooms, extracurricular activities and community programs they would attend if they did not have a disability.
- Children and youth with disabilities should have all necessary supports to ensure successful experiences and achievement of potential.
- Children and youth with disabilities bring their inherent gifts to their schools and communities.
- Children and youth with disabilities must be afforded the dignity of risk.
- Communities should have the capacity to support participation of children and youth with disabilities in all aspects of community life.
- Children and youth with disabilities must be guaranteed their civil and educational rights as defined in Section 504 of the Rehabilitation Act of 1973, the IDEA and the ADA.
- The value system of the school and community should be based on the belief that all children belong.

**Project Design**

Via a train-the-trainer parent curriculum, ACB project staff will train parents from each participating Parent Training and Information (PTI) center throughout the country. These PTI trainers will train and support parents within each state on the benefits of inclusion in school and community life. From this pool of trained parents or through other means, the PTI trainers will recruit 15 parents (five per trainer) to establish and serve as liaisons to Community Inclusion Action Teams (CIATs) in their own communities.

These teams bring all of the key stakeholders together—parents, educators and community leaders—to promote school-family-community partnerships. CIATs will support the inclusion of children and youth with disabilities through creative problem-solving and collaborative team building.
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ABILITIES EXPO
Chicago
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In conjunction with RCW Productions Inc.
Additionally, coalitions or networks that are currently working to promote inclusion within states can operate as CIATs. The parent liaison can provide support to such teams or coalitions just as he or she would to a newly-formed team.

**Project Materials**

All Children Belong materials consist of a train-the-trainer curriculum, community inclusion action kits, a related readings manual, an electronic resource database and videos.

- **Train-the-Trainer Curriculum:** The train-the-trainer parent curriculum corresponds to four phases of planning for children and youth with disabilities—from awareness of inclusion and individualizing supports, through statewide efforts to promote system change. The materials are consistent with the four phases of the evolvement of inclusion that have been identified through research and practical experience.
- **Community Inclusion Action Kit:** The second major element of All Children Belong is the “community inclusion action kit” which serves as a starting point for local CIATs, existing state or community coalitions, networks or collaboratives. The kit provides the team with an introduction to the project and a brief overview of inclusion, its benefits and its implementation. The kit includes community self-assessment tools to assist the team in determining what changes, if any, are necessary to improve their project.

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**ACB MATERIALS**

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<tr>
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<tr>
<td>Train-the-Trainer Manual</td>
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<td>Related Readings Manual</td>
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Order these materials from NPND, 1000 Prince Street, #115, Alexandria, VA 22314.

* Exceptional Parent / July 1994
As the project evolves, examples of leadership, innovation and insight will be recorded in an electronic database. This information will be available to all ACB sites. It will be disseminated through a variety of channels including print material and the telephone.

**Project Activities**

After preparing training materials and holding an orientation meeting, the first NPND national teleconference was held on March 9, 1994. The teleconference was “downlinked,” or shown simultaneously, at 22 sites. It involved over 250 participants. The three-hour interactive teleconference included live and pre-recorded participation by Judith Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education; Tom Hehir, Director of the Office of Special Education Programs, U.S. Department of Education; Bob Williams, Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services; Martha Fields, Executive Director, National Association of State Directors of Special Education; parents of children with disabilities and the ACB national staff. Questions from participants provided a healthy “reality check” for teleconference presenters.

The ACB national teleconference is now available on a three-hour video tape. Shortened versions of the teleconference will soon be available for presentations at conferences and training sessions. As other video activities occur, tapes of these events will also be made available.

Following the teleconference, the ACB national trainers held on-site training for the Technical Assistance for the Parents’ Project (TAPP) southern region in Hot Springs, Arkansas and for the midwest region in Milwaukee, Wisconsin. Next spring, training sessions will be held in west and northeast regions.

In future months, articles in *Exceptional Parent* will update the activities of the ACB operational sites as the successful inclusion of children with disabilities in their schools and communities picks up momentum.

For more information about ACB, please contact Orah Raia or Gaye Hasslinger at (908) 654-0980 or Larry Searcy at (703) 684-6763, voice/TTY.
Chairman of the Board.

That's my son Jedidiah. He's the reason I started Special Designs Inc. You see, as a parent of a disabled child, I had a lot of trouble finding furniture to fit my son's special needs. Furniture that's durable and sturdy. Easy to adjust and easy to take along to a restaurant or to Grandma's. Furniture that looks like it belongs in a home—not in a hospital.

Finally, I got tired of looking and made it myself. Then it occurred to me—maybe other parents have the same needs. That’s how it all began. If you want to know more about our full line of furniture for disabled children, call us at the number below, or write for a free catalog.

What's it like working for Jed? Easy. I've never had a more lovable boss.

-Peter Quenese

Small Town Life

I think that one reason my inclusion worked was because I lived in a small town. In Bismarck, everybody knew each other. They couldn’t imagine John Kemp's son, Johnny, not going to school with the same kids he played with every summer. It was just unthinkable. They just couldn’t imagine that they would know somebody that they would then reject. There is a lot to be said for small towns and rural America where they just accept you for the way you are. In big cities, you’re a number; you get to be a disability, not a person. You are slotted into a category and nobody connects with you as an individual.

Of course, I still got teased a lot. One day, I came home crying that these kids had been making fun of me. They said I had wooden arms and wooden legs and a wooden head—which probably isn't too far off the mark!

My dad said, "Well, those kids have a handicap, too." He said something that folks with disabilities today believe in very strongly. He told me that I might have a disability, but other people who don’t accept me have a handicap. A handicap is something external to me that interferes with my freedom to be a part of my community. A curb without a curb-cut is a handicap to someone in a wheelchair. A shiny, round doorknob is a handicap to someone who has clamps and hooks. People's negative stereotypical thinking about individuals with disabilities is a handicap to our acceptance. That was the first time someone had lifted the burden of "handicappism" off of me. I got teased, but my dad put it into perspective—"it's their problem not yours."
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Crotched Mountain Rehabilitation Center serves a multiply-handicapped population with the finest combination of contemporary technology, sophisticated learning theory, a beautifully-engineered environment, compassion and caring. An resident being served in this program is fortunate and is receiving the very highest standard of care, treatment and education.

New York State Multiservice Review Team 1993
Not For A Nickel and a Dime
by David M. Cameron

The lights... the lights are the thing. And the spinning. Sound and colors attract as well, but it's mainly the lights and the spinning. A ticket costs 50 cents—half a dollar for a few minutes riding the carousel, spinning with the lights and circling within the rotating wheel. Fifty cents buys little these days, so to spend it on a few minutes of merciful delight is well worth it—especially since for those few minutes, Will's squeals of glee sound no different than the squeals of the 10 or 15 other children. His gap-toothed smile is not out of place. His inability to speak makes no difference. He is a four-year-old where a four-year-old should be.

I go to the ticket booth. A kindly woman puts her sandwich down and wipes mayonnaise from her smile. "One," I say, holding two quarters with one hand and Will with the other. She tears off a ticket and directs me around the railing to the line where other would-be jockeys wait.

As we leave the ticket booth, Will does his "Will Thing"—part squeal, part dance, part earnest response to a stimulus I don't share. I don't even think about it, it's such a part of who Will is and who I am in relation to him. But the kindly ticket-taker notices. In a conspiratorial hush, she whispers, "Is he handicapped?"

"Yes," I conpire back, wondering why she has to ask and why I feel compelled to answer.

"Then, his ticket is only 35 cents. Handicapped children get a discount."

Don't get me wrong. There is a place for discounts, a need for parents with financial burdens to be able to lay some of those burdens down. But the label is costly, too.

For the few minutes of a carousel ride, if Will can be happy, if he can be simply one child among others, if he can spend an instant without being judged according to his deficits, then I gladly forego his discount. I would not trade those moments for a hundred dollars, certainly not for a nickel and a dime.

David Cameron joins Will for a ride on the carousel.

Will Cameron rides the carousel in Greensboro, North Carolina where he lives with his six-year-old sister, Katie, and parents, David and Kathryn. Kathryn is associate pastor at First Presbyterian Church, Greensboro; David is a Presbyterian pastor and therapist at the Presbyterian Counseling Center; Will, who has autism, is learning to communicate through sign language and other methods. When not in school, Will enjoys his weekly gymnastics lesson, backyard tree house, hula hoop and Big Wheel.
When behavioral problems obstruct medical treatment, call Cumberland at 1-800-368-3472.

At Cumberland Hospital, we care for the difficult-to-treat—children and adolescents whose medical treatment is being hindered by behavioral problems. And, we've developed specialized programs to treat the psychological as well as the medical symptoms created by injuries or illnesses such as head injury, seizure disorders, diabetes, anorexia/bulimia, colitis and asthma. For complete information about Cumberland's extensive treatment programs and capabilities, call toll-free 1-800-368-3472. Sometimes your last resort can be the best solution.
Honor Thy Son

It started out as an adventure, but turned into a love story

Like all good adventures, mine started late one night. Of course, it was stormy. I was awakened by my wife.

"It's time," Michele said.
"How do you know?" I asked.
"My water broke."
"All right," I answered. "Remember what we learned in our Lamaze class. Don’t panic. Just lie there and wait."
"For what?"
A moment later, it hit me. I leapt to my feet, panicked. "Come on! Let’s go. The baby’s on its way!"
Michele was already in her robe, bag in hand. We hurried to the car. The rain was gone. So were the clouds. Left was a huge full moon. All I could think of was the pull of the moon on tides and babies.

Ten days later, during Hillary’s first early intervention class, I had grown up enough to be grateful for our decision.

The Adventure Comes Full Circle

Five years later, I wrote and produced an episode on The Fall Guy television series that involved a 10-year-old boy with Down syndrome. I cast a 10-year-old boy with Down syndrome, Jason Kingsley, to play the part—47 pages of dialogue. The show was a critical and ratings success.

Ten years later, my adventure has come full circle with Honor Thy Son, a novel I have written dealing with a 21-year-old young man who has Down syndrome.

When I wrote the script for the television show, I was resolved to depict a boy with Down syndrome who was capable of following his dream with the same determination as any other child. Likewise, in the novel, I was steadfast in my intent to show a young man, JJ, aspiring and already building toward a full and productive adult life. Through the character of JJ, I wanted to convey that a person with Down syndrome does not need to be pitied or patronized. What he needs—like everyone else—is acceptance, understanding, love and, above all else, the right to be what he wants to be in the best way he can.

I have always felt an empathy for parents who are deeply troubled at the thought of raising a child with a disability. When such a baby is born, life-long expectations are often shattered. I wanted the character of JJ’s father to be a man who, feeling bitterly betrayed and unable to cope with what seemed to him to be a catastrophe, lived in extreme anger and denial. To heighten these emotions, I chose to lock father and son together in a mystery/thriller.

Acceptance and Bonding

JJ is framed for a murder. His father, who deserted him and his mother immediately after his birth, soon finds himself a fugitive along with the son he has never been able to accept. Through their shared

Lou Shaw with 10-year-old Hillary.

It was 4:30 a.m. Three hours later, Hillary was born.
Ten hours later, we learned that Hillary had Down syndrome.
Twelve hours later, I was drunk.
Twenty-four hours later, Michele was dealing with two infants, Hillary and me.
Twenty-nine hours later, I had grown up enough to agree that, despite the doctor’s dire warnings, we would bring Hillary home.
ordeal and on-going conflict, the father struggles out of the morass of denial. With grief, he buries the "remarkable, highly intelligent and 'gifted" son of his shattered expectations.

At last, the father becomes able to see his son as a unique individual. This long-belated acceptance enables them to bond.

You see, to my surprise, my adventure turned out to be a love story.

—Lou Shaw

Lou Shaw is the creator of QUINCY and has written for or produced the television shows MCCLOUD, COLUMBO, MAUDE, the SMOTHERS BROTHERS and THE FALL GUY. He won an Edgar award—the mystery writers' equivalent of the Oscar—for QUINCY. He also won two Media Access Awards and numerous other honors for the episode of THE FALL GUY that included the character of a 10-year-old with Down syndrome and cast a 10-year-old boy with Down syndrome to play the part. Lou lives in Los Angeles with his family.

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**From HONOR THY SON...**

... How could a love that seemed so right go wrong?

Jack was struggling to stay together. The inner claustrophobia had whipped him into a frenzied panic. "I was there and you still insist you did nothing. That means someone framed you. Why? Tell me! Why would someone bother framing you? You're not that important to anybody!"

JJ could only stare at him tearfully. "Think! Why would someone frame you?" As JJ shrugged, "Come on. Think about it! Why? Answer! You're not that slow!"

*Slow.* The word flew around Jack's brain, darted through his body, went back to his brain, but could find no further escape. Jack took a long swig of scotch. Choked. Nearly threw up. *Slow.* Jack knew the statistics. A great percentage of the prisoners on death row were retarded. *Slow.* Who could be a better patsy!

Mystery lovers will enjoy HONOR THY SON. In addition to being an exciting, fast-paced thriller, the book will have special meaning for many readers of EXCEPTIONAL PARENT. HONOR THY SON is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910 ($12.95, paperback).
Disability Really Isn’t That Romantic
by Elaine Greenbaum

With imaginative public awareness campaigns, we advocates have convinced many important people that disabilities don’t matter as much as rights, attitudes and accessibility. Stories, and the words we use to tell them, seem to matter more than IQs or difficulties in walking, talking, hearing or seeing.

People with “differing abilities,” which seems to be the new preferred usage, do not “suffer” nor are they “afflicted.” Cute children “just happen to have” Down syndrome or spina bifida or cerebral palsy. Adults, who may be physically or mentally “challenged,” will overcome, get jobs and live “as independently as possible.”

The medical model of disability, which focused on deficits and conditions that needed to be treated and fixed, has been rejected. Now, the major questions about disability are addressed from the more romantic view of the civil rights model. The speeches and statements at the signing of the 1990 Americans with Disabilities Act (ADA) made us all feel so very good. But no matter how well-written the stories, no matter how cute the kids, no matter how strongly we accentuate the positives with euphemisms, having a disability is not that romantic.

Romance Versus Reality
Twenty years ago, we were thrilled and relieved when professionals told us to treat our newborn son with Down syndrome “normally.” When Nate thrived in a regular Montessori preschool, we were delighted. We were convinced of the benefits he would reap from an inclusive education. But the conviction that his disability did not matter began to weaken somewhat as reading, writing and arithmetic became more important than juice pouring, circle time and creative dramatics.

Inclusion in a regular middle school certainly was tougher. Regular-education teachers found it difficult to adapt curricula. And, in an atmosphere where simply wearing the wrong brand of jeans is grounds for exclusion, Nate’s peers had a hard time befriending someone with an extra chromosome.

But life goes on, and partial inclusion in a regular high school has worked well. I think a major reason for this success has been the use of “reverse mainstreaming” in which the most self-assured regular-education students come into our son’s self-contained, special-education classroom. Zealots might argue that bringing regular-education students into a self-contained classroom is “second best” and philosophically unacceptable. In their view, “best” would be defined as the elimination of all separate classrooms and special education. I am not so sure.

The Uncertain World of Work
What I am sure of is that the years after high school will be less romantic than challenging. The romance of disabilities turns on words that stress similarities rather than differences. But the differences are nonetheless real. During this, Nate’s last year of high school, we do not worry about drinking and driving, SAT scores or college admissions. Nate does not drive, nor do most of his close friends. And instead of thinking about post-secondary education, we are agonizing about the job market.

For our son and millions of other young adults with disabilities, the real world after high school graduation offers only a small chance at complete economic independence. Despite the occasional success story and the rhetoric about ADA, employment and earnings statistics for persons with disabilities are abysmal. Fewer than half of all working-age adults with disabilities are employed.

Nearly seven million adults with disabilities receive income support from the government. Eligibility for monthly checks from Supplemental Security Income (SSI) or Disability Insurance (DI) is viewed by many as...
Nate Greenbaum, age 20

In mid-1992, the monthly check for an individual on SSI was about $400; the check for an individual on DI was about $600. Both programs stop providing income support when an individual consistently earns $500 or more per month.

Since both public income support programs are linked to health insurance (Medicaid and Medicare), the certainty of a $400-600 monthly government check with health benefits dominates most decisions about work. Only the person with a really strong work ethic will choose the uncertain world of work over a monthly check from the government that includes health care coverage.

In the romance and emotion surrounding our embrace of the civil rights model and ADA, we advocates have ignored important economic lessons. Simple mandates have never produced enough high-paying jobs to lift large numbers of individuals out of poverty. Moreover, since many of the working poor lack health insurance, the lure of programs like DI and SSI with their link to medical insurance is easy to understand.

While the work disincentives for mothers on welfare are widely recognized, almost no one worries

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Barbara Ruben, parent Canoga Park, California

“It’s changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!”

Kim Leonetti, parent Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

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about similar disincentives for persons with disabilities. And when welfare reformers require that all “able-bodied” persons work, the implication is that persons with disabilities may not have to. Policy debates about workfare and health care reform tend to ignore the way that current policies work to erode the work ethic of persons with disabilities.

We Want our Son to Work
We worry. We want our son to work. Employers at all three of his part-time jobs have commented upon his good work ethic. As he graduates, he has developed certain competencies that should serve him well as an employee. His disabilities do not prohibit work; they just make it much more difficult for him to earn much more than $500 per month for the next few years.

People with disabilities are not typically viewed as welfare cases. But most do not work. The rhetoric surrounding ADA suggested that most adults with disabilities could and would work once discrimination and other barriers were removed. If it turns out that most could work but don’t, the nation’s reservoir of good will for person with disabilities is sure to leak away no matter how many romantic stories we tell. If it turns out that most cannot work, then the ADA is a fairy tale.

Elaine Greenbaum is co-chair of the Adult Issues Committee of the National Association for Down Syndrome (708/325-9112) and serves as a patient services facilitator at the Adult Down Syndrome Center of Lutheran General Hospital in Park Ridge, Illinois. She lives with her husband, son and daughter in suburban Chicago.

Nate graduated from high school on June 9, 1993. In August 1993, he started what his parents thought would be the perfect job working in food service at his alma mater. The job lasted only six weeks. Nate had trained in that position for two years, but when his employer had to pay him minimum wage, it turned out that Nate worked too slowly to be a cost-effective employee. The next job he landed, folding laundry at Northwestern University’s executive training center, has worked out much better.

For calendar year 1993, Nate opened an IRA and received a full refund of all federal income tax deducted from his paychecks; he paid $110 in state income tax. He spent some of his earnings on a California vacation and dreams of an acting career in Hollywood.
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because every birth defect has a cause.
Questions about incontinence

Q I know that my child has a disability, but I believe he can be potty trained. How much longer than average will it take and are there any tricks that will help?

A First of all, children with or without disabilities potty train at different ages depending on their physical and developmental maturity. Normally, bowel control is achieved before bladder control. When a child is developmentally ready, bowel training can begin. For the average child without disabilities, this is usually about age two.

Before potty training can begin, the child must be willing and able to sit with feet touching the ground and with good balance—a problem for some children with certain disabilities. The child also must be able to understand what his parents expect with regard to using the potty.

Children with disabilities—physical, intellectual or both—typically take longer to potty train. Regardless of the child's disability, it is important to go at his or her own rate. Rushing the process inevitably results in delaying the training. A reasonable goal for many children with disabilities is for them to be trained by the time they enter grade school. In studies of individual children and young adults with mental retardation, approximately 70 percent had bowel control by age seven. Full bladder control occurred by the same age in approximately 60 percent.

**Bowel control:** The use of incentives (bribes) and "tripping" (taking the child to and placing the child on the potty at regular intervals) are good techniques to use in bowel training. Timing is also important. The best time to take the child to the potty is after a meal; this takes advantage of the reflex that encourages a bowel movement after eating.

The ultimate goal is to teach the child to empty his bowels daily at a regular time.

Some children with disabilities can never be bowel trained because they do not have, nor can they develop the necessary control of their external anal sphincter. This is a physical limitation that has nothing to do with a child's intellectual abilities or motivation.

**Bladder control:** Urinary continence is another area of concern in many children with developmental disabilities, although often not as pressing as bowel control. As noted above, approximately 60 percent of children with mental retardation, who may or may not have other disabilities, achieve bladder control by age seven.

Blow and bladder control are often related in that a child who is chronically constipated may have more difficulty with bladder control. Overnight bladder control is typically achieved at later ages for children with disabilities, especially those who are very sound sleepers.

Q My eight-year-old has static encephalopathy and is unable to eat. She is on gastrostomy tube feedings and is incontinent. Her stools are either very loose or very hard. This seems to make her uncomfortable.

A Children who are tube fed usually cannot regulate their intake of enteral preparations (special formulas fed through a tube directly into the stomach or small bowel) and "free" water (additional water that is not part of the enteral preparation). This, along with the fact that many children on tube feedings are not as active as their peers, may lead to inconsistency in bowel movements.

If chronic constipation or diarrhea is a problem, your child's pediatrician may have to make changes in her enteral formula. Most often, however, relatively simple changes will help. Additional fiber will help mild constipation or excessively loose stools. Stool softeners, many of which are available over the counter, can help mild, intermittent constipation as long as they are used with additional free water. Also, additional water needs to be given to a child during hot or dry weather.

It is best not to allow constipation or very firm stools to continue over a long period of time because it will become more difficult to control.

It is relatively common for parents to complain of "diarrhea" in a child who actually has severe constipation. A severely constipated child may appear to have diarrhea because only very loose stool can be expelled around the very hard or impacted stool in the lower part of the large bowel. It is important for parents and their health care provider to discuss this distinction so that the proper therapy can be recommended.

David Hirsch, M.D., a board-certified pediatrician, is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses. He is a member of the Section on Neurology and the Section on Developmental Disabilities of the American Academy of Pediatrics. He is affiliated with four hospitals in the Phoenix area—Phoenix Baptist Hospital, Phoenix Children's Hospital, Good Samaritan Hospital and St. Joseph's Hospital. He is a member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. He is married and has two children.
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ERICA
The good news is, young people with disabilities are living and thriving. The challenge families and professionals face is guiding them through adolescence into adulthood.

“We are faced with a significant number of young people who are maturing into adulthood—crossing almost all conditions that were historically fatal in childhood. Now we are facing the realities of what we as professionals do to meet the needs of these populations of young people in ways that can foster successful adult functioning,” Dr. Blum goes on to explain what teens with disabilities share with teenagers in general: Their body image is not more distorted; their emotional well-being is not significantly worse off; there is no significant difference in sexual activity.

None of this information is necessarily comforting. Many American adolescents have a pretty distorted sense of self. And, according to Blum, one in six or seven U.S. teens has significant emotional illness.

While some adults are surprised that teenagers with chronic illness or disability are sexually active like their peers, teens with disabilities are less likely to receive any meaningful sexual health education or information than other teens.

So while adolescents with chronic conditions share the same risks as their peers, their conditions can place them at additional risk.

It turns out, however, that teens with the least visible disabilities may be at the greatest risk of having significant emotional problems. “Often they try to ‘pass’ as not having a disability, but the price is living a lie,” Blum says.

It’s actually easier for those with visible disabilities. Tom Strax, a physician in New Jersey with cerebral palsy, says: “Every time I looked in the mirror from the day I grew up, I knew what I had. You can’t deny it. You work it through.”

Coming to terms with one’s physical condition within the context of one’s life is clearly related to positive outcomes.

While facing a fatal prognosis is challenging, those young people who live with continual uncertainty also pay an exceptionally high price. The young person with epilepsy never knows

Charting the Course

Turn to page 56

Coming to terms with one’s physical condition within the context of one’s life is clearly related to positive outcomes.
Young Adults Speak Out:
Living the Course

Three young adults held a candid conversation led by Dr. Blum. Wendy Harbour, President of the Disabled Student Cultural Center at the University of Minnesota, began losing her hearing as a child. Today she is a young deaf woman, redefining her place in both the deaf and hearing worlds. Dave S. Johnson is a personal care attendant majoring in recreational therapy at the University of Minnesota. After acquiring a spinal cord injury at age 19, he began his life as a person with a disability. Chad Pierro is a transition health specialist at the PACER Center in Minneapolis, MN. He sustained a stroke shortly after birth and has lived with cerebral palsy since he was born. Here are some of their thoughts on moving into young adulthood.

On acquiring disabilities and being born with disabilities...

Dave: The biggest thing has been support—family support, mainly. When I became disabled, most of the friends I had no longer talked with me. They no longer wanted to do things with me, either because they were uncomfortable with me or didn’t know what to do with me. I don’t know which. I don’t think I had a huge personality change! ... I do have two friends now who I had before ... they are pretty cool friends!

Chad: Unlike David, my condition—disability—came when I was born. I haven’t known anything different. For me, I didn’t lose anything, so I really admire what Dave’s done.

Wendy: I guess I started losing friends, because they didn’t know what to do with me anymore. I didn’t want to go to

The goal of *Youth Connections* is easy to state, a little more complicated to achieve. All of us at the National Center for Youth with Disabilities (NCYD) now know that young people with disabilities, their parents, and their families and friends see what the future can be. But, when you consider how little we really do know about the future for youth with chronic conditions, that’s a pretty tall order. One thing is for certain, children born with, or acquiring chronic conditions, disabilities, are living into adulthood. Twenty years ago, the life expectancy for a child with cystic fibrosis was under 10 years of age; today, the average age of survival for children with CF in the United States is 26 years of age. And survival beyond age 21 is expected for most childhood conditions: spina bifida, cerebral palsy, diabetes and even leukemias.

"I feel like I am a pioneer," a 25-year old young man with CF explained. And he is. We don’t know what the future holds. No one has lived long with these conditions. We are pioneers together and we need to teach each other about what the future holds.

At its best, *Youth Connections* should showcase the young people and programs that are leading the way. You won’t read stories about extraordinary teenagers who are running marathons or climbing Mt. Everest. Rather, we hope to bring stories of "ordinary" kids making their way into work, college and careers. In this issue:

- Three young people identify some of the issues they dealt with as they became young adults.
- A high school sophomore, who understands discrimination all too well, talks about a program for teens with mental retardation at her high school.

Nothing has engaged my imagination more through the years than meeting young people with disabilities who are a year or two older than my children. I hope these young people help you and your family see into the future. They lead the way in EVERY new and exciting world.
movies. I didn’t want to go to dances. I didn’t like parties that were loud. And so for my own mental health, my own well-being, I lost friends. It wasn’t them who severed the connection, it was me.

**On the impact of having a disability on social relationships:**

**Chad:** I think I see a lot of people being defined as “non-sexual” because they have a disability. It is something I had to find out on my own.

**David:** It took a while until I would ask a girl out again. I was self-conscious more than anything else. Even if she were very short, I would still look up to her. I think I stand 4’8” in my wheelchair, and going from 6’1”—that’s really a difference.

**Wendy:** I went to private schools so I was pretty serious. I really didn’t know anything about sex from anyone.... I researched sex on my own. I remember the only person who ever said anything about being deaf and my sexual life was the person who fitted my hearing aids. She said I’d have to learn to be an aggressive flirt, because if someone started whispering sweet nothings in my ear, I wouldn’t hear them!

**Chad:** People do not properly acknowledge the full sexuality because it does not mean just intercourse. It does not mean getting what you want and just leaving. It means touching. It means feeling. It means hugging somebody. It means talking with somebody. It means intimate interactions. I didn’t know that when I was younger and growing up. If I had more people when I was younger to tell me what I’m saying now, it would have helped me along.

**Wendy:** I have a different situation because I’m gay. Professionals will ask me if I’m sexually active and I say, “yes, sort of ... I need your definition”... because they are assuming all disabled people are straight. I think that the thing for me was getting involved in the DSCC [Disabled Student Cultural Center] and I got to know other gay disabled people.

**Options**

by Deb LaMarre

Students with disabilities in Independent District #287 come from 13 different towns. Some attend Edina High School and are part of the Bullets Program.

The progress made by these students has been remarkable. Student aide, Sage Summers, has helped these students since she was in 7th grade. Now as a junior, she says, “We are really proud of all our students. I really enjoy the rich rewards.” Four attendants help the 10 students. The attendants are responsible for the student’s progress, safety, and that of others around them.

Each student’s daily program is adapted to his or her need. In addition, whenever possible, the students have “on-the-job-training” at restaurants like Fuddruckers, Pizza Hut or the Vo-Tech. The benefits of this are obvious. After all, isn’t the main purpose of education to yield individuals who can contribute to society?

The Bullets are an interscholastic athletic team. The south suburban Bullets compete against neighboring teams of athletes in floor hockey, softball and soccer.

Some people debate the full inclusion of kids with disabilities in public schools. Some feel that with District 287 being funded by public school taxes, students with higher potential are being deprived. They feel class sizes could be improved. When addressing the issue of mainstreaming, one might ask, “What is the true purpose of education?” Is it not to produce an organized cooperative society? If so, everyone must be taught to tolerate diversity. They must understand that outside the borders of their school is a world full of people unlike them. They should not fear these differences, but embrace and learn from them.

Society has responsibilities to all its citizens. All Americans have the right to a life of fulfillment and accomplished goals. The Edina program and others like it meet these needs, and are beneficial to those enrolled and to the community.

Debbie LaMarre is a student in the ABC (A Better Chance) program at Edina high school.
Developing A Service Provision Report Card

Based on the comments made by Colleen Wieck, here's a "report card" you can use in evaluating the service you and your family receive from physicians, social workers, therapists, teachers, nurses—anyone who is helping to "Smoothing the Course of Transition for Adolescents with Chronic Illness and Disabilities." The left side represents the most positive qualities and the right side represents the least positive qualities.

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<td>Helps me identify my strengths</td>
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<td>Expects a lot from me</td>
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<td>Believes everyone has the same goals, just different access and resources</td>
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Charting the Course from page 53

when "it" is going to happen. Parents must constantly reevaluate: "Should my child drive? At what point should he or she reduce medication?"

Blum explains that the role of an adult, parent or other caring person is very powerful.

In a 35-year longitudinal study of children growing up on the island of Kauai, Hawaii, researcher Emmy Werner learned that 50% of the children who originally told her they had a disability at age 10 reported that they did not have a disability when asked the same question 10 years later, at age 20.

"Disability and chronic illness don't just vanish!" Blum explained. What Werner discovered seems even more puzzling: The conditions that "vanished" crossed a whole range of diagnoses. Those who said they didn't have a disability, said whatever "it" was, didn't limit their lives. They often recalled a parent or other adult who stayed with them and nurtured their conviction.

"We know that having high expectations makes a difference," Blum says. "For those in Werner's study who grew up believing in themselves, they went on to function at a very different level than those who saw their lives as handicapped."
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Circle # 171
SUPPORT GROUPS

- The Dystonia Medical Research Foundation is making a special effort to reach out to young people with dystonia, a disorder dominated by involuntary muscle contractions that interfere with movement and posture. They have published a free booklet, "8 to 18: A Guidebook for Young People with Dystonia," which addresses medical treatments, educational rights, social-emotional concerns and "tricks" for coping. The Foundation also provides a Young Person's Newsletter and Pen Pal Network; plans for a computer network for young people are in the works. Contact the Dystonia Medical Research Foundation, One East Wacker Drive, Suite 2000, Chicago, IL 60601-2001, (312) 755-0198.

- The Association for Hydrocephalus Education, Advocacy, and Discussion (AHEAD) is a national network of people with hydrocephalus and their families. The purpose of the group is to provide support; the organization does not provide medical referrals or information. Members are able to contact each other through telephone conversations, letters and the Prodigy online service. Regional chapters exist throughout the United States and there is a special subgroup for parents of young children with hydrocephalus. Membership is free; applications are available from Shawn Crudup, 2106 Concord Dr. Apt. A, Chesapeake, VA 23324, (804) 543-3275.

- The mother of a child with DiGeorge syndrome started a national support network for parents of children with the syndrome. The group offers information and resources pertaining to DiGeorge syndrome, and helps parents in the same area of the country contact each other. For more information, contact Natalie Ward, 27859 Lassen St., Castaic, CA 91384, (805) 294-5820.

PUBLICATIONS

- Let's Face It, a support network for people with facial difference, publishes an annual directory, Resources for People with Facial Difference. The 40-page booklet lists relevant organizations, books and videos, and has special sections listing resources especially for parents, children and young adults. This publication normally costs $10 but is available free to Exceptional Parent readers who request it and include a 9 x 12 inch, self-addressed envelope stamped with postage in the amount of $2.90. Let's Face It, Box 711, Concord, MA 01742-0711, (508) 371-3186.

- ADD-ONS is a bimonthly newsletter described by publisher Mary Daum, the mother of a nine-year-old child who has attention deficit disorder (ADD), as a "paper support group" for people living with ADD. All aspects of ADD are discussed and reader participation is encouraged. The newsletter is available from ADD-ONS, P.O. Box 675, Frankfort, IL 60423; $15/year.
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Therafin Corporation, Mokena, IL 60448-0848
Circle # 221

BIG/LITTLE II
This pre-reading tutorial and modified game program teaches children the concepts of big and little, categorizing and classification. The single-switch scanning program allows up to four players to construct a bear in various sizes by selecting appropriate body parts and clothing. For Apple II and Macintosh computers.
UCLA/LAUSD Microcomputer Project, Los Angeles, CA 90024
Circle # 222

ACTION ROCKET
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Action by Invacare, Elyria, OH 44035
Circle # 223

EARLY RECOGNITION INTERVENTION NETWORK (ERIN)
ERIN is a compilation of academic tutorial and assessment programs designed as a curriculum for students with early childhood learning disabilities. Assessment tools, curriculum guides and hands-on activities are included on two disks—one for infants and toddlers, the other for primary school-age children. For use on Apple II or IBM-compatible computers.
J. E. Stewart, Seattle, WA 98155
Circle # 224

THE APPLAUSE
This lightweight manual wheelchair fits young adults and is easy to fold and transport. Its construction of aerospace-quality aluminum and graded hardware provides strength and durability with a weight of only 30 pounds (without footrests). Removable swing-away footrests, padded rear-pivot armrests and a lifetime warranty on the sideframe and cross-brace are just of few of its many features.
Damaco/Freedom on Wheels, Chatsworth, CA 91311
Circle # 225

THE PRO-CYCLE
Now available for both youths and adults, this three-wheeled handcycle lets teens with mobility disabilities take over the bike path! Each cycle is custom built to the user's height and will accommodate individuals with heights of four feet to more than six feet. Shimano components, quick-release hubs, a chain guard, adjustable crank shaft to fit individual arm length and an internal drum-reversing brake system are all standard! Custom paint jobs, quad cuffs, racing or mountain bike tires and a cordless computer are just a few of the options that can make this cycle the envy of the neighborhood.
Top End by Action, Pinellas Park, FL 34665
Circle # 226

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0316, VTDD, (301) 588-9294, VTDD or (301) 387-1967, FAX.
FAMILIAR FACES

Three-year-old Jonathan Feres enjoys a day at the beach. Jonathan, who lives in Quebec, Canada, has Down syndrome and a severe hearing loss. Jonathan attends an integrated preschool program that was founded by his adoptive mother, Pamela, and other parents. Jonathan, who was born in Cambodia, may soon be joined by an adopted Cambodian sister.

Sixteen-year-old Christine Adrian gives a lift to rollerblading cousins Bobby and Mallory. The three are navigating a hill near Christine's home in Romney, West Virginia. Watching the action from the sidelines, Christine's dad, Herb, and aunt, Sharon, seem to be having as much fun as the kids. Christine's mom, Sandy, says that looking at this picture always makes her smile! Christine has cerebral palsy.

Brianne Nicole Prada of Turlock, California is described by her mother, Karen, as "a very determined little girl." Brianne, 32 months, has Cornelia de Lange syndrome (CdLS). She was born with only one finger at the end of each arm, but, Karen says, "that doesn't seem to slow her down." Brianne's picture also appears in a brochure that is available from the CdLS Foundation (1-800-223-8355).

Pre-teens (from left to right) Amber Lund, 11, Lacey Mosteller, 10, and Ana Gimlen, 10, show off their "shiny" smiles at Disneyland. All three girls were born with cloacal exstrophy, a condition that has required one or more ostomies and constant monitoring of kidney function. Lacey's mom, Lee, says that despite the hundreds of miles between these special friends, they try to get together as often as possible.

Three-year-old Heather Wiegman giggles while posing with her mother, Carolyn. Born nine weeks prematurely, Heather, who lives in Orlando, Florida, has cerebral palsy. Carolyn, who wants to "stress the importance of advocating for children with disabilities," has many goals for Heather's future including a motorized wheelchair, enrollment in a private Catholic school and a canine companion.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
to speak with a variety of people involved in health insurance issues—consumers, insurance company executives and attorneys, industry spokespeople, Medicare experts, government representatives and legislative officials.

Over the years, I've learned a lot about the way insurance companies work and about the types of health insurance claim problems that occur. I've learned that such problems are often complex and involve a variety of technical issues. Unless consumers have a background in health insurance, economics or law, they generally find it difficult to fully understand the issues involved.

Many parents of children with disabilities are quite knowledgeable about insurance issues. By necessity, they have become sophisticated in regard to this and other issues of concern for their children. Still, few have technical backgrounds. Health Insurance Troubleshooter will be written in a clear, easy-to-understand style, with appropriate examples to illustrate specific issues.

If you're having a problem obtaining health insurance for your child, if you have health insurance but are having difficulty obtaining appropriate insurance benefits or if you have a general question about health insurance, write and let me know. If the problem relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number so that I can get in touch with you if further information is necessary. To insure privacy, only your initials and state will be used in the column. Due to time limitations, it is not possible to respond to letters individually, but I will choose as many letters as possible to discuss in this space.

Write to me at Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. I look forward to hearing from you.
My 10-year-old brother, Jeff, has autism. Many people with autism also have mental retardation, but Jeff does not. Jeff has always been good with numbers. He learned to multiply in first grade. He can also spell well. Sometimes some of the kids in his class might ask him how to spell a word.

Jeff likes fans because they spin around. He enjoys just sitting in front of a fan and watching it spin. He always remembers all the fans that he sees. If he visits someone's house, he will memorize the location of all the fans. The next time he goes to that house he might ask, "Where's the fan with the three blades and the broken knob?"

Jeff has to have a routine. If we change just one little thing he gets mad; that makes me mad. If we are going somewhere, he has to know where we're going and what time we are supposed to leave. If we are even one minute late, he'll say, "We were supposed to leave at 4:00! Now it's 4:01!" But he doesn't really understand time. To him, time is just numbers.

One time, I was drawing and Jeff tried to draw the same thing. I got mad at him and told him not to copy me. Then my parents told me that's how he learns—by imitation and repetition. For example, if he rents a video and there's one part he likes, he will just keep rewinding it and watching it over and over. I get tired of hearing it all the time.

When my brother began attending public school, he became popular with his classmates. I think the kids were interested in him because first of all, he's a lot bigger than they are—some people say that he looks like a football player—and because they'd never seen anyone with autism. They would talk to him and ask him questions. That soon became too much for him. He can't take too much stimulation at once.

Once we were in a restaurant and a family with a baby came in. Jeff said, "Oh no! Here comes a stupid baby!" Jeff said that because he literally can't stand the sound of babies crying. If he hears one, he will plug his ears and make a humming sound so he can't hear it.

Jeff does not socialize well. If someone he knows comes up to talk to him, Jeff might say, "Go away." It doesn't mean that he doesn't like them—just that he doesn't want to talk.

Living with a brother who has autism has had its ups and downs, but all in all, I'd say it has been a good experience.

Katie Hershberger lives in Goshen, Indiana. She wrote this essay about her brother when she was 12 years old. She is now 15 and will be a sophomore at Goshen High School where she plays the clarinet in the marching band. She also takes piano lessons and enjoys art, writing and playing Nintendo games with her brother, Jeff.

Jeff is 13 years old and will enter seventh grade at Goshen Middle School. He has been successfully mainstreamed since second grade. He has a playing card collection, an electric fan collection and many stuffed animals. His big dream is to turn 16 years old and drive a Ford Mustang.
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Cover:
Two-year-old Reanna Dixon enjoys outdoor play with her mother, Gwen, during a Mommy & Me class at the Blind Children's Center in Los Angeles. Gwen, who has cerebral palsy and a visual impairment, is one of the young "stars" of Let's Eat, the Center's new video. For more information, see page 63.

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Children's Page: LIVING WITH MOEBIUS SYNDROME by Natalie Abbott 68
For most of our growing family of readers, concerns about adequate and compassionate health care are part of everyday life. This summer, it appears possible that some major health care reform legislation will actually work its way through the legislative process. Simultaneously, election campaigns for the House and Senate are gaining momentum. As a result, during the late summer and early fall, many of our elected leaders will be campaigning at home and working on health care legislation in Washington. Campaigns provide unique opportunities to tell our stories personally to our elected officials and those who aspire to replace them. Many readers have already found the time and energy to communicate with members of congress. They have told their stories to ensure that individuals with disabilities and special health care needs will finally have access to the kind of health care everyone deserves—and that caring parents will no longer have to beg, borrow or go bankrupt in their pursuit of that care. Now, during the campaign season, we must continue to deliver our messages.

Research shows that parents’ readiness to collaborate with health care providers is determined by the ways in which those parents and providers interact. When parents are respected as the most important experts in the care of their children and when providers are compassionate and understanding, children and parents do better—and at no extra cost! When I heard a presentation by parents in South Carolina involved in a wonderful program called the Parent and Professional Alliance (PAPA), I invited them to share their story with our readers. PAPA is a group that is having a profound impact on the education and training of physicians and other health care providers. While we are pleased to bring you their story in this issue, we know there are other, similar efforts underway in other parts of the country. We are working on identifying these other programs—to do so, we need to hear from involved parents.

As Peggy Mann Rinehart explains in A Bit of Teenage Savvy, young people with disabilities and/or special health care needs can also influence the training of health care professionals. This is especially true when the professionals realize that health care consumers—children as well as parents—have a great deal to teach.

For many parents, access to adequate, compassionate dental care is one of their most difficult health care challenges. Steven P. Perlman, D.D.S., a member of Exceptional Parent’s Editorial Advisory Board, and other members of the Academy of Dentistry for People with Disabilities are devoted to changing that reality. They are working on the creation of educational materials on oral health for parents and children; they are also working to change the educational preparation of dentists and oral hygienists—goals not unlike those of the PAPA parents. In this issue, Dr. Perlman presents the first of a series of articles with practical information on dental care for children with disabilities.

Bathrooms are daily centers of activity that can require special attention and equipment so that children can gradually learn to care for themselves as independently as possible. In Special Bathrooms, Linda Nitteberg provides bathroom safety and design suggestions; her article is accompanied by a directory of manufacturers. This issue also includes a similar directory of manufacturers of incontinence products along with a discussion of health insurance reimbursement for incontinence products. (See “Health Insurance Troubleshooter.”)

At every Abilities Expo I have attended this year, I have had the pleasure of meeting informally with readers to listen to their suggestions and concerns. The topic of relationships between sisters and brothers have come up in each of those meetings. In Mimi, My Friend, Anita Stohs shares her observations and insights about the special relationships among her three children. In the September issue, we will begin a series of excerpts from a very important new book about siblings.
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Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.
Laughter Helps!
I agree with the letter from P.C. (May 1991) that humor is a real survival tool for the families of loved ones with disabilities. I can never resist telling the following story to coworkers who are feeling frustrated with toilet training their toddlers:

My youngest son, Adam, is nine years old and still not potty trained due to severe mental retardation and a real lack of motivation on his part! He also dislikes water—bathing and swimming are not his idea of fun activities.

After six years of trying to get him to use a potty chair, I got the bright idea to have him try to stand up and pee into the toilet—a skill his older brother mastered by the age of two. It was right before bedtime and Adam was wearing only a diaper and tee-shirt. I stood him in front of the toilet, lifted the seat and reached for the faucet to turn on the water—the old running-water makes-you-go-uck. This was a mistake; as soon as I let go of his hand, Adam took a giant step forward into the toilet. He was so proud of himself for stepping right into that water that he just grinned from ear to ear and looked at me as if to say, “How about that, Mom?”

What could I do but laugh? I lifted him out of the toilet and sat down on the floor and laughed so hard that the tears rolled down my face. I still get a big smile every time I remember the look on his face. He was one proud little boy! I just wish he’d get that excited on those rare occasions when he uses the potty. Oh well, that’s life with Adam! M.S., Pennsylvania

Indispensable Information
I have been meaning to write to Exceptional Parent for several years. The information this magazine provides and the stories families share are indispensable.

The membership of our organization—Mothers of Supertwins (MOST)—consists of families of triplets, quadruplets, quintuplets and sextuplets. Almost all of our babies are born prematurely and need some NICU stay. We strongly support high-risk clinic follow-up for all preemies and early intervention programs when needed. Just as in the general population, our member families often face a number of physical or developmental challenges with one or more of their children. I refer to your annual resource directory (January 1994) on a daily basis. The Search column has been a godsend to several of our families.

I’m thrilled that your publication is now being offered on a monthly basis. Keep up the wonderful work!

M.A.B., New York

Language Reveals Prejudices
I was rather surprised by the letter from S.R. of Washington (April 1994) who wrote, “As the parent of a child with Down syndrome who—thank God (emphasis added)—does not have physical limitations...” I thought that was a rather insensitive remark. How would this parent feel if I had written, “As the parent of a child with orthopedic disabilities who—thank God—is not developmentally delayed?”

As we strive to educate the general

EXCEPTIONAL PARENT / AUGUST 1994

EDITOR'S NOTE: MOST can be contacted at P.O. Box 951, Brentwood, NY 11717, (516) 634-6678.

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Circle # 234
public on their use of language as it relates to our children, we must also look inside ourselves. Many times, our choice of language reveals our inner stereotypic thinking and prejudices.

If we want the world to value our children—to stop segregating, stigmatizing and staring at them—we first need to clean up our own acts.

J.L., California

Remembering Daniel
I had to write after reading Nathan Reiff’s Children’s Page article, Remembering Daniel (June 1994). My three-year-old son, Stephen, also has pyruvate dehydrogenase deficiency. He has a nine-year-old brother, Trevor, and an eight-year-old sister, Meghan.

I was so moved by Nathan’s article because of the love that was given to Daniel. We love Stephen just as much and cherish every day we have with him.

Thank you for a wonderful magazine!

A.B., Pennsylvania

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An Outpouring of Support
Thank you so much for publishing my Search letter (Benign Congenital Hypotonia, April 1994) and forwarding the responses. The outpouring of support has been wonderful.

S.C., Virginia

Missing F.Y.I.
I am writing in response to the changed format in your magazine. Overall, I enjoy the content matter very much and find it quite informative.

However, I do miss the brief column you used to run called F.Y.I. In each issue, this column highlighted a specific disability or condition. I found it particularly helpful when you highlighted uncommon or rare disabilities on which little information can be easily found.

Please consider resuming this column. It didn’t take up much space, so you should be able to squeeze it in somewhere. Thank you.

D.V.W., Oregon

Editor’s Note: We have heard from several readers who miss the F.Y.I. column. We are planning to bring it back on a regular basis in the near future. Thank you for taking the time to write to us.

A Sense of Connection
I’m the parent of a five-year-old boy who has cerebral palsy. I would like to thank you for continuing to publish a magazine that provides my wife and me with a sense of connection and a feeling of support. We look forward to receiving your magazine each month.

We have started a parent support group in our area and Exceptional Parent magazine has been a big help to our group.

I think it would be good if you started a pen pal page and let us have the option of using our full names and addresses. This would allow parents of children with the same disabilities to find each other.

T.M., Texas

Editor’s Note: Many readers—both children and adults—have asked about the possibility of a regular pen pals page. We currently are exploring the logistics of putting such a department together. We know that a pen pals page would be very popular, so it is something we would like to do.
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Adoptive Parents
I am the adoptive mother of a beautiful, sweet-spirited three-year-old girl who has multiple disabilities as a result of "shaken baby syndrome" at seven months. She has cerebral palsy, developmental delays and a visual impairment. I would like to correspond with other adoptive parents of similar children. Because my daughter has multiple disabilities, I haven't found a support group that meets my needs.

M.W., Alaska

Editor's Note: Alaska's Parent Training & Information Center may be able to help you connect with other parents in your area. Contact the Alaska PARENTS Resource Center, 540 International Airport Road, Suite 250, Anchorage, AK 99518, (800) 478-7678.

Infantile Spasms
We are the parents of a beautiful one-year-old son, Eric, who has infantile spasms (hypsarrhythmia EEG pattern), microcephaly and visual disabilities.

Eric was born eight weeks prematurely, but progressed with no apparent problems and came home at 16 days of age. At 31 days, Eric refused his formula, had increased urine output and was extremely fussy. We took him to the emergency room, but doctors found nothing wrong. Our pediatrician was consulted and wanted Eric admitted so she could check him.

While waiting to be admitted, Eric had his first crisis—he began to turn blue around his mouth and a code was called. While being treated, Eric had his first seizure and required ventilation. After two and a half weeks in the hospital and many more seizures, Eric came home again. He was on Phenobarbital and his seizures were controlled—all seemed well again. Despite numerous tests, no cause for the seizures was found.

At five months of age, Eric had a follow-up EEG and hypsarrhythmia was present. He was given two daily injections of ACTH for nine weeks. He is currently on Depakene, and his seizures are pretty well controlled. He is irritable most days, but when a smile is coax ed out of him, it melts your heart.

We are very anxious to talk to other families who have dealt with infantile spasms. Since so little information is available, it is difficult to understand or look to the future. Eric appears "normal." This sometimes leads to heartbreaking comments from well-meaning people.

We would also appreciate suggestions from families with children who have visual disabilities on how to motivate movement and interest in objects and people. We'd like to hear about particular toys that a child with a visual impairment may find interesting.

J.L. & A.L., Nebraska

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or Fax: Search or Respond
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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rte 37, P.O. Box 8832, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1994 Resource Guide (January 1994).

Ventilator Dependence
My two-and-a-half-year-old son has been diagnosed as having nemaline myopathy, a form of muscular dystrophy. The muscle weakness throughout his body has resulted in respiratory problems and he is ventilator-dependent.

I am interested in talking with parents who are taking care of a child who is ventilator-dependent at home. How you deal with everyday life?

D.S., Tennessee

Two Children With Spina Bifida?
We are parents of a two-year-old daughter who has spina bifida. We also have a three-and-a-half-year-old son. We are considering the possibility of a third child and are weighing all the issues. We are interested in hearing from parents who have two children with spina bifida. Doctors tell us that we have a three-to-five percent chance of having another child with spina bifida, and we would like some insight into what life would be like with two affected children.

D.H. & D.H., Tennessee

Band Heterotropia
My five-year-old daughter has a rare brain disorder called band heterotropia causing an uncontrolled seizure disorder and two-year developmental delay.

I would like to hear from parents of other children with this diagnosis. I have been told there are at least 20 other children with this disorder. I would like to know how other parents cope with their child learning new words and skills, then losing those skills and having to start all over. Since Rene has been taking a new seizure medication, she is doing and learning much more, but we still have to cope with many different seizures. Recently, she has gone from drop-attack seizures only, to drop-attack with complex and absence seizures, startle seizures in her sleep and tonic-clonic seizures requiring oxygen.

On the positive side, Rene just recently learned how to ride a two-wheel bike. That might not seem like a big deal to most people, but with a child like Rene, everything she learns is a big deal.

I would really like to hear from any parents who have a child with band heterotropia. It would be great to talk with someone who is going through similar experiences and who would
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understand my frustrations and the fear of not knowing what the future holds.

M.D., Vermont

Low Brain Stem

I am the mother of a seven-year-old son with spina bifida and Arnold-Chiari malformation, Type II. Carl’s brain stem goes down to the C-5 vertebra. He also has multiple shunts for hydrocephalus. At age three, he had posterior fossa decompression surgery in which the surgeon enlarged the foramen magnum, shunted his fourth ventricle, did a laminectomy to the C-3 vertebra and enlarged/expanded the tight fascia, even grafting on some tissue to allow for expansion.

Carl has had multiple neurological problems as a result of his low brain stem. He has had difficulties managing a variety of food textures, some temporary facial paralysis and speech difficulties. Most recently, he has had episodes of high blood pressure resulting in episodes of high intracranial pressure, profuse sweating, flushing of the face and grunting. Carl is taking a diuretic and medication for high blood pressure. The doctors have ruled out kidney and heart problems and seizures. They believe that these episodes are related to Carl’s low brain stem. I am interested in hearing from other parents of children who have spina bifida with this type of symptomatic Arnold-Chiari malformation or other parents of children with brain stem problems similar to Carl’s.

Despite all his medical problems, Carl has been able to attend half-days of school. He enjoys school and makes friends easily, but misses many days due to the episodes described above, frequent illness and general lack of stamina.

S.B., Washington

Lipomyelomeningocele

My daughter, 19-month-old Ashlen, was born with spina bifida, type lipomyelomeningocele. My daughter’s spina bifida is very unique. Ashlen’s spinal cord grew to an unusually long length, escaped her vertebral column, went through a fatty tumor and continued out her back as an appendage. The odd characteristic of Ashlen’s lipomyelomeningocele is that it is not midline—it is off to the left side of her lower back.

My daughter had reconstructive surgery shortly after birth and has been able to participate in normal motor activities—walking, running and jumping. Now, however, Ashlen’s spinal cord and nerves have begun to get tangled up again. This can cause nerve damage. She has problems walking now, and if untreated, she could lose her ability to walk. Next week, Ashlen is going to have surgery to untether her spinal cord.

Little information is available on lipomyelomeningocele. We don’t know how Ashlen will function after this surgery or in the future or whether she will need additional surgeries later. I would like to hear about the experiences of other parents so that I can form an idea of what Ashlen’s future may be like.

V.M., Florida

Chromosome XXXXX

I am the physical therapist of a darling 13-year-old girl who has penta-X syndrome (five X chromosomes). We are unsure of what her future holds. Her orthopedist states that he may have to fuse both her elbows due to irregular bony surfaces that are causing inflammation and pain. This seems like a drastic measure to me!

I would love to share information with anyone out there—parents, therapists or physicians—who have contact with an older child with this syndrome.

B.K., California

Kabuki Makeup Syndrome

My three-year-old daughter has been diagnosed with kabuki makeup syndrome. Her doctors have very little information to give us. I have written to every organization I know of, and although I have discovered some limited information, I am more interested in hearing first-hand experiences of other parents. I want to know about typical developmental milestones and difficulties associated with the syndrome.

I have only been able to locate five other children in the United States with this syndrome, and the three that I have been in contact with have kabuki

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**Undiagnosed**

Our five-year-old daughter remains undiagnosed. Katie appeared normal at birth but had very high bilirubin levels and Rh incompatibility. At nine months of age, after she had failed to meet a number of developmental milestones, we began to look for some answers.

As an infant, Katie always smiled easily; however, she was very irritable at night and had very irregular sleep patterns for her first three and a half years. (Sometimes, she still wakes up to “play” at 2:00 a.m.) Katie sat up at 12 months. She never really crawled, but walked at age three and a half. She has had extensive tests—CAT scans, an EEG, an EKG, an MRI and three genetic evaluations. All the doctors who have evaluated her feel that her cluster of characteristics indicates a syndrome, but they don’t know what it is.

Our description of Katie is as follows: She is a very happy, social child. She is petite and has hypotonia, microcephaly and mental retardation. She is non-verbal; we feel that she understands more than she can express. She makes inconsistent eye contact and drools. Katie walks with a wide gait and seems somewhat off balance. She likes to have her hands rubbed and tends to fixate on things she likes such as Disney characters. She loves to look at books and tries to interact with other children.

Katie has been tested for tuberous sclerosis and fragile X syndrome. She has been thought to have Rett syndrome and Williams syndrome. As parents, we have felt that she might have Angelman syndrome but have been told that it is not possible. We would welcome responses from anyone who can help.

**D.T. & B.T., Illinois**

**Telecommunications Corrections/Additions**

The distribution address of the ADD-PARENTS Internet mailing list has been changed. The new address is majordomo@mv.mv.com.

An addition to the list of Disability-Related Electronic Bulletin Boards is as follows: ABLE INFOM (Maryland) (301) 589-3563, up to 9600 bps. Emphasis on assistive technology and rehabilitation/disability literature. Searchable databases, resource guides, fact sheets.
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Exceptional Parent / August 1994
Prader-Willi Syndrome
C.M. (May 1994) is the parent of a three-year-old girl who has been diagnosed with Prader-Willi syndrome. C.M. wanted to contact parents of other children with this disorder — especially parents of children, like her daughter, whose DNA tests have come back negative.

My seven-year-old son, Steven, has Prader-Willi syndrome and shows a chromosomal deletion. However, various sources say that only 50 to 75 percent of individuals with Prader-Willi syndrome show a deletion.

Molecular genetics is another area to explore. Your daughter could possibly have a maternal disomy in which she would have two strands of chromosome 15 from her mother and none from her father. The father's chromosome 15 could have been lost, or may have translocated to another chromosome.

My understanding is that Prader-Willi syndrome can also occur as the result of some sort of brain damage in which the hypothalamus is affected. This would result in symptoms of the syndrome, but it would not be genetic in nature.

I am a parent, not a professional. You need to seek expert advice from a professional who can give you a detailed and more fully accurate account of the various genetic and non-genetic causes of Prader-Willi syndrome.

D.O., North Carolina

Teeth Grinding
A.T. (June 1994) is the mother of nine-year-old Nicole who has been diagnosed with PDD/Autism and bipolar disorder. A.T. hoped to find a solution to Nicole's habit of grinding her teeth. Nicole now has several permanent teeth, and her mother worries that the constant grinding will seriously damage them.

I am an adult who has a problem with teeth grinding. My dentist made me a mouth guard to help me stop.

I also have a friend whose daughter has disabilities that sound similar to Nicole's. Like me, her daughter was fitted with a mouth guard. Now, when she grinds her teeth, they do not touch.

I agree with you that Nicole's teeth will not last if she keeps grinding them.

A.T., North Carolina

Benign Congenital Hypotonia
S.C. (April 1994) is the mother of one-year-old Matthew who has fine- and gross-motor delays, speech delays and feeding problems. After initially suspecting hypotonic cerebral palsy, doctors classified his disorder as "benign congenital hypotonia." S.C. wanted to contact parents of children with similar problems. "During the last two years, I have felt very alone. Outwardly, my son looks like a perfectly normal one-year-old," she wrote. "It is hard for friends and family to understand." She also requested information on learning disabilities or other long-term problems that may be associated with hypotonia.

My three-year-old son, Matthew, was diagnosed with hypotonia at the age of 16 months. Since this diagnosis, I have met a number of people familiar with hypotonia. I met a 35-year-old man and his older brother who were diagnosed with hypotonia as infants, however, one would never know this today. The younger brother has a slight speech impediment, but operates his own flourishing business selling sound systems.

A woman I work with has a daughter who was diagnosed at birth with hypotonia. As an infant, she was fed by G-tube. Now, this child is in a regular fourth-grade classroom. She has excellent reading skills, but receives some remedial help in math.

My son currently receives physical, occupational and speech therapy. Nathan started taking steps by himself at 21 months. His gait is slowly improving. He now can put two syllables together — he says things like "mama," "dada," "purple," "big bird" and "big boy." His fine motor skills have improved considerably.

Intellectually, Nathan exceeds his age level in nonverbal tasks like identifying objects and putting interlocking puzzles together. He understands everything that is spoken. However, I must admit that a year ago, I had my doubts about how much he could comprehend. This was because he was too uncoordinated to follow through with many commands. He may also have experienced some frustrations that prevented him from demonstrating his abilities.

We are a family of five who feel extremely blessed with Nathan; he has more compassion than most children his age and a terrific sense of humor.

C.M., Pennsylvania
When Home Feels Like a “Prison”

... help may be a phone call away.

“We were prisoners in our own home.”

These were the descriptive words spoken by one mother. Another mother characterized her family as a “war zone”.

Maybe you, too, can identify as Rebecca’s mother describes her daughter ripping her clothes, throwing plants from their pots, and screaming. Sean’s mother says he has given himself bloody noses, black eyes, and would cling to people because he was afraid to let go.

In the new Heartspring school video, both mothers speak candidly about their children, their home lives, and what it’s been like since they’ve enrolled their children at Heartspring. Heartspring has opened up a whole new world to these children. A team of specialists, including their parents, develop individualized programs designed to meet the special needs of each child.

Now Sean’s mother says, “He’s becoming more of an adult … taking responsibility for himself and doing things for himself that I had previously done for him.”

After describing what some parents are still doing for their children, Rebecca’s mom summed it up by saying, “I now believe that for all of our children, it doesn’t have to be that way.”

And it doesn’t. If you, too, feel your home is like a prison, call Heartspring today. We can also send you this video so you can learn more about the lives of Rebecca and Sean.

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P.M., Missouri

□ My six-year-old daughter, Rachel, is also quite hypotonic although she has a working diagnosis of developmental verbal and motor apraxia. Her developmental milestones were all very delayed—she crawled at 12 months, walked at 21 months and gagged on solid food that was not completely puréed until 18 months. At three years, her vocabulary consisted of seven words. (Now, three years later, I can’t get her to stop talking!)

I know what you are going through! Rachel is a very pretty, happy child who has always attracted attention. No one could understand why she never answered when asked her name or age; after all, she looked so “normal.” I was also criticized by people who told me Rachel would walk if I would only stop carrying her! People just don’t understand invisible disabilities.

Your son should probably begin speech therapy now. He probably has weakness in the muscles that control his vocal cords, tongue and lips; you should be prepared for long-term therapy.

Using a computer also helped my daughter’s language immensely. Laureate (110 East Spring Street, Winooski, VT 05404, 800/562-6801) has marvelous software to help teach speech and language to very young children.

Learning to use a computer now will also prepare Matthew for school where he may need to use a computer for writing if his fine-motor problems persist. My daughter started with a single switch, then a touch window, and now uses the keyboard and mouse.

Rachel just completed kindergarten. We had a huge battle with the school system to get her into a regular classroom, but even they now agree it was
the right placement. This is not to say that all our problems are over. Rachel still has difficulty with sequencing, visual-motor tracking, fine-motor skills and phonics. She gets a lot of private therapy and some additional help in school. On the positive side, she loves to swing and can pump her legs as well as her classmates with whom she loves to play. She rides a two-wheeled bike with training wheels, and can print all the letters and numbers—some better than others. Most importantly, Rachel has shown everyone that when given a chance and some appropriate help, she can accomplish a great deal.

M.S., California

Feeling “Different”
K.M. (June 1994) is the parent of an eight-year-old girl with Down syndrome who has mild retardation and is included in a regular second-grade classroom. Lately K.M.’s daughter has become more aware that she learns more slowly than the other children. She has been “acting out” and engaging in inappropriate behavior. K.M. hoped to find “new approaches to handle discipline in an appropriate manner while helping her to maintain her self-esteem and get in touch with her emotions.”

I am also the parent of an eight-year-old daughter with Down syndrome who has mild retardation. Like your daughter, Holly is in inclusion classrooms at the school she attends. Holly has been in some sort of included setting since her preschool years.

We have always dealt with the inclusion classrooms by giving the other children information on a level they can understand. We want them to begin the year with a basic understanding of disabilities and the awareness that we are all different. For example, Holly’s kindergarten teacher talked to the class, read them a book about differences and had them “experience” different disabilities (for example, placing socks on their hands, then trying to put a puzzle together). The teacher asked the children to “help” Holly by being patient with her. She told the class that Holly would be able to do everything they could do, but it might take her a little longer.

This past spring our district’s special education advisory committee set up a booth at the school fair to allow children from the community to “experience” various disabilities. The comments from the “normal” children were interesting—“Wow, next time I see someone in a wheelchair I will try to help” and “I won’t make fun of people with handicaps again.”

My point is that I don’t think it’s your daughter’s problem; it’s the people around her. If you can give them more knowledge and understanding, they will be more accepting.

We have never seen a lot of “acting out” on Holly’s part. I believe it is because the children around her have accepted her for who she is; their acceptance helps her to accept herself. The best thing that has come out of her class learning about disabilities is that Holly feels “special” rather than “different.” I agree that you need to handle your daughter’s inappropriate behavior now, but perhaps working from both sides will help her.

A.B., Rhode Island

DiGeorge Syndrome
T.A. and J.A. are the parents of a three-year-old boy who has DiGeorge syndrome, a very rare disorder. They have had difficulty finding current information on the syndrome and hoped to correspond with both parents and professionals who might be able to help.

Since my original description of this rare disorder, we have learned that its symptoms can range from severe to mild. Most children with DiGeorge syndrome have a small deletion of chromosome 22 which can be readily identified by a recently developed test.

I would be happy to talk with T.A. and J.A. and provide them with further information. They will also be happy to know that there is a support group for families affected by this disorder—DiGeorge Syndrome Families, c/o Natalie Ward, 27859 Lassen St., Castaic, CA 91384, (805) 294-3623.

Angelo M. DiGeorge, M.D.
Pennsylvania

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AUGUST 1994 / EXCEPTIONAL PARENT 17
Nutrition and growth

Q My six-year-old has cerebral palsy (spastic quadriplegia) and epilepsy. He is nonambulatory and is on Phenobarbital for his seizures. He goes to school and gets his lunch there. We feed him breakfast and dinner at home. He eats table foods that are pureed or chopped finely, and he drinks some milk and juice. He is becoming more difficult to feed. Meals are a great effort, usually taking more than an hour to complete. This is stressful for him and for us. He seems to be developing an aversion to food. He weighs 27 pounds and is 42 inches long. Is there anything else we can do to help him nutritionally?

Adequate nutrition is extremely important for any child and especially for those children with disabilities, who often have special nutritional needs and are at greater risk for developing nutritional problems. Many children with disabilities have physical and/or intellectual impairments that may affect adequate nutritional intake. These include, but are not limited to inability to feed oneself, obtain food independently or make wise food choices; inability to sense thirst or communicate the need for fluids; decreased appetite due to constipation or gastroesophageal reflux (severe “heart-burn”) which is common in children with cerebral palsy; incoordination of swallowing or chewing; and/or abnormal reflexes such as tongue thrust (a tendency to push the tongue out when chewing).

Medications, especially anticonvulsants—such as Phenobarbital and many others—can adversely interact with or hinder the proper metabolism of essential nutrients such as vitamin D. Subsequently, this affects the body’s ability to utilize calcium.

A child with neurological or physiological disabilities needs adequate nutrients to optimize or maintain performance and function. In order for such a child to reach his full potential, he needs nutrients adequate for growth and development.

Growth failure is common in children with cerebral palsy. One cause of growth failure is undernutrition due to lack of adequate calories in daily food intake over a prolonged period of time.

Studies have shown that children with moderate to severe cerebral palsy and growth failure require two to twelve times as long to eat a pureed meal as their peers without disabilities. Meal times can be...
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exhausting for both child and parent. Prolonged eating time may lead to an aversion to food by your child.

Also frustrating for parents is that the additional time spent feeding a child with a disability leaves less time for other types of interactions with that child and other family members, as well as for household chores or employment responsibilities. Of course, the child may share this frustration. The child also may become frustrated when he or she is fed by many different individuals.

In the case of your son, it seems that the first step should be an assessment of his dietary intake and the changes which need to be made. Your child will need adequate calories and protein - first, for catch-up growth; later, for maintenance of normal growth. Whenever possible, you can add high-calorie, high-nutrient-density foods to the child's diet - foods such as high-fat dairy products (milkshakes, ice cream, butter and eggs), canola oil, peanut butter and wheat germ. The temporary use of these high-fat foods for more rapid weight gain should not cause any long-term detrimental effects. More expensive over-the-counter preparations - such as Ensure, Pediasure and Enrich - have 30 to 60 calories per ounce and can be used as supplements. A multivitamin and mineral supplement, also commercially available, should be added to your son's diet as well. Because of his use of anticonvulsants, it might be appropriate to choose a supplement that has additional vitamin D and calcium. Your pediatrician can tell you the proper dosages for a child of your son's age and weight.

Smaller, more frequent feedings should be attempted. In addition, caregivers should try to make eating as pleasant an experience as possible. It is especially important to have consistency at school - ideally, your son should be fed in the same manner by the same individual every day.

If a short-term trial of this sort of modified diet does not seem to work, a period of enteral supplementation - such as continuous, nighttime nasogastric-tube feeding - can be considered. As always, you should consult your pediatrician for more advice and options.

Nutrition in the child with developmental disabilities is a crucial issue that needs careful and ongoing monitoring. This monitoring requires a multidisciplinary approach utilizing input from health care professionals, educators and therapists who are familiar with your child. If your son's aversion to food makes it difficult to implement necessary changes in his feeding program, a mental health professional may also be able to provide useful assistance.
Familiar Faces

Fifteen-year-old Rachel Oliver of South Hill, Virginia cuddles a stuffed bear at bedtime. Rachel, who has autism, is always laughing, smiling and very happy. "She is the joy of our life," says Rachel's mother, Jane.

Two-year-old Chantel Thennes of Mifflinville, Pennsylvania celebrates a birthday with big sister Amanda, who is seven. Chantel has spina bifida. The girls' mother, Debra, recalls the day a year ago when Amanda asked if a friend's new baby cousin was "special like Chantel." When told that the baby had no special needs, Amanda looked sadly at her friend and said, "I'm sorry the baby is just plain."

Evan Siegal, of Bryn Mawr, Pennsylvania proudly displays a yellow ribbon won at his first horse show. Two-year-old Evan, who has cerebral palsy, loves his therapeutic horseback-riding lessons. Evan is pictured on his favorite pony, Bruno, with riding instructor Maire Guggenheim and great-grandmother Elizabeth Hall.

Sherisa May Wallace tries out her new swim tube during a therapy session at home. She uses the tube in her family's hot tub and at the local pool in Palmer, Alaska. Sherisa is almost three years old and has multiple disabilities.

Bath time is Joseph Glen Seidel's favorite time of day—he so passionately loves water that he sometimes can't wait to get undressed before getting into the tub. Two-and-a-half-year-old Joey, who has Down syndrome, lives in Ellsworth, Michigan.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. Sorry, photos cannot be returned. On a separate sheet of paper, write your child's full name, age of the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue.
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"Where's my friend?" asks three-year-old Christopher as he searches the house for six-year-old Miriam, or "Mimi" as her brothers call her. Mimi is the second of our three children, eighteen months younger than Matthew and three years older than Christopher.

Christopher asks for Mimi when he wakes, and he often falls asleep in her room at bedtime. "Mimi, come play with me!" is his request during much of the day. Christopher misses his sister terribly when she is at school. At the end of the school day, he watches from the window as she gets off the bus. "Mimi's here! Mimi's here!" he cries as she walks through the door. The fact that Miriam was born with Down syndrome means nothing to Christopher—Mimi is his sister and in his own words, "my friend."

Almost Like Twins
Christopher has provided an interesting balance to the family; he interacts in a positive way with both his older brother and with Miriam whose mental age makes her more like his twin than a sister three years older. Because of Christopher, Matthew has a companion in the rough-and-tumble world of little boys, and Miriam is no longer the "baby."

One of the more surprising consequences of adding a third child to the family is the positive relationship that has developed between Miriam and Christopher as both reach a mental age of three years. They seek each other out; then, chattering away as they play together, they come up with projects that often have chaotic consequences.

Tonight I found them emptying out Mimi's room. All the toys that could be dragged, pushed or carted had been moved out into the hallway. With Mimi's toy table, sink, refrigerator, cradle, dolls and high chair, they had set up housekeeping in the hall. When I happened upon this scene, the big rocking chair was halfway out of the door—Mimi providing the muscle and Christopher the direction.

Positive Benefits for Both Siblings
When Christopher is not around, Miriam watches television or plays alone, often using different voices to act out events from school, television or videos. A few days ago I heard her yelling outside and discovered she was calling "Lassie."

Christopher helps Mimi learn how to interact with others—to give and take, to share—skills that will help her later in life. When Christopher paints, so does Miriam; if he builds, she builds, too. They do "gymnastics" together and chase each other around the house. Miriam's "running-walk" has improved greatly as she tries to catch her speedy little brother. It's hard for Mimi to become a "couch potato" with Christopher around.

Christopher's company has also had a positive impact on Miriam's language development. Christopher is very verbal and constantly chatters. Mimi talks back to him, and the two carry on little conversations as they work together on their self-appointed tasks throughout the day.

The relationship is hardly one-sided, however. While boys tromp in and out to play with Matthew, they are too old for Christopher. He finds in Miriam a more appropriate playmate. She provides him with an opportunity to learn how to share and work together with another person. "Take turns," says Christopher as he stands with his hands behind his back by the slide, waiting for his sister to go down.

Their concern for each other is touching. "It's okay," says Mimi when Christopher falls down and cries. "Call doctor," she goes on to suggest. If Mimi gets hurt, it is Christopher who comes in to say, "Miriam's crying; she wants Mommy."
The Gap Widens
As Christopher gradually passes Miriam intellectually, I see him beginning to help her with difficult activities like puzzles. In doing so, he is taking the first steps toward becoming a caring, compassionate person. Christopher’s first pediatrician, himself the younger brother of a child with a disability, is a good example of the positive way that a younger sibling can develop in a family situation like ours.

For me, there is also a sense of sadness in seeing Christopher advance, doing so easily what Mimi struggles to accomplish. At three, he has already passed her, and the gap will only widen. A parent who is watching a normal child develop can have no illusions about the reality of the sibling’s disability; Christopher’s development highlights what Mimi is unable to do.

Challenges and Blessings
Caring for two children, both operating on a preschool level, requires incredible energy. After having two “two-year-olds” for the past year, we now have two “three-year-olds”—better, but still a combination that demands constant watching. Sometimes their “big ideas” get out of hand; two “preschoolers” can wreck a room in minutes. And just try catching two kids zooming off on big wheels in opposite directions—a definite logistical problem to say the least!

I know that the time will come when Christopher will need to play with other little boys and develop friendships and interests outside the home. I hope that Miriam will grow as he does. Perhaps the skills that she has learned from her interactions with Christopher will make her better able to play with children she meets at school or in the neighborhood.

Christopher has proved to be a good namesake of the Saint Christopher of legend. In his own way, he “carries” Mimi, as he helps her to grow both socially and intellectually.

Mimi is his best playmate, and he is hers. Would that everyone else could see the person, not the disability, as Christopher does with Mimi, his “friend.”

Postscript
It is now three years since the evening when I wrote the first part of this article. Miriam is now nine years old; Christopher is six. In many ways, what I had anticipated has happened. Christopher has moved on to a neighborhood gang of little boys who chase each other around the yard and stampede through the house. They generally avoid Mimi—not because she has a disability, but because she is a little girl. When his buddies go home for the day, Christopher plays with his sister.

During the last three years, both Christopher and Mimi have grown socially. In testing this year, Mimi’s highest score was in the area of social development. As Christopher also interacts easily with other children, I wonder if his abilities in this domain are a direct result
of his early experiences in learning to work and play with Mimi, his first friend.

At the end of this year, with Christopher in kindergarten and Miriam testing at the five-year-old level academically, both children are learning to read. The two are still "twins," and the result has been a certain amount of rivalry. If one child tries to read flashcards from school, the other has to read them, too. When one sits at the table to write numbers, the other one joins in. As one sibling learned to swim, so did the other. Whatever one learns to do, the other child has to try.

In terms of sibling relationships, it is interesting that now, as the children grow older, Matthew, now 11, is the sibling who interacts best with Miriam. He provides a more age-appropriate role model than does Christopher. Because he is more intellectually mature, he also exhibits a greater ability to see things from Miriam's point of view. Matthew's friends also have become protective of Miriam, reminding their younger brothers and sisters not only to be nice to her, but also to behave well so she doesn't imitate bad habits.

It is hard to predict the long-term effects that a child with a disability has on her siblings; it is equally hard to analyze the influence that siblings have on the child with a disability. In our case, one positive result has been a heightened sense of competition that pushes both Christopher and Miriam to work harder to achieve basic skills. Social skills have also been enhanced for all of the children—through interactions with Christopher and Matthew, Mimi has learned many of the skills required to get along with others; her brothers have developed sensitivity toward their peers and people in the community.

Anita Reith Slobs lives in Shawnee, Kansas with her husband, Eugene, and their three children. She has written a variety of craft and activity books, mainly in the area of religious education. She has also written several articles about disability.
Although early intervention policies strongly suggest working partnerships between parents and professionals, parents sometimes perceive busy physicians as insensitive or condescending. While many parents feel enormous gratitude to health care professionals, others have stories to share about health care providers who considered their parental insights as anxiety-ridden exaggerations, gave them faulty information or dwelled so much on the impossible that they forgot about the possible.

Parents who met through the Caring Connection, a parent support group in South Carolina, had these kinds of stories to tell each other. They wanted to share these stories with physicians to help them become better able to provide appropriate health care to children with disabilities and their families. They wanted doctors to learn something about the daily joys and difficulties of raising a child with a disability. Physicians may not be taught family-centered care in medical school; instead, they are often taught to "take charge"—an attitude that can hinder collaboration between parent and professional.

Getting Started

Georgia Murphy, coordinator of the Caring Connection, understood the parents' collective wish to improve the physician-parent relationship. Along with consulting clinical pediatric psychologists Timothy Daugherty, Ph.D., and Conway Saylor, Ph.D., Murphy contacted faculty at the Medical University of South Carolina (MUSC), and made arrangements to have parents speak at noon conferences which are routinely scheduled to enhance the education of pediatrics residents. Residents responded so favorably to the first of these presentations that additional invitations followed—from both MUSC and local colleges. To make their message more portable and available, the Caring Connection contracted with a professional production crew to create a videotape. Volunteers interviewed nearly 40 parents, grandparents, adult siblings and friends of children with disabilities. Their heartfelt remarks became a half-hour video program entitled Coping: Through the Eyes of Special Families.

Getting Funded

With these preliminary experiences, the Caring Connection parents and staff were well-prepared when the state Developmental Disabilities Council announced an intention to fund programs that trained medical professionals, and invited groups to submit proposals. Consulting pediatric psychologists Saylor and Daugherty, both Citadel professors with University resources and considerable grant-writing experience, agreed "To promote understanding and cooperation among physicians, parents of developmentally disabled children and those with chronic health needs, along with the agencies and health care professionals who serve them."

—PAPA mission statement

PAPA presentations make liberal use of photographs and videos of children with their families, teachers and friends. Such images give audiences a sense of the rhythms of everyday life in these families. In this photo, Alexander Bethke holds down his end of a conversation with Karen Salter.
Home from the hospital: Dr. Edward Wilson reads to his son Leland. It is 3:00 a.m.—Leland's first night home from the hospital after surgery—and his pain keeps the whole family awake. Leland has cerebral palsy.

to apply for the grant on behalf of the Caring Connection. The grant was awarded and the Parent and Professional Alliance (PAPA) was born. PAPA hired Christy Bethke to serve as project coordinator, and formed a steering committee that included health care professionals and parents of children with special needs.

The parents and professionals of PAPA, now in their third year, are more active and involved than ever. Last year, more than 400 health care professionals and trainees attended PAPA panel presentations, viewed PAPA videotapes and used PAPA-provided educational materials. Audiences for PAPA presentations ranged from a dozen medical students to more than 100 trainees in health care specialties such as pediatrics, psychiatry, psychology, ophthalmology, pharmacy and dentistry. Private practitioners and faculty also attended PAPA presentations that were given as part of continuing education forums.

Preparing a Presentation

PAPA arranges parent presentations for many different audiences—MUSC students, practicing physicians and other professionals. To plan a presentation at MUSC, for example, Bethke contacts the “training director” of a department—such as pediatrics or ophthalmology—and proposes a specific presentation. Each department’s training director, appointed by the department chairperson, is responsible for scheduling speakers for special classes, seminars and lectures. In addition to scheduling PAPA events within their departments, training directors help panelists gear their presentations to the training level and special interests of each audience.

Once a presentation is scheduled, PAPA assembles a group of two to six parent panelists, making a special effort to ensure that the panel reflects the diversity of age, disability and ethnicity in the community. Whenever possible, PAPA chooses parents who have experiences that are especially relevant to the trainees’ discipline.

All parent volunteers undergo a training session before their scheduled presentations. At the training session, the PAPA coordinator educates the parent volunteers about the levels of physician training (student, intern, resident, practicing physician) and gives them information about the level and probable needs of their audience.

The training session is also an opportunity to expose the parents to the physician’s point of view. Dr. Edward Wilson, MUSC faculty member in ophthalmology and father of a child with special needs, has explained to parents that physicians face disability, suffering and death on a daily basis. Doctors, like parents, find different ways to cope. Some cultivate an objective distance that comes across as clinical and cold, some try to speak only briefly to the parents, and others are unsure about what to say.

During training sessions and presentations, PAPA arranges child care for panel participants. In the past, MUSC occupational therapy trainees and cadets from The Citadel have volunteered as child care workers. It is a system that benefits the volunteers as well—in addition to supplying a needed service, many of these trainees plan to work with children who have disabilities and benefit from their interactions with such children in the child-care setting.

The Presentation

PAPA presentations last from one to two hours. The panels often include one doctoral-level professional who gives a formal presentation about relevant public policy and psychosocial research, and several parents—some live, others on videotape—who offer their stories and lessons to the audience.

Parent panelists describe their child’s diagnosis and condition, and talk about good experiences with physicians as well as the unpleasant ones. During the talk, the parent shows pictures of her child to the audience. As they speak, presenters may also play background video footage of their children at home.
J.J. Hastings enjoys a day in the park with his mon, Sissy.

These images give audiences a flavor of everyday life in a family where one member has special needs.

At the beginning of each presentation, PAPA volunteers distribute handouts for future reference. These handouts may offer information about disabilities, legislation and resources; they may also include poetry or prose that illustrates the parental perspective. A list of local parent support and resource groups are handed out at every presentation. PAPA believes that doctors, from the very beginning, should refer parents to local parent organizations for emotional support and practical information. Some questions can only be answered by another parent.

A question and answer period takes place after all the panelists have spoken. Many times, audience questions lead to further discussion of important issues.

“Nothing But Praise”

In the last two years, PAPA has received positive feedback from parents, trainees and professionals alike. They have won the gratitude of parents and the respect of professionals. Parent Beverly McCarty of Charleston writes, “It is rewarding for me to know that attitudes are being shaped and changed as a direct result of the presentations made by the PAPA parents.” Dr. Edward Wilson says, “I have heard nothing but praise from trainees in the pediatrics, physical therapy and ophthalmology [departments]. The use of parent panels and videotape has stimulated much discussion and deeper understanding.” Clearly, the efforts of these parents are making an impact in the medical community.

Worth a Thousand Words

PAPA has used video in creative, effective ways. The videotaped segments of each presentation allow medical students and physicians to see important facets of daily life in families with children who have disabilities. Video enables parents to share their stories even if they are unable to attend a presentation. PAPA also records each presentation and adds the tape to their video library. In-state parents and professionals who were unable to attend the presentation can borrow it to view later or make a copy for their own records. (Others may purchase videos from The Citadel, Department of Psychology, 171 Moultrie Street, Charleston, SC 29409, $29.95 each. Ask for a list of available tapes by calling PAPA at 803/953-6351.)

Now, PAPA is using video to spread the word about its program. A recently-completed video, Parent and Professional Alliance: How to Get Started, explains PAPA’s mission and history. It shows scenes from parent training sessions, parent and professional panels and the videotapes used in presentations.

Parents, agencies or training programs can use the video to learn more about this type of parent-professional collaboration. As parent Nancy Bryant tells doctors in the video, “Parents [can be] very helpful to you if you will ask them. Parents will spend countless hours in the library looking up articles published concerning their child’s birth defect... they have a great networking capability. They’re willing to share it with you if you’re willing to ask.” (The video is available from The Citadel, Department of Psychology, 171 Moultrie Street, Charleston, SC 29409, $29.95. A manual to assist groups in implementing this kind of program is due out in the summer of 1995.)

Parents interested in implementing a program like PAPA need to know about the resources that are available in their community. Local parent support groups already have extensive network capabilities. They serve the needs of parents; if many parents articulate the need to personally promote family-centered care to the medical community, that local group may have the interest and the resources to help. Established parent support groups may already have professional contacts within the
community. This can help parents gain access to the medical education system. The following tips may help as well:

- Any concerned parent can become involved—many roles are possible. A parent can participate in panel discussions, arrange schedules, train volunteers or offer to allow home visits by medical students.
- Participating on a panel can bring up uneasy emotions about one's experiences. A support system should be made available to panelists.
- Money is not essential to pursue this project, but considerable time and commitment are vital. Funding helps, however, by allowing a paid coordinator to arrange training sessions and presentations.
- Members of groups interested in seeking funding can take a course in grant-writing or ask local colleges or universities for assistance.
- Be persistent when making proposals for presentations to medical training programs. Tell training directors about PAPA and note that a number of similar programs have emerged in recent years.
- Use video, as PAPA does, to capture the lives of families in their home. Bethke advises, "Tape children at play with siblings, interacting with friends and professionals, and interview parents where they feel most comfortable. Today's video cameras are easy to use and often can be rented if not owned. If no special editing facilities are available, just hook up two VCRs and make your own edited copies."
- After parents and professionals make presentations, audience evaluation forms should be distributed—a sample evaluation form is available from PAPA. Evaluations give valuable feedback on those aspects of the presentation that were most effective as well as those that need more work.

**Any parent can do it.**

Beverly McCarty, the mother of three children, including twin sons who have autism, says "Any parent can do it. You need not be an experienced speaker. Your life's experiences qualify you. If you've ever sat across the room from, or at a table with, a dozen experts during an IEP meeting, then by comparison, speaking your heart out to a group of professionals won't seem too hard."—P.Y.

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**FAMILIES, PHYSICIANS, AND CHILDREN WITH SPECIAL HEALTH NEEDS: COLLABORATIVE MEDICAL EDUCATION MODELS**, a book edited by Rosalyn Darling and Margo Peter, offers a variety of medical education approaches to facilitate communication between the families of children with special health needs and health care professionals. This book will be available in September from EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.

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A Bit of Teenage Savvy
Adolescents with disabilities advise health care providers.
by Peggy Mann Rinehart

The Division of General Pediatrics and Adolescent Health at the University of Minnesota, home of the National Center for Youth with Disabilities (NCYD) and the Center for Children with Chronic Illness and Disability, combines clinical and community-based fellowship training with policy research in general pediatrics, adolescent medicine, ambulatory pediatrics, behavioral and developmental pediatrics and developmental disabilities. The Division is interested in strategies to promote quality health care for children and adolescents. They are also interested in the creation of programs to foster collaboration among the University, community agencies that work with under-served minorities and children, and youth with disabilities and their families.

Among the Division's innovations has been the design and creation of a developmental disabilities rotation for pediatric residents in which parents and community providers serve as teachers. They also are conducting a longitudinal study of resilience in families of children with chronic conditions. And last fall, they went into the community looking for young people who might be interested in serving on a "youth board" designed to provide advice to the Division and its projects. Here's an update.

No one was really sure what the "youth board" would do. Not Division head Robert Blum, M.D., Ph.D.; not project directors Judith Kahn and Bill Malcolm. Not the teenagers who responded to ads and search letters sent to their schools. "We only knew it was a good idea," Malcolm explains. "If your mission is to promote child and adolescent health and to be a part of the communities that serve adolescents, it is a good idea to consult teenagers."

Kahn and Malcolm spent most of September and October recruiting, reviewing applications and conducting interviews. By November, nine young people between the ages of 15 and 19, with visible and invisible disabilities, had become charter members of the Youth Advisory Board. "We're very diverse with respect to gender, race, ethnic identity, ability and geographical background," Malcolm says.

"When I first began, I didn't know what to expect," confesses Shannon McBride, a recent graduate of Cretin-Durham Hall High School. "But I was interested in building leadership skills and going out into the community."

Christine Pui, now a senior at Wayzata High School, already knows she's interested in medicine. This summer, she's working in a research lab. "I found out about the youth board at school," she says.

Teenage Savvy and Unique Experiences

Each member brings a bit of teenage savvy and unique experiences to the board. Dan Thompson, a senior at St. Paul Central High School, is an athlete. He was a member of the Junior Timberwolves, the 1993 national junior wheelchair champions. John Underwood, Jr., graduated from Anoka High School and is actively involved in community theater.

"I was on the Prevention and Risk Reduction Curriculum Review Com-
mittee for my school district," recounts 15-year-old Molly Galloway, who starts her junior year at White Bear High School in the fall.

"We spent a lot of time talking about sexually transmitted diseases and pregnancy within the schools." Molly is interested in politics and has firsthand knowledge of how hard it can be to create change.

"There are so many restrictions," she explains. "[When speaking in schools], you can't show different kinds of birth control or anything like that."

Defining the Board's Role

In May, the youth board attended a workshop to improve their individual leadership skills and help them define the board's role within the
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Division, but it was not as useful as they had hoped. "It was geared toward student boards that were just starting out," Molly explains. "They kind of said, 'So you've toyed with the idea... well here are some reasons why you should do it.'" This board had already formed and was looking for ways to become involved with a wide range of projects.

During the 1993-94 school year, the board has developed stories for Division newsletters as well as national publications, including an issue of NCYD's Youth Connections that was published in Exceptional Parent (July 1994). The board has learned about and provided feedback on several Division research projects designed to improve services for youth with disabilities, youth with HIV/AIDS and youth dealing with substance abuse issues. The board also has evaluated

Youth Advisory Board Members

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<td>Molly Galloway</td>
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<td>Britta Lindvall</td>
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<td>Raquel Zamorano</td>
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University and community programs and conferences.

Delving into Health Care Reform

Beyond these typical board functions, the youth board wanted to make a bigger contribution. During a discussion of their own experiences, several members recounted some of the health care experiences common to many adolescents with disabilities and their families:

"I like going to a specialist better than going to regular doctors because I feel like they know a lot about my problems."

"We changed insurance a couple of years ago, and now I have a real nice lady [doctor], but... I never really expect very much."

"I don't really have a doctor. I'm between doctors. They kicked me out of pediatrics, and I haven't found an adult doctor yet."

Armed with ambition and experience, the board has decided to write a position paper for the Surgeon General's Conference on Adolescent Health.

"This country is working to dramatically change its health care system," Malcolm says. "We feel that a youth perspective needs to be included in order for all sectors of the population to benefit from these changes. Health care reform must be
responsive to the needs of youth in terms of the health care system, critical health services and education. Our main intention is to analyze these issues and provide recommendations which would make health care more responsive to our needs.*

Risk and Insight

Teenagers like those sitting on the board live with the kinds of "risk behaviors" we read about in the newspapers. Their friends and acquaintances have babies in their teens, experiment with alcohol and other controlled substances and become addicted to gambling. They know kids who have experienced depression, used tobacco or found themselves in violent situations. "These health risks affect youth with disabilities to the same extent that they affect other youth," Malcolm explains.

But these youth board members also have insight. One of their recommendations has been to have teenagers take the lead in designing a relevant innovative health curriculum for high schools.

Looks like they've discovered next year's project.

Peggy Mann Rinehart is director of communications and dissemination for the National Center for Youth With Disabilities and director of dissemination for the Center for Children With Chronic Illness and Disabilities. As the parent of three children, two of whom are deaf and have other chronic conditions, Peggy has developed a keen interest and expertise in the areas of health, chronic illness and disability, social service systems, special education, deaf culture and medical/technical writing.

Peggy is active in various disability movements and serves on many state and national boards and committees including EXCEPTIONAL PARENT’s Editorial Advisory Board and the advisory council to the Minnesota State Academies for the Deaf and Blind. She also chairs the consumer subcommittee of the Great Lakes Regional Genetics Group.

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AUGUST 1994 / EXCEPTIONAL PARENT • 33
Meeting the Public

John Kemp, Executive Director of the United Cerebral Palsy Associations (UCPA), was interviewed by EXCEPTIONAL PARENT in June 1994.

John, who was born with multiple limb anomalies, grew up in Bismarck, North Dakota and Frankfort, Kentucky where he attended a regular public school and private Catholic schools. He graduated from Georgetown University in 1971 and Washburn University Law School in December 1973.

After law school, John worked for seven years as an environmental attorney and consultant on disability-related legal issues. From 1982 to 1990, he served in a number of positions at the National Easter Seal Society. He has served in his current position at UCPA since June 1990, the first person with a disability to hold this post.

Since 1980, John has been married to photographer Sherry Marcy. John enjoys activities with grandson Seth, age five, the son of Sherry's daughter from a previous marriage.

This is the second part of our interview with John; part one appeared in the July 1994 issue of EXCEPTIONAL PARENT.

In high school, I was not the only student with a disability. We had moved, and I attended a very small, Catholic high school in Frankfort, Kentucky. The other student with a disability was a boy who'd had polio. He and I would stay up on the third floor of this really old high school. We both walked with great difficulty, up and down those stairs. We would walk up the stairs in the morning and come down when the school day was finished. The cafeteria was in the basement, so someone would run downstairs and get our lunch and bring it up to us. He and I ate lunch alone upstairs. We would stay up there all day.

My older sister was very attractive—a homecoming queen type. I always tried to relate to the guys that she was dating. I wanted to grow up to be like them, but it was very difficult just getting up the courage to talk with girls. I didn't date very much at all. I was the kid with acne, and I thought that was my disability. I thought that was the big reason why girls didn't want to go out with me. My little sister used to tease me about playing connect-the-dots on my face.

When it came time for my senior prom, the only girl I could get a date with was the one girl at the other high school who had a disability. It wasn't that I didn't want to date her because she had a disability. I just thought, "Isn't that a little trite? Isn't that so typical?" I had been such an integrated guy that it just seemed unfair.

College and Law School

When I got to Georgetown University in 1967, my social life changed completely. Maybe my acne cleared up—I have no idea! But, I met a lot of young women who accepted me for who I was, and I had lots of dates.

At that time, there were very few students with disabilities at Georgetown—certainly not many with mobility limitations; there were steps everywhere! The Vietnam war was raging, and I must have been asked a million times if I had acquired my amputations in Vietnam. Sometimes, people would just walk up to me and say, "Vietnam?" And I would say, "No." It was a very difficult time on campuses; it was a wild, crazy period in American history.

I loved my four years at Georgetown. If I were to pick out the four best years of my life, it would have to be my years at Georgetown. I didn't exactly excel in the academic parts of college life, but I was definitely a
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straight-A student when it came to the social aspects. My dad didn’t quite buy that argument, by the way. Not at all!

I started out in pre-med, and in the first two weeks, I was taking classes that were so far beyond me that I had to get out. I was taking physics, chemistry and some exotic math class. I was just on the wrong track. In the first semester, I changed my major to American political history.

I graduated from Georgetown in 1971 and decided to go to law school. I went to law school in Topeka, Kansas. Life was very different in Topeka. In Washington, DC, I could get a date whenever I wanted one. But in Topeka, I just couldn’t seem to bump into anybody that I really liked. Finally, I got to know a woman who was living in the same apartment building and asked her out to dinner. She said, “I hate to say this to you, but I can’t go out with you because you’re handicapped.”

I must have been very naive, but I just didn’t believe that people would be rude enough to say something like that, especially not to me! That was the beginning of a rough two and a half years. I decided I was going to get out of Topeka as quickly as I could. I went through summer school and graduated in December of 1973. I haven’t been back to Topeka since the day I graduated.

**Meeting the Public**

Society still has a long way to go. For example, I just got back last night from New Mexico—when I can, I like to go to Santa Fe and just relax. In Santa Fe, I went to the club on the top floor of a hotel to have a drink. The club had one step at the entrance, and I was with a guy who was in a wheelchair. So, I walked in and asked a man working there if there was a ramp available. The guy said, “Handicapped people are not allowed here.”

I looked at him and said, “Don’t you ever say that to anyone again! I can’t believe in 1994, that you would dare to say to me that handicapped people are not allowed here.” I am going to file an ADA charge against the hotel unless they tell me that they have developed an appropriate plan of action to deal with this access problem in thirty days.

Children deal with disabilities better than adults.

Children confront us; adults avoid us. I don’t mind answering honest questions—“What happened to your hands; why do you limp?” Children’s questions are sincere and practical. They want to know if I can drive a car, play basketball and write; a kid might ask, “How do you go to the bathroom?”

If a child stops me in a supermarket and asks me questions, his mother and father are usually horrified. They walk up and grab Timmy and put a stop to his interactions with me. I use this example to explain the difference between a handicap and a disability—I have a disability; mom or dad has a handicap; Timmy is doing fine.

Adults, on the other hand, will see me walking down the street, and at a distance of about 30 feet, they will start whistling or humming and looking everywhere else but at me. They don’t want to stare and make me feel uncomfortable, but their avoidance basically eliminates me from the face of the earth. Finally, I figured out that when these people got about three steps past me, they usually turned around to check me out. Now, when I walk by someone who is looking all around the place and won’t look at me, I always count off three steps after we pass, then turn around to catch the person sneaking a peek at me. And I wave.

I make these people feel uncomfortable on purpose because those of us with disabilities know very well that we look different. We have mirrors in our homes; we go past plate glass windows. We know what we look like. For people to use the fact that we look different as a basis for completely disassociating themselves from us is a subtle form of discrimination.

Younger adults who have attended schools where children with disabilities were mainstreamed are much more comfortable with us. Studies have shown this. They have learned that disability is not a seriously distinguishing feature; it is just another characteristic.

When I meet new people, I always have to initiate the handshake because they don’t know quite what to do. Sometimes, they don’t grab my clamp; they grab my arm or my shoulder, or they start bowing like we are in Japan—they freak out. Seeing how well people
handle that introduction and handshake has become my little barometer for how "cool" a person is.

**Taking Risks**

I think confidence is instilled at an early age. Confidence involves being truthful with yourself about your own abilities. Sometimes, I venture into things that I don't succeed at, and the sooner I figure out I can't do something or can't do it well, the better off I am. This is not to say that people shouldn't try to do things that they can't do. But sometimes, I have to admit that I am not very good at certain things. I think we all need to understand our strengths and build on them.

My overall advice to parents is to let your kids take some risks. All too often, parents are very worried about allowing their children to venture into new areas. They want to protect them from humiliation, teasing and failure, but that isn't the real world. In the real world, they will have to learn how to deal with the discrimination that will happen to them, and they will have to learn how to cope with people who are jerks. Parents have to be able to put that into perspective for their kids, but they also have to let their kids take some risks. That's probably the hardest thing in the world for parents.

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**PLACEMENT FRONT PAGE**
Dental Care for Children with Disabilities

Preventing Dental Disease with Daily Oral Care
by Steven P. Perlman

Every child can have healthy teeth and gums. Children with disabilities are no exception. This series of articles will explain some important facts about dental disease and its prevention, focusing on the particular needs of children with disabilities. Future articles will deal with a number of topics including special techniques for daily oral care, common pediatric dental problems and appropriate methods of behavior management during visits to dental professionals.

Part One

Good oral health is an important part of a child's total health. Children with good strong teeth are able to chew a wider variety of foods for healthy nutrition. Healthy teeth aid in speech development by helping children make the proper sounds for speaking clearly. And clean, healthy-looking teeth help children look better and feel better about themselves.

With all the medical, nutritional and emotional needs of children with disabilities, it can be hard for parents to find time for proper daily oral care. Getting a child to the dental office can be difficult, too. But preventive care now can spare the child unnecessary pain and costly dental procedures later.

Prevention with daily oral care

Dental problems can be prevented before they start. That means cleaning the teeth at home every day. Daily brushing and flossing remove plaque, the primary cause of tooth decay. Plaque is a sticky, colorless film of bacteria that constantly forms on the teeth. When food particles, especially from sugary foods, stick to the teeth, the bacteria use the food to produce acids.

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to maintaining a private practice in Lynn, Massachusetts, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their "Special Athletes, Special Smiles" program. Dr. Perlman lives in Swampscott, Massachusetts with his family.
which cause cavities. If plaque is not removed every
day, it can lead to gum disease; and gum disease, if left
untreated, can lead to tooth loss—all of which could
be painful for the child.

Although daily oral care is a necessity, it should be a
pleasant experience as well. Even if the child can’t
brush and floss properly, letting the child play at cleaning
a little when you’re finished can add to the fun.

If possible, children should clean their own teeth.
You can explain why daily brushing and flossing are
important and show a child how to do it. By placing
your hand over the child’s hand, you can guide the
child through each step.

Some children will be unable to clean their own teeth,
however. In such cases, the parent must do the cleaning.

**Where should you do it?**

Daily oral care can be performed in any well-lit room
that is convenient. If the child is in a wheelchair, the
kitchen might be ideal. If the child is in bed, that’s
okay, too. Have the child sit up. Then let the child sip
water from a glass through a straw and rinse out in a
basin. The best place for daily oral care is a place
where the child is most comfortable, or where you are
able to give the best care.

**Positions**

There are a number of positions you can use to clean
the child’s teeth. In any position, it’s important to sup-
port the child’s head. Be careful to avoid choking or
gagging if the child’s head is tilted back. It is also
important for you to be able to see what you are doing
and easily manipulate dental floss and brush. Ask your
dental professional to recommend the safest, most
comfortable position for your child.

**Wheelchair**

Stand behind the
wheelchair. Use
your arm to brace
the child’s head
against the chair
or against your
body. Use a pillow
for the child’s
comfort.

Or sit behind the
wheelchair.
Remember to lock
the chair wheels
first, then tilt the
chair back into
your lap.

---

**Special Children are at Greater Risk**

There are a number of reasons why children
with disabilities are often more prone to dental
disease.

**Oral conditions:** Some genetic disorders or very
high fevers in very young children can cause
defects in tooth enamel that make the enamel
prone to decay. Congenitally missing teeth and
teeth that do not align properly are frequently
seen in children with cleft palates and other cran-
iofacial disorders. Gum problems often occur in
children with Down syndrome.

**Physical limitations:** Children who cannot chew
or move their tongues properly cannot benefit
from the natural cleaning action of the tongue,
cheek and lip muscles. Children with disabilities,
especially those with poor motor coordination—
such as those with spinal cord injuries, muscular
dystrophy or cerebral palsy—may not be able to
clean their own teeth or may not be able to use
the usual brushing and flossing methods.

**Special diets:** Children who have difficulty
chewing and swallowing may often eat puréed
foods which tend to stick to their teeth. Frequent
eating of sugary foods or sleeping with a bottle of
formula, milk or juice can increase the chances
of tooth decay. Children who need help drinking
may drink less fluid than other children, so they
don’t have enough fluids in their mouth to help
wash food particles off of their teeth.

**Medications:** A number of medications that may
be used more frequently by children with disabili-
ties can lead to increased risk of dental disease.
*Medications that use syrup or sugar to sweeten*
the taste can cause tooth decay if used over a
long period of time. Some *seizure medications*
may cause the gums to bleed or become
enlarged. Excessive gum growth can interfere
with chewing and speech; it can also lead to gum
disease. *Sedatives, barbiturates, antihistamines*
*and drugs used for muscle control* may reduce
the flow of saliva. With less saliva, there is less
cleansing action to help protect the teeth against
cavities. *Aspirin*, taken in large doses and dis-
solved in the mouth before swallowing, can pro-
vide an acidic environment that fosters tooth
decay. Some *antibiotics* should be prescribed
with caution because they can stain or discolor
newly erupting teeth.

continued on next page
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Lying on floor
The child lies on the floor with his or her head on a pillow. You kneel behind the child's head. You can use your arm to hold the child still.

Lying on bed or sofa
The child lies on a bed or sofa with his or her head in your lap. Support the child's head and shoulders with your arm.

If the child is uncooperative or uncontrollable a second person can hold his or her hands or feet as needed.

Beanbag Chair
For a child who has difficulty sitting up straight, a beanbag chair may let the child relax without fear of falling. You should be in the same position as for bed or sofa.
Raul’s mom learns oral hygiene techniques that she can use for daily oral care at home. Nine-year-old Raul has a progressive, neuromuscular disease.

This article has been adapted with permission from materials originally published by Johnson & Johnson Dental Care Company.
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Providing Comfort to Those Who Want It!
Fathers are Caregivers Too!
by Steve Fischer

When the doctor walked into the room, his intense, focused eyes already communicated the message that his voice was about to deliver. The words he so mechanically began to speak did not come as a surprise. My daughter was extremely sick. Medical science had yet to determine the cause of the illness that had resulted in her being born with profound retardation, cerebral palsy and many other problems. I do not remember much of that day—I believe that the mind protects us by somehow clouding the details of extremely traumatic events. But I remember one peculiar detail that has since become a recurring feature of my encounters with the medical establishment.

When the physician walked in to deliver the message that day, he looked squarely into my wife's eyes. Even though my wife and I were sitting side by side on a chair-turned-hospital-bed, his eyes never made contact with mine. I surely can empathize with the physician, who clearly recognized the pain in my beautiful wife's eyes. But I too was in a state of complete emotional collapse. This physician's body language seemed to convey one of two messages—either that I was not hurting, or that I should simply "take it like a man."

I have to believe that this extremely capable doctor did not treat me this way with any degree of premeditation. Rather, he avoided both eye contact and dialogue out of conditioning. While the mother-child relationship is undeniably powerful, health care providers have been slow to recognize the equally powerful bonds between father and child. I have spent countless nights with grieving fathers over seemingly endless cups of coffee; many of my brothers are hurting and have few outlets to express their emotions.

We are all at different places along the road to acceptance of the various challenges we face. Wherever we are, however, the important role we play in our children's lives should be acknowledged and respected. I readily admit that my wife assumes the greater portion of the day-to-day care of our child. However, I am also a caregiver in my little angel's life and deserve the consideration medical professionals give to my wife.

It has been interesting to note those aspects of a child's care that physicians seem to automatically assign to each parent—and it has been equally interesting to observe their reactions when I have dared to question these assumptions. Mothers are invited to support groups, asked to grant permission for various tests and called to conferences considering the appropriateness of do-not-resuscitate orders. Fathers are relegated to handling paperwork.

We have a long way to go in educating our health
care providers about the emotional needs of fathers who have children with disabilities. We fathers must take the lead in educating medical professionals and advocating for ourselves. We must support, encourage and share with each other. We must remind our health care providers that fathers are caregivers, too.

Fathers’ Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father’s Network, focuses on fathers’ experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Father’s Network (NFN) or to receive their newsletter, write or call: National Father’s Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax).

Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children’s and families’ lives.

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Join us. Together we will reach our journey’s end.
Special Bathrooms
by Linda Nitteberg

A poorly-designed bathroom often results in a somewhat less than user-friendly environment for a child with a disability. This article describes adaptations that can make a bathroom more accommodating for the child with a disability and for other family members as well.

When planning a bathroom project, the first concern should be safety. A child should never be left unattended in the bathroom. Children need to learn that the bathroom is not a place to play. At an early age, children should be made aware of the possibility of household accidents and taught how such accidents may be prevented.

Space requirements
It is important to remember that little children grow into big children. As children grow, they become heavier, their adaptive equipment becomes larger and they require more space.

For many children, growing older means they will be able to perform more tasks independently. But the nature of some disabilities may make it more difficult for some children to develop independent self-care skills—regardless of age. It is important for parents and designers to communicate with doctors, physical therapists and occupational therapists so these factors can be taken into account before any remodeling project is undertaken.

In planning for space needs, it may be helpful to sort your child’s activities of daily living into three categories: 1) activities your child can do independently, without difficulty or assistance; 2) activities the child can perform with difficulty and/or minimal assistance; and 3) activities the child can accomplish only with great difficulty or complete assistance.

Special bathrooms need to be designed with adequate clearances. The “three-four-five rule” is an easy way to remember the most important distances. If a person in a wheelchair is to use the bathroom, it should have three-foot (36”) doorways, four-foot (48”) halls (leading to the bathroom) and “aisles” (the space between one wall and an object such as the toilet or sink), and a five-foot (60”) turning radius. With these clearances, the space should accommodate an average, full-sized wheelchair and will allow a caregiver to move alongside the child as needed. The five-foot turning radius will allow a wheelchair to turn around easily.

If diapering is a concern, a space should be designed for this activity. One idea is to incorporate a fold-down changing table. Be sure to provide for nearby storage of diapers and supplies.

Storage
Storage space is an important issue in the design of any bathroom. The design of storage space should consider the needs of each family member who will be using the bathroom. You may want to consider the storage of hygiene and health-care items such as medications, IV supplies, feeding supplies, catheter and enema equipment, diapering supplies and exercise equipment (for example, if the child does therapeutic activities such as range-of-motion exercises and needs storage for items like small weights).

It is also important to store items such as medications, razors, makeup and cleaning supplies separately and out of the child’s reach. Consider using locking devices on cabinets or drawers that contain these types of products.

Products
Depending on the child’s abilities and needs, a range of special products may be useful:

- **Grab bars** should be carefully placed at the entry to all showers and bath tubs. They must be installed according to manufacturer’s instructions—preferably by a carpenter. Make sure that there is adequate wood backing behind sheet rock to securely anchor the bars. Behind the wall, bracing can be installed at heights sufficient for current and future needs.

As your child grows, you can move the grab bars higher. Keep in mind that most adults like their grab bars placed 33 to 36 inches...
above the finished floor. Never use a grab bar as a towel bar (to avoid grabbing for an unstable towel in place of the grab bar or vice versa).

Scald-resistant faucets should be installed in all bathrooms used by children. Most manufacturers make a pressure-balance mechanism and some offer thermostatic control. Most faucet users who have difficulties with grip or strength prefer styles with long, lever handles. There are a few faucets on the market that can be operated without even a touch. These may be ideal for individuals who have severe fine-motor or hand-strength limitations.

- **Tub and shower controls** should be positioned near the entrance to the tub or shower, out of the water stream. This allows for added safety. It also allows the caregiver to operate the controls without getting wet.
- **A hand-held shower on a pole** can be useful. The pole, which resembles a vertically-attached towel bar, connects the shower head to a sliding piece that allows the unit to be positioned at the right height for any user. Because the shower head is detachable, rinsing is much easier. It also comes in handy for cleaning the tub or shower.
- **Shower doors** come in a variety of styles. Some have no track on the top or bottom. Consider using a non-glass enclosure for safety.
- **Fold-down shower benches** should be considered for all showers. A bench provides a place for the person being cleaned to sit, an opportunity to rest if fatigued and an easier way to wash one's feet or shave one's legs. Look for a bench that offers the size and support needed. As with grab bars, proper installation into solid-wood bracing is essential.

**Electrical outlets**

Safety is a primary concern when electrical outlets are being considered. **Ground fault circuit interrupt (GFCI) outlets** protect against electrocution by deadening electrical appliances upon contact with water. **Childproof outlets** are secured behind a plastic cover when not in use. **Grounded switches** are connected to an underground system that protects electrical appliances in the event of a power surge or outage. For added safety, **shatterproof light fixtures** are also strongly recommended.

**Flooring**

Certain non-slip flooring such as vinyl, linoleum and certain ceramic tiles may be installed to increase safety. Rugs should not be used. Carpets are hard to clean and difficult for wheelchair users to maneuver on. Throw rugs are likely to slide around and could get in the way of canes or walkers.

**Additional resources for design assistance:**

The National Easter Seal Society (230 West Monroe St., Suite 1800, Chicago, IL 60606, 312/726-6200) offers a free, nine-page brochure that includes accessibility checklists and design ideas. Ask for Easy-Access Housing for Easier Living. Send a self-addressed, stamped envelope with your request.

The National Kitchen and Bath Association (NKBA, 687 Willow Grove St., Hackettstown, NJ 07840, (800) 367-6522) can provide lists of certified designers and rules for kitchen and bath design. (Keep in mind, however, that some rules may not apply to certain disabilities.)

Linda Nitteberg, CKD, is a general contractor, designer and the owner of CONCEPTS KITCHENS AND BATHS PLUS. Linda has been a long-time advocate for the rights of individuals with disabilities. She is a regular speaker at design classes and teaches at NKBA national conferences. Linda, herself a wheelchair user, brings a unique mixture of expertise and personal experience to the topic of accessible and adaptive design. Readers are invited to contact her at Concepts Kitchens and Baths Plus, 466 Meridian Ave., San Jose, CA 95126.
Manufacturers of Bathroom Acess Aids

Key
Bath items manufactured by these companies are indicated by the following numerical codes:
1. grab bars, tub rails
2. accessible showers
3. adapted bathtubs
4. seats, benches, chairs for shower; or tub transfer seats
5. bathtub lifts
6. adaptive toilets, commodes, portable commodes
7. toilet seats, supports, accessories
8. adaptive sinks
9. faucets, temperature-control faucets, fixtures, handsheld showers, accessories
10. whirlpool baths, hydrotherapy devices

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(619) 695-2122

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(800) 927-1267

Briggs Plumbingware ........... 2, 3, 6, 7, 8
4350 West Cypress
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(813) 878-0178

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2909 Ingersoll Ave
Des Moines, IA 50312
(515) 453-8880

Bath Eaze ...................... 3
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Palm Harbor, FL 34685-2911
(813) 782-6793

Bathroom Fixtures .......... 1, 5, 6, 7
Bath & Shower Fixtures
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Van Nuys, CA 91406-2913
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The HIP Resource Guide

The 1994 edition of the Help for Incontinent People (HIP) Resource Guide provides information on products and services for people with incontinence. The guide was developed to assist people who are undergoing medical treatment for incontinence and for people whose incontinence cannot be cured.

The resource guide lists all companies that manufacture or distribute incontinence products and have made themselves known to HIP. The guide categorizes products, manufacturers, distributors and mail/phone-order resources. The last section of the resource guide provides help for people with incontinence.

The Simon Foundation for Continence

The Simon Foundation for Continence is an organization dedicated to bringing the topic of long, self-addressed, stamped envelope to HIP, P.O. Box 544, Union, SC 29379. The referral service and support and advocacy. For a free information packet, send $1.00 and a newsletter and provides audio/visual programs, books, educational leaflets, a continence service provided by HIP, a national, nonprofit organization. HIP also publishes a quarterly newsletter and provides audio/visual programs, books, educational leaflets, a continence service provided by HIP, a national, nonprofit organization. HIP also publishes a quarterly newsletter and provides audio/visual programs, books, educational leaflets, a continence service provided by HIP, a national, nonprofit organization. HIP also publishes a quarterly newsletter and provides audio/visual programs, books, educational leaflets, a continence service provided by HIP, a national, nonprofit organization. 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Parents Help Set The National Agenda

On July 10-12 a conference in Washington, DC introduced the National Agenda for Achieving Better Results for Children and Youth with Disabilities. The National Parent Network on Disabilities (NPND) participated in this conference with a team of five Parent Training and Information Center leaders.

The National Agenda includes a mission to guide future program planning for children and youth with disabilities:

All children and youth will have the right and responsibility to participate as members of the global community. In concert with the Goals 2000: Educate America Act and the Individuals with Disabilities Education Act (IDEA), it is our mission and in the national interest, for all children and youth, including those with disabilities, to be educated to their fullest potential. Further, all children and youth will have the opportunity and necessary supports to become caring, productive, socially involved citizens who are committed to life-long learning.

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Location: The St. James Hotel, Washington, D.C.
Reception: Sunday Evening, October 2

The National Agenda reflects the belief that a more effective educational system can be created by the year 2000 through a commitment to the values and principles embodied in its mission statement. By achieving the goals set by IDEA, every child can be assured of the best possible educational opportunities. The achievement of these goals requires a commitment to honoring these rights of children and youth with disabilities:

• Access to appropriate options designed to meet their individual needs;
• Preparation for inclusion in an integrated society; and
• Optimal and appropriate opportunities to be educated with peers who represent diverse cultures, languages and abilities.

The National Agenda describes a vision for the year 2000. The vision begins with images of children and youth with disabilities having access to services that will lead to self-actualization, self-determination and independence. The National Agenda envisions these children as highly motivated learners with individual identities, a strong sense of values and access to supports necessary to ensure a high quality of life.

This vision is fully compatible with national education goals and the intent of the Goals 2000: Educate America Act. The National Agenda also describes the following program components that must be in place to ensure success for children with disabilities:

• Enriched and broadened appreciation of diversity;
• School-community collaboration;
• Appropriate personnel;
• Specific accountability for better results for children and youth; and
• Appropriate technology.

For further information or to receive a copy of the National Agenda, contact your state director of special education or call NPND, (703) 684-6763.

Positive SSI Stories

NPND is seeking stories from families of children with disabilities about positive impacts of the SSI benefit program.

Recently, the success of national outreach programs, like the one NPND operated between 1990 and 1992, has been turned upside down. Critics of the SSI program are now complaining in the press and on television that SSI is out of control. Beginning in 1990, after the supreme court's decision in Sullivan v. Zebley made SSI medical-eligibility requirements less restrictive, a number of children with disabilities began receiving SSI for the first time. Skeptics contend that this number is far too high to accurately represent the number of truly eligible children. They have charged that families coach children to act as if they have disabilities and that families abuse the funds that they receive on behalf of their children.

Allowing these types of criticisms to stand unchallenged will seriously jeopardize the continued ability of children with disabilities to participate in the SSI benefits program. We urgently need to collect as many positive stories as possible about the impact of the SSI program on families of children with disabilities.

Please send your story to Patricia McGill Smith, Executive Director, National Parent Network on Disabilities, 1600 Prince Street, Suite 115, Alexandria, VA 22314.

For more information, call (703) 684-6763.
Parent Case Management for People of Color

Members of ethnic minority groups are less likely to receive community services and supports for individuals with disabilities and their families. To assist in addressing this issue, the University of Minnesota's Institute on Community Integration (ICI) is developing a program called Parent Case Management for People of Color.

This program is a collaborative effort between the Institute's Research and Training Center on Residential Services and Community Living, Arc of Hennepin County and leaders in the African-American and Native-American communities. The program's goal is to develop information, procedures and materials that can be easily used by existing community organizations. The program hopes to provide these existing community organizations with resources for parents or guardians of individuals of color who have developmental disabilities. These resources can be used to encourage these adults to take leadership roles in the management of services that they or their children receive.

The fundamental premise of parent case management is the idea that individuals with disabilities and their families can effectively handle the choices and decisions involved in their case management. Through training and technical assistance, the program gives participants the background information and skills needed to take the lead when identifying, selecting and managing the services and supports they receive. Participants develop knowledge in case management, rights, quality indicators, state-of-the-art service delivery, effective use of resources, maintenance of appropriate records and inclusion. Parent Case Management for People of Color adapts the training, materials and assistance of the Parent Coordination Project to create an effective, culturally-sensitive tool to empower individuals with disabilities, leaders and families within these communities.

Parent Case Management for People of Color is focusing first-year efforts on collaboration and networking with communities of color in selected areas of Minnesota. Next year the program will develop training and technical assistance projects, including a newsletter, in the African-American community. Third-year plans call for the extension of these services into the Native-American community. By the fifth year of the program, facilitator training and technical assistance will be in place in each of these communities.

The National Parent Network on Disabilities will collaborate with Parent Case Management for People of Color by distributing information about the materials developed by this program.

For further information contact Marijo McBride, University of Minnesota, Institute on Community Integration, 103 Pattee Hall, 150 Pillsbury Drive, Minneapolis, MN 55455, (612) 624-6830.

Leadership Changes Around the Network

This year seems to be one that will be characterized by changes in Parent Training and Information Center leadership. Deidre Hayden has resigned as executive director of the Parent Educational Advocacy Training Center in Fairfax, Virginia.

Deidre Hayden, Cherie Takemoto and Nola Flynn at the Parent Educational Advocacy Training Center in Fairfax, Virginia.

Educational Advocacy Training Center (PEATC) in Virginia. She will be replaced by Cherie Takemoto. Joan Kilburn is retiring from MATRIX in California and will be replaced by Deidre Hayden. Does this mean the creation of PEATC west and MATRIX east?

In other leadership changes, Carla Lee-Lawson will be leaving Iowa Pilot Parents later this summer to hang her hat at the Iowa Federation of Families for Children's Mental Health. We congratulate Cherie Takemoto on her new leadership position.

Joan Kilburn

Joan Kilburn

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Sue Pratt, CAUSE, Lansing, MI, Vice President
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Janet Vols, Federation for Children with Special Needs, Boston, MA
Patricia Smith, Executive Director

The national leadership will bring their immense skills and energy to MATRIX to carry on in the tradition of excellence that Joan Kilburn has established there.

If you know of any other leadership changes, please let us know, and we'll share them here.
Health Insurance Troubleshooter

by Richard Epstein

Insurance Coverage for Incontinence Products

My child has a disability and is incontinent. He will never be potty-trained. Is there any way to get our insurance company to cover the cost of his diapers?

K.D., Texas

This is a problem for many parents of children with disabilities. Diapers are expensive, particularly when required on a long-term basis. And if they are being used as part of a doctor-recommended treatment program, logic suggests that unless they are specifically excluded by your insurance policy, they probably should be covered.

A number of issues may be related to your insurance company's decision on coverage, however. First, there is no clear set of national standards regarding items that insurance policies should cover. One of the goals of President Clinton's health care reform proposal is to establish such standards. Hopefully, this will occur in the not-too-distant future. In the meantime, an insurance company may exclude coverage for specific items as long as it does not violate contractual obligations (its agreement with the policy-holder) or state or federal regulations.

Second, insurance companies seem particularly reluctant to pay for items that are not considered a part of traditional medical care, or that may be used in a non-medical situation. One can certainly understand an insurance company's concern about establishing a precedent by covering such items. However, companies may pay for these items if it can be shown that they are part of a treatment plan for a specific medical condition that the policy covers.

Generally, insurance companies do not pay for items unless they are included on the company's list of "medically necessary expenses" and have been assigned a specific procedure code. Therefore, you must first determine whether your insurance company includes diapers on its list of "medically necessary expenses" in regard to disabilities. If diapers are not on the list, the solution needs to begin at that point.

Since this issue affects large numbers of parents, and since groups are often more effective than individual consumers, it may be useful to enlist the help of a local parent support group and a local medical organization that includes doctors specializing in the treatment of children with disabilities (your child's doctor may be able to give you the names of such organizations).

The parent support group can ask the medical association to write a letter to the insurance company confirming that the use of diapers is part of a medical treatment plan in the case of specific disabilities. In addition, the medical association may consider working with the insurance company to develop appropriate rules and procedure codes for such situations.

If diapers are already on the list of "medically necessary expenses," however, your problem is to determine why the insurance company won't pay the claims you have sent in. The problem may involve technicalities. For example, the company may pay for disposable diapers only, rather than cloth diapers, or it may require a doctor's letter explaining how the diapers are related to the treatment of a specific medical condition. A call to a supervisor at the insurance company should provide this kind of information.

Let me know what happens. Your experiences in dealing with this issue may be very helpful to other parents.

Note: When children are eligible for Medicaid, incontinence products may be covered. In the September issue of EXCEPTIONAL PARENT, I will discuss the Medicaid program.
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**Let's Eat** is a new video that provides practical information on feeding a child who is visually impaired, and on helping the child to develop independent eating skills. The video, which costs $15.00, explains the stages a child goes through in learning to eat. The video features parents with children of various ages. It also discusses common feeding problems of children with visual impairments and possible solutions to these difficulties. A 28-page booklet, also called Let's Eat, is available in English or Spanish and is free to parents of children with visual impairments ($3.00 for others).

Both video and booklet are available from the Blind Children's Center, 4120 Marathon St., Los Angeles, CA 90029, (800) 222-3567 (CA only), (800) 222-3566 (US). (Add 20% of total order for shipping and handling.)

The Blind Children's Center offers a number of other booklets and videos covering topics such as play, language development, motor skills and family coping. All booklets are free to parents of children with visual impairments ($1.50-3.00 for others). Contact the Center for more information.

**Support Groups**

- **Moebius syndrome** is caused by absent or decreased sixth and seventh cranial nerve development, and results in facial paralysis. The Moebius Syndrome Foundation, an information and communication network, was recently formed by parents of children with this condition. Moebius Syndrome Foundation, P.O. Box 993, Larchmont, New York 10538, (914) 834-6008.

- A new support group is available to families of children with Lesch-Nyhan disease (LND). LND is a genetic disorder that affects only males. Individuals with LND have mental retardation and, in most cases, engage in self-mutilation. International Lesch-Nyhan Disease Association, c/o Leslie Conely, 11042 Ferndale St., Philadelphia, PA 19116, (215) 677-4206.

- The **TEF-VATER Support Network** is a group dedicated to the support of children and adults born with tracheoesophageal fistula, esophageal atresia or VATER association (vertebral anomalies, imperforate anus, tracheoesophageal anomalies, renal anomalies and/or radial dysplasia). Services include family matching, referral, a quarterly newsletter and a directory of members. Contact Terri Burke, 15301 Grey Fox Rd., Upper Marlboro, MD 20772, (301) 952-6837.

- **Prevent Blindness in Premature Babies** (PBPB) is a group that provides support and information to parents of children who have **retinopathy of prematurity** (ROP). ROP is a retinal disease that prevents proper development of the eye and can lead to permanent damage and blindness. Contact Margaret Watson, PO. Box 44792, Madison, WI 53744-4792, (608) 845-6000. A free copy of PBPB's newsletter is available (specify print or Braille); tax-deductible donations are much needed and gratefully accepted.

- **Mucolipidosis Type IV** (ML4) is a neurometabolic genetic disorder that primarily affects people of Ashkenazi Jewish descent. Experts believe that many cases go undiagnosed or misdiagnosed as "cerebral palsy" or "pervasive developmental delay of unknown etiology." Families who have one child with ML4 have a 25 percent chance of having another affected child; non-affected siblings may be carriers. Accurate diagnosis of ML4 requires analysis of skin or conjunctival biopsies with an electron microscope.

Early symptoms of ML4 may include strabismus (crossed eyes), visual problems, excessive drooling, impaired speech, variable degrees of corneal clouding and delay in reaching major motor milestones such as sitting, crawling or walking.

For more information, contact the ML4 Foundation, 6 Concord Dr., Monsey, NY 10952, (914) 425-0639 or (718) 434-5067.

**Publications**

- The University of Kansas offers a 40-page booklet entitled **What You Need To Know About Your Child With An Emotional Disability and the Individualized Educational Plan**. The booklet, which costs $3.00, is intended to give parents the information they need to be effective advocates for an education that will meet their children's unique needs. Some information in this booklet applies specifically to the state of Kansas; much is applicable anywhere. Available from John Poertner, School of Social Welfare, University of Kansas, Lawrence, KS 66045-2510, (913) 864-4720. Make checks payable to "School of Social Welfare."

- The National Down Syndrome Society has introduced a new magazine designed to educate teenagers and young adults about people with Down syndrome who are included with them in the community, at school, on the job and in social and recreational activities. The premier issue of **News 'n Views** includes articles written by number of teens and young adults with Down syndrome. Editor-in-chief Chris Burke is well-known for his role as "Corky" on the long-running television show Life Goes On. Subscriptions to News 'n Views are free; contact the National Down Syndrome Society, 666 Broadway, New York, NY 10012, (800) 221-4602.
NEW PRODUCTS

ZOOMCAPS
These large-print, adhesive computer key labels are designed to assist individuals with low vision; they may also be useful for children who are learning to type. Labels are printed in 40-point type and include alphanumeric characters and other special keyboard keys. ZoomCaps labels are available with white characters on a black background or black characters on an ivory background to suit individual preferences and needs. The 91-label sets are available for IBM and IBM-compatibles, Apple IIe and IIc, and Macintosh keyboards.

Circle # 238

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Plum Enterprises, Worcester, PA 19490
Circle # 239

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One finger is all it takes to communicate! The Abovo Personal Communicating Device (PCD) has a unique keyboard with 41 large keys and a built-in keyguard. Its 40-character, super-twist liquid crystal display can be read from any angle. An optional Remote Display Unit can be read by individuals up to 20 feet away! This unit also can be used with Apple and IBM computers—text can be downloaded to a computer for use with word processing software.

Abovo, Springfield, MA 01129
Circle # 240

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This program is designed to allow a person using a single switch or any pointing device to run software for Macintosh and Windows (IBM and compatibles) applications. The single switch is connected through a switch-adapted trackball. Single-switch mouse moves and clicks, double clicks, drags and use of menu bars are performed by direct cross-scanning. This software can be fine-tuned to the needs of the user. Text can be entered via an on-screen keyboard.

R.J. Cooper & Associates, Dana Point, CA 92629
Circle # 241

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Magic Quest, Palo Alto, CA 94301
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Bows, bi-colors, prints, hearts, splatter designs and 10 assorted colors mean an almost unlimited number of ways to make protective helmets for kids more attractive and fun to wear. These Lycra® covers fit over Danmar's protective helmets and come with a “hard visor” and optional decorative bow!

Danmar Products, Ann Arbor, MI 48103
Circle # 243

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 9455 Colesville Rd., Ste. 915, Silver Spring, MD 20910-3319, (800) 227-0216, VT/TTDD, (301) 588-3294, VT/TTDD or (301) 587-1907, FAX.
Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices. The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

Potty Learning For Children Who Experience Delays, by Susanne R. Hays, M.S., R.N., C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of “bathroom” skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. ED 0770D

Effective Intervention For Self-Feeding Success, by Christine A. Nelson, Ph.D., OTR.

Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. ED 0780D


This video will show parents how to stroke their infants and children with special attention to methods which honor the infant’s individual concerns. A valued resource for every parent to assist their child’s development. ED 079DD


Nippling for infant’s born with cleft lip and/or palate can be very difficult. Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies parents can follow. ED 0800D

Mail to: Exceptional Parent, Dept. EP9408, P.O. Box 8 045, Brick, N.J. 08723
Or call 1-(800)-535-1910

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Circle #227
ATTENTION défICIT DISORDER

HELP! THIS KIDS' DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder
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Information about typical behavior characteristics; offers suggestions on how to foster the development of appropriate behavior.
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Guidelines for working successfully with ADHD and ADD in children, adolescents, and adults. For teachers, counselors, and parents.
PE038AD $14.00

AUTISM

AUTISM Information and Resources for Parents, Families, and Professionals
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Resources book, presented in a question-and-answer format.
PE043AD $24.00

CHILDREN WITH AUTISM A Parent's Guide
EDITED BY MICHAEL POWERS
A complete introduction to autism, answers questions, and gives hope to parents coping with this perplexing disorder.
WB017AD $14.95

CHOICES IN DEAFNESS A Parent's Guide
EDITED BY S. SCHWARTZ, Ph.D.
A clear, thorough, reassuring book that will help parents make the best choices. Written by professionals with frank personal accounts by parents.
WB020AD $14.95

CHILDREN WITH EPILEPSY A Parent's Guide
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Chapters on diagnosis, medications, daily care, family life, advocacy, and special education.
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COUNT US IN Growing Up with Down Syndrome
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EP055DR $20.45

HONOR THY SON A novel by Edgar Award winner Lou Shaw
This unforgettable story combines suspense, terror, and international intrigue—and a father & a son each pursuing a dream.
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Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
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IT ISN'T FAIR! Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
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S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
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RUSSELL MARTIN
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E. SCOTT, H. JAN & R. FREEMAN
Practical guidelines for helping visually impaired children reach their full potential.
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M. BATSHEW
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.
PB071AD $20.00

THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products for kids with special needs.
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You can order any of the books listed here with the coupon below or by calling (800) 535-1910

ATTENTION défICIT DISORDER

HELP! THIS KIDS' DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder
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A clear, thorough, reassuring book that will help parents make the best choices. Written by professionals with frank personal accounts by parents.
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I have enclosed my check payable to Exceptional Parent or charge to my: __ Visa __ Mastercard

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Signature ____________________________

Mail Order Form
I was born with a mild case of Moebius syndrome, a condition which affects the cranial nerves and causes facial paralysis. The whole left side of my face is immobile. My smile is lopsided and I can only move my eyes up and down, not side to side. I can't move my tongue very much, so it's kind of hard for me to eat, and I slurp a little too much. It is hard to drink from a straw because I can't move my mouth in a sucking motion.

As a result of Moebius syndrome, I have an asthma-like condition which involves shortness of breath, wheezing and coughing. I have had a lot of eye problems also. I have had two surgeries on my eyes—neither of which I remember—and I've worn sunglasses since I was two.

Moebius syndrome affects me a little bit in school, too. For one thing, I am not able to be alert during games in gym class. When we play tag, I often get tagged because I can't look around enough. In class, I have problems because the muscles in my hands are really weak. It hurts when I write for a long time. Sometimes, I get kind of annoyed when my teacher walks around the class while talking—the other kids can just move their eyes to follow her, but I have to move my whole head.

My mom did not tell me that I had Moebius syndrome until I was nine years old. I think it would have been easier on me if my mom had told me when I was younger. Before my mom explained it to me, I only knew was that I was different. I had started to feel self-conscious. Once I found out that my differences were caused by Moebius syndrome, it was easier to handle.

I go to a psychologist once a week. Mostly we play, but sometimes we have long discussions about certain things that are bothering me—some involve Moebius syndrome, and some do not. She tries to give me suggestions about my problems.

I have had speech therapy since I was two and a half years old. Now, I have speech therapy twice a week—once with a therapist at school and once with a private therapist. Recently, I started to feel self-conscious about going to my speech therapist away from school. My speech therapist's office is right on a main street, and there are a lot of people around. I think, "What if a person I know sees me here?" I know that nobody will tease me about going to a speech therapist, but I still feel a little bit afraid and self-conscious.

As a pre-teen, I think that Moebius syndrome is really starting to affect my self-esteem. Even at nine and ten, I was not mature enough to realize that I was really, really different. Now, I have all these questions that even the doctors can't answer.

I should develop more self-esteem, but it's hard. I always worry about things like whether people will understand me when I talk.

Moebius syndrome has really affected me. I've been different all my life, and for a long time, I didn't know why. If I didn't have this syndrome, I think I would be a totally different person. Having Moebius syndrome has given me more self-awareness and I've matured faster because of it.

[Natalie Abbott, 11, lives in Piedmont, California with her parents, Marcia and Wayne, and her cat. She has no siblings, but enjoys playing with her nine cousins. In September, Natalie will begin sixth grade at Piedmont Middle School.]
MENTOR'S PEDIATRIC PROGRAM

Mentor Urology has patient education materials available to educate patients, parents, and care-givers on bladder care products and their usage.

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- TOOBIE COLORING BOOK
- PARENT GUIDE TO INTERMITTENT CATHETERIZATION
- SELF-CATH ACCESSORIES

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Imagine an infant stander so adaptable it can change its appearance instantly to become a stroller or even a highchair. Tumble Forms®, a leader in early intervention products, now introduces the Chameleon™.

Perfect for home or school use, the Chameleon accommodates children from 25 to 37 inches and up to 50 lbs. With this one lightweight unit, you can create numerous vertical, prone, and supine positions, for sitting, lying, or standing. The seat, seat back, and foot support each adjust for infinite possibilities. Meanwhile, the child is cradled against cushioned supports to ensure proper body alignment. You get three versatile products—stander, stroller and highchair—all for the price of one.

The Chameleon features a removable tray to allow easy transfer as well as swivel casters for portability. Breathable fabric covers are conveniently removed for laundering.

Leave it to Tumble Forms to change the way you view standers.

For more information, call 1-800-631-7277. In Canada call 1-800-665-9200.
22ND Annual Education Issue
Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers want your active life to include a new Ford or Lincoln-Mercury car or van or Ford light truck. And that's why the Mobility Motoring Program was created — to make adopting your new Ford or Lincoln-Mercury product easier and more rewarding!

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The Ford Mobility Motoring Program also provides ...
- friendly toll-free and special "TDD"... information line to answer your questions.
- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
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Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!"

So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TDD-0312). You'll discover that Mobility Motoring is your kind of reward!

Free Mobility Motoring Video!
This video shows how easy it is to open the door to Mobility Motoring rewards. You'll meet people who have learned the process is really simple. You'll also see how Ford products adapt ... for versatility, convenience and just plain motoring fun. Just ask for your free video when you call us.

Program Period
October 1, 1993 — September 30, 1994

Customer is responsible for a 121 day minimum activation on the Ford Cellular System. Some local individual centers may require a longer agreement as well as other related service and usage charges. To participate in this program, in addition to being eligible for the complimentary Ford Cellular telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.
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Angela is supported by a circle of friends.
Since Exceptional Parent's first issue in 1971, we have advocated for the existence of a range of good educational choices for all children. Because we believe that parents are the best experts on their own children, we have published a number of articles by parents who have made a variety of different educational decisions for their children. Our failure to "take sides" has been criticized both by proponents of inclusive education and those who support relatively separate educational programs for some children.

As I listen to arguments about educational choices, I am reminded of a boy I once knew in the days before the major legislation to provide a free, appropriate, public education for all children with disabilities. This boy was in a special class for children with mental retardation in a public school in his neighborhood, an impoverished urban area. He had been placed there solely as a result of his score on an intelligence test—that was the way placement decisions were made in those days. I was asked to review this placement because some people thought the boy should not be classified as "mentally retarded"—especially because in those days. I was asked to review the this placement because some people thought the boy should not be classified as "mentally retarded"—especially because his IQ score was just below the cut-off point that was rigidly applied to determine class placements.

I visited the boy's school to observe the special class in which he was currently placed and the regular classroom in which he would be placed if it were determined that he was not "mentally retarded." The special class had a small number of students and a talented teacher who had extensive training in special education. The boy was flourishing in this placement, both academically and socially.

In contrast, the regular classroom was a chaotic, overcrowded environment. The teacher was overwhelmed, and had no supports. Because it was hard to imagine that such a classroom would be appropriate for any child, I recommended that the boy remain in the special class. I wish more choices had been available.

Educational Program Awards
Our 17th Annual Education issue—September 1989—brought the first Mainstreaming Contest, honoring educational programs nominated by readers. Last September, the award was presented to a good example of School Inclusion. This year, in the interest of promoting good educational choices rather than any specific type of placement, the award was renamed the Educational Program Award.

We received far more nominations than ever before. This year's awards go to a variety of different programs—individual inclusive schools, a statewide inclusion plan, a private "special education" school and a group of parochial schools.

Winners are profiled within a series of articles which present different perspectives on educating children with disabilities. Also within this section is an article which illustrates the hard work and planning necessary for Making Inclusion Work.

At the White House
Assistant editor Kim Schive and publisher Joe Valenzano were at the White House on July 27 for a celebration of the fourth anniversary of the Americans with Disabilities Act (ADA). President Bill Clinton, Hillary Clinton, Vice President Al Gore and Tipper Gore addressed the group gathered on the South Lawn. While celebrating the ADA's many contributions, all of the day's speakers emphasized that health care reform would play an essential role in removing still-existing barriers to employment for people with disabilities.

Young Contributors
We need more submissions for our Children's Page. This is an important feature of the magazine. We encourage contributions from children with disabilities, their siblings and their friends. Be creative! Send stories, photos and artwork to Children's Page, Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146-5005.
Outcomes: Posture, function, and mobility improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.
I read Dr. Edwin Martin's guest editorial, *Inclusion: Rhetoric and Reality* (April 1994), with interest. I have just been through a due process hearing whereby I sought residential placement for my son, Charles. Currently, our case is in the United States District Court. By the end of these proceedings, we hope to discover what it takes to get "residential placement" on a child's IEP—the criteria for residential placement are ambiguous at best.

In the course of pursuing the due process procedure, we have spent almost as much as a single year's tuition at the school where he is now a resident. So far, the only clear winners are the attorneys and consultants involved in the case.

While the trend toward inclusion is admirable and noble, it hurts those children, like my son, for whom residential placement is appropriate. Holding to the standard that a school district's program need only provide "some educational benefit" unfairly penalizes children who need 24-hour, seven-day-a-week continuity and structure.

J.R.W., Alabama
Everyday Heroes
A "Happy Issue"
Halfway through your July issue, I found myself checking my checkbook to make sure I had renewed my subscription. I had thought, several times, that I would not do so.
I hope this issue was just the beginning of a new Exceptional Parent. The many "personal glimpses" and personalized articles make this issue a gem!
Many "personal glimpses" and personalizing of a new found myself checking my checkbook. Halfway through your July issue, I of seeing how other "real people" live, provide, but we also need the "perks" of letter writers; she asked that read-

Familiar Faces
I have been an avid reader of Exceptional Parent for more than two years. I really enjoy the recent addition of the Familiar Faces page. Thank you for continuing to publish an excellent magazine for parents such as myself.

J.T., California

Readers Speak Out
Exceptional Parent recently published a letter entitled "Magazine is Less Useful" (May 1994). The writer (E.M., Texas) criticized the magazine for failing to include enough articles by parents: she felt that recent issues had placed too much emphasis on political advocacy and inclusion. E.M. also disagreed with the magazine's policy of publishing only the initials and state of letter writers; she asked that readers be given the option of using full names and addresses.

I agree completely with E.M. I have written to you several times to express my desire to network with parents; your policy hinders that. If parents do not want to publish their names or addresses, let that be their choice. We are all "grown-up" enough to handle mail solicitors. I deal with that every day!

I also agree that not all of us are on the inclusion bandwagon. Our choices should be respected, too.

Thank you for putting parents in touch with one another. I cannot think of a greater purpose. In numbers we will find strength. To correspond with a parent who knows my pain is the best gift you could offer.

L.B., no address given

First of all, I don't care if you print my name or initials. I think you have done both over the years I have been writing to you. All magazines have the right to set their own editorial/stylistic policies. I wasn't aware that this publication was run by popular consensus. Go ahead and do what you will with the names initials on letters.

Perhaps E.M. is being defensive because the general trend of the more progressive thinkers in the field of special education—parents and professionals alike—is to move away from segregated placements for children with disabilities. I think it is part of Exceptional Parent's responsibility to keep up with changes and movements within the field.

I am glad Exceptional Parent is reaching out more to "politically active parents." They are the ones who helped to push legislation through Congress which now guarantees our children a free, appropriate, public education. The political is the personal; the personal is the political. Our children's options in life will be shaped by the political process. It is foolhardy to think that we can opt out of it.

Actually, E.M.'s letter helped me to clarify my thinking about the magazine. I knew that I had started reading Exceptional Parent a lot sooner after it arrived and reading a lot more of the articles. Now, I know why. The magazine has become more politically aware and more scholarly, and therefore, a lot more interesting to me. I can live without maudlin parent testimonials about how their children with disabilities changed their attitudes toward God and their religion and how it made them better people.

Please, Exceptional Parent, continue to be political, scholarly and useful to me.

J.L., California

I specifically disagree with E.M. from Texas. I am the mother of a gifted adolescent with learning disabilities and attention deficit disorder. I had previously let my subscription lapse because I was not able to relate my son's situation to the magazine articles.

I wasn't finding the magazine very helpful or relevant to our family. I am finding Exceptional Parent much more relevant and supportive this year.

K.M., Rhode Island

I would like to add my vote for publishing names and addresses in the Search section. I have always felt it was a bad move to stop doing that. It seemed like yet another example of the disability professionals putting as much distance as possible between parents.

We parents desperately need each other. I have long puzzled over and resented being kept away from other parents artificially—"for my own good." Yeah, right.

Parents with knowledge are parents with power. They are thorns in the sides of disability professionals. This gives professionals a vested interest in keeping parents apart. I was very disappointed when Exceptional Parent bought into that idea. I thought it was a magazine for parents!

I also must say that in general, Exceptional Parent is excellent. I have learned from, laughed at and cried over articles you have published. Keep listening to parents—that will keep you on track.

M.D., Michigan

Exceptional Parent's Note: We appreciate the many thoughtful letters we received in response to E.M.'s comments. We agree that letter writers in this section should be given options about how to identify themselves. From now on, writers of letters to the editor will have the option of being identified by initials and state, full name and state; or full name, city and state. When no preference is stated, we will continue to use initials and state.

On the other hand, we will continue to identify writers of Search letters only by initials and state, and to forward responses through this office. This decision has nothing to do with a desire, as M.D. put it, "to keep parents apart." On the contrary, we are thrilled by the fact that so many parents have found each other in the pages of this magazine over the years. But being able to handle responses allows us to select a representative sample to publish in Exceptional Parent, allowing many readers to benefit. It also gives us another avenue of insight into our readers' interests and con-
Introducing the River Tank Ecosystem:

Your fish have been dreaming of this. A playground of sorts where they move up and down the rapids and waterfalls. And where they travel from pool to pool as they do in a natural river habitat.

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The patented River Tank Ecosystem is a dynamic, living habitat where plants, fish, frogs and reptiles interact in ecological balance. Like a real river, the rushing water generates a healthy, oxygen-rich environment. When the water seeps through the gravel-filled plant cavity, biological balance is naturally maintained. And since plants use fish waste as food, there is no need for fertilizer.

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Homes. Schools. Workplaces. Now everyone can have a river view. The River Tank is available in four sizes: RT-10, RT-20, RT-30 and RT-45. It’s very affordable. And you don’t need a life preserver to enjoy it.

Call 1-800-808-8822 for more information or the dealer nearest you.
Pen Pals

As a result of many requests from readers, we will begin a Pen Pals Page in an upcoming issue.

If you are an adult seeking a pen pal, send us your name and address along with two or three sentences to introduce yourself and explain the type of pen pal you would like to find. Please include a daytime telephone number (where we can reach you; it will not be published).

Children's pen pal requests should include the above information plus the child's age and sex, the daytime phone number of a parent and a parent's signature confirming permission to publish the child's request.

Here's one to start with:

Scott Richards
RR #1, Box 1888E
Whitefield, ME 04483
Age 9, male. Has brother with Coffin-Lowry syndrome; likes rock-collecting and karate. Wants to hear from anyone.

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Community Involvement
My son is a delightful nine-year-old with attention deficit hyperactivity disorder (ADHD), auditory processing disorder, and secondary autistic tendencies. He has just completed a year of supported inclusion in second grade. Academically, he did fine. Socially, however, the year was abysmal. He was never invited to birthday parties or play dates. We tried Cub Scouts and a swim team. Other children avoided him. Involved adults were patronizing but intolerant. My husband and I offered our help in all extracurricular activities. We have tried everything to get our son involved in our community but have met with no success. I would appreciate suggestions from parents who have been successful in involving their children in their communities.

J.R., New Jersey

Wernding-Hoffmann Disease
Our five-year-old son, Daniel, was diagnosed with Werdnig-Hoffmann disease (spinal muscular atrophy, type I) at 12 months. At age two, he was diagnosed with a seizure disorder and had a feeding tube inserted. He has been hospitalized frequently due to aspiration pneumonia.

Daniel cannot roll over, sit up, crawl or walk. However, he has an electric wheelchair and is very mobile. He can still control his arms and hands. He is exceptionally bright.
My husband and I would like to hear from anyone who has information on or experience with this disease.

B.O., Rhode Island

EDITOR'S NOTE: Families of SMA (P.O. Box 1465, Highland Park, IL 60035-7465, 800/886-1762) can put you in touch with other families of children with this condition.

Catheterization?
I am the mother of a three-year-old who has been diagnosed with cystic periventricular leukomalacia. She has cerebral palsy, infantile spasms and is tube-fed.

She has had recurrent urinary tract infections and is currently on Bactrim, in hopes of preventing further episodes. After she had a cystogram, our doctor advised us that we will have to start catheterizing her intermittently. Her bladder is extremely small and does not empty out totally.

We are very discouraged and hope that someone can provide alternatives for us. We don’t know if there are other options besides catheterization.

C.M., California

Unsure About the Future
My three-year-old son, Nevada, was born at 31 weeks weighing three pounds, fourteen ounces. He has been diagnosed with bronchopulmonary dysplasia, bilateral spastic hemiplegia, hydrocephalus, asthma, central nervous system damage/dysfunction, oral-motor dysfunction and a seizure disorder. He has a tracheotomy, VP-shunt and g-button. He is oxygen-dependent.
Despite his many problems, Nevada is an alert, happy and social child. He seems to understand what is going on around him and is starting to talk. He can sit and stand with assistance. Although Nevada does not take any nutrition by mouth, he is starting to taste different foods.

I have always been an advocate for full inclusion, and I try to include Nevada in as many social activities as possible. Next year, he will be starting in the regular preschool program at our local school. My husband and I try to treat him as though he does not have disabilities.

I would like to hear from other parents who have a child, Nevada’s age or older, who has similar disabilities. I feel unsure about Nevada’s future as far as school, feeding, family attitudes and social activities.

B.L., Kentucky

Severe Disabilities
I would like to correspond with other parents who have a child with severe disabilities. My 10-year-old son has autism and mental retardation. He is still in diapers.

I have rheumatoid arthritis. On a “bad day,” caring for my son is quite a challenge. I would like to be able to write a letter to someone who can identify with what I am going through.

L.B., Arizona

Undiagnosed
Our one-year-old daughter, Marissa, is developmentally delayed. To date, her main symptoms have been severe hypotonia (low muscle tone) and, recently, myoclonic seizures involving her arms and eyes. At six months of age, she had two seizures and has been on Phenobarbital since, with no more occurring. Her vision was poor, but seems to be improving as she gets older. She is very tall for her age—almost 34 inches long, putting her at the 110th percentile for her age.

Marissa has had the following evaluations and analyses: cranial MRIs, EEG, bone-age, lumbar puncture, urine and plasma amino acids, urine organic acids, EMG, muscle and nerve biopsies, thyroid hormone levels, ammonia, lactate, pyruvate, calcium, very long fatty acids, creatine kinase and high-resolution metaphase chromosome examination. All were normal except that the muscle biopsy showed thicker-than-normal mitochondria. Biochemical studies, however, showed normal enzyme levels. A DNA study on her
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Progressive Neurological Disorder

My 14-year-old son, Michael, has been diagnosed with familial spastic paraparesis. Doctors have told us this is a "wastebasket" diagnosis they use for unknown disorders. We have searched without success for a diagnosis so we can better prepare for his future. We know he has a progressive neurological disorder that involves the white matter of the brain and the myelin.

Mike's development seemed normal until he was about three years old. In preschool he was unable to cut, paste, color or put on his snow-pants or boots. Between the ages of three and four, he started to walk on his toes. Then, he began dragging his right leg. Since age 10, he has been unable to walk independently. Now, he cannot stand independently. He uses a motorized scooter and wheelchair. He is no longer able to write, and his speech has deteriorated to a point where he is almost impossible to understand.

Mike has just completed seventh grade in a regular classroom. He is of average intelligence, although he is below grade level in some subjects. He has a full-time aide in school.

Mike has undergone numerous tests. All have been normal except the MRI which shows decreased myelin of the white matter of the brain. I would appreciate hearing from anyone whose child has a similar condition.

F.B., Wisconsin

EDITOR'S NOTE: The United Leukodystrophy Foundation (2304 Highland Dr., Sycamore, IL 60178, 800/728-5483) can put you in touch with families of children who are similar to your son. They may also be able to help you obtain a more specific diagnosis for his condition.

Johanson-Blizzard Syndrome

I'm a mother of a beautiful 11-month-old boy named Joey, who was born with a rare condition called Johanson-Blizzard syndrome.

The syndrome causes pancreatic malfunction, imperforate anus, deafness, hypothyroidism, dwarfism, absence of permanent teeth, malabsorption, aplasia of the alae nasi (absence of nostril openings), mental retardation and developmental delays. Joey receives physical and occupa-
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**Neonatal Herpes Encephalitis**

Our six-year-old son has bilateral temporal lobe damage as a result of neonatal herpes encephalitis.

Jimmy does not process sound, so he does not speak. He also has epilepsy and mental retardation. He is considered hyperactive and has been placed in a program for children with autism. We would like to communicate with other parents or caregivers who have had experience with children who have been affected by neonatal herpes encephalitis.

*B.W., Michigan*

**Trisomy 4p, Monosomy 5p**

My beautiful, 20-month-old daughter has been diagnosed with a chromosomal unbalanced translocation resulting in trisomy 4p, monosomy 5p. She has significant developmental delays and is visually impaired. I would like to correspond with any parents of a child with this diagnosis.

*H.H., New Jersey*
Nail-Patella Syndrome

C.M.T. (April 1994) has a son with full-blown Nail-Patella (N-P) syndrome, an easily-diagnosed but rare genetic condition characterized by nail dysplasia, bone deformities and sometimes kidney failure. Ian’s parents were looking for up-to-date information on N-P and hoped to hear from another individual or family with the syndrome.

I am 30 years old and have N-P syndrome. I have only the thumbnail involvement and have lived a busy, athletic life. I have two children. My second was born with excessive tibial torsion caused by the lack of a patella in his right leg and a small, distal patella in his left leg. He wore casts for six and a half weeks after birth, and a Dennis-Brown bar for 14 months after that. He is 30 months old now and walks with a slight limp, but is otherwise happy and healthy.

We have spent four to five hours with a geneticist learning more about N-P syndrome. We learned that N-P syndrome is caused by a dominant gene that is passed on by an affected parent. A person with the syndrome has a 50 percent chance of passing it on. N-P syndrome may be expressed slightly, moderately or severely.

My immediate family is a good example of the various ways the syndrome may be expressed. My grandmother has thumbnail and first-fingernail involvement with elbow dysplasia. My mother has thumbnail and first-fingernail involvement, elbow dysplasia, 56 percent scoliosis and a small/square patella. I have thumbnail involvement only. My sister Barbara has thumbnail involvement, elbow dysplasia and six percent scoliosis. My sister Joan has thumbnail involvement, elbow dysplasia, eight percent scoliosis and small kneecaps. I have three other siblings who do not have N-P and, therefore, can’t pass it on.

My grandmother, who came over from Ireland, remembers that her mother had N-P, but she doesn’t know who had it in previous generations. Since my extended family has 16 affected members, doctors at Johns Hopkins University are collecting blood from affected and non-affected family members for a study. They already know that the gene for N-P syndrome is on chromosome nine but are hoping to pin down the exact location.

M.K.L., California

Rhizotomy

C.S. (May 1994) has a three-year-old daughter with spastic quadriplegic cerebral palsy. She is non-ambulatory and does not crawl. She has poor trunk control but can sit unsupported on the floor in a ring-sitting position. Her doctor has recommended rhizotomy surgery. Before making a decision, C.S. wanted to hear from parents of similar children who have had this surgery.

My daughter, Leah, sounds a lot like your daughter. Leah had rhizotomy surgery six months ago.

The surgery helped Leah in several ways. It greatly reduced the spasticity in her legs, and it reduced the spasticity in her arms to a lesser degree. Now, she is more comfortable and seems more confident and sociable. We’ve also noticed that her speech is more fluent, and her articulation is better.

M.K.L., California
Before the surgery, my expectations were too high. I'd spoken to only one other parent whose child had undergone rhizotomy surgery. Two months later, her kid was practically doing taps, playing the piano and reciting the Gettysburg Address!

Needless to say, our results have not been so dramatic; however, it has been only six months since the surgery. I've heard it is a one-to-two-year process in most cases. At least, Leah no longer has to fight the spasticity day and night. It has improved the quality of her life.

Was the surgery a hassle? Yes. A nightmare? Pretty much. Would I do it again? Yes. But I'm glad I don't have to.

C.M., New York

☐ Your child's condition is very similar to my son's at the same age. Kenny also has spastic quadriplegic cerebral palsy. At 30 months, his only means of mobility was combat crawling. He could not sit or stand unsupported. Fine motor skills were delayed in his right hand and nonexistent in his left.

The doctors cautioned that following rhizotomy surgery, the typical child regresses. They told us it might be a year before any improvement would be seen. That was not true for Kenny. He had the rhizotomy surgery on his third birthday. The stiffness in his body was gone almost immediately.

Following the surgery, Kenny went to physical therapy five days a week for almost a year. Within months after the surgery, he could sit unsupported, crawl and walk short distances with a walker. Later, he learned to stand unsupported. His fine motor skills also improved. Doctors tell us that his gains are among the best they have seen.

I was apprehensive about putting Kenny and us through the surgery. It required a great commitment from his family and his school. The costs—and not just the financial costs—were great, however the benefits have been priceless. I have known the families of a few other children with cerebral palsy who have had rhizotomy surgery; none have regretted it. Not every child will benefit from the surgery as much as Kenny, but I recommend you give it serious consideration.

C.G., Michigan

Our 11-year-old son also has spastic quadriplegic cerebral palsy. A few years ago, we also were seriously considering rhizotomy surgery for him. Brian sits cross-legged, uses a walker, crawls and transfers almost independently.

We first went to a children's hospital where we met with a neurologist and a physical therapist. Just from watching Brian walk down the hallway without his braces, they immediately determined he was a good candidate for the surgery. They told us they wanted to do it as soon as possible.

We felt uneasy with the speed of their decision and the urgency they conveyed, so we decided to get a second opinion at a different hospital. Brian spent three days there. His evaluations included a gait lab and in-depth evaluations by physical and occupational therapists. Following these evaluations, Brian's case was discussed by a team of doctors and therapists. The team concluded that a rhizotomy was inappropriate for Brian because of the weakness in his trunk. They determined that the surgery would leave him unable to crawl, sit cross-legged and transfer; it might also interfere with his use of a walker. They left the final decision up to us; we felt very strongly that we could not take the chance that Brian would lose some of his function.

I'm telling you our experience only because I want you to make sure your daughter is evaluated very carefully by a team of professionals who have had extensive experience. Once the surgery is done, there is no reversing it. Whatever your decision, we wish you luck.

L.E., Iowa

Bilateral Aniridia

S.G. (May 1994) is the mother of 21-month-old Katie, who was born with bilateral aniridia, a rare condition involving absence of the iris. Katie's diagnosis includes foveal and macular hypoplasia, optic nerve hypoplasia, nystagmus, congenital cataracts, hyperopia, strabismus and amblyopia. Genetic screening has shown that Katie's chromosomes are normal.

S.G. was interested in contacting families of children with aniridia who have had cataract surgery or experience with intraocular or contact lenses with a painted, fixed iris. S.G. also wanted to locate people with aniridia or other eye abnormalities in which there was a history of penicillin or penicillin derivatives being used during the first 10 weeks of pregnancy.

My daughter, Lauren, also has aniridia. Like Katie, Lauren has foveal and macular hypoplasia, nystagmus and strabismus. Her visual acuity is about 20/100 in her better eye and 20/200 in her weaker.

You asked if anyone has had experience using contact lenses with a painted iris—we have. Lauren was fitted with soft, extended-wear lenses at the age of three months. It was extremely difficult to change the lenses for cleaning. A three-month-old does not stay still long enough! Our family had a system, but it was not fun. When it was time to change her lenses, our son laid across her legs with a pillow so she could not kick. My husband held her arms over her head to help keep the head steady, and I took out the lenses. When her lenses were clean, we repeated this process to put them back in. Lauren fought it all the way! She also got a lot of eye infections. We finally gave up on the lenses when Lauren was about nine months old. By that time, she had learned to rub her eyes in a certain way and pop the lenses out. I'll never forget the day she ate one!

Lauren had strabismus surgeries at 18 and 24 months of age. They were very successful. Not only did they give her eyes a more normal appearance, but they seemed to greatly reduce the broad swings of her nystagmus. Her surgeries were uneventful, even easy.

I would like to tell you about Lauren now. She is fully mainstreamed in our local schools. She sees a vision resource teacher twice a week. She has reading glasses and all kinds of magnifying glasses. She maintains a low-B average in a very competitive school.

We are very proud of Lauren's ability in sports. Two years ago, she was ranked sixth in the state in swimming (50-meter freestyle); she has also set many cross-country and track records. This past spring she joined a local softball league; she turned out to be a good batter and second baseman. This summer, she taught swimming at a local day camp. Not too bad for a "blind kid."

Lauren has lots of friends and is forever talking on the phone. Her room is papered with posters of rock stars. She is just like any other teenage girl. We are very proud of her.

R.B., Illinois
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We have a 13-year-old daughter, Caroline, who has aniridia. Caroline has the chromosomal abnormality associated with aniridia—a deletion of 11p13. My understanding is that the deletion may be quite small and may require DNA probe studies to find, but if a person has aniridia, the deletion is there. We were told about the possibility of Wilm's tumor. We put Caroline on a schedule of ultrasounds every six weeks, and an IVP (x-ray of the kidneys with dye contrast injected) every six months. Some doctors felt this schedule was excessive, but in our case it worked well. Caroline developed the tumor in her left kidney at 18 months. She had the kidney removed and underwent chemotherapy for a year. Since then, she's had no recurrence. We have been told that Wilm's is a risk for children with aniridia to develop glaucoma. Since then, she's had no recurrence. We have been told that Wilm's is a risk for children with aniridia to develop glaucoma. We have a 13-year-old daughter, Caroline, who has aniridia. Caroline has the chromosomal abnormality associated with aniridia—a deletion of 11p13. My understanding is that the deletion may be quite small and may require DNA probe studies to find, but if a person has aniridia, the deletion is there. We were told about the possibility of Wilm's tumor. We put Caroline on a schedule of ultrasounds every six weeks, and an IVP (x-ray of the kidneys with dye contrast injected) every six months. Some doctors felt this schedule was excessive, but in our case it worked well. Caroline developed the tumor in her left kidney at 18 months. She had the kidney removed and underwent chemotherapy for a year. Since then, she's had no recurrence. We have been told that Wilm's is a risk for children with aniridia to develop glaucoma. Since then, she's had no recurrence. We have been told that Wilm's is a risk for children with aniridia to develop glaucoma.

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FAMILIAR FACES

Eight-year-old Russell Carter is delighted to get a big hug and kiss from five-year-old sister Rosey. Russell and Rosey live in Mint Hill, North Carolina. Russell has cerebral palsy.

Gregory Kornacki loves to wear hats, but in a pinch, the lid from his crayon box works just as well. Greg has spina bifida and is 22 months old. He lives in Northville, Michigan with parents Ed and Nancy, big brother Brian, 5, and twin brother Keith.

Four-and-a-half-year-old Timothy Carl Hammaker of Port Trevorton, Pennsylvania shares the easy chair with two-month-old brother Ryan Patrick. Timmy has VACTERL syndrome, and has undergone 13 surgeries and two heart catheterizations. Timmy attends an integrated preschool program. Timmy's mother, Kelly, supervises the early intervention program in two Pennsylvania counties.

Just five days after brain surgery, 10-year-old Laura Giles was feeling well enough to meet musical trio Peter, Paul and Mary at a local record store. Laura, who has syringomyelia and scoliosis, is entering fifth grade at Roosevelt Elementary School in Poca City, Oklahoma.

Hannah Beth Williams' love of blackberries is written all over her face. Fifteen-month-old Hannah, who lives in Garber, Oklahoma, "doesn't slow down for much," according to mom Peggy. Whenever Grandpa Glen has work to do in the garden, Hannah is right there beside him. Of course, when it comes to blackberries, she eats all she picks.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, with your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
Our daughter is six years old. She has cerebral palsy. In the last two years, she has had many bouts of pneumonia and bronchitis requiring hospitalization and respiratory treatments at home. Her doctors feel she is having increasing difficulty swallowing her food and even her saliva properly. They also feel she may be having gastroesophageal reflux and aspiration. Is there anything we can do to prevent more of these complications?

Many children with disabilities, especially those disabilities which are moderate to severe, are more prone to respiratory problems (as well as other medical problems). Respiratory problems alone are at least twice as likely in children with moderate to severe disabilities.

There are several reasons for this:

- **Inadequate cough:** Children with neurological or neuromuscular disorders may have difficulty coughing adequately. An adequate cough is one where the child can cough up phlegm (lower respiratory secretions) when the phlegm is blocking some of the lower airway passages. If this blockage persists, the child will have a greater possibility of developing bronchitis, bronchospasm (wheezing) and pneumonia.
- **Aspiration of stomach contents:** Children with moderate-to-severe cerebral palsy and neuromuscular disorders who have abnormalities of gastrointestinal function such as gastroesophageal reflux (abnormal backflow of stomach contents into the esophagus) or dysphagia (swallowing disorders) are more prone to aspiration (breathing in) of stomach contents. This, too, may lead to bronchospasm and pneumonia.
- **Swallowing disorders:** Aspiration of injurious material from the mouth, such as saliva contaminated by infected teeth, is more likely if the child has a swallowing disorder. This may lead to pneumonia and other respiratory complications. Good oral hygiene and regular dental visits will lessen the possibility of aspiration of infected saliva.

Parents should be careful to avoid positions and manipulations (such as chest percussion with the head lower than the chest) where aspiration of saliva or stomach contents may be more likely to occur.

- **Aerophagia:** Behavioral problems which cause aerophagia (excessive swallowing of air) may increase pressure in the stomach. This can make reflux and aspiration more likely.
- **Compromised immune response:** Individuals with severe physical disabilities often appear to be less able to “fight off” infections. This may be related to the long-term effects of the illness or disability such as anemia or fatigue. Lack of adequate nutrition and the long-term effects of certain medications may also impair a child’s immune response.

After consulting with your daughter’s doctor, there are some actions you can take to help prevent some of her more severe respiratory infections.

Use preventative measures to help prevent accumulation of secretions and mucus in your daughter’s lungs. Preventative measures may include regular use of small-volume nebulization (inhalation) treatments using medications prescribed by your daughter’s physician. Your daughter’s physician may also prescribe chest percussions (striking the chest in a non-painful but organized manner to facilitate the loosening of phlegm). These treatments may help your daughter have a more productive cough, too.

Certain studies may be needed to determine if your daughter has gastroesophageal reflux. If reflux is occurring, especially with aspiration, your daughter’s physician will recommend corrective measures to prevent further complications.

As noted above, good dental hygiene is important, too. Optimizing your daughter’s nutritional status will also help in the prevention of some infections and will improve her overall ability to “fight off” respiratory infections.
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Finding Your Way Through the Medicaid Maze

Medicaid often serves as the primary health insurer for children with disabilities. While the Medicaid program offers some important benefits, it is complex and can be difficult to understand.

These problems have to do with the way in which Medicaid was established and developed. Most industrialized nations offer universal health care, administered by the government and supported by tax dollars. Usually, these countries have clear rules regarding coverage so there is no confusion about what will be covered.

However, the American health insurance system is fragmented and confusing. There's an enormous web of individual- and group-health insurance programs, managed-care plans, health maintenance organizations (HMOs) and state and federal insurance programs.

Established in 1965, Medicaid was intended to provide insurance for families whose income was below the poverty level and for people with severe disabilities. Run primarily through state agencies, Medicaid provides a core of basic services— including doctor visits and hospital care—that's provided in all states, in accordance with federal regulations. However, optional portions of the program may be offered by different states. As a result, Medicaid rules differ substantially from state to state.

Furthermore, some states have been granted "waivers" in regard to specific federal program rules. Such waivers are issued at the request of a specific state's Medicaid program. Once a waiver has been granted to one state, other states may apply for it as well, but they are not obligated to do so.

One waiver that's been granted to several states allows Medicaid funds to be used to pay for at-home treatment for a child with a disability where hospital-based treatment is excessively expensive. This waiver was first granted in the early 1980s, and may apply in certain cases even where the family's income is above the usual Medicaid guidelines.

A more recent waiver deals with rehabilitation programs for children or adults who have experienced severe head injuries. This "head injury waiver" permits Medicaid funds to be used for community-based rehabilitation programs, in addition to the more traditional inpatient programs.

Lawmakers have changed Medicaid over the years. One such change established the Early Periodic Screening, Diagnosis and Treatment (EPSDT) program. EPSDT provides for a periodic medical screening program for children with disabilities enrolled in Medicaid. Medical needs identified as a result of the screening program should generally be covered by Medicaid, even if they would not ordinarily be covered for adults under general Medicaid rules.

Regulations that govern EPSDT are complicated and may be subject to different interpretations, but the program remains a major key to obtaining services for children with disabilities. The very technical EPSDT Reference Law Manual is available for $25 through the National Health Law Project at (310) 204-9010.

It is important for parents to know where to turn for help when a Medicaid claim is denied. You can also find your local protection and advocacy office by calling the National Association of Protection and Advocacy Systems at (202) 408-9514.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 309 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742.

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coverage under your state's Medicaid regulations, legislators, support groups and disability rights organizations may also help. Legislators can propose new laws to change the rules under which Medicaid operates. Support groups or disability rights organizations can work with state and federal Medicaid officials to develop an application for a waiver so Medicaid funds can be used to provide services or equipment that are not covered at present.

While the Medicaid system is complex, it can be changed and improved by appealing inappropriate claim denials, and by working with support groups, disability rights organizations, Medicaid officials and legislative leaders. I think that process is essential in helping to clarify current Medicaid regulations and in helping Medicaid to better meet the needs of children with disabilities.

The federal government publishes the 1,000-page Medicaid Source Book which provides a good overview of the Medicaid system. It's available for $34 through the Superintendent of Documents, U.S. Printing Office, Washington, DC 20402. The book's stock number is 052-070-06848-5. The book may also be found at public, university or federal depository libraries.

Your local Parent and Training Information Center may also help you find your way through the Medicaid system. Local numbers are listed in The Exceptional Parent 1994 Resource Guide (January 1994).

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Circle #167
Abraham Nemeth

His parents taught him he could do whatever he wanted—he just had to think of a way to do it

Dr. Abraham Nemeth has led a long and interesting life—one that is difficult to condense to a few magazine pages. Nemeth, who was born blind, became a renowned scholar of mathematics—a field once considered too difficult for people without usable vision. Creator of the Nemeth code for Braille mathematics, he was a professor of mathematics for 30 years at the University of Detroit. He retired in 1985.

"Retired" is a relative term, however, and Nemeth has remained very active. He serves on the Research and Development Committee of the National Federation of the Blind, through which he has developed a talking scientific calculator. Currently, he is working to upgrade this calculator by making it programmable. He recently completed a two-year term as chairman of the Michigan Commission for the Blind.

I was born in 1918 on the Lower East Side of Manhattan. I grew up in a very close and loving family. My parents were immigrants and lacked formal education. They knew nothing about blindness, but had an innate understanding of what was necessary to raise a blind child.

Without realizing it, my father taught me what today would be called mobility and orientation. Whenever we were out walking, he would describe the landmarks we were passing and say things like "Now, we are walking west, and when we make a left turn, we will be walking south. Listen to the traffic. All of it is going in the same direction on this street. But when we get to the next street, you will notice that all the traffic starts traveling in the opposite direction."

My father encour-aged me to touch the raised letters on mailboxes, fire hydrants and police and fire call boxes. That’s how I learned the letters of the alphabet.

My mother was equally perceptive in dealing with my blindness. When I was very young, she would send me on a trip to the grocery store. She would give me five or six items to memorize, and tell me exactly what to buy and in what quantity. Of course, the grocery store was just around the corner and my grandfather was the grocer. But, I was very diligent in remembering every single item and would bring back everything she had asked for.

My parents also bought me a tricycle. Now remember, I had no sight at all. My father told me that I could ride the tricycle around the block, but that I must remember to make a right turn every time I came to a corner. "Ride slowly," he told me. "Don’t bump into anybody, and come back here." That’s what I did. I rode my tricycle around the block, and I came back home. One time, my brother, Aaron, and I went on some kind of an expedition. We got separated, and my brother, who had normal vision, got lost; I came home.

A curious little fellow

One of my uncles was a handyman. He taught me to thread electrical wire through walls and replace light bulbs. I was fascinated by the way things went together.

This mechanical sense got me in trouble one day, however. In my grandfather's grocery store, he had an icebox which was mounted over a sink. As the ice melted, the water would drain into the sink through a rubber hose. I was a curious little fellow, and one day I went around to the back of the store and discovered...
this hose trailing to the sink. My mechanical sense told me the end of that hose should be connected to something. So, I felt around and happened upon the faucet. “Aha,” I thought, “this hose must belong on the faucet!” I connected the hose to the faucet and left the store, proud of having corrected my grandfather’s obvious oversight. A few hours later, I was confronted by my grandfather. I will end the story here.

Learning to fend for myself

My father did not overprotect me. You know, kids will tease a blind kid. They would get after me, and I would yell, “Pa, he hit me.” My father would ask, “So, why didn’t he hit me?”

He was trying to teach me to fend for myself. One time, in the park, a sighted kid was teasing me. When I ran after him, he shimmied up a ladder on the jungle gym. I followed him. He wanted to get out of my way, so he grabbed the highest bar and swung over to the right. He ended up dangling above the ground some distance from the ladder. I climbed back down, but he got so scared that he was unable to move. After that, he left me alone.

An integrated education

I was lucky to have had an integrated education. The New York City public school system provided a resource room for blind children in one school in each of the five boroughs. The one in Manhattan, P.S. 110, was within walking distance of my home. Some kids in the resource room had no sight; some had a lot of sight—but everyone learned Braille.

I went to my regular classroom for academic subjects like arithmetic, geography and history. I went to the resource room when the other kids were doing subjects like penmanship or art. The resource teacher would teach me blindness skills like Braille and typing.

Now, you may not believe this, but I experienced particular difficulty with arithmetic. By the time I graduated from the eighth grade, I had fallen far behind my classmates in mathematics.

In the fall, I entered Evander Child’s High School in the Bronx. This school had a very good resource teacher, who also taught some of the regular math classes at the high school. Upon discovering my deficiency in arithmetic, he immediately took steps to remedy it. In one year, I not only caught up on all the arithmetic skills I should have acquired in elementary school, but I also received top grades in a first-year algebra course. It was during this time that I became keenly aware of an ambition to be a teacher—in particular, I wanted to teach mathematics.

Psychology major

After graduating from high school, I entered Brooklyn College. I wanted to major in mathematics, but my guidance counselors insisted that it was too technical a subject for a blind person, that the notation was too specialized, that volunteer or even paid readers would be difficult to recruit and that I would never get a job in the field. Being compliant, I backed down. In 1940, I graduated with a B.A. in psychology. I had also managed to complete elective courses in analytic geometry, differential and integral calculus, modern geometry and statistics. I continued my education and, in 1942, graduated from Columbia University with an M.A. in psychology.

Better an unemployed mathematician

Despite my years of schooling, I could find only unskilled work. At one time, I worked at a sewing machine, sewing and hemming pillowcases at piece-work rates. I also worked for seven years at the American Foundation for the Blind. There I counted needles for Talking Book phonographs and collated Talking Book records. I loaded and unloaded trucks in the shipping department. I typed incoming Braille letters on the typewriter. I also designed and organized Braille itineraries for Helen Keller, who was an active fund-raiser for the organization. I was fortunate to become well-acquainted with this talented and admirable lady.

After working all day, I relaxed by taking evening mathematics courses at Brooklyn College. By 1946, I had taken all of the undergraduate math courses.

That year also brought the end of World War II and the return of many Brooklyn College students. Many veterans had passed first semester calculus before the war and were now returning to face their second semester.

I volunteered to assist those men in reviewing their first semester’s work. A large room was set aside for this purpose. All the available walls of that room had blackboards, and each student had a panel of blackboard on which to work.

He was instructed to work through as much of a problem as he could, then ask for help. I would ask each student to read his problem from the textbook, and then to read what he had written on the blackboard. Since I had learned to write despite my blindness, I could pick up a piece of chalk to help him complete the solution.
The Nemeth Code

Though I was an undergraduate psychology major, whenever there was an opening for an elective course, I always chose one from the math department. In taking these courses, I found that there was no way of expressing mathematical notation in Braille—just as my counselors had warned. So I began to improvise Braille symbols and methods which were effective for my needs and consistent from one course to the next. By the time I began working toward my Ph.D. in mathematics, I had a code that worked very well. In 1952, my system was published as the Nemeth Code for Braille Mathematics.

The Nemeth Code closely approximates the printed text. This enabled me to communicate with my students as if I were holding the printed text in my hand. Or maybe it was even better than having a textbook in front of me. Before teaching a class, I would put very complicated formulas on cards which I arranged in a small card file in my left jacket pocket. At the right moment, I would casually put my left hand into my pocket to read the formula while writing it on the board with my right. This trick made students believe that I had actually memorized these incredibly complex formulas. It gave them the impression that I was a big genius—and I tried very hard not to disappoint them.

Unbeknownst to me, I was being observed. One Friday, I received a telegram from the department chairman informing me that one of his instructors was ill and would be out for the semester. He asked if I would be willing to assume this man’s teaching load. I scrambled to get the textbooks and to prepare a lecture for the following Monday evening. That is how my teaching career began.

By 1951, my wife had convinced me I would be happier as an unemployed mathematician than an unemployed psychologist. She went to work so I could begin my studies toward the Ph.D. in mathematics. In 1955, after a series of part-time teaching jobs, I finally landed a permanent job at the University of Detroit.

A “normal life”

I have led quite a normal life. I think I have been able to do this because I was not overprotected as a child. I had a wonderful support system in the form of relatives, parents and teachers who expected me to do normal things. Because of their high expectations, it never occurred to me that I couldn’t do whatever I wanted—I just had to think of a way to do it.

My family gave me opportunities to learn. That’s what made it all possible. And that can make things possible for your kids, too. Let your kids participate in household activities and chores. Let them change a light bulb. Let them do the dishes. They will learn if you expect them to do things and if you give them the chance to experiment.

I once had a teacher who told me I was a genius because I was able to read Braille at the rate of a high school student. Now, I don’t know what other qualifications I might have for being rated a genius, but reading at the rate of a high school student is certainly not one of them! Expect your kids to do normal things, and then react normally when they do. Encourage them, and do not overprotect them.
O Lukken, Miriam W.—READ THIS BOOK BEFORE YOUR CHILD STARTS SCHOOL. '94, 240 pp. (7 x 10), 5 ill., 1 table, $29.75.

Anderson, Frances E.—ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES. '94, 284 pp. (6¼ x 9¼), 100 il., 14 tables, $42.75.

Holley, Shelby—A PRACTICAL PARENT’S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES. '94, 308 pp., 13 il., 1 table, $59.75.

Jones, Carroll J.—CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS. '93, 174 pp. (7 x 10), $36.75.

Giordano, Gerard—DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION. '93, 320 pp. (7 x 10), 85 il., 26 tables, $58.75.

Kluwin, Thomas N. & Michael S. Stinson—DEAF STUDENTS IN LOCAL PUBLIC HIGH SCHOOLS: Backgrounds, Experiences, and Outcomes. '93, 174 pp. (7 x 10), 30 il., 10 tables, $36.75.

Jones, Carroll J.—CASE STUDIES OF EXCEPTIONAL STUDENTS: Handicapped and Gifted. '93, 272 pp. (7 x 10), $51.75.

Irons-Reavis, Donna—EDUCATIONAL INTERVENTION FOR THE STUDENT WITH MULTIPLE DISABILITIES. '92, 140 pp. (7 x 10), 31 il., $30.75.

Lombana, Judy H.—GUIDANCE FOR STUDENTS WITH DISABILITIES, 2nd Ed. '92, 198 pp. (7 x 10), 1 table, $45.75.

Fadely, Jack L. & Virginia N. Hosler—ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLESCENTS. '92, 292 pp. (7 x 10), $49.75.

Reavis, Donna—ASSESSING STUDENTS WITH MULTIPLE DISABILITIES: Practical Guidelines for Practitioners. '90, 110 pp. (7 x 10), 13 il., $27.25.


Rose, Harriet Wallace—SOMETHING’S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children. '87, 210 pp. (7 x 10), $35.75.

Dudley, James R.—LIVING WITH STIGMA: The Plight of the People Who We Label Mentally Retarded. '83, 146 pp., 4 tables, $22.00.

Oppenheim, Rosalind C.—EFFECTIVE TEACHING METHODS FOR AUTISTIC CHILDREN. (2nd Ptg.) '77, 124 pp., $26.00.
Today is the first day of school. My son, Andy, is entering the first grade. He gets on the bus as if this were any other day. But I know that today is very special. I am excited for him and very nervous. I want him to like his new school and his teachers. I want him to be accepted and to make new friends.

On this first day of school, I have the same hopes as all parents. But my fears are different—as different as my son.

When Andy was very young, my husband and I knew that something was wrong. His language was not developing appropriately, and his behavior was “not quite right.” After many evaluations, Andy was diagnosed with autism.

Andy spent three years at a wonderful “special” school. He learned to make friends with the children in his class because social skills were a part of every child’s IEP. In a world where being the same as everyone else is so important, his school was a safe haven. There, he was the same as everyone else. No one stared when he made funny noises or flicked his fingers in front of his eyes. No one thought it strange that he could not communicate like other children his age.

On his last day at that school, I walked him around the classroom to shake hands and say goodbye. Some children wished him luck; others wanted to know if his new school was very big or if he was scared. Each of his teachers gave him big hugs and kisses. Everyone told me how much they would miss him. Some of the teachers cried as they said goodbye. I cried, too.

Today is the first day of school. It is time to move on, time to give inclusion a chance. Other parents who have done this tell me that even though it is not easy, it is the right thing to do. I try to believe this, but there are times when I have my doubts. A good and wise friend tells me that if I wait for Andy to become more normal before sending him to regular school, I will be waiting forever. I know she is right. It is unfair to Andy to keep him sheltered in a special school forever—I know that he will have to face the real world someday. But in my heart, I long to have him back in that safe place.

Andy’s sister, Allison, is worried too. She is 10 years old—a self-conscious age when everything is a potential embarrassment. She is afraid the other kids at school will think that her brother is “weird.” She worries they will call him names. She worries they will make fun of her, too. I can’t promise that her worst fears will not be real-ized. I tell her if kids tease, it is because they don’t know any better. Allison considers that small consolation.

Today is the first day of school. How will Andy cope with this new world? For the first time ever, he will have recess, library time, music class and lunch in a cafeteria. He will be one in a class of 30 instead of eight. When he gets confused or upset, I hope he will not bite his hand and scream “No!” like he does at home. I also know this hope is unrealistic.

Today is the first day of school. I will worry, hope, pray and dream. I want this to work; I want this more than anything I have ever wanted before. I want Andy to be happy. I want him to make a friend. I want people to see him for what he is—another child, just like all the others.

**Hard work pays off**

Andy’s first year in public school was ultimately successful, but it was a success born of great challenges, teamwork and a willingness to try new ideas.

Initially, Andy had a hard time adjusting to this new and often overwhelming environment. He responded by having tantrums and biting himself.

Fortunately, his teachers and the special education director were willing to be creative. Andy’s sensory integration therapist came into school to train his teachers and his aide. An inclusion specialist helped everyone work more effectively with Andy, and helped them understand the reasons for his problems.

By mid-year, Andy was doing well in school and seemed happy. He was interacting with the other children, making friends and getting invited to birthday parties.

This past year wasn’t an easy one, but we accomplished something important. Andy became the first child with autism to be included in a regular classroom in our town’s public schools. Now, second grade is just around the corner. This year, I face the first day of school without the doubts and fears of last fall. Andy has proven that with the proper supports, he can succeed in public school.

Jan and her husband, Bob, live in Seekonk, Massachusetts with Allison, 11, and Andy, who will be nine in October. Jan recently started a support group for mothers of children with autism who live in southeastern Massachusetts and Rhode Island. She works at Community Autism Resources, a public service agency.
INCLUSION: What It Is, What It’s Not, and Why It Matters
by Dorothy Kerzner Lipsky and Alan Gartner

Few educational topics have attracted as much recent attention as inclusion. Inclusion has been the subject of news stories, opinion pieces, television specials and heated debate in professional journals. This attention comes in response to pressure from parents and educators to set higher standards and goals for all students. The concept of inclusion is based on the recognition that we live in a society of increasing diversity, where success will come to those who learn how to work and live cooperatively with others. For the parents and families of children with disabilities, the topic of inclusion raises critical questions about quality education for their children.

Inclusion is not...
Inclusion is not “dumping.” It does not fail to recognize the reality and the legal requirement—that each child requires a program designed to meet his or her unique individual needs. It does not benefit some students at the expense of others.

Inclusion is not a new label for “mainstreaming.” Mainstreaming was an educational philosophy and practice which assumed the existence of two separate systems—regular education and special education—in which integration was largely limited to non-academic activities.

Inclusion is not a way for school districts to save money. Inclusion does not involve cutting needed services.

Inclusion is...
Inclusion is the provision of services to students with disabilities, including those with severe impairments, in their neighborhood schools, in age-appropriate regular education classes, with the necessary support services and supplementary aids for both children and teachers. The goal of inclusion is to prepare students to participate as full and contributing members of society. Inclusion means meeting the law’s requirement of a “free, appropriate public education” in the “least restrictive environment.”

What makes inclusion programs successful?
The National Center on Educational Restructuring and Inclusion (NCERI) recently completed a national study of inclusion programs in urban, suburban and rural locations. The study identified several components of many successful inclusion programs. These include:

Columbine Elementary School
Woodland Park, Colorado

Columbine Elementary School’s journey toward inclusion began three years ago when Principal Mike Galvin decided that all children belonged together. Today, there are no segregated classrooms at the Woodland Park, Colorado school. Children with disabilities, in kindergarten through fifth grade, are included in regular education classrooms, in the playground, in the cafeteria and in extracurricular activities.

Seven-year-old Benjamin Snow, who has cerebral palsy, enjoys classroom activities with his friends. Chris Doyle, 10, a fourth-grader who has cognitive impairments, listens to his book-on-tape while reading along with other students who read silently.

Because of techniques and strategies like teacher training, team teaching, environmental adaptations, assistive technology and positive behavior plans, inclusion at Columbine has been accomplished.

Nominated by Kathie Snow, mother of student.
• **Strong leadership:** Leaders must recognize that students with disabilities can benefit from quality educational programs with their regular education peers—and that students without disabilities will benefit as well. They should have an optimistic view of the capacity of teachers and schools to change and to accommodate the needs of all students.

• **Collaboration:** No single teacher should be expected to have the expertise to meet the educational needs of every student in the classroom. Rather, individual teachers must be given support systems that provide collaborative assistance and enable them to engage in cooperative problem solving.

**Historically, we have had two educational systems—one for students with disabilities and one for everyone else. We are working to create one educational system that values all students. The regular classroom in the neighborhood school should be the first option for students with disabilities. Administrators and teachers must receive the training and the help they need to make that the best option as well.”**

—Judith Heumann
Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education

Kids Kampus
Huntington, Indiana

Built specifically for children with special needs, Kids Kampus in Huntington, Indiana, also integrates its students with more than 77 three- to five-year-olds without disabilities.

Five-year-old Stephanie Pruitt, who is developmentally delayed, has been attending the school for three years. “Stephanie is age appropriate in most areas and will be attending regular kindergarten in the 1995-96 school year,” said Stephanie’s mother, Nancy. “She has one more year at Kids Kampus and I dread the day she has to leave.”

Children at Kids Kampus benefit from three outdoor playgrounds, an indoor playscape equipped with sand and water tables, bubble balls, riding toys for children with special needs, various climbing equipment and fully equipped therapy rooms. With field trips and visits to a nearby college for some swimming, the students are also exposed to activities that promote integration into the community.

Parents receive training in areas like sign language and advocacy and receive emotional support as well.

*Nominated by Nancy Pruitt, mother of student*

**Supports for students:** Supports include everything necessary to enable the child to meet IEP goals and to succeed in a regular classroom. This may include adapted curricula, tutoring, counseling and both in- and out-of-class therapies.

**Re-focused use of assessment:** Instead of using assessment to document student inadequacies, assessments should focus on what students can do and how educators can help them meet IEP goals and objectives in the regular classroom.

**Funding:** Funding must be sufficient. Inclusion is not done to save money at the expense of student needs. Preliminary research shows that districts which are implementing inclusion report that it does not cost more over time; rather, costs are shifted.

**Effective parental and family involvement:** Successful inclusion programs encourage parental participation through family support services, such as support groups and counseling, and the development of educational programs which involve parents and other family members.

**Your role as a parent**

• Learn about successful inclusion practices so you can make an informed decision about whether inclusion is the best educational approach for your child.

• Learn about the law and recent court cases. Inclusion is not something a child must earn. The school system has a legal obligation to pro-
Seven severely challenged junior high school students are now integrated in science and government classes at their local school, thanks to staff and parent efforts on their behalf. This past school year, parents and Mountain Sky staff decided on team teaching in regular classes to provide extra assistance for all students. They also created a study hall for added support.

The response from students and staff has been positive. One staff member commented, "If you want to know who inclusion has helped, it's been the regular kids who are less frightened of people who are different. And they've learned that it's OK to be different."

Nominated by school staff as suggested by a parent of a student

Cooperative learning groups benefit all students.

A summary of the NCERI report is available at no cost. The full report, which includes a listing of school districts implementing inclusion, is available for $9, prepaid. Write to NCERI, The Graduate School and University Center, The City University of New York, 33 West 42nd St., Room 1530, New York, NY 10036.

JC Sweeny Kindergarten
Pascoag, Rhode Island

Ann M. Bisson says you can't tell that her eight-year-old daughter, Holly, is any different from the other children in her kindergarten class. Holly, who has Down syndrome, joined a regular class "partly because we knew she could do it and partly because the teacher wanted to have Holly...because her belief is that all kids are kids," Ann says.

Now, Holly is required to do all the work that her peers do. "When the class was tested at mid-year...she came up in the middle of all the kids," her mother notes.

Holly is considered to be one of the gang. "This inclusion is real because you cannot pick Holly out of a crowd of kindergarten kids and because her teachers fight for her rights to be a person," Ann says.

Nominated by Ann M. Bisson, mother of student

Holly Bisson is just one of the gang during a class outing to the local fire station. (She's in the front row, wearing a red shirt and glasses.)
Inclusion and Ideology
by Albert Shanker

The movement in American education that is taking hold the fastest and is likely to have the most profound—and most destructive—effect is not what you might think. It's the rush towards full inclusion of children with disabilities in regular classrooms.

Advocates demand that all children with disabilities be put into regular classrooms, regardless of their ability to function or benefit, and regardless of the effect on other children in the class. And they are being successful. Full inclusion is happening quickly, all over the country, without substantial debate in state legislatures and school boards, through court orders and federal directives.

As a result, we are seeing children who are medically fragile and children with severe behavioral disorders placed in regular classrooms where teachers who have had little if any special training—and get little if any extra help—struggle to deal with the youngsters' special needs. This could mean suctioning mucus from a child's lungs or giving him a medicated enema. Or it could mean trying to figure out how to handle a child who bites and kicks others with no apparent provocation and shouts or cries and exposes himself throughout the school day. All this while the teacher is attempting to give other students the grounding they need in math and reading and science.

Full inclusionists argue that all the supports that children with disabilities have in special education settings must follow them into regular classrooms. This is no more likely to happen for children with disabilities than it did for people with mental illness who were de-institutionalized years ago. Their supports were also supposed to follow them when institutions were closed, but the supports never materialized; now, as we know, many of these people are out on the streets.

That's one reason why many parents of children with disabilities oppose full inclusion. They fear their children will lose the range of services now available and end up, like those people who were de-institutionalized, with nothing.

We usually think of schools as performing three functions: imparting knowledge and skills; preparing students for the working world; and helping them become good citizens and develop socially. But those demanding full inclusion are interested in only one thing—socialization. Teaching kids with and without disabilities to get along together is worthwhile (as many schools that don't practice full inclusion would agree), but it is only one value. And it's certainly not the only reason taxpayers support the schools.

HMS School For Children With Cerebral Palsy
Philadelphia, Pennsylvania

The HMS School for Children With Cerebral Palsy in Philadelphia, Pennsylvania encourages its students to achieve the highest levels of independence and freedom that they can.

For example, the language arts program helps students build their language skills while talking about their feelings, creating stories and writing letters to former classmates.

Parents of children who attend HMS boast of the many opportunities offered to students at the school—assistance technology devices, participation in recreational activities and plays, and a chance to help run the school's convenience store. Many students are given the chance to demonstrate independence by running errands, collecting attendance slips and going to therapy sessions without supervision.

The school's medical staff proved to be "life-saving," according to one mother who called HMS her son's "second family and his home away from home."

Nominated by Carol A. Olinick, Rebecca Little and Marie A. Campagne, mothers of students
Full inclusion is often justified by an analogy with the racial segregation practiced during a good portion of our history. Just as "separate but equal" always meant "inferior," inclusionists feel the same is true of any separate classes for any children with disabilities. But the analogy is faulty. African-American children have the same range of abilities and needs as white children. They were excluded only because of the color of their skin, which was irrelevant to their ability to function in a regular classroom and to benefit from being there. This is quite different from putting a youngster who is blind into a special class so he can learn Braille or excluding a youngster who is emotionally disturbed because he will disrupt the education of the other kids—while deriving little benefit himself.

Recently, I received a letter from Edwin Martin, who was the first director of the U.S. Bureau of Education for the Handicapped and now heads an advocacy group for people with disabilities. He, too, opposes full inclusion, and he is especially troubled by the idea of making sweeping changes without any data or research to support these changes. Where are our figures on how well students with disabilities in regular classrooms do in comparison with those in special education settings? How many drop out? How many go on to college or vocational programs? Without this kind of information, we have no way of knowing what is working for these youngsters and what is not. "Special education programs," Martin says, "must be judged on their successes, not on our wishes for a more inclusive society."

Many children with disabilities can be, and are now, included in regular classrooms and, with adequate supports, many more could be. These decisions should be made on an individual basis—depending on the nature and severity of the disability—and remade if a placement turns out to have been wrong. And these decisions should be based on what is good for all the children involved—the children with disabilities and the others. But full inclusion makes no room for individual judgments. It is an ideological position that children with disabilities and children without disabilities must always be fully integrated, regardless of the circumstances or consequences.

Some full inclusionists talk as though they are in a battle pitting the forces of morality against the forces of immorality. In reality, the battle pits ideologues who, without any evidence, would force destructive changes on our schools against people who believe that children's interests come first.

Albert Shanker.

Albert Shanker is president of the American Federation of Teachers (AFT), an affiliated union of the AFL-CIO which represents 890,000 education professionals. Shanker's comments appear in The New York Times every Sunday in a space paid for by the AFT. This column appeared on Feb. 6, 1994.
When we discuss improving results for children and youth with disabilities, we need to talk about both our successes and our shortcomings. Many children and youth with developmental disabilities are now living in and enjoying community life, but many continue to be segregated in our education system. This needs to be taken very seriously because we know that the degree to which students with disabilities are integrated with their peers without disabilities is critically important to their future success in employment and community living.

Impact of P.L. 94-142
Since the 1975 passage of P.L. 94-142—originally called the Education for All Handicapped Children Act, but later renamed the Individuals with Disabilities Education Act (IDEA)—the institutionalization of people with mental retardation has gone down 63 percent, which is an enormous change in a very short period of time. But for me, a more impressive statistic—although we would like it to be lower still—is that only 1.4 percent of young adults with developmental disabilities in the U.S. are institutionalized. This is a testimony to what we have been doing over the last 19 years.

Prior to the passage of P.L. 94-142, the needs of many children with learning disabilities were not recognized. We now know that results are better for those who receive appropriate support, placements and access.

We know from our research that we have made gains in employment for young adults who have left our educational system. But the rate of employment among adults with disabilities should and could be higher.

Without this legislation, hundreds of thousands of people would be in institutions and the school dropout and unemployment rates among people with disabilities would be much higher.

Although many children are achieving at levels never before thought possible, we still must be very concerned about the 38 percent dropout rate for students with disabilities in this country—almost double the dropout rate for students without disabilities.

On the National Agenda...

Integration and Inclusion: Our longitudinal study shows good results for students who are integrated into regular education classrooms with appropriate supports, aids and accommodations, and with access to the regular-education curriculum. For example, young people with physical impairments who had...
been in regular education full-time, were 43 percent more likely to have a job than those who had been in regular education only half-time.

- Support services: Research shows that significant numbers of students with disabilities who have been integrated into regular classrooms receive next to no support from special education. Few receive modification in the way material is presented or in the curriculum itself. Many regular classroom teachers have not received adequate training.

If we redefine special education as services and placements that students need in order to be successful, then we will go a long way toward addressing a lot of concerns that people have. Children with disabilities should be educated in an individualized manner in the least restrictive environment, with appropriate supports, aids and accommodations.

- Job training and placement: Although we feel strongly that students with disabilities must have access to all the options that students without disabilities have, it is particularly important to recognize the importance of vocational education. According to our research, students with mild disabilities who received concentrated vocational education that included job placement possibilities, now have a more than $6,200-a-year earnings advantage over students without disabilities who have not had this type of program.

Although vocational programs are not appropriate for all students with disabilities at the secondary level, we should have a good idea of the type of program he or she needs to prepare for the future. We need to take a broad view of the IEP. We need to get away from the myopia of short-term objectives and look at the ultimate results we want to see three or four years from now.

- Higher education: It disturbs me that only 13 percent of students in special education go on to higher education. We should be looking at appropriate community colleges and four-year colleges for these students.

- Earlier interventions: The later we intervene with students who have reading problems, the poorer their results will be. If we do not intervene with students until the third or the fourth grade, we can almost be sure to have poor results.

- Problems in minority communities: Special education is not highly supported in some minority communities. Many students with disabilities in minority communities are placed in dead-end programs with low expectations and are removed from instructional accountability systems.

- Participation of parents and adults with disabilities: We need to develop better ways to involve parents. Too often, there is an unfortunate assumption that school districts and parents of students with disabilities are adversaries. Parents should be actively involved in the decision-making process.

It is also important that we recognize that our students with disabilities become adults. For this reason, adults with disabilities should have a say in the education of the children who follow them.

- Low-incidence disabilities: We have to pay more attention to low-incidence disabilities. Often, due to the low incidence of certain disabilities, students who are blind, students who are deaf and students who have multiple disabilities do not receive the kind of attention they should from their school systems. In many cases, this seems to be caused by a lack of expertise at the local level.

A Focus on Results

I believe it is important for all of us to take the theme of "a focus on results" very seriously—all of us need to focus on improvement and better results for students with disabilities.

Secretary of Education Richard W. Riley frequently uses the expression, "Only the educated are free." As we concentrate more on providing students with better educational opportunities, we can help "free" all children, youth and adults with disabilities in this country.

Thomas Hehir is the director of the Office of Special Education Programs, U.S. Department of Education. This article was adapted from his speech, "A National Agenda for Achieving Better Results For Students With Disabilities."
Making Inclusion Work

Angela is supported by a circle of friends.

by Janine Guida, Stephanie Pirsos, Katherine Schempp and Diana Cuthbertson

**ALL CHILDREN BELONG** is an awareness and training program designed to enhance the ability of communities to support the participation of children and youth with disabilities in schools, workplaces and community activities.

The first phase of the ALL CHILDREN BELONG curriculum is the awareness phase—when parents, educators and community members learn about the basic concepts of inclusion. Key planning activities take place at this time. A hallmark of this second phase is the development of teams that will build on an individual’s strengths to find ways to facilitate meaningful participation in activities.

There is no single recipe for inclusion. Each child is unique; each school or community setting is unique. But no attempt at inclusion will succeed without teamwork. The story of how Angela’s family, school and community worked together to ensure her successful inclusion offers a compelling illustration of the teamwork required to make inclusion work.

When Angela Hart was born with Down syndrome, her mother, Vicki, resigned herself to being Angela’s caregiver-for-life. Now, eight years later, Vicki and her husband, Lynn, envision Angela’s future differently. They believe that Angela, as an adult, will be a contributing member of her community.

Much of the change in her parents’ perspective has had to do with Angela herself—her sunny personality and many abilities. But they agree that inclusion has played a part as well.

### Getting Ready for Inclusion

Merle Soroco, the learning consultant on Angela’s multi-disciplinary team, believes that Angela’s family played a strong role in preparing her for inclusion. “Vicki took Angela everywhere she went—to the store, to her brothers’ sports competitions and to church,” Merle comments. “Everyone in the community knew Angela before she entered kindergarten, so no one was surprised to see her.”

Angela had some other advantages also. Merle cites Angela’s outgoing personality and good language skills. “Angela’s language skills helped her to make new friends,” Merle says, “but as importantly, her language abilities kept her from becoming frustrated. She was able to communicate her needs.”

### Building a Team

Angela, her parents and brothers, her regular education and special education teachers, the school principal, related-services providers (occupational, physical and speech therapists) and the multi-disciplinary professionals (social worker, psychologist and learning consultant) are the members of Angela’s team. The team plans Angela’s goals, learning activities and supports. They also assume cooperative responsibility making accommodations or adaptations in Angela’s educational program and for evaluating her progress.

Angela’s team meets four times each year. Meetings start with a review of Angela’s many accomplishments. Then, any major concerns are addressed. Day-to-day issues are discussed during teachers’ planning times and through home-school communication.

### Strengths and Needs

Completing a “Positive Student Profile” was one of the first activities Angela’s family did to prepare for her inclusion in public school. Angela’s parents and older brothers—Bobby, 12, and Tony, 13—wanted the important information they knew about Angela’s strengths and interests to be available to the team that would be developing Angela’s IEP. In this year’s profile, Angela’s family describes her as a child who loves school, friends, sports, dancing and the Brownies. Her strengths include a “terrific sense of humor,” good manners, an ability to ask for help and an “I do it” attitude.

The profile also documents Angela’s successes at home and school. She knows her address and phone number, uses slang properly and sits through quiet activities. She uses a calculator to compute math problems and does some homework without assistance.

The profile also documents Angela’s needs. These include a need to speak more clearly, read independently, learn from peers and adults who can show her how they solve
problems and receive support in extracurricular activities. Safety issues are also a high priority for Angela's family. They want her to use care in selecting friends and in traveling in her community. These strengths and needs are kept central to all planning activities.

Honorable Mention

Parkview Montessori School, Mt. Prospect, Illinois
P.S. 279, Brooklyn, New York
Searies Elementary School, Union City, California
E.H. Slaybaugh School, Egg Harbor Township, New Jersey
Center Elementary School, Brookfield, Connecticut
Fairfield Elementary School, Maumee, Ohio
New Vision Dance program at Clarkstown High School South, West Nyack, New York
Beach Channel High School, Rockaway, New York
Weight Conditioning Program at Tren-

Identifying Resources

Before children with disabilities can successfully attend neighborhood schools, it is important to understand the supports which can facilitate participation. A "support" is anything it takes to provide assistance to children with disabilities and all the people working with them.

Angela's supports can be divided into five categories - personnel, environmental, curriculum adaptations, evaluation and peers. Having Angela's teacher complete a "Classroom Activity Analysis Worksheet" helps her team to choose appropriate supports. The worksheet includes a list of daily activities. Some activities require no special adaptations; others require adapted materials and/or assistance from peers, the teachers, a therapist or an aide.

Classroom Activity Analysis Worksheet

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<th>Activity</th>
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Adapted from "Exceptional Children: 1992-1993 Educational Year," the American Council on Exceptional Children, Washington, DC. 

• Personnel: Many people contribute to Angela's success. The school's principal is very supportive of inclusive education. His leadership sets the tone for the school.

The classroom teacher is Angela's most important support. Angela is placed in a relatively small class. She has a full-time aide, but the aide is available to any child in the class.

In addition, Angela has a resource room teacher and occupational, physical and speech therapists. Her therapists do both in-class and pull-out activities with Angela. For example, one of Angela's goals is to be able to speak in public. Her speech therapist taught Angela's class about public speaking and had each of them do an assignment. The resource room teacher works in the regular classroom on specific curricular goals that have been tailored to Angela's needs.

• Environment: Angela's classroom is set up to help meet her needs. For example, her teacher chose a "U-shaped" seating arrangement for the classroom. This ensures that Angela will always have a peer supporter on either side.

• Curriculum: Angela spent her second-grade year in a classroom with a
Positive Student Profile

This form is to be filled out by the parent to provide a "snapshot" of your child which should be reflected in his/her IEP.

1. Who is ________? (Describe your child, including information such as place in family, personality, likes and dislikes.)

2. What are ________’s strengths? (Highlight all areas in which your child does well, including educational and social environments.)

3. What are ________’s successes? (List all successes, no matter how small.)

4. What are ________’s greatest challenges? (List the areas in which your child has the greatest difficulties.)

5. What supports are needed for ________? (List supports that will help your child achieve his/her potential.)

6. What are our dreams for ________? (Describe your vision for your child’s future, including both short-term and long-term goals.)

7. Other helpful information. (List any pertinent information, including health care needs, that has not been detailed elsewhere on the form.)

Adapted from Collaborative Teams for Students with Severe Disabilities: Integrating Therapy and Educational Services, Beverly Rainforth, Ph.D., Jennifer York, Ph.D., Cathy MacDonald, M.A., C.C.C./S.L.P.

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talked with the class about her expectations regarding their attitudes and behavior toward Angela.

Initially, some children were hesitant to approach Angela. Mrs. Brown did not discipline them for feeling this way. A positive class environment allowed Angela to develop friendships.

**Specialized Assistance**

Supports should be flexible; they should come and go as needed. If the team determines that specialized assistance is needed, look first within the school district for the added expertise. Avoid "quick fixes"—rather than flying an expert in for the day, seek an ongoing relationship with consultants. A consultant from the University-Affiliated Program of New Jersey worked with Angela's school district to help establish Angela's "circle of friends."

**Angela's Circle of Friends**

A "circle of friends" can help a student to become included. Angela's circle first met in June 1994. Thirty people came to the meeting—Angela's family, several child and adult friends, her Brownie leader, neighbors and the school principal and other educational professionals.

Individuals in Angela's innermost circle include her immediate family and closest friends—people who love her deeply and on whom she can depend the most. In the next circle are people who really like Angela and want to offer her support—many are Angela's peers. The third circle includes neighbors, coaches, Angela's Brownie troop and her troop leader—people Angela knows and likes to do things with. The outer circle are people who are paid to be with Angela—the many professionals in her life. Of course, many of these people also have strong emotional ties to her.

Many people with disabilities would have very few people to include in the second and third circles. Angela's inclusion in school and the community—as well as her outgoing personality—are reasons why her circle of support is so full.

The first meeting of Angela's circle began with her parents giving a brief history of her life. Members shared their dreams and fears for Angela. Then, each member of the circle shared his or her perception of Angela. Continued on page 8...
Whenever I meet with parents, sibling relationships are one of the first topics that come up for discussion. Parents always tell me how helpful it would be for the sisters and brothers of children with disabilities to meet with other children from similar families.

I always agree. In the next breath, I tell them about Don Meyer, the creator of "Sibshops," and the wonderful work he has done in bringing these children together. I always urge parents to contact this dedicated and talented man to find out how they can do Sibshops in their own communities.

Finally, Don Meyer has put his vast experience into a fine book that will be useful to everyone who cares about the needs of the whole family. We are delighted to collaborate with the Paul H. Brookes Publishing Company to bring our readers a series of excerpts from this book. Sibshops is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910. —S.D.K.

For the adults who plan them and the agencies that sponsor them, Sibshops are best described as opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. They often reflect an agency's commitment to the well-being of the family member most likely to have the longest-lasting relationship with the person with special needs.

However, for the young people who attend them and the energetic people who run them, Sibshops are best described as events. Sibshops are lively, pedal-to-the-medal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, for others a not-so-good thing, and for many somewhere in between. They reflect a belief that brothers and sisters have much to offer one another—if they are given a chance. The Sibshop model intersperses information and discussion activities with new games (designed to be unique, offbeat, and appealing to a wide ability range), cooking activities, and special guests who may teach participants mime, how to juggle or, in the case of one guest artist who has cerebral palsy, how to paint by holding a toothbrush in your mouth. Sibshops are as fun and rewarding for the people who host them as they are for the participants...

Sibshops are not therapy, group or otherwise, although their effect may be therapeutic for some children. Sibshops acknowledge that most brothers and sisters of people with special needs, like their parents, are doing well, despite the challenges of an illness or disability. Consequently, while Sibshop facilitators always keep an eye open for participants who may need additional services, the Sibshop model takes a wellness approach...

Who Attends Sibshops?

Originally developed for 8- to 13-year-old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger and older children. It has been adapted for brothers and sisters of children with other special needs, including cancer, hearing impairments, epilepsy, emotional disturbances, and HIV-positive status. Sibshops have also been adapted for use with children who have experienced the death of a family member...

Who Sponsors Sibshops?

Any agency serving families of children with special needs can sponsor a Sibshop, provided it can offer financial support, properly staff the program, and attract sufficient numbers of participants. However, we strongly recommend that agencies work together to cosponsor a local Sibshop...

Who Runs Sibshops?

We believe Sibshops are best facilitated by a team of service providers (such as social workers, special education teachers and professors, psychologists, and nurses) and adult siblings of people with special needs. At the very least, the team of facilitators will need to: be knowledgeable of the disability or illness represented, possess a sense of humor and play, enjoy the company of children, and respect the young participants' expertise on the topic of life with a brother or sister with special needs...
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Elwyn, caring for over 10,000 children and adults with varying disabilities, has locations throughout Pennsylvania, New Jersey, Delaware, California, and Jerusalem.

What Is The Optimal Number of Participants For A Sibshop?

Sibshops have been held for as few as 5 children and as many as 45. Around a dozen children, with at least two facilitators, is a comfortable number...

When Are Sibshops Offered?

Usually Sibshops are offered on Saturdays, often from 10 a.m. until 2 p.m. This allows ample time for games, discussion and information activities, and making and eating lunch. Of course, Saturdays from 10:00 to 2:00 will not be ideal for all families or communities...

How Often Are Sibshops Held?

Depending on the needs and resources of the community, Sibshops may be offered as frequently as weekly (as with a one-and-a-half-hour after-school program) or as infrequently as yearly (as with an all-day Sibshop that is a part of an annual conference for families from around the state or nation). Generally, Sibshops are presented monthly or bimonthly...

What are the goals of the Sibshop model?

Goal 1: Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.

The chance to meet other brothers and sisters in a casual atmosphere and join them in recreational activities has several benefits for participants. First, it can help reduce a sibling's sense of isolation...

Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Friendships begun during Sibshops and continued outside the program offer siblings ongoing sources of support.

Third, the recreational aspect of the Sibshops makes them enjoyable to attend. If children perceive the Sibshop as yet another thing that they have to do because of their sibling, they may find it hard to be receptive to the information and discussion presented in the workshop...

Goal 2: Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

At Sibshops, participants share stories, experiences, and knowing laughs with peers who truly understand the ups and downs of life with a sibling who has special needs. This opportunity allows participants to learn that they are not alone with their experiences and their often-ambivalent feelings.

Goal 3: Sibshops will provide brothers and sisters with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.

Brothers and sisters of children with special health
and developmental needs routinely face situations that are not experienced by other children. Defending a brother or sister from name-calling, responding to questions from friends or strangers, and resenting the time and attention required by the sibling with special needs are only a few of the problems siblings may experience. At a Sibshop, participants learn how others handle difficult situations. This experience can offer a sibling a broad array of solutions from which to choose...

**Goal 4:** Sibshops will provide siblings with an opportunity to learn more about the implications of their brothers' and sisters' special needs.

...Brothers and sisters have a need for information to answer their own questions about their sibling's special needs as well as the questions posed by friends, classmates, and strangers...

**Goal 5:** Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

Because they may be unaware of the wide range of sibling concerns, some Sibshop activities attempt to help parents and service providers better understand "life as a sib." One activity allows parents and professionals to meet with a panel of young adult and adult siblings to learn about the special joys and challenges of growing up with a special brother or sister. Parents learn about what the panelists appreciated in their parents' treatment of the children in their family, and also what they wish their parents had done differently...

Donald J. Meyer is the director of the Sibling Support Project - Children's Hospital and Medical Center in Seattle. Funded by the U.S. Department of Education, Special Projects, the Sibling Support Project seeks to increase the number of peer support and education opportunities for brothers and sisters of children with special needs through training, demonstration and technical assistance.

Don was a founder of the Supporting Extended Family Members program which pioneered services for fathers, siblings and grandparents of children with special needs. During the past 14 years, he has written curricula, chapters, articles and a book for children. He has also made many presentations to parent and professional audiences throughout the U.S. and Canada.

**Sibshops: Workshops for Siblings of Children with Special Needs** details the program that won the 1992 National Award for Innovation from the Association for the Care of Children's Health.

Don is the younger brother of two siblings who have epilepsy. He is married and the father of four children.

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Halloween Magic

Making a wheelchair part of a Halloween costume

by Juanita Stotts

Do you feel like your child is lost in his Halloween costume when you put him in his wheelchair? Why not make the wheelchair a part of the costume?

Costume ideas for your child and his wheelchair are endless. Let your child decide what he would like to be for Halloween, then expand on that idea for the chair. For example, a policeman can sit in a policeman car, a fireman can drive a fire engine or a flower can grow out of a pot.

These directions are for a jack-in-the-box wheelchair costume, but the same basic steps can be used to create many different costumes. It’s a fun project you can work on with your child in whatever way he can participate.

Directions:

1. Cut the box: Begin by cutting the flaps off one end of the box. This will be the bottom. Next, cut off one side of the box for the back opening. Cut this piece in half and set it aside to use as the jack-in-the-box lid. With the flap side up, place the box over the wheelchair tray or armrests. Fold down the three flaps for the top and glue together securely. Make any necessary cutouts for wheels, brakes or table top.

2. Cut the striped fabric so it covers the three sides of the box and overlaps six inches on top. First, glue the fabric to the sides of the box. Next, fold down the top two sides and glue. Finally, fold the front flap down and glue.

3. Cut a square piece of felt slightly larger than the area remaining to be covered on the top of the box. Glue into place.

4. Take the piece of cardboard that you have set aside to use as the jack-in-the-box lid. Cover it on both sides with striped fabric and glue.

5. Cut a scalloped border from felt for the top and bottom edges of the box. Glue into place.

6. Use stencils to trace letters on felt. Cut the letters out, position them on the box and glue into place.

7. Add finishing touches: Glue rickrack around the lid, the square of felt on the box top and the top edge of the box. Glue sequins onto the felt borders. Attach the lid to the back of the chair using Velcro.

Jack-in-the-Box Supplies:

One large box: The size of the box depends on the wheelchair. The box must be big enough to slide onto the wheelchair easily, and must fit over armrests and the tray. It must clear the ground by at least two inches.

Fabric: You will need enough striped fabric to cover three sides of the box and part of the top. You will need enough solid-colored felt to cover the top of the box and create decorative borders and lettering.

Decorations: sequins, rickrack.

Other: glue, adhesive-backed Velcro.
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The same basic steps that go into the jack-in-the-box costume can be used to create many different costumes. In this photo, Benjamin Stotts and his wheelchair become a fireman and his truck. The family's Dalmatian, Razzy, adds a touch of authenticity.

Dress your child up in a clown costume which coordinates with the striped colors of the fabric on the box. He will be very proud of his costume, and he surely will get noticed. My son, Benjamin, did!

Juanita Stotts lives in Mesa, Arizona with her husband, Joe, and children, Benjamin, 5, and Rachel, 4. Juanita studies writing, and Joe is a general contractor. Benjamin has static encephalopathy and attends a special education class at Franklin Elementary School in Mesa.
Dear Timmy...

by Wayne Stauffer

I have learned so much from you that I should be learning from your brothers who do not have disabilities.


And I am not finished with my education; I learn something new from you every day.

I learn I am not the center of the universe. The evening news will still be as depressing even if I don't see it because I'm helping you eat, do your homework or organize one of your collections. Books will wait to be read; my students' papers will wait to be graded. This article will take longer to write because I took a few seconds to turn on a light you can't reach. I can be selfish about my time and about the things I want to do, but I will always have “Dad time” for you.

I improve my problem-solving skills by figuring out how to get you into the rides at AstroWorld, the bleachers at the Dome or the seats at the movie theater. I no longer take aisle-width for granted as I did before you came into my life. I now can judge wheelchair-width pretty well. And I'm working on the job possibilities that will be available to you in less than 10 years.

I take more time to examine the important things—like toads, blossoms and rabbits in the tall grass—because I'm looking for things to point out to you.

I learn not to take myself so seriously. Your slapstick sense of humor helps me see that it is funny when I dance in pain after dropping a box on my foot or shake my hand after hitting it with a hammer.

I learn that the little things in life are important—a giveaway pen from a convention, a toy from a fast-food kid's meal, a two-minute call home, a trip to the corner to gas up the car or to the hardware store to get the right plumbing joint.

I learn that it's not the amount of time I spend with my children that counts—it's the timing. Being there at the right time—Timmy, you remind me of this every day. The day you went into surgery to have nine silver caps put on your teeth, I got stuck in the rain. By the time I finally got there, you were out of the operating room and slowly recovering from the anesthesia. You were fine, but I missed being there for you before you went in.

I was working the day you walked for the first time. The surgery a few days earlier had gone as planned, and you were able to walk with a walker sooner than expected. If the therapists had not videotaped it, I would have been unable to share in your triumph.

But I was there to help soothe your dignity the day you fell face-first in the playground's sand pit. You were doing so well walking in the sand with your walker. Then, the front got stuck and you went down before I could catch you. All I could do was help you get up, clean off the sand and be there to share your embarrassment.

You remind me every day that although your cerebral palsy affects who you are, it does not define who you are. There is much more to Timmy Stauffer than the cerebral palsy that keeps him from standing without a walker and causes him to lose his balance in a chair without armrests.

Wayne Stauffer is a technical writer, junior high English teacher and community college instructor who lives in Houston, Texas with his wife Debbie, twin sons, Andrew and Timmy, and their younger brother, Mark. He is looking for a publisher for several short stories he has written for children.
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Your cerebral palsy does not have to limit you from realizing your dreams. Your problem is not really cerebral palsy. It is getting others—people with small imaginations—to expand their ideas about the special qualities and unique abilities that make all people successful.

These are things I should be learning from your brothers, who don't have cerebral palsy. But if it weren't for you, I don't think I'd be paying attention to these lessons. Because your brothers can fend for themselves on most occasions, I tend to take them for granted more than I should.

Since I can't take you for granted, I make sure to listen to you more closely, and this reminds me to listen to your brothers, too. You help me to be a better dad. Thanks.

All my love,
Dad

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.
Cut From the Same Bolt of Cloth

Abby's escapades help Sheila's mother gain a new perspective
by Nancy Holroyd

“Abby, AB-by, AB-BY!”
I chuckle, not to offend the woman calling to her child, but out of a sense of relief. That mother’s voice has that exasperated tone I often hear in my own voice when Sheila is running off on her own little tangent. There have been times when I wondered if Sheila ignores me and does what she wants because she has Down syndrome. But Abby is a “normal” child.

By the end of choir rehearsal, it is clear to me that Abby and Sheila were cut from the same bolt of cloth—even if Sheila’s section of the bolt had an altered thread count. Since that day, about three years ago, I have continued to watch Abby and Sheila develop and grow. To be sure, I see differences, but the similarities are striking.

Eating Flour
One day, early in the Christmas season, I set out to bake cookies. Sheila, who loves to “help,” joined me in the kitchen. Declaring loudly, “I do dat,” she helped me add ingredients and stir them together.

I turned my back on her long enough to turn on the oven. When I turned around again, flour was flying. Sheila was merrily stuffing her fists—both full of flour—into her mouth. As I cleaned up the mess, I attributed Sheila’s behavior to her Down syndrome. What normal child would eat flour?

That night, my husband and I headed out to a party with the cookies Sheila had helped me make. It was a festive affair, with a tree waiting to be decorated by guests and the host’s children. The attendees were a congenial group of folks—fellow church members, Abby’s parents among them.

Abby’s mother is a great storyteller, and I soon heard peals of laughter as Jean regaled the group with Abby’s latest escapade. I listened to her story and stood there thunderstruck—“You mean Abby eats flour, too? Sheila did the same thing this afternoon. I thought it was because she has Down syndrome!”

Just Trying to Help
Sheila goes at her own pace, but her development follows typical patterns. In some areas, her delays are very apparent. In others, they are not so easily noticed. Sheila has a long way to go, but she is well on her way—just like the rest of our children.

In one area, Sheila is way ahead of her older sister; she is quick to notice what needs doing and tries to jump right in and “help.” Sometimes her help is of the “who-needs-it” variety. Like the day she opened the refrigerator door because she thought the baby was hungry. The eighteen-month-old grabbed an open can of peaches and spilled it. Sheila tried to wipe up the sticky peach juice with a small wash cloth. I was in the basement wrestling with the laundry during this caper.

I didn’t laugh until much later, but even while scrubbing the floor in front of the refrigerator, I knew Sheila was only trying to be helpful. For all the mischief she can get into, there is a thoughtful quality about her that far outweighs some of her lagging skills.

More Alike Than Different
Our friendship with Abby’s family has been invaluable. It helps me keep some things in perspective. It is too easy to attribute all of Sheila’s misbehavior to her disability. It is easy to lose sight of normality when society keeps reminding me that our family is different.

Abby’s antics have taught me that Sheila’s age and personality have a lot to do with her behavior—perhaps more than the Down syndrome does. And at those times when she is exasperating me the most, I know there is probably another little girl—“normal” in her development—having the same effect on her mother.

Nancy Holroyd lives in Dunnspury, New York with her husband, Forrest, and daughters, Andrea, 9, Sheila, 7, and Colleen, 3. Sheila attends a local school where she is fully included. Nancy is the editor of News & Notes, the newsletter of Down syndrome/Am High!, a local Down syndrome support and advocacy group. For the last two years, Nancy has served on the Educational Directions Committee in her local school district.
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Brushing, Flossing and Rinsing
by Steven P. Perlman

FLOSSING

Brushing is not enough. Flossing is needed to remove plaque between the teeth, where a toothbrush can't reach.

Step-by-Step Flossing

Take an 18-inch piece of floss and wind it around the middle finger of each hand. Or tie ends together in a circle.

Grasp the floss firmly between the thumb and index finger of each hand. Hold a half-inch section taut for more control. Work it gently between teeth until it reaches gumline.

Curve floss into a C-shape around tooth. Slide floss up and down side of tooth gently. Remove floss gently and repeat for all teeth. Be careful not to injure gums with floss.

BRUSHING

If the child gags easily or cannot spit, brush his teeth with a fluoride rinse instead of toothpaste. First, brush without the rinse. Then, pour a little rinse into a cup, dip the toothbrush into it, and brush with the rinse.

Adapt a Toothbrush

Attach the brush to the child's hand with a wide elastic band.

For children with limited grasp, enlarge the brush handle with a sponge, rubber ball or bicycle-handle grip.

Bending the brush handle may make it easier for some children to grasp. The handle will become soft enough to bend after running hot water over it. Do not run hot water over the head of the brush.

For children who cannot raise their hand or arm, lengthen the brush handle with a ruler, tongue depressor or long wooden spoon.

For a child who cannot manipulate a regular toothbrush, an electric toothbrush may allow him to brush his teeth independently.

If the child cannot keep his mouth open, use a mouth prop—for example, three or four tongue depressors taped together, a rolled-up moistened washcloth or a rubber doorstop. Ask your dentist how to use a mouth prop correctly so you can avoid injuring the child's mouth.
Step-by-Step Brushing

Start with the upper teeth, brushing outside, inside and chewing surfaces. Repeat for the lower teeth. Be sure to brush each tooth.

Place the toothbrush bristles at the child's gum line, at a 45-degree angle to the gums. Press gently and use short strokes with a vibrating, back-and-forth or light scrubbing motion.

Reposition the brush vertically to clean inside the surfaces of front teeth, both upper and lower.

To freshen breath, brush tongue, too. The tongue can harbor many odor-causing bacteria.

GROWTH AND DEVELOPMENT CHECKLIST

1. Try to minimize thumb-sucking, finger-sucking or pacifier use. These habits may cause future malocclusions (bite abnormalities).
2. Keep an infant's gums clean to reduce teething discomfort. Clean the gums with a piece of gauze or a washcloth.
3. The American Academy of Pediatric Dentistry recommends that a child have his first dental exam within six months of the first tooth's eruption and no later than 12 months of age. At this time, a dentist can check for proper tooth growth and development and the possibility of dental decay.

Good early experiences with the dentist will help the child develop a positive attitude toward the dentist, so he will be more likely to cooperate during future dental visits.

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For further information, contact the Admissions Office at (414) 674-4330, Ext. 226.
4. Avoid "nursing-related caries." Do not put a child to bed—even for a nap—with a bottle of sweetened liquid (such as milk, formula or fruit juices) in his mouth. When the child is sleeping, a decrease in salivary flow allows the sugary liquid to remain in the child's mouth for an extended period of time. This causes tooth decay. Breast-feeding over a long period of time can cause a similar problem. If the child needs a bottle at bedtime, fill it with water or a noncarbonated, artificially-sweetened liquid like a fruit-flavored drink or iced tea.

5. Note that some liquid medications contain from 30 to 50 percent sucrose. This includes medications used for heart disease, seizures or recurrent infections. When these sugar-laden oral medications are given to a child before naps or at bedtime—when salivary flow is diminished and will not wash the liquids out of his mouth—tooth decay may result. Medications should be given during the child's waking hours. After a dose, have the child rinse thoroughly. If possible, have him brush, too. Inform your dentist about the medications the child is taking, and the frequency and time of day medications are given.

6. The eruption of primary and permanent teeth takes place at different ages in different children. Frequent dental care—visiting the dentist at least once every six months—can help to insure proper guidance of developing teeth and, if necessary, early intervention for developing bite abnormalities. If the child's permanent tooth is erupting before the primary (first) tooth has fallen out, seek care as soon as possible. Prompt removal of the primary tooth can prevent the development of orthodontic problems that may be difficult to correct in the future.

7. If tooth crowding is present, an early orthodontic consultation is advisable. Certain procedures may be done to limit or possibly avoid extensive orthodontic treatment later.

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The child takes the recommended dose of a fluoride rinse (usually a capful), swishes it around his mouth for 60 seconds, and spits it out. The child should be careful not to swallow it. To get full fluoride protection, the child should not eat or drink for 30 minutes after rinsing.

If the child is unable to rinse without swallowing, use a cotton swab or toothbrush to place a little fluoride rinse on his teeth. Your dentist may also recommend a prescription, fluoride-gel treatment.

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to maintaining a private practice in Lynn, Massachusetts, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their "Special Athletes, Special Smiles" program. Dr. Perlman lives in Swampscott, Massachusetts with his family.
This wonderful new book is another example of the power of parents to change the world. Less than 10 years ago, a few parents recognized that technology could help their children with disabilities. They began a collaborative effort which became the Alliance for Technology Access, a nationwide network of community-based technology centers. Today, these centers serve thousands of children and adults with disabilities, parents and professionals. Now, this group has produced their first book—an overview of hardware, software and other adaptations which give people with disabilities equal access to computer technology.

We will be collaborating with this outstanding group to create editorial material for the November issue—our 12th annual technology issue. —S.D.K.

Imagine having a keyboard that changes effortlessly from a standard layout to one that includes only the keys you need for a specific task... Imagine a computer that talks to you, that reads messages sent to you from all over the world. Imagine having the ability to make choices by simply touching a picture on your computer screen. Imagine having the ability to type without using your hands by simply looking at the right letter on a keyboard pictured on the screen. Imagine going to the Library of Congress to gather materials for a research project without ever leaving your home.

These scenarios are just a few examples of what you can do today with computers. For a person with a disability, today’s applications offer new promise and excitement. These new abilities level the playing field for all of us.

**Why This Book Was Written**

... We want to share with you what we have learned about the ways assistive technology is literally changing lives by creating new abilities for children and adults with disabilities—sensory, cognitive, learning or physical disabilities. Everyday, in the course of our work, we are asked questions about available technology and its applications: "I have a vision impairment. Which computer should I buy?" "My son has a learning disability and his teacher said a computer might help him do better in school. Which should I buy?" "I have a girl in my sixth-grade class with cerebral palsy, and the school has agreed to provide her with a computer. Which is the best?" "Your questions may be similar.

The goal of this book is to help you begin answering your questions for yourself, and to allow you to take advantage of the incredible new tools on the market today. We won’t teach you about the insides of the latest computers or list every computer product ever developed. Our intention is to help you create a purpose and a framework for approaching technology so you can make initial decisions about the role it can play in enhancing your life. We have included many stories about real people who are using technology successfully—people of all ages and all disabilities...

This book is written for a community that has not yet discovered the power of technology. This community includes people with disabilities, but it also includes family members, advocates and friends of people with disabilities. It encompasses thousands of professionals in the fields of education and rehabilitation who are concerned about quality-of-life issues and options for children and adults with disabilities. It includes the technologists, engineers, and designers who will be the developers of tomorrow’s technology. This broad group represents a huge constituency that will be dramatically impacted by technology in this and the next century...

**Structure of the Book**

The book is divided into three parts. *Part I, The Search for Solutions*, will guide you through the process of defining your needs, developing a technology plan, building a supportive team and making technology-related decisions...

*Part II, The Technology Toolbox*, focuses on the technology itself... helping you to zero in on the technologies most likely to match your abilities and goals... You will learn enough about the categories of products on the market today to feel comfortable taking the next steps...

*Part III, Helpful Resources and References*, contains lists of resources, references and organizations that we have found valuable... Much of what we offer are the right questions and some key resources. If you find that, after reading this book, you have a goal in mind, some easy first steps to take and a range of supporters to help; if you are armed with enough information to talk comfortably with your local computer dealer; or if you are inspired or excited by someone’s story, we have accomplished our goal.

Crystal Springs School
A PROGRAM OF THE
INSTITUTE FOR DEVELOPMENTAL DISABILITIES, INC.

Providing quality residential, special education and treatment services in a professionally caring, homelike environment since 1953.

- 30 acre campus in Southeast Massachusetts, close to Boston, Cape Cod, Providence and Newport, R.I.
- Programs for severely and profoundly multiply handicapped children and young adults from birth - 22, including those young people characterized as medically fragile.
- 365 day programs providing 24 hour nursing availability.
- Licensed by the Massachusetts Office for Children.
- Approved by the Massachusetts Department of Education.
- Member of the Massachusetts Association of Approved Private Schools.

For information, Please Call:
Cheryl Andrade, Admissions Coordinator
(508) 644-5537

THE RIGHT DECISION
New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a non-pressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments set on a beautiful 75-acre wooded site some 25 miles south of Boston. Our vocational center provides for the satisfaction and dignity of productive employment in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future. Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

Special Care for Special People
Progressive education, home environment for the mentally handicapped child and adult. Opportunity for educational progress at any age—multiple recreational and social activities. A year-round program with an active and full lifestyle among friends on a 750-acre bluegrass estate. Est. 1893.

Phone 502-875-4664 or write for brochure
THE STEWART HOME SCHOOL
Box 20, Frankfort, KY 40601
John P. Stewart, M.D., Resident Physician

Exceptional Programs For Exceptional Children.
At St. Coletta Schools we believe life is what happens today. Our goal is to provide the best possible life experience for your exceptional child. Students here are not only preparing for tomorrow, they are living quality lives everyday. Founded in 1947, St. Coletta Schools offer a wide range of programs for children with mild to severe developmental disabilities. Twelve-month residential and day programs for ages 6-22.

- Extensive Vocational Training
- Functional Academics
- Community Skills Training
- Daily Living & Social Skills
- Adapted Phys. Ed. & Recreation Activity Program
- Special Olympics
- Music, Art & Computers
- Prader-Willi Program

Cardinal Cushing School & Training Center
400 Washington Street, Hanover, MA 02339
Braintree St. Coletta Day School
85 Washington Street, Braintree, MA 02184
Contact: Lynne Goyak
Tel (617) 826-6371
Fax (617) 826-6474
Sponsored by
The Sisters of St. Francis of Assisi of Milwaukee, WI

Exceptional Parent / September 1994
**Annandale Village**

Private, 501(c)(3) Nonprofit Community

**The Arborway School**
A 24 hour learning experience which provides individualized services for multihandicapped students.
- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
**Arborway School**
144 South Huntington Avenue
Boston, MA 02130
617-232-1110

**Brehm Preparatory School**
1993 BLUE RIBBON WINNER
Brehm Preparatory School is a Midwest boarding school designed to meet the academic, social, and emotional requirements of adolescents, age 12-21, with learning disabilities. Brehm offers specialized academic instruction, Orton training, speech and language therapy, and social skills guidance. Certified staff, family atmosphere, NCA accredited.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
[618] 457-0371

**Chileda Habilitation Institute**
- Intensive
- Progressive
- Specialized

Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608)782-6480 (608)782-6481 (Fax)

**Oak Hill School**
100 Years of Compassion
Exceptional people deserve exceptional care. CIB/Oak Hill School enters its second century of compassionate care and ground-breaking education for children and adults with severe developmental disabilities.
- Residential living
- Day and vocational programs
- Loving, supportive environment
- Dedicated, highly-qualified staff

CIB/Oak Hill
120 Holcomb St.
Hartford, CT 06112
(203) 243-2224

**CIB/Oak Hill**

“THEIR COMMUNITY ... WITH OUR HELP” Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30074
(404) 945-8381

**Camp Huntington**
33rd Year

**Chileda Habilitation Institute**
- Intensive
- Progressive
- Specialized

Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608)782-6480 (608)782-6481 (Fax)

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- Dedicated, highly-qualified staff

CIB/Oak Hill
120 Holcomb St.
Hartford, CT 06112
(203) 243-2224

**THE DUVALL HOME, EST. 1945**
A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:
- 24-hour nursing care.
- Loving, supportive environment.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 358-0450

**THE DUVAL HOME, EST. 1945.** A private, nonprofit residential facility providing a warm, loving atmosphere for ambulatory and non-ambulatory people with mental retardation of all ages:
- 24-hour nursing care.
- Lovely 24-acre rural campus.
- Recreational and training activities.
- Respite care available.

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 358-0450

- Intensive
- Progressive
- Specialized

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LaCrosse, WI 54601
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120 Holcomb St.
Hartford, CT 06112
(203) 243-2224

- Intensive
- Progressive
- Specialized

Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608)782-6480 (608)782-6481 (Fax)
RESpite SERVICES provides short term residential care for children, adolescents and adults with disabilities. Respite Services gives a weekend break, vacation or help in times of illness or other crisis. Summer camp sessions are also available. Family style care and welcome in a country setting.

Contact: John & Pat Ryan
Respite Services
RRI Box 458
S. Gibson, PA 18442
(717) 756-2750
(717) 756-2870 Fax

See ad on page 74

CONNECTICUT
Intensive Education Center, Inc.
27 Park Road
West Hartford, CT 06119
(203) 236-2049

FLORIDA
Ralph J. Baudhuin Oral School
3301 College Avenue
St. Petersburg, FL 33714
(813) 372-1300
A humanistic learning environment for children, birth-8th grade with communication disorders, learning disabilities and ADD.

Threshold, Inc.
P.O. Box 1110
Goldenrod, FL 32733
(407) 671-7690

GEORGIA
Agape Village
3711 Agape Village Rd.
Macon, GA 31210
(912) 471-3700
Providing mentally disabled with 50 acre protected place to live, work in greenhouses and enjoy active life with supervision.

See ad on page 14

Annandale Village
3500 Annandale Lane
Suwanee, GA 30074
(404) 945-8301
Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote well-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta.

See ad on page 63

ILLINOIS
Allendale School
PO Box 1688
Lake Villa, IL 60046
(708) 356-3334
Allendale School is a special education program providing comprehensive services to youths with emotional/behavioral disabilities.

Brehm Preparatory School
1245 East Grand Avenue
Carbondale, IL 62901
(618) 457-0371
Residential school designed to meet the academic, social and emotional requirements of adolescents (age 12-21) with learning disabilities.

KANSAS
HeartSpring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 252-8271
HeartSpring serves students ages five through 18 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments, short-term treatment programs, and hearing center services are also offered.

See ad on page 84

KENTUCKY
The Stewart Home School
Box 25
Frankfort, KY 40601
(502) 875-4654
Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Ext. 1893. Call or write for brochure.

See ad on page 62

MAINE
Bancroft
Lighthouse Road
Orchard Head, ME 04854
(207) 594-7261
Year-round programs and vacation options for people with developmental disabilities/head injury. See Bancroft in New Jersey Section.

MARYLAND
The Harbour School
1277 Green Holly Drive
Annapolis, MD 21401
(410) 974-2448
Seeks LD & multi-handicapped children ages 5 through 21. Services include counseling, OT, job training & a HS diploma.

MASSACHUSETTS
Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523
For children who are severely retarded, multiply disabled. Private, non-profit residential school located in the Berkshires.

See ad on opposite page

Crystal Springs School
38 Narrows Rd. Box 372
Assonet, MA 02702
(617) 644-3101, Ext. 328
Established in 1963, Crystal Springs offers licensed home-like residences; and approved private school; full rehab. program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults, birth-22 yrs.

See ad on page 62

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with development disorders, behavior disorders age 3-22. Integrated preschool, inclusion services, staff intensive program, functional activity based curriculum, supported employment in modern school and group homes.

See ad on page 73

New England Villages, Inc.
684 School Street
Pembroke, MA 02359
(617) 293-5461
Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities.

See ad on page 62

St. Coletta's of Massachusetts Cardinal Cushing School and Training Center
401 Washington Street
Hanover, MA 02339
(617) 826-6371
Residential school for students who are developmentally disabled and require education or assistance in self-care, community living, adapted communication, mobility training or behavior control due to psychiatric/behavioral, medical or therapeutic needs. An intensive program is available for severely maladaptive or self-injurious behavior.

See ad on page 74

A PLACE TO CALL HOME

Contact:
Special Force Family Ministries
P.O. Box 47, Waconia, MN 55387
(612) 442-4441

LEAGUE SCHOOL OF BOSTON
225 Nevada Street
Newtonville, MA 02160

SEE AD ON PAGE 54

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 801-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.

See ad on page 63

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with development disorders, behavior disorders age 3-22. Integrated preschool, inclusion services, staff intensive program, functional activity based curriculum, supported employment in modern school and group homes.

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Residential school for students who are developmentally disabled and require education or assistance in self-care, community living, adapted communication, mobility training or behavior control due to psychiatric/behavioral, medical or therapeutic needs. An intensive program is available for severely maladaptive or self-injurious behavior.

See ad on page 74

Crotched Mountain Rehabilitation Center, Inc.
1 Varnery Drive
Greenfield, NH 03047
(603) 547-3311, ex. 235
A comprehensive preparatory school and rehabilitation center providing the best in education, a guided return to the community, access to community...
Berkshire Meadows

is a private, non-profit year-round residential school for children and adolescents who are severely developmentally delayed and may be multiply disabled.

Like other young people all over the world, residents of Berkshire Meadows are collected by bus to go to school five days a week. In this instance, the "buses" are specially-adapted vans, and "school" - the Learning Center - is where they are taught techniques to help them compensate for their tremendous difficulties, and where their bodies are gently persuaded to move more freely and with greater control.

The Learning Center divides the students into two groups: children, and young adults. The groups work in separate Centers, each focusing on different, graduated skill levels. Class sizes and schedules vary from day to day, to accommodate the particular needs of each student.

In the Vision and Sensory Stimulation Center we address those factors that are seminal to the children's physical and emotional development. While all the senses are addressed, our major emphasis is on sight. In the Light Room we use different types of light to determine which is best for a student with visual deficits, and then work under that light to improve his or her use of vision before gradually incorporating the use of conventional white light. The Visual Stimulation room is designed to increase visual awareness and choice-making, as well as to be downright fun: it is equipped with mirror balls, lighted bubbling water, fiber optics and any number of other visually attractive and stimulating light displays.

The Main Room is geared toward stimulating the use of all the senses: there are musical activities and movement to increase auditory awareness; busy boxes, vibration toys and texture boards to improve the sense of touch; and at all times there is social contact and "talk" about what is going on. Outside these three rooms in the spacious "hallways" the students work with brightly-colored therapy balls, gently swinging hammocks, soothing rocking chairs and many other devices that encourage vestibular development.

The Task Center is devoted to cognitive development based on Piaget. The children learn to interact with others, to make choices and to feel themselves to be active participants in their environment. We use toys and tasks to develop memory, awareness of the presence of others, and foresight.

The Applied Functional Skills Center teaches young adults to make use of the techniques they have acquired in other areas. For example, pouring skills can be used for mixing ingredients; stacking and matching skills translate into sorting the laundry. The

Our program for young adults also includes Applied Academics, where the students practice skills that will foster independence: name recognition, the use of money, very basic computer skills, packaging and various vocational skills.

All our students, regardless of their ages, participate in the fifth area of the Learning Center, which is Augmentative Communication. We use Functional Communication as an approach to behavior modification.

At Berkshire Meadows, we work to provide the best care and education that expertise, technology and experience can offer. Our intent is for our students to become more independent, more self-sufficient and empowered, so that they might exercise some control over their destinies.

Gail Charpentier, Exec. Dir.
Berkshire Meadows,
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523)
housing, education, and support services for lifelong planning. See ad on page 51

NEW JERSEY

Bancroft
Hepkins Lane
Haddonfield, NJ 08033
(609) 429-0010 ext. 347


Durand Academy, Inc.
230 N. Evergreen Avenue
Woodbury, NJ 08096
(609) 845-0888

Durand Academy provides certified educational programs, residential programs and family support to children age 3 through 21 with autism, emotional disorders and multiple handicaps. The program emphasizes a structured curriculum and social skills development.

ECLL of New Jersey
302 North Franklin Turnpike
Ho-Ho-Kus, NJ 07423
(201) 670-7880

ECLL of New Jersey
21 Lirn Avenue
Chatham, NJ 07928
(201) 635-1705


NEW YORK

Conductive Education Center of Long Island
224 W Park Avenue/Ste 305
Long Beach, NY 11561
(516) 432-6260
Fax: (516) 899-5154

New York University—Para-Educator Center
One Washington Place
New York, NY 10003
(212) 998-5800

Two year post-high school program for severely learning disabled young adults. Courses supervised and job training in human services, while emphasizing independent living skills. Graduates qualified to work with infants, toddlers, children or senior citizens.

Pathfinder Village
PR #1/Box 32-A
Edenfield, NY 13335
(609) 353-1726

Located in the forested wilderness of

Central Oregon, Mount Bachelor Academy guides youths 13-18 through a year round course of emotional growth and college prep. For more info on what experts call "the future of education," call or write.

Pennsylvania

The Devereux Foundation (609) 345-1292, Ext. 3045
(610) 964-3045 fax
230 N. Evergreen Avenue
ECLL of New Jersey 201) 670-7880


Elwyn, Inc.
111 Elwyn Road
Elwyn, PA 19063-4699
(610) 891-2000/(800) 345-8111

Residential, day and community-based treatment centers nationwide. Comprehensive services to individuals of all ages with emotional disturbances, developmental disabilities, mental retardation, dual diagnosis, autism, and post-head trauma. See ad on page 48

Martha Lloyd
Community Services
111 Elwyn Road
Elwyn, PA 19063-4699
(610) 964-3045 fax
(800) 345-1292, Ext. 3045

Superior quality community living with experienced, caring staff; excellent safety skills and community involvement. Graduates qualified to work with children or adults with special needs. See ad on page 71

McKee
Wayland Road
Benyon, PA 19312
(610) 353-1726

A unique community of alternatives near Valley Forge. Pa. Children/adolescents/ adults receive special education/day programs/ OT/PT/ speech-language/aquatic/PT/ music therapy/horsemanship. Self-help/safety skills and community involvement promote a more independent lifestyle. See ad on page 52

Roger-Greaves School
118 S Valley Road/Po Box 1007
Paoli, PA 19301-0913
(610) 644-1810

Approved school for blind. Community home for MR (sighted or blind). Adult Training Center. Recreational opportunities. See ad on page 49

OREGON

Mount Bachelor Academy
246301 E Highway 26
Prineville, OR 97754
(503) 492-3404

Located in the forested wilderness of

continued on page 74
A. Are you a subscriber to Exceptional Parent?
☑ Yes ☐ No (If no, please see the subscription card in this issue.)

Name

Occupation/Title

Company/Association

Address

City __________________________ State _______ Zip.

Phone( ) ______________________ Fax( ) ______________________

B. Annual Household Income (include all family members)
☑ $30.001 - $40.000 ☐ $40.001 - $50.000 ☐ $50.001 - $75.000
☐ $75.001 - $100.000 ☐ $100,000+

C. Do you live in a(n):
☑ Home 8 Own 9 Rent
10 Apartment 11 Own 12 Rent

D. In all, how many automobiles do you and others in your household own or lease?
13 One 14 Two 15 Three or more

E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):
16 one month 17 three months 18 nine months 19 one year

FREE PRODUCT & SERVICE INFORMATION

Issue Date: September 30, 1994
Expiration Date: December 31, 1994
HMS School for Children with Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- Physical Therapy
- Occupational Therapy
- Speech and Language Therapy
- Communication Aids
- Special Education
- Music Therapy
- Special Medical Attention
- Adapted Recreational Activities

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:

Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

The National Association of Private Schools for Exceptional Children (NAPSEC)

Founded in 1971, NAPSEC is dedicated to promoting excellence in private special educational settings for exceptional children.
For more than 65 years, Martha Lloyd Community Services has provided superior quality day, residential and vocational programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. A new community-based program for men has been added. The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

All Programs Offer These Advantages

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

For Information Call
(717) 297-2185
or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947
Standing Outside the Fire

Country music star Garth Brooks has made a powerful video portraying a young man with Down syndrome. The video, directed by Jon Small for Brooks’ hit song Standing Outside the Fire, depicts a young man’s desire to compete in a high school track meet despite the skepticism of his father and coach.

Inspired by wife Sandy’s volunteer work with the Special Olympics, Brooks chose to illustrate his video with a person eager and determined to participate in all aspects of life. “This song is about passion,” Brooks told Exceptional Parent, “and one of the most passionate things I’ve ever seen is an athlete striving to be his or her best in spite of physical or mental challenges. In this video, the parents, in spite of their differences, find a common ground of support for their son and help him turn his dream into a passionate reality.”

Gerard Fobes, a 28-year-old California resident, was chosen to play the role of the determined young athlete. Fobes is a former Special Olympian. Other Special Olympic athletes were also part of the filming. Brooks’ production company, Picture Vision, made a donation to the Special Olympics for every Special Olympic “extra.”

The video can be seen on TNN, CMT, and VH-1.

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Publications

- **Making the Most of the Law: Education and the Child with Disabilities** is the first comprehensive book on the educational rights of students with disabilities in Canada. The book explains public school acts and regulations of Canadian provinces and territories and explains how to be an effective child advocate. The book costs $220 (Canadian), and can be ordered from the Learning Disabilities Association of Canada, 323 Chapel St., Suite 200, Ottawa, Ontario, Canada K1N 7Z2, (613) 235-5391.

- The Candlelighters Childhood Cancer Foundation has published *The Candlelighters Guide to Bone Marrow Transplants in Children*, a book that explains the procedure and answers many commonly-asked questions.

- Also available is *Educating the Child with Cancer*. The publication discusses issues of communication between families, school educators and treatment centers; school re-entry; cognitive effects; legal rights and siblings.

Single copies of both books are free to parents of children who have cancer; cost to others is $7.50.

- **Candlelighters, 7910 Woodmont Ave., Suite 660, Bethesda MD 20815-3015, (800) 336-4363.**

- **The Alliance of Genetic Support Groups (AGSG), in cooperation with the March of Dimes, has published** *Children With Limb Loss: A Handbook for Families* are based on three general phases of child development. *Book One* deals with birth to five years; *Book Two* deals with ages six to twelve; and *Book Three* deals with adolescence. Other titles include *Children With Hand Differences: A Guide for Families and Children With Limb Loss: A Handbook for Teachers*. Each booklet costs $2, plus postage and handling—$7.50 per copy for 1–3 copies; $50 per copy for 4–9 copies. Available from Area Child Amputee Center, Mary Free Bed Hospital and Rehabilitation Center, 235 Wealthy St., SE, Grand Rapids, MI 49503; (616) 495-7988.

- **The Alexander Graham Bell Association for the Deaf** has published a brochure on cochlear implants. The brochure explains how the implant works and describes implant surgery. Single copies are free from Publication Sales Department, A.G. Bell Association.
A recent episode of Mister Rogers' Neighborhood introduced young viewers to wheelchair basketball. Surrounding Mister Rogers are (from left) Darius Carlins, John Sikora, Leah Hans and Bradley Ramage.


Developmental Delay Survey
The Developmental Delay Registry (DDR) is conducting a survey to determine any apparent cause-and-effect relationships in children diagnosed with severe developmental delays, including autism and pervasive developmental disorder. The survey can be completed in about 10 minutes. The registry hopes to gather information on 1,000 children. If you are interested in participating, contact Patricia S. Lerner, DDR, P.O. Box 12394, Silver Spring, Md. 20908, (301) 924-3060. The survey can be accessed on CompuServe in the ADD Forum, TS/PDD/Autism Library. Names of participants are requested, but not required.

Reader Survey
Early this year, we mailed a survey to some of our subscribers; many responded by telling us about themselves and their families. We were pleased to learn that most of our subscribers read every page of each issue, often spending more than an hour in the process. We also learned that 86 percent save their issues; others pass them along to friends. Our readers also told us that their children are likely to need extra help in self-care, communication, mobility, computer technology and recreation.

We appreciate this feedback, but we remain frustrated by the fact that many parents and professionals do not know about our magazine. Please help us spread the word by sending a note to the acquisitions librarian at your local public library and by encouraging subscriptions among the professionals who are involved with you and your child.

—S.D.K.
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Circle # 27

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Effective Intervention For Self-Feeding Success,
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Massage For The Infant With Developmental Disabilities,

This video will show parents how to stroke their infants and children with special attention to methods which honor the infant’s individual concerns. A valued resource for every parent to assist their child’s development. **ED 079DD**

Near Normal Feeding For Infants With Oral-Facial Anomalies,
by Susanne R. Hays, M.S., R.N., C.R.R.N.

Nippling for infant’s born with cleft lip and/or palate can be very difficult. Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies parents can follow. **ED 0800D**

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PROTOCOL-CE

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Circle # 260

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, VTDD, (301) 588-9284,VTDD or (301) 587-1967, FAX.
Child Care: Who Cares for the Children with Chronic Illness and Disability?

Historically, child care (or daycare) has been treated very differently than education. While schools are mandated to provide educational programming for children with special health care needs, parents are responsible for providing daycare.

So what happens when children from birth to three-years-old need early intervention services? That’s one of the questions researcher, Lynne M. Lent, set out to answer in her regional study of “Child Care for Children with Special Needs from Birth to Three Years.” She found mounting evidence that early intervention appears to be most effective when it is:

- part of a child’s daily routine, and
- when the family’s basic needs are met.

What she found is, regardless of the potential effectiveness, child care is seldom included in early intervention services.

Like most parents in the U.S. today, child care is a critical issue for Child Care.

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Child Care
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families with children who have special health care needs, and it may be even tougher to find. However, it appears that the benefits of placing children with chronic illness or disabilities into the least restrictive child care setting far outweigh the barriers. Lent reports one success story:

Amy is a bright, active child who was born two months prematurely and diagnosed with cerebral palsy and seizures. Her child care providers remember that, when Amy started child care, her physical therapists came to the center and provided instruction about appropriate exercises and activities. “Open communication and commitment from everyone—parents, teachers, therapists and even the bus driver—made this a very successful experience,” the care provider explained. Today, Amy, a high school student, works as an assistant at that same child care setting. She is bright, enthusiastic, and is great with young children.

There is no doubt, when parents and child care providers are committed to including all children in daycare, everyone wins.

Providers respond to questionnaire

Many providers said they believe that having children with special needs had a positive effect on all the children enrolled in daycare. They believe having children with special needs helped both children and adults to accept differences among people.

Still, more than one-third who responded to Lent’s survey believe that the needs of children with chronic conditions caused the other children to be “short-changed.” Some reported that

Where do they go for child care?

- Small family child care home 20.8%
- Large family child care home 71.0%
- Child care centers 4.9%
- Nursery school 5.0%
- Sick child care 0.3%
parents withdrew their able-bodied children from the child care program. Some expressed concern about behavior problems. Still some did not know how to keep children from making fun of the child with disabilities.

Clearly, the perceived barriers to providing care for children with chronic illness or disability could be improved through training; however, currently, most training of providers is done by the family. Lent's summary calls for including child care providers in the IFSP (Individual Family Service Plan) loop.

When asked, those who provide child care to families with children who have chronic illness or disability say they are often left out of the development of Individual Family Service Plans (IFSP).

When asked, the same providers would like to be a part of the planning team and would like be trained to work with children with special needs.

Lent sent surveys to 1,014 licensed providers in one metropolitan county in Minnesota; she received 304 responses.

She asked providers 21 questions that included descriptions of the child care setting, services provided to children with special needs, participation in the IFSP process, communication and overall satisfaction. She also asked for recommendations to improve a provider's ability to service children with special needs.

Parents Respond

Parents of children with special needs who responded to this survey preferred small and large family daycare to center-based daycare. By and large, they found providers through the grapevine rather than using child care resource and referral services.

Families report that the type and severity of their child's condition had little to do with the success of, or disenchantment with, child care. Rather, they credit communication and commitment. When child care providers are committed to including a child with special needs into their program, and when they communicate with all the parents and children in the program, and when the program is made convenient, they are successful. Lent surveyed parents of children enrolled for at least two months in an early intervention program for children from birth to three years. Forty nine (of 180 surveys sent) were returned.

What Can Be Done?

Clearly, daycare and early intervention need to be linked. One way is for families to ask their daycare providers to attend the IFSP meetings along with the rest of the team.

In addition, all states accepting Part H funding are required to form state- and community-level interagency councils. These are formed in many different ways. In Minnesota, for example, there is a Governor's Coordinating Council on Early Childhood Intervention. Councils like these should include not only publicly-funded programs like Head Start, but private child care agencies.
Provider, Family and Early Intervention:
A Working Together Checklist

Here's a checklist of questions that parents with children who have chronic illness or disabilities can use when working with their child care providers and early intervention staff. Use this to help formalize the roles and responsibilities of each person involved in providing child care.

How do the family and the child care provider communicate?

Some families like to use notebooks that go back and forth to the child care provider. Others prefer brief daily conversations and weekly or biweekly conferences.

What happens when something goes wrong?

Some families write instructions for the child care provider in case of an emergency. This can include what to do in the event of a seizure to more complicated events. It can detail which doctor to call, how to transport the child, which medications to give, and how to contact the parents. Some families rent or buy "beepers" so they can be easily contacted in the event of an emergency.

How do the child care provider and early intervention team (including therapists, social workers, and others) communicate?

You might want to ask your child care provider to become a member of the early intervention team.

Who teaches the child care provider about the needs of the child?

What Happens Next?

Child care is still a "parent" driven issue. Here are some recommendations that will increase the inclusion of young children into child care:

- Explore ways to include child care providers into the IFSP.
- Encourage early intervention personnel to provide consultation and technical assistance to child care providers.
- Teach IFSP team members collaboration skills.
- Develop programs that assist families in locating and selecting quality programs.
- Provide pre-service and in-service training programs for child care providers.
- Develop more equitable funding for child care programs that include children with chronic illness and disability.

Are there video tapes available from your local or regional parent training program or from condition-specific organizations like the Epilepsy Foundation?

Can your child care provider attend continuing education programs along with other early intervention specialists?

How will any extra cost of providing care be covered?

Many child care providers are concerned that the staff-to-child ratios needed to stay in business reduce their ability to include children with special health care needs into child care programs. Check with your county social worker or early intervention coordinator to see if there are any funds available through your state or county to assist your child care provider in making modifications.

What happens next?

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- Provide pre-service and in-service training programs for child care providers.
- Develop more equitable funding for child care programs that include children with chronic illness and disability.
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A multi-disciplinary guide to terminology defined and clarified terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.

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Angela’s strengths, gifts and talents. People described Angela as “courageous, a pioneer, someone who knows how to make you feel better when you are down, a good bike rider and a ballet dancer.”

Finally, the group discussed plans for the summer and upcoming school year—Brownie camp, maintaining relationships with distant relatives, open communication among staff and parents. Circle members thought about ways to help to make these plans succeed, and committed themselves to providing support.

Angela’s peers thought it was very important that Angela be allowed to go to the neighborhood playground with her friends, but without her mom. One of Vicki’s ideas was to start a homework circle in the fall where small groups of children work on assignments together. She obtained the support of other parents to put this idea into action. Angela’s circle will meet again in September.

“One of the Gang”

Mrs. Brown, Angela’s teacher, recently summed up the year’s achievements. “Angela can follow classroom routines with more independence,” Mrs. Brown says proudly. “She views her work time as an important part of the school day. She takes turns and shares. She pays attention to stories and group activities for longer periods of time. She can write her own sentences by sounding out words. And most of all, she’s one of the gang!”

Angela Hart is now a third-grader at School One in the Scotch Plains-Fanwood School District in New Jersey. She has been included in her neighborhood school throughout her entire school career.

ALL CHILDREN BELONG is a collaborative program of the National Parent Network on Disabilities in Washington, DC, and the Statewide Parent Advocacy Network (SPAN) in New Jersey. Support for ALL CHILDREN BELONG is provided by the DeWitt-Wallace-Readers Digest Fund. For more information, call NPND (703-684-6763) or SPAN (908-654-7726).
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All children enjoy toys. By their excitement about toys, games and play, children with disabilities clearly remind us that, first and foremost, they are children. Parents may be overwhelmed when selecting toys their children will enjoy because there are so many to choose from, family budgets are limited or a child has unique needs and may not be able to enjoy off-the-shelf toys and games.

This issue features a special section on choosing toys for children with disabilities. In "Forza For Every Child," Marilyn Hammond describes principles for choosing toys, along with ideas for adaptations. In "Forrest Pumps," Jean Isaacs shares her efforts to adapt toys for her son's use, and her excitement at discovering an off-the-shelf water gun that allowed him to shoot straight!

In the quarterly Oppenheim Toy Portfolio Newsletter, Joanne and Stephanie Oppenheim evaluate products for children. Each year, they publish "The Best Toys, Books & Videos for Kids." Portions from a chapter of that book, "Using Ordinary Toys for Kids with Special Needs," have been adapted for this issue.

**Grieving**

The emotions parents experience after learning their child has a disability has been described as a mourning process—mourning the loss of the "perfect" child of their dreams. Understanding that this is a normal human reaction has helped parents deal with its many variations. But until I read "Grieving a Dream," I had never seen an article that described in practical terms how a parent, with the help of others, can facilitate this process.

**Teaching About Disabilities**

In our education issue (September), we did not address disability awareness programs for children without disabilities. In this issue, we report on "Friends Who Care," a national program that helps children learn to respect differences and reach out to one another. We are very interested in learning about other, similar programs.

**Reader Participation**

In the months since our first Familiar Faces page appeared, reader response has been extraordinary. We enjoy receiving your photos and accompanying letters. And although parents tend to take fewer photos as children get older, we would like to receive more photos of older children.

Beginning with this issue, we want to encourage a new kind of reader participation. In each issue, we will ask for reader input about a topic we plan to cover in a future issue. Readers now can have an even more active role in editorial development. See page 8 for our first request.

**Health Care Reform and Elections**

It has been disappointing and frustrating that, as we go to press, health care reform remains an unfilled dream. Now, all candidates for Congress must be informed about the health care needs of children with disabilities often are short-changed.

**An Apology**

In the list of Honorable Mentions of the 1994 Educational Program Awards in September, one program was listed incompletely. We regret this production error and apologize to the Weight Conditioning Program at Trenton High School in Trenton, New Jersey.

**Special Thanks**

Valerie Steele, a dedicated Exceptional Parent staff person for many years, has decided to move on. We will miss her friendly spirit and readiness to do whatever is needed. We wish her well.
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Circle # 31
 Priests with Disabilities
I was very interested to read about the early childhood and educational experiences of John Kemp (Role Models, July 1994). What insight his advocate/father had to promote inclusion from the same perspective with which it is encouraged today.

The unfortunate rejection of John’s boyhood interest in the priesthood calls for a response. Physical disabilities are no longer considered an impediment to ordination. This has been true since 1983. Even earlier, some exceptions were made, but there is no need for special treatment any longer; candidates are accepted based solely on their ability to minister to others.

R.B., Florida

Comfort and Ideas
Your magazine has brought endless comfort and numerous ideas for both my husband and myself. Our four-year-old son, Dustin, has a seizure disorder and developmental delays. We had another son who died at 14 months of age as a result of similar problems.

Your magazine and the articles written by other parents have helped us to realize that we are very blessed to have such special people in our lives. Our eight-year-old daughter has learned endless facts of life that can’t be taught in school. Keep up the great work; you provide a wonderful service!

D.C. & C.D., Illinois

A Father Speaks Out on Inclusion
I have just finished reading my first Exceptional Parent magazine and have enclosed my subscription. I am very impressed with two things. First is the regular feature of Fathers’ Voices. So many times, fathers are left alone to deal with their struggles and emotions, wondering how their child with disabilities will turn out. The second thing that impressed me were the stories about inclusion.

Our 11-year-old daughter, who has Down syndrome, has just been "dumped" into a segregated training center, 20 miles from home. That means she will spend between two and three hours a day on a school bus. She has many times, fathers are left alone to deal with their struggles and emotions, wondering how their child with disabilities will turn out. The second thing that impressed me were the stories about inclusion.

The support of friends and family, helped us learn to enjoy Jordan as a developing and happy little boy.

Jordan Leslie was born on August 8, 1992. By the time 1993 rolled around we had accepted the fact that he had some sort of disability, and found ourselves in an unfamiliar world of surgeries, tests, therapies and constant challenges. We spent most of the year dealing with fabulous medical, support and therapeutic professionals. Their support, along with the support of friends and family, helped us learn to enjoy Jordan as a developing and happy little boy.

Jordan made great strides in 1993. His initial reaction to a new task was usually anger. Jordan had terrific lung capacity! But once he decided to try something, he would put all his effort into it and eventually become quite proficient.

By September, Jordan had gained head control and enjoyed sitting up in his new wheelchair. Jordan’s brother, Wade, would play hide and seek with Jordan by talking to him on one side of his chair and then running around behind the chair and surprising him on the other side. Jordan and his sister, Jessica, enjoyed playing peek-a-boo. Jordan had a very hearty laugh and found Wade and Jessica very amusing.

Just as we thought we had a handle on our new life, our little Jordan passed away. On November 2, 1993, Jordan went into the hospital to have some of his medications adjusted—we were used to this routine. On Thursday, the hospital unexpectedly called and told us Jordan had taken a turn for the worse. By the time we arrived at the hospital, he had already fought back from one episode with severe shock. He opened his big, beautiful, blue eyes and smiled at us—a moment we will always treasure. Early in the morning on November 5, Jordan went into shock again; this time he couldn’t come back.

Jordan taught our whole family that everyone is worthy of as happy and fulfilling a life as possible. He also taught us about the power of determination. Although many of his accomplishments were small, they seemed larger than life to us and we celebrated each one. The little things in life are the most important, but they are also the things that most people take for granted. Our New Year’s resolution is to take particular note of those little things that Jordan taught us to recognize and treasure. Thanks Jordie and God bless you—we all miss you so much.

—A.G. & R.G., Saskatchewan, Canada

Remembering Jordie

Exceptional Parent has been a wonderful source of support for us. We always looked forward to receiving each issue and always found a comforting and/or motivating article in it.

In November 1993, our son, Jordan, died. Since his death, we have continued to receive your magazine, but have been unable to bring ourselves to read it. But when the June 1994 issue arrived, I opened it to the Children’s Page and read “Remembering Daniel,” Nathan Reiff’s moving story about the life and death of his brother. Nathan’s story was one I could really relate to, and it made me want to share our story.

I have enclosed a letter that we sent to my family and friends after Jordan’s death. I wondered if you might print it with Jordan’s picture? Our little Jordan taught us to be “exceptional parents.” This is something all of us must learn, but we are lucky enough to have exceptional teachers—our children with disabilities. Unfortunately, not all children with disabilities have the opportunity to grow up and show us what their true potential would have been, but whatever amount of time they are here has a profound influence on those people they touch.

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—A.G. & R.G., Saskatchewan, Canada
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had been attending a program at a school just around the corner. Now the school system is telling us that our daughter must be "protected" from a regular middle school environment.

I have written letters and made phone calls requesting a reevaluation of her placement. People tell me that I don't understand that the professionals know what is best for our daughter.

I will look forward to reading Exceptional Parent every month. Please help us get inclusion accepted everywhere.

R.Z., Florida

Wheelchair Tennis

We enjoyed Stephano Cargnel's article about the way sports changed his life ("Becoming a Contender," May 1994). After reading Stephano's story, I just had to send you a picture of my daughter's tennis group. Like Stephano, my daughter, Danielle (front right), and most of the other children in this photo have spina bifida.

We travel an hour each way from our home in Salem, Oregon so Danielle can be part of the Kids On The Move tennis program in Portland. It is a wonderful program that has added so much to Danielle's life and the lives of the other children. I can't say enough about how important these activities are. Thank you for publishing Stephano's wonderful article.

D. M., Oregon

Prejudice or Oversensitivity?

I was extremely surprised by the letter written by J.L. of California (August 1994) which said that the language in a previous letter revealed prejudices. The writer of that previous letter, the parent of a child with Down syndrome, had stated that she was thankful her child did not have physical disabilities.

J.L., the parent of a child with a physical disability, took great offense to that statement, but I think she missed the point—many of us thank the Lord every day that our children are no worse off than they are! This does not amount to prejudice against children who have different disabilities than our own. Speaking for myself, I thank God that my child seems to be right on target intellectually despite having very severe physical disabilities. If my child had different disabilities, I would still be very thankful for anything he could do. Just because we try to look at the bright side of our individual situations does not mean we think less of children or families who are dealing with a different set of circumstances.

"If we want the world to value our children—to stop segregating, stigmatizing and staring at them," as J.L. put it, we need to be proud of our kids for what they can do, and we need to allow other parents to be proud of and thankful for their kids, too.

No, J.L., I don't think the letter you responded to was insensitive. Please allow us to be happy for the blessings we receive without feeling that it is an insult to you or your son.

K.T., Tennessee
Disability Really Isn't That Romantic
Thank you for publishing Elaine Greenbaum's opinion piece entitled “Disability Really Isn't That Romantic” (July 1994). As the mother of a child with multiple disabilities, I found it affirming and refreshing to read about the realities—not just the miracles or major achievements—of life with a child who has disabilities. We all need to keep a positive attitude and to push for better things for our children, but as much as we love happy endings to our family stories, we can't always make them happen.

Greenbaum's piece exposes our short-sightedness. We work so hard to prepare our special children for the “world,” only to find that economic realities mean there are far fewer options out there than we were led to believe. If we put as much medical, social and parental energy into helping young adults with disabilities “make it” in the world as we put into newborns at risk, we would be in good shape. We need to look at our priorities.

K.H., North Carolina

I read Elaine Greenbaum's article with some sadness. I have worked in state government for more than 20 years and have had the opportunity to see how various laws which were passed to resolve specific issues can have unexpected or unintended results—one person's solution can become another's problem.

As the parent of a child with significant disabilities, I have worked hard—with varying degrees of success—to have him involved in the mainstream of life. I quickly realized that his disabilities were not the reason he was excluded. His greatest barrier to inclusion is the ignorance and prejudice of others who grew up and were educated in a world that did not include people with disabilities. The regular education teachers who found it difficult to adapt curriculum materials for Greenbaum's son are prime examples.

Greenbaum worries that the existing forms of financial support to people with disabilities serves as a financial disincentive to work. But I think discrimination is a bigger problem. We should worry more about ending discrimination so people can strive for jobs in keeping with their abilities. Only then can we begin to worry about financial disincentives.

The Americans with Disability Act (ADA) gave us a new box of tools, not a magic wand. I have had several recent conversations about the ADA with people who do not have disabilities but who now work with people who do. Their ignorance about the law was discouraging. These people did not think people with disabilities had the right to participate in programs open to the general public or use public facilities.

If we do not use our rights, we will lose them again. We need to begin a campaign of public education to ensure a high level of awareness and understanding of the ADA. We need to have discussions with the people who teach our children so they understand and respect our children's rights and act in a manner which increases our children's sense of their own inherent worth.

M.R., New York

The issue number listed in September 1994 was incorrect. September was Vol. 24, Issue 9. Exceptional Parent apologizes for the error.
Voice Amplification Equipment
My five-year-old son has a muscle disease known as centronuclear myopathy. His language skills and speech are excellent. However, his voice is so soft that it is difficult, if not impossible, to hear him in a classroom or group situation.

Can anyone recommend voice amplification equipment that he might be able to use? It would have to be compact and portable so he could use it in and out of his wheelchair.

D.C., Ontario, Canada

Partial Deletion of Chromosome 8
We are the proud parents of a three-year-old boy who has been diagnosed with partial deletion of the short arm of chromosome 8. My husband and I love our son dearly and hope to find someone who has a child with similar problems.

Anthony has been diagnosed as having mild to moderate mental retardation. He was born with several heart conditions—atrial septal defect and pulmonary and aortic stenosis. He also has hypospadias (a condition in which the urethral canal opens on the underside of the penis, before reaching the tip) and undescended testicles. His facial features appear normal.

We have been unable to find much information about this disorder. We would like to be in touch with other families who have had experience with this disability so we can know what his future may be like.

J.B., Illinois

Down Syndrome and Nonverbal
My seven-year-old daughter has Down syndrome. Jennifer started speaking at age two and a half, but by three and a half, she had stopped. During this time period, she had frequent ear infections resulting in two sets of ear tubes and an adenoidectomy. Recently, she had her tonsils removed. Before Jennifer stopped speaking, she was able to say approximately 75 understandable words.

In addition to the speech services she receives in school, Jennifer has attended private speech therapy sessions two times a week for more than three years. I can't say I have seen any benefit from these services. Jennifer vocalizes but says nothing understandable.

We have taught her to use sign language and have provided her with an augmentative communication device. She understands what is said to her and will try to vocalize, sign and use the augmentative communication device to communicate. Her signs are immature and inaccurate due to her low muscle tone. She is beginning to use the augmentative communication device, but still uses it mostly to communicate with her peers.

Tell us about...
...your successful and unsuccessful experiences with child care for a preschooler with a disability.

(K.E., Illinois)

At the same time, I am trying to face the reality that she probably won't ever speak intelligibly. I would really appreciate any advice and support as well as tips on communicating with a child who is non-verbal.

Augmentative Communication Aids
Our child has a physical disability that affects only his gross motor skills; his fine motor abilities are good. He has just started school and we are investigating augmentative communication aids. I would like to hear from parents who have had good and bad experiences with augmentative devices for their children.

D.F., Texas

Editor's Note: See "Augmentative and Alternative Communication Devices" (June 1994). This article lists a number of factors that parents should consider when choosing an appropriate augmentative and alternative communication (AAC) device for an individual child. A list of manufacturers of AAC devices follows the article.

Disability Awareness in Public Schools
My 10-year-old son, Allan, has Asperger syndrome (a type of "high-functioning" autism) along with some neuromuscular dysfunction. He is extremely...
bright—possibly even gifted in the areas of science and social studies. Allan's school has finally agreed to allow him to be mainstreamed for these subjects.

Although more inclusion for Allan has been one of our goals, we are concerned because the school has done nothing to educate the other children about disabilities. I have seen children be cruel to Allan in the past, however, when I explained about his disability, the teasing gave way to acceptance. We feel that awareness and education will promote acceptance of our son and other children with disabilities who are now included.

The special education liaison at my son's school agrees that something needs to be done. We want to establish an educational program for regular-education students that will promote awareness and foster acceptance of people with disabilities. I would like to hear about good curriculums, model programs, books, puppet shows or any other disability-awareness tools that have been used in public schools. Allan's school has agreed to review anything I can present.

M.G., Florida

EDITOR'S NOTE: See page 33 for an article about FRIENDS WHO CARE, a disability-awareness curriculum from the National Easter Seal Society. EXCEPTIONAL PARENT is eager to hear about and report on other, similar programs.

Klinefelter Syndrome, 48-XXXY
I am looking for parents of children with Klinefelter syndrome or 48-XXXY. My 14-year-old son has this condition. He has a lot of problems, but his doctors don't know if they are all related to his chromosomal abnormality.

P.T., Pennsylvania

EDITOR'S NOTE: Information on Klinefelter syndrome is available from: Klinefelter Syndrome and Associates, P.O. Box 119, Roseville, CA 95661, and Klinefelter Syndrome Association of America, P.O. Box 93, Pine River, WI 54965. The National Institute of Child Health and Human Development (P.O. Box 29111, Washington, DC 20040, 301/496-5133) also offers a booklet with up-to-date and very complete information on this condition. Ask for UNDERSTANDING KLINEFELTER SYNDROME: A GUIDE FOR XXY MALES AND THEIR FAMILIES.

Identical Twins Who Are Different
We are the parents of 10-month-old identical twin boys. I had a complication of pregnancy called twin-to-twin transfusion. To explain it simply, blood intended for one twin (the donor) was diverted to the other (the recipient).

The twins were born seven weeks prematurely. One of the twins (the donor) has been diagnosed with spastic quadriplegic cerebral palsy and a cortical vision impairment. He also developed infantile spasms at six months. The other twin is developing normally. We also have a three-year-old daughter.

We would love to hear from other parents of twins—especially identical twins. We would like suggestions for coping...
Vomiting Problem

J.K. & T.K. (June 1994) are the parents of one-year-old Jimmy, who was born with meconium aspiration and a grade-IV brain hemorrhage. Jimmy, who has cerebral palsy, a seizure disorder, cortical blindness, temperature instability, diabetes insipidus and a poor suck/gag reflex, is fed exclusively through a G-button. Jimmy had a G-tube, but it was replaced with a G-button when he was three months old, which was when he began vomiting. Since then, the amount of formula he can take in without vomiting has decreased from six to two ounces per feed.

Gastrointestinal scans show some reflux, but anti-reflux and stomach medicines have not helped. Jimmy has had trouble gaining weight, despite being fed every few hours with a high-calorie, concentrated formula.

Our 17-month-old son, Zachary, was also born with meconium aspiration and an unknown amount of brain injury caused by the lack of oxygen to his brain. Like Jimmy, Zachary has cerebral palsy and experienced seizures for a few days following his birth. He also has temperature instability and a poor suck/swallow reflex. Zachary is fed primarily through a G-tube, although he is capable of eating orally if we remain quite persistent.

To enable us to meet his total caloric needs, Zachary had a NG-tube inserted at three months of age. At nine months, this was replaced by the G-tube; at the same time, the Nissen procedure was done to prevent reflux. We began giving Zachary his feeds by venting his tube to allow for my air or vomiting episodes to occur out of his tube.

At about 12 months of age, Zachary began to exclusively vomit orally. His vomiting episodes had no particular pattern and did not seem related to the volume of his feedings. Zachary began to vomit large quantities—sometimes as often as five to eight times a day. Zachary has had the pH probe test twice and has also had the upper-barium test. Both tests indicated only a small amount of reflux and some occasionally fluctuating pH levels.

Like you, we have tried various medications—including Zantac, Reglan, Cisipride and Bethanecol—with no success. However, Zachary takes regular doses of Donital to calm his stomach, and it seems to be moderately successful. Zachary also suffered from inconsiderable irritability—the Donital has helped substantially in improving his mood without causing him to become lethargic.

We also use a high-calorie formula and have used a number of additives, from MCT oil to simple baby cereal. Although you did not say, we hope you have a feeding pump, as it does help in the slow continuous flow of the feeds. Zachary also has a lot of "pooling" of mucous in the back of his throat because of his poor swallowing reflex. We find that he vomits less frequently if we are able to keep this mucous under control. Elevating his upper torso during feeds seems to help.

Zachary's vomiting has decreased somewhat with age. We give him a slow continuous feed during the night to supplement what he needs for growth. Although we fight for every ounce, we have gradually been able to increase his weight.

K.C. & C.C., Georgia

EDITOR'S NOTE: J.K. & T.K. received a number of responses to their SEARCH letter. We invited Dr. David Hirsch (Ask the Doctor) to comment on these responses. Dr. Hirsch noted that almost all of the parents who responded described similar evaluations and trials of medications and formulas with their own children. Some of these may work on an individual child, often in conjunction with a formula change, a change in feeding method (e.g., drip versus bolus or open versus closed systems) or the addition of food additives (e.g., polyene, MCT oil or concentrated formula powders).

Dr. Hirsch noted that some children seemed to "outgrow" the problem. In others, a relatively easy solution (such as a change in positioning) or the use of a commonly available medication (such as Donital) made a useful difference. In another case, the diagnosis of a rare condition and its appropriate treatment "cured" the vomiting problem. While all cases are different, Dr. Hirsch added that most have significant similarities that may lead to relatively straightforward solutions.

Two Children With Spina Bifida?

D.H. & D.H. (August 1994) are the parents of a two-year-old daughter with spina bifida and a three-and-a-half-year-old son, who does not have a disability. They are thinking about having another child, but doctors have told them they would have a small chance of having another child with spina bifida. D.H. & D.H. wanted some insight on what life would be like with two children with spina bifida.

We read your letter and felt like you were talking to us! We have three children—Michael, 8, Colin, 6, and Bethany, 4. Colin and Bethany both have spina bifida.

We did not know Colin had spina bifida before he was born. Things happened very fast; in fact, his whole newborn period is a big blur in our memories. We grieved, read everything we could get our hands on and eventually came to terms with the situation. We tried to carry on and to make our lives as "normal" as possible. We even learned to feel fortunate because Colin's lesion was fairly low (L5-S1), and his prognosis for walking was good.

When Colin was about a year old, we began to discuss whether and when to have another child. We decided fairly easily that we wanted another baby because doctors told us we had a two to three percent chance of having another child with spina bifida. To us, that meant a 97 to 98 percent chance of having a healthy baby—so much for statistics!

Just as we had decided to wait a year to have another child—so that Colin would be walking better—we discovered the question was moot! The new baby would be born around Colin's second birthday. We immediately began shopping for a double stroller.

A level-II ultrasound at about 15 weeks gestation revealed that the new baby did, indeed, have spina bifida. Of
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course, we cried. Although we knew the risks and had been confident that we could handle having another child with spina bifida, we had hoped this baby would be okay. We took the ultrasound pictures to our neurosurgeon for a consultation. We learned that the baby’s lesion was in the L4 area, and that everything else seemed fine. With this information, and with what we already knew about spina bifida, we felt comfortable about our decision to continue the pregnancy.

We continued to monitor the baby’s development with frequent ultrasounds and made plans for a C-section. Things went well and we were thrilled to have a daughter.

Now, Bethany is four. It is hard to believe these years have passed so quickly! In a way, the first few years are hard to remember because we were so busy. It was hard to keep up with double diapers, two sets of braces and double therapy sessions. And going anywhere required a fair amount of planning and equipment. But we figured it all out and did whatever we would have done anyway. At first, we felt very conspicuous going places with our two strollers and two little pairs of crutches, but we soon got used to it.

We have found that having two children with spina bifida is not all that different from having one child with spina bifida. We both feel that it was easier the second time around because we were better prepared. We have even discussed the idea that having a sibling with a similar disability might actually be beneficial to a child, in that they feel less “different.” Having two children with spina bifida also helps us avoid putting too much pressure on one child.

Of course, having two children with spina bifida is no picnic! There are times when the little inconveniences can really add up, but we try to keep our sense of humor and to rely on friends for moral support. We also are aware of Michael’s needs—with so much time and energy devoted to the other two children, we try to make sure Michael receives his share of attention.

For us, the decision to have a third child was the right one. Bethany has such a strong, engaging personality that it is hard to imagine our family without her.

J.D. & E.D., Pennsylvania

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Obsessive Compulsive Disorder
P.P. (July 1994) has a 10-year-old son who has been diagnosed with obsessive compulsive disorder (OCD) and is currently taking medication. He also has some learning disabilities. P.P. wanted to "compare notes" with parents of similar children.

Our 11-year-old daughter was diagnosed with OCD a year and a half ago. Like your son, Laura has some learning difficulties; she also has a progressive hearing loss. We have found OCD to be another challenge in her life, but a manageable one.

Laura's OCD is manifested in compulsive hand washing. The symptoms became quite pronounced before we realized what was going on. Laura was quite distressed by her compulsions, so it didn't take us long to seek professional help. Fortunately, we were quickly referred to a child psychiatrist who has had experience working with children with OCD. He reassured us that it is a biochemical disorder, and is quite treatable. Laura has been on medication since her diagnosis and is doing very well.

Laura continues to have some difficult behavior, but as we have learned about OCD, some of it has become easier to understand and manage. Laura has always been somewhat anxious and fearful, and does not adapt easily to change. We have learned to give her clear, concrete directions and plenty of warning when her routine needs to change. She responds well to structure and becomes anxious when she has "time on her hands." She enjoyed going to day camp several weeks this summer.

Laura has always behaved well at school, but she needs structure in that situation, too. When she was younger, it helped her to have a written schedule for each day.

We have discussed OCD with Laura's teachers. None of them had previous experience with this disorder, so we felt it was important for them to understand the anxiety that is part of the condition. They have all been very supportive, and have been able to give Laura reassurance when she needs it. If Laura's teachers had not been willing to 

continued on, page 76

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Circle #103
"Moo-ve over, sis," says Kyle Blecha (right). Big sister Rachel Blecha was the cutest little bunny in Kewaskum, Wisconsin last Halloween. Rachel, now 3, has cerebral palsy. She loves to play outside on her swing and with her new puppy, Rose.

Lee Joseph Grube is a very happy little boy who loves to show off for friends and family. Dressed as a pumpkin last Halloween, he got his fair share of attention. Lee, who will be two years old in January, has multiple disabilities. He lives with his parents Lee and Angela in Champlain, Minnesota.

He didn't scare too many crows last Halloween, but three-year-old Michael Andrew Verdin of Tulsa, Oklahoma did a great job of trick-or-treating. Michael has tuberous sclerosis.

It was no wonder Matthew Charland, 5, of Manassas, Virginia, made a jolly jester last Halloween. Matthew, who has Kabuki Makeup syndrome, is always entertaining everyone with his sense of humor and funny antics, says his mom, Amy.

He may have been "Oscar the Grouch" for Halloween, but Jeffrey John Lewis, 5, was a happy grouch when he won two prizes for his costume. Jeffrey, of Esopus, New York, had a left hemispherectomy in July 1993 to remove Rasmussen syndrome, a rare brain disease. Although he was left with some paralysis on his right side, it doesn't stop him from doing much.
Grandpa Gino Fioravanti enjoyed spending last Halloween with this little tiger from Penfield, New York. Nicholas Fioravanti, 3, loves to dress-up for Halloween, says mom Julie. Nicholas has cerebral palsy.

Who says trolls can't be cute? Donna Jensen says daughter Annan Leigh Jensen "is the cutest troll I know." Twenty-eight-month-old Annan was born with tracheomalacia and now has cerebral palsy. Annan lives in Gulf Breeze, Florida.

With a mobile of flying bats and ghosts above her head, witch Desirie Lord, 8, clutches her broom and prepares for a night of tricks and treats. Her mom, Elizabeth, says she always tries to make Desi's wheelchair a part of her costume. Desi, who has cerebral palsy, lives in Centreville, Virginia.

Linda Fa'nestock (right) and her granddaughter, Jordynn Rae Lakatos, made a great pair of Raggedy Anne twins with the costumes Linda made for Jordynn's school Halloween party two years ago. Jordynn, now 6, lives in Torrance, California. She is undiagnosed, but has microcephaly, a seizure disorder and other disabilities.

Kristin Costanzo, 7, loves to clown around at Halloween. Kristin, of Altamonte Springs, Florida, attends a private Catholic school and enjoys ballet lessons. She has Down syndrome.

Where's Tinkerbell? Brothers Joseph Keawe Broc and John Kealoha Broc won first prize for their Peter Pan and Captain Hook costumes at a contest sponsored by a shopping center near their home in Haleiwa, Hawaii. The boys' grandmother, Juanita, made the costumes—even sewing long ringlets of hair to the inside of John's Captain Hook hat. Joseph, now 6, has spina bifida.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
Irritability

My 14-year-old daughter has cerebral palsy and hydrocephalus requiring a shunt. She is mentally retarded and nonverbal. She gets most of her feedings by gastrostomy button, but can eat some pureed foods which she really enjoys. The problem is that she has recurring episodes of irritability lasting from three to five days at a time. During these periods, she is irritable for three to four hours at various times each day and will not take any food by mouth. She may have five to ten good days in-between. We have taken her to the doctor for this, but she always seems to be fine in the doctor's office.

These recurring bouts of irritability make it difficult to plan family social events or for my husband and I to go out and leave her unless we have skilled respite care. Is there anything we can do to find out the cause of this irritability and help her through these times?

Irritability, in a child with a disability, whatever the cause, is one of the most difficult and frustrating problems for both parents and health care providers—not to mention how frustrated the child may become. In individuals with multiple medical problems and the inability to communicate, the cause of the irritability can be very difficult to determine. Acute (sudden, short-term) irritability may have an obvious cause such as an ear infection, gastritis (stomach flu) or trauma. With chronic (ongoing, long-term) irritability, the cause may not be complicated even though it is not immediately obvious. To further complicate the diagnostic process, an irritable child will often be fine when brought to the doctor's office. Nevertheless, chronic irritability is extremely stressful for the child and parents, and as you pointed out, can make it extremely difficult to schedule family functions.

Chronic irritability may have multiple causes, but major causes can be categorized as physical (most cases) and psychological:

- **Gastrointestinal reflux (abnormal backflow of stomach contents)** is probably one of the most common physical causes of irritability, especially for children with cerebral palsy who are tube fed. Symptoms of reflux may include vomiting or poor weight gain. Sometimes, however, irritability may be the only symptom.

  - Some forms of reflux are easily treated with changes of feeding methods, for example using the drip method (where the feeding is given slowly over a number of hours) as opposed to bolus (where the feeding is given over a much shorter time period at a much faster rate). Venting, opening the button or feeding tube to allow more air to escape from the stomach, may decrease reflux, too. A doctor may also prescribe medications or changes in positioning.

  - More severe forms of gastrointestinal reflux may require more complicated evaluations by your child's physician or a gastroenterologist, and more aggressive treatment.

- **Chronic constipation** is another very common problem in children with disabilities. If you have ever suffered from "irregularity," you know that it can be painful and can become a chronic problem if left untreated. Modifications of diet and the use of natural laxatives, fiber or other approaches recommended by your child's physician may take care of this problem. (See Ask The Doctor, July 1994.)

- More severe gastrointestinal disorders such as gastritis, ulcers and other forms of digestive tract dysfunction may also cause chronic, recurrent irritability. Diagnosis of these conditions may require extensive evaluation.

- **Orthopedic problems** such as dislocations, especially of the hip, and subtle fractures, often not associated with known trauma, may be aggravated when the child moves. This causes pain and irritability. X-rays or other imaging studies may be needed, especially after a thorough examination reveals a painful area.

Ask the Doctor is a regular department of EXCEPTIONAL PARENT in which questions from readers are answered by David Hirsch, M.D., a board-certified pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Whenever possible, Dr. Hirsch makes specific suggestions. However, since Dr. Hirsch is responding to letters and will not have personally examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch occasionally mentions specific products or medications, he is doing so to illustrate his suggestions; he is not endorsing any specific product.

To submit a question to Dr. Hirsch, write or fax: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.
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SPECIAL HOLIDAY RATE!
Certain neurological problems may also be difficult to detect in children who cannot communicate. Migraine-like headaches may cause pain and irritability which is periodic but not usually daily. In children with other neurological problems such as cerebral palsy, some of the other symptoms seen in classic migraine, such as sensory and motor disturbances (certain visual disturbances, temporary paralysis or numbness of an extremity among others), may not be recognized.

Central nervous system shunts are special plastic tubes that drain excess fluid from the ventricles of the brain. A child with a shunt that is working only intermittently may experience episodic pain and irritability without the more pronounced symptoms of a sudden shunt failure. If there is any question about the functioning of your daughter’s shunt, her pediatrician or neurosurgeon should be contacted.

The effects of medications and combinations of medications that are used on a continual basis may cause irritability by themselves or may lead to other problems, such as gastritis, that cause irritability.

If your daughter has started menstruating, especially if she has had periods for a year or two, she may be experiencing periodic bouts of cramping. This is another potential source of episodic irritability.

A feeding anxiety or aversion is a possible psychological cause for irritability. If your daughter has had previous experiences with feedings that made her physically uncomfortable, she may have developed worries or fears about the act of eating. In this case, she would probably be more likely to seem irritable around feeding times. If possible, it may help to eliminate those factors that seem to make the child uncomfortable with feeding. If necessary, trying a different feeding method may work.

Psychological problems are harder to diagnose in children who have severe medical problems. Many health care providers feel that a child with a medical condition such as cerebral palsy cannot also have psychological problems such as depression, anxiety and/or compulsive behavior. This mistaken belief is especially common if the child in question is mentally retarded. But my experience suggests that psychological problems, especially those described above, are at least as common in children with disabilities.

Your child’s pediatrician should be able to refer you to a neuropsychologist or a developmental psychologist or psychiatrist who has had experience treating children and adolescents with developmental disabilities. These are the more common causes of irritability that I see daily in my practice. There are many others. Please consult your daughter’s physician for further evaluation.
Funding Power Wheelchairs

Q I have a five-year-old son with cerebral palsy. He is not able to walk on his own, but he has the ability to get around with a children's power wheelchair.

My insurance company will only cover the costs for a manual wheelchair. Is it possible to get coverage for a power wheelchair if it is recommended by a therapist? Also, is it likely the insurance company would cover the cost of buying a used power wheelchair?

A When people purchase a health insurance policy, they often assume that the insurance company will provide reimbursement for the cost of all medical services and equipment, aside from the usual deductibles and co-payments. That’s a reasonable assumption, but it’s not always the way the system works.

Many insurance policies specifically exclude coverage for certain services or equipment, including power wheelchairs—sometimes listed as “durable medical equipment.” The first question, then, is whether your insurance policy has such an exclusion. That information should be clearly listed in your policy manual (if it’s a group policy, check the “master contract”).

If no exclusion of power wheelchairs is listed, you need only to demonstrate that the equipment is “medically necessary.” That requires “documentation”—letters from your child’s doctor and physical or occupational therapist describing your child’s condition and explaining why he cannot use a manual wheelchair.

It is important to ask the doctor and therapists also to list any additional wheelchair-related equipment your child may need, including special seat belts, switches, remote-control devices or other items. If additional equipment is listed in the original claim, and is medically necessary, the insurance company may pay for it. But if it is not part of the original claim, many insurance companies will pay only for the wheelchair.

Some insurance companies require that power wheelchairs meet certain specifications before they will pay for them. One way to ensure that your choice meets those specifications is to file a request for the insurance company to make a “pre-determination of benefits” before you purchase the chair. (Check with your insurance company to determine the procedure and forms the company requires.) The process generally takes three to four weeks. The insurance company usually will respond with a written statement approving or rejecting the claim.

Power wheelchairs and related equipment can be expensive. And since children’s needs may change rapidly, it is not unusual for a child to need a new power chair every three or four years. If such items are not covered by your health insurance policy, you may wish to try to find a policy that does cover them. Large group insurance policies—generally offered as an employee benefit in a large company—frequently have the fewest exclusions.

Alternative Funding

If it is not possible to switch to an insurance policy that provides coverage for power wheelchairs and related equipment, another alternative is to try to obtain funding from local charitable or civic groups, or from state agencies. Although the main function of state vocational rehabilitation agencies, for example, is to help people with disabilities make the transition to full employment, these agencies or others may occasionally provide funds for medical equipment for children as well.

In addition, some state health departments include a program designed to help meet the medical needs of children with disabilities. That program may be able to provide funds for the purchase of a power wheelchair for a child. Under certain circumstances, the local public school district may also be able to help, as long as the need for the power wheelchair is included in the child’s Individualized Educational Plan (IEP).

Used Wheelchairs

Insurance companies usually don’t deal with used equipment. In fact, they generally won’t even accept the return of a used power wheelchair when the company is replacing it with a new one. Insurance companies could, I think, perform an important public service by donating used power wheelchairs and other expensive equipment to social service agencies and needy families.

In this column, Richard Epstein answers readers’ questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742. If your question relates to a specific health insurance claim, please include copies of any materials you’ve received from the insurance company. (Please, don’t send originals!) Include your address and phone number. To insure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.
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Harelyn Rousso is the founding director of the Networking Project for Disabled Women and Girls in New York City. She is the author of DISABLED, FEMALE, AND PROUD! and executive producer of the documentary video, POSITIVE IMAGES: PORTRAITS OF WOMEN WITH DISABILITIES. She is a member of the board of directors of the Ms. Foundation for Women, the editorial advisory board of EXCEPTIONAL PARENT and a former commissioner with the New York City Commission on Human Rights.

Rousso began painting about six years ago because of a "real desire to do something that was a little less intellectual and a little more visually oriented." She says she wants to include more people with disabilities in her paintings "because I don't think we see ourselves out there in the art world."

I was, in my mother's mind, very eager to be born because I wanted to arrive before the doctor even got to the hospital. My mother didn't know I had a disability until I was about one and a half, when I seemed to be somewhat delayed, particularly in walking. Doctors told her she was a hypochondriac on my behalf. When I was finally diagnosed with cerebral palsy, she didn't know too much about it. The doctor told her that although I had cerebral palsy, I was very smart and should be kept away from other kids with disabilities and raised like a "normal" child. I think this attitude was a reflection of a time when people didn't expect or realize people with disabilities were normal.

I attended public schools in New York City. If the principals had any hesitations about my enrollment, my guess is that my mother talked them out of these doubts fairly quickly. Throughout my school years, I never knew other students with disabilities. If there were others, I never saw them. At that time, special education classes were even more segregated—they were much more like separate schools.

I only had friends without disabilities. I played all of the games, including punchball. I may not have played as well as kids without disabilities, but I did well enough to be part of the group. Of course, there were also the kids who made fun of, pointed at and ostracized me. They—particularly the older boys—would ask what my problem was and they would imitate me.

The teasing was very painful, but I also felt like, "This is who I am, this is my body, this is how it looks, this is how it acts. I want to be me. I don't want to have to live up to people's expectations." Sometimes I would look in the mirror and be surprised at what I saw. In a way, I felt like everyone else, but I was confronted with some images that said I was different, and it was startling. I think I began to feel even more isolated in my teenage years when the focus shifted from just playing games to the social scene.

A Social and Sexual Life?

During my teenage years, my friends started dating, thinking about boys, getting periods and developing breasts. Although I went through all that, I felt that I was not going to be part of the dating scene and that sex, marriage and children were not possible for me. My sister, who is five years older than me, taught me some things and I learned others by observing other kids or by reading pamphlets.
about menstruation in Kotex boxes. However, I didn’t think the information had much relevance to me. I concentrated instead on my studies. I thought my role was to do very well in school and to get good grades and just to achieve. It wasn’t until I was in my 20s that I began to consider the possibility of a social and sexual life.

**Overcoming Stereotypes**

When I was 22, I had an unexpected, but important experience. I worked one summer for a prominent woman economist who had cerebral palsy. When I interviewed for the position, it was like looking in a mirror. Her effects on me are still with me. I was impressed that a woman with cerebral palsy could become so successful in her career, particularly in the “man’s field” of anti-trust economics. Married to a wonderful man, Betty gave me the ability to see that I could have both a career and a social life.

My self-esteem really began to improve when I found a career I liked, being a psychotherapist. However, my road to a career was not an easy one. When I completed a Master’s degree in social work, I went on for advanced training in psychotherapy. After attending a psychotherapy training institute for a year, I was asked to leave because some of the teachers did not think that a person with my disability should become a psychotherapist. They claimed that my disability would be too stressful for patients to handle. They suggested I consider a different career. It was shocking to me—the super achiever who had always done so well was told she couldn’t succeed. Consequently, my life as a disability rights activist began after I successfully sued the institute.

**The Women’s Movement**

At some point I achieved a certain level of self-confidence to be able to consider not just my brains, but my whole self. I wanted more than just to be smart. I became involved in the women’s movement. Although I was the only woman with a disability involved with my women’s groups, I had a real sense of commonality with the other women. I realized that a lot of reasons that I felt different—my body wasn’t right, I didn’t look a certain way or I wasn’t graceful—were the same for women without disabilities. I felt much more a part of the sisterhood of women than ever before.

**Networking Project for Disabled Women and Girls**

In 1984, I approached the YWCA of New York City to sponsor a mentoring program I wanted to start for girls with disabilities. Named the Networking Project for Disabled Women and Girls, the project allows women and girls with disabilities to meet and share experiences. I wanted to help girls with disabilities avoid certain things that I had experienced, especially the isolation and the acceptance of negative stereotypes. Participants in the project talk openly about various topics, from jobs to relationships and sex. Here, women and girls can see others who are doing interesting things in their lives, who have parties, children, jobs and lives. I want girls to feel OK about themselves at age 13 rather than waiting until age 30.

**Disabled, Female, and Proud!**

A few years after I started the Networking Project, I wrote a book to help young women with disabilities learn about the experiences of women who had “been there.” Published by Exceptional Parent Press in 1988, Disabled, Female, and Proud! profiles 10 women with disabilities.

Rousso began painting about six years ago “because of a real desire to do something that was a little less intellectual and a little more visually oriented.” She wants to include more people with disabilities in her paintings.
Roussos has been involved with her partner, Gene Brown, for eight years. "I have a wonderful relationship," she says. "For him, my disability is part of the many parts of who I am."

their Operation SMART program that addresses the under-representation of girls and women in science and math so that it is accessible to girls and young women with disabilities. More jobs require a knowledge of scientific principles, but because girls with disabilities are stereotyped as helpless, dependent and not smart, they are denied exposure to math and science. The program's goal is to develop a curriculum for girls with and without disabilities to learn math and science together and to obtain the needed skills, attitudes and opportunities to pursue science and math courses and careers.

Looking back
I guess it would have helped me to have had relationships with adults and peers with disabilities who I could have looked up to. My parents were a product of their generation; they believed if you had a disability you couldn't have a social life.

Hopefully, things have changed. Parents should be more hopeful that their daughters can have relationships and be socially active, and should express that hope to their children with open and honest discussions. I would love girls to have a real sense of pride in their femaleness, pride in being precisely who they are—disabilities and all. I deeply feel that every woman really has wonderful potential and that she needs to have friends and family and an environment that helps her to celebrate herself.

DISABLED, FEMALE, AND PROUD! is available through the EXCEPTIONAL PARENT LIBRARY for $12.95 plus postage and handling. To order, call (800) 535-1910.

For more information on Positive Images: Portraits of Women with Disabilities (not available in home-video-cassette format), contact Women Make Movies, Inc. at 462 Broadway, Ste. 500, New York, NY 10013 or call (212) 925-0606.
Grieving a Dream
by Susan Blanchard

In March 1992, my first and only child was born. I had a delightful pregnancy; despite some nausea at the beginning, I was very happy being pregnant. I loved feeling my child inside me. I envisioned a labor ending with my child being laid upon my chest, everyone smiling and happy.

I didn't get the dream I envisioned. Marie was born not breathing. Doctors immediately carried her to a table on the other side of the room to be revived, then rushed her out of the room to the neonatal intensive care nursery. Alone in the delivery room shortly after her birth, her father and I wondered if she would live. We cried, but mostly we were in shock. Nothing could have prepared us for a birth like this.

Later, when I learned that my daughter had cerebral palsy, I didn't just cry; I wailed. I went home and I cried and I wailed and I was very loud about it. I did not like this news; I did not want my daughter to have a disability.

Taking the Blame
I believed God was punishing me for past sins—if only I had done something differently, my daughter would not have cerebral palsy. If only I had picked a different doctor; if only my body had not been in labor so long; if only I had finished that art piece before her birth. It was easier to take the blame for Marie's condition than to accept it.

I desperately wanted to talk with other parents who had been through similar experiences. I finally found a group sponsored by the Arc of Multnomah County—a seven-week support group entitled "Accepting a Difference." The parents in the group discussed how hard it had been to find emotional support for our experiences. How wonderful it would have been if someone had been there to offer support immediately following a traumatic birth, someone to counsel us during and after the initial diagnosis.

Finding other parents who understood my pain helped me to stop blaming myself for Marie's condition. I began to see the child beyond the disability. Even though I didn't get the daughter I had dreamed of—one who could walk and talk and move independently, I had a daughter who was beautiful, sweet and happy. Still, the “dream child” I had wanted hovered in my consciousness, sometimes blocking the view of my real-life daughter.

Grief Ritual
Other members of the group suggested that I do a “grief ritual.” As soon as I heard these words, I knew I would do this ritual, and that it would be important for my mental health and for my relationship with Marie.

I began by leafing through magazines to find pictures of my “dream child”—the child I didn’t get. I cut out any picture that moved me. I especially looked for pictures of the ideal birth where everyone is smiling and the wet, shining baby is laid on the mother's chest. I found pictures of babies sitting up and crawling, of young girls running and playing.

I cut out a paper doll from a large piece of blank paper and was amazed that holding this piece of paper to my chest caused me to cry. I glued my dream child pictures all over the paper doll. I decorated her with glitter, paint and colorful markers. I cut out a back for her, and stuffed her with more of my “dreams.” I wrote the ideas that corresponded to each of my dreams directly onto the pictures I had cut out. It was important to make this paper doll as real as possible, to name each of my dreams and to bring them into the light so they could no longer haunt my subconscious.

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Paul Blanchard with Marie, 15 months.

After my paper doll was stuffed and decorated, I held her in my arms and cried some more. This was my dream child; I wanted to hold her, but I knew I needed to let her go. I love the daughter I have; I didn’t want my grief about her disability to get in the way.

Four friends gathered to help me with the ritual. Each of them shared stories of lost children and lost dreams.

I had decided to burn this dream child—to transform her energy and let her float away. So, after discussing my dreams with my friends, I put the paper doll in the fireplace, lit a match and let her go.

then presented my dream child to my friends and shared my dreams with them. I talked about all the things I had wanted but didn’t get. I had decided to burn this dream child—to transform her energy and let her float away.

So, after discussing my dreams with my friends, I put the paper doll in the fireplace, lit a match and let her go.

After the fire died down, I shared the dreams that became reality for me—a wonderful pregnancy, being able to breast-feed, a loving and playful child. This process helped me to realize that although my child has a disability, many of my dreams about motherhood did come true.

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Finding Freedom

In the short time that has passed since I performed this ritual, I have felt a great sense of relief. I realize, however, that the grief process is a continuous one, and I will continue to seek support from other parents, my friends and my family.

I encourage other parents who have a child with a disability to be aware of the need to let go of their “dream child.” A personal ritual or a simple prayer may allow you to express your grief in a safe way. Learning how to accept what is—and to let go of what had been hoped for—can be very liberating.

Our culture is not very practiced in expressing sorrow. Sometimes we feel guilty when we express disappointment or sadness. But if we don't express our grief, it will covertly affect us and those around us—most of all, it will affect the child with a disability.

I encourage other parents to get the help and support you need to deal with the sadness and disappointment that can come from having a child with a disability. Letting go of your dream child will give you and your real-life child the freedom to find your own way to a happy life.

Susan Blanchard is a legal secretary who lives in Portland, Oregon. She is an artist, avid nature walker and believer in magic.

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• EXCEPTIONAL PARENT / OCTOBER 1994

734
THE ONLY PRESCRIPTION FORMULATION OF LEVOCARNITINE IS NOW AVAILABLE FOR REIMBURSEMENT

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- CARNITOR® is the only prescription formulation of levocarnitine available and "...should not be confused with dietary and health supplement L-carnitine products.... Such supplements have not undergone review by FDA for safety and effectiveness."¹
- "Unless these dietary supplements...have been approved...recommendations/requirements by State Medicaid agencies would be inappropriate for the treatment of systemic carnitine deficiency."²
- "The data from this and previous studies indicate a lack of quality control in the manufacturing process of tablets and capsules in products sold as food supplements, resulting in gross inconsistencies in the properties of the tablets to disintegrate under physiological conditions within a reasonable time. Furthermore, there is evidence that many of the products contain significantly less than the stated amount of the active substance, suggesting also a lack of quality control in the formulation of the product."³
- "Only the prescription form of levocarnitine is indicated for the treatment of carnitine deficiency. Over-the-counter and health food store products should never be substituted."⁴

The Only Prescription Formulation!
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CARNITOR®
(LEVOCARNITINE)

Please see full prescribing information on adjacent page.

Circle # 287287 35

Sigma-tau Pharmaceuticals, Inc.
A leader in metabolic research
CARNITOR® (LEVOCARNITINE) Tablets and Oral Solution

For oral use only. Not for parenteral use.

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g per 10 mL multidose)

CARNITOR® (levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency.

Carnitin Tablets and Oral Solution are also indicated for the acute and chronic treatment of patients with an inborn error of metabolism which results in a secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS

General
CARNITOR® Oral Solution is for oral/internal use only. Not for parenteral use. Gastrointestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquids to reduce taste fatality. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3–4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility
Mutagenicity tests have been performed in Salmonella typhimurium, Schizosaccharomyces pombe, and Saccharomyces cerevisiae, and not indicate that CARNITOR is mutagenic. Long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine.

Pregnancy
Pregnancy Category B
Studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion


Pediatric use See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D, L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D, L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient bluets or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD50 of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSEAGE AND ADMINISTRATION

CARNITOR® Tablets: Recommended adult dosage is 980 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which Is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 5 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assuring tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED

CARNITOR® Tablets are supplied as 330 mg, individually foil-wrapped tablets In boxes of 90. Store at room temperature (25°C/77°F). CARNITOR® Oral Solution is supplied in 118 ml (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection

For Intravenous Use Only
CARNITOR® (levocarnitine) Injection 1 g per 5 mL
CARNITOR® (levocarnitine) Injection 10 g per 100 mL

Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:

For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS

CARNITOR® Oral Solution, and Ampoules for Intravenous Use...
As a first-year special education teacher in the late '60s, Sandy Gordon was appalled at the way her students were treated. "My kids were basically ostracized," she remembers. "Not only did other kids make fun of them, but so did the teachers and the principal. I saw what it did to their self-esteem. It was horrifying." Gordon vowed that someday she would do something to change things.

In 1987, as a senior vice president for corporate communications at the National Easter Seal Society, Gordon saw her opportunity to make a difference. Campbell-Mithun-Esty (CME) Advertising, Minneapolis had offered to provide creative services at no charge for Easter Seals’ multi-media public service advertising campaigns. In the first months of this collaboration, Gordon and CME designed Easter Seals’ Friends Who Care television and radio public service spots, print ads and posters.

Originally targeted to middle school students, the multi-media campaign generated hundreds of requests from elementary schools for materials to use in disability-awareness workshops. A grant from Ronald McDonald Children’s Charities allowed Gordon and her staff to begin developing a hands-on teaching curriculum for elementary students.

In 18 months of research, writing and classroom testing, priorities for the Friends Who Care curriculum became apparent. First, the program had to use humor and an "in-your-face" approach to challenge negative attitudes about disabilities. Second, it had to provide essential information about the types of disabilities students were likely to encounter, and about the range of abilities within each disability. Third, enhancing the curriculum and helping people get beyond stereotypes and sympathy required guest speakers with disabilities; curriculum planners created guidelines for students and teachers to invite people with disabilities to talk about how they do things. This proved especially effective in allowing kids to see Brailled magazines, try out Ms (which enable people who are deaf to use the telephone), learn words in sign language or see and touch racing wheelchairs.

In the fall of 1990, the Friends Who Care disability-awareness program was introduced to 20,000 schools nationwide. Kits included a 16-page teacher’s guide—written in a style that would inform teachers without insulting them; a pre- and post-program attitudes survey; worksheets to expand the activities for sections on vision, hearing, learning, developmental and physical disabilities; guidelines for guest speakers; five posters; bookmarks with tips for disability etiquette and a 45-minute videotape to accompany specific activities.

Teachers have been enthusiastic. More importantly, students have written to Gordon about their enthusiasm for the program. "Your program has made me look at disabled
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people with a whole new perspective," wrote Justin Dwyer of Wisconsin.

"I had a lot of fun. Now I know disabled people can do just about anything anyone can do," Krista Zywicki said.

Gordon wishes that we no longer needed to be teaching teachers and students about disabilities. "We're still a long way from fully accepting people with disabilities as people, and seeing them as individuals who have something to offer as students, friends, employees and volunteers in our communities."

But five years into the program, Gordon is optimistic and emphasizes that Friends Who Care is a starting point for the integration of students with disabilities into regular classrooms. "We can't begin to address the needs of students with disabilities in school without understanding what it means to have a disability."

Sarah Brewster, assistant vice president of corporate communications for the National Easter Seal Society, has been working with the Friends Who Care program for five years.

A Friends Who Care curriculum kit costs $25. Each kit includes a 16-page teachers manual, worksheets, letters explaining the program to parents, a 45-minute video, classroom posters and other materials that may be reproduced. To order, write or call: National Easter Seal Society, 230 W. Monroe St., Suite 1800, Chicago, IL 60606; (312) 726-6200, voice or (312) 726-4258, TTY.

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Circle # 217
Everyday Heroes
Playing is one way that children experience and make sense of the world around them. Play helps children develop intellectual abilities, including language. They learn social skills through interacting with other children. And participating in physical activities improves strength and coordination.

Toys are an important part of play. Providing appropriate toys for children with disabilities may be challenging, but it can be done. Playing with toys can teach children about cause and effect. Most importantly, opportunities to control objects or events in the environment leads to feelings of success, self-confidence and mastery.

**Commericially-Available Products**

Often, widely-available commercial products are appropriate for many children with disabilities or require only simple adaptations. (For some examples, see pages 42-45.) Such products include magnetized shapes and letters, various kinds of building blocks, small musical key-boards or large ones that can be walked on, pop-and-go cars, large crayons of different shapes, books, sound-activated toys (see page 40) and marble chutes.

Minor changes may make it possible for children with disabilities to play with an existing toy. For example, changing the rules of a game may help a child with mental retardation, or a scooter board could supply the necessary mobility for some children to reach toys and explore their surroundings.

For a child with a motor impairment, restricting the movement of a toy—with a tray, box lid or pillows—may be the only necessary adaptation. Toys also will stay within reach if they are tied to a pegboard with string. Magnets, suction cups or Velcro may be another way to stabilize a toy. Rubber pads or light-weight carpet padding that is cut to fit the base of a toy is another good way to prevent skidding.

For some children, toys will be easier to grasp if handles are added or enlarged. Hanging or suspending toys within a child’s reach may also help. A cubicle with several hanging toys can be constructed for a child who is blind. Children with visual impairments may enjoy tactile or Braille books, cards, dice and games, as well as gloves, frisbees and balls that beep. Many such toys are available through catalogs.

**More Complex Adaptations Using Switches**

Electronic games and battery-operated toys can be controlled by switches. Switches may also be used to control computers, environmental-control systems, appliances, cassette players and communication boards. Switches are available in many styles, shapes and sizes, and can be activated with various type of physical movement.

Many mail-order companies sell switches and adapted toys. Parents, teachers or therapists may also adapt toys for a specific child.

Inexpensive switches and battery adapters can be made at home with minimal training. For example, one easy and low-cost adaptation requires only the purchase of an inexpensive foot switch at Radio Shack or a similar store. The jack on this unit will fit directly into the remote jack of a standard cassette tape player. Unscrew the casing and replace the springs with foam so the switch will respond to a light touch. Many children enjoy being able to control a tape recorder to listen to music or talking books.

Several videotapes provide step-by-step instructions for making a variety of switches for various toys.
The Toy Guide for Differently-Abled Kids

The Toy Guide for Differently-Abled Kids is a 20-page booklet that aims to provide guidance to adults in selecting "off-the-shelf" toys for children with disabilities. A joint initiative of Toys "R" Us and the National Parent Network on Disabilities, the booklet provides full-color pictures and descriptions of more than 75 toys. Each toy is ability-coded for children with different disabilities. To receive a free copy, circle number 50 on the reader response card on page 67. (Please allow 3–4 weeks for delivery.) You may also pick up a copy at your local Toys "R" Us store.

Characteristics of Good Toys:

Whether toys are borrowed or purchased, some criteria for toy selection may include:

- **Fun**: Is the child enthusiastic about using the toy?
- **Age-appropriateness**: Do other children of the same age play with similar toys?
- **Ability level**: Does the toy match the child's current abilities?
- **Interactivity**: Does the toy move, make a sound or respond to the child's actions in some way?
- **Learning potential**: Will use of the toy contribute to the development of physical or intellectual abilities?
- **Socialization potential**: Does the toy promote interaction and communication with others?
- **Control**: Can the child operate the toy with minimal assistance?
- **Durability**: Is the toy sturdy enough to last with repeated use?
- **Safety**: Chose toys made from non-toxic, nonflammable materials without sharp edges or small parts that may be removed or swallowed. Watch out for strings or elastic that may entangle the child. Use only safety-inspected electric toys that plug into standard household electrical current.

The condition of a child's toys should be monitored over time. Make sure batteries do not leak. Broken toys should be repaired or discarded. Frayed cords and wires can be replaced.

Providing play experiences for children with disabilities may involve hunting for appropriate commercially-available toys, making simple or more complex adaptations to existing toys or purchasing already-adapted toys. Through play, children can make choices, discover new ideas.

Toy Libraries

Probably the best way to try out different kinds of switches and toys is through a toy library affiliated with Lekotek or USA Toy Library Association. Toy libraries lend out toys, like a regular library lends books. See pages 46–50 for more information.
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Circle # 202

The Battery Interrupter
This small device offers big benefits
By Steven E. Kanor

A little device called a battery interrupter allows parents of children with disabilities to easily adapt any battery-operated toy so it can be operated with a switch. The battery interrupter has a jack at one end and a disk at the other. To use it, slip the disk between the batteries of a toy and plug the jack into any of the special switches made for children with disabilities. Now, a child can operate the toy by activating the switch.

With the battery interrupter, there is no need to modify each toy separately or spend money buying already-adapted toys. You can use the battery interrupter and appropriate switches with any battery-operated toy. The battery interrupter can be removed when the toy wears out or breaks, and you can use the same battery interrupter in any other toy that takes the same size batteries.

The battery interrupter may be purchased from Toys for Special Children, 385 Warburton Ave., Hastings-on-Hudson, NY 10706, (914) 478-0960. The battery interrupter is available for AA, C and D batteries ($9 plus shipping and handling) and 9-volt batteries ($13 plus shipping and handling).

Dr. Steven E. Kanor is a rehabilitation engineer and founder and CEO of Toys for Special Children/Enabling Devices, a small company making 100,000 devices a year for people with physical disabilities.

Adapting a Toy With the Battery Interrupter

Everything you need: (clockwise from left)
A switch, a battery-operated toy, batteries and the battery interrupter.

Position the battery interrupter.

With the battery interrupter in place, close the lid of the toy's battery compartment. The battery interrupter is now installed.

Once the battery interrupter's jack has been plugged into the switch, the toy can be controlled by the switch.
acquire self-confidence and acquire the skills that will allow them to develop to their fullest potential—and have fun!

Marilyn Hammond is a training and public awareness specialist for the Utah Assistive Technology Program for the Center for Persons with Disabilities at Utah State University. She has a Masters degree in Instructional Technology and is pursuing a Ph.D. in Family and Human Development. She has one child, a seven-year-old daughter, Michelle.

The author acknowledges the assistance of Mary Cadez and Amy Henningsen for their content suggestions, Nancy Noha for additional toy resources, Grace and Jim Sisco and Don and Penny McMahon for photographs and Martell Menlove for his support.

Guide to Toys for Children Who Are Blind Or Visually Impaired

The Guide to Toys For Children Who Are Blind Or Visually Impaired is a joint initiative of the Toy Manufacturers of America and the American Foundation for the Blind. The 20-page Guide provides full-color pictures, descriptions and age ranges for 70 commercially-available toys that are especially appropriate for children with visual impairments. To receive a free copy, circle number 194 on the reader response card on page 67. (Please allow 3-4 weeks for delivery.) You can also receive single or multiple free copies by sending a postcard to Toy Manufacturers of America, 200 Fifth Avenue, Suite 740, New York, NY 10010. The postcard should say that you want the Guide and should specify the number of copies requested.

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In a nationwide network, Devereux provides services to individuals of all ages who have a wide range of emotional disorders and/or developmental disabilities.

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- foster care homes
- family counseling and therapy
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Forrest Pumps
A sound-activated water gun works without adaptations
by Jean Isaacs

When my son, Forrest, was about 15 months old, he got his first adapted toy—a police car complete with flashing lights and a siren. I remember holding out the big yellow switch as Forrest slowly moved his tiny fist to touch it. His eyes were so full of joy—finally, a toy he could control. Even with the big switch, Forrest had difficulty making the toy work; it was comparable to someone asking me to move a very large rock. Still, we all hoped that the fun of seeing the car move would motivate Forrest to gain more control of his arm movements.

A few weeks after the toy arrived, the therapist and I were working on Forrest's feeding skills while my other son, Fielding, was busy playing in our backyard sandbox. Involved in the therapy session, I didn't notice that the police car had been called upon to chase down a sandbox criminal. By the time I turned my attention back to Fielding, so much sand had been sucked into the motor that the toy no longer worked.

This incident prompted me to find a book about adapting toys. My first two attempts were disasters; following my "adaptations," the toys never worked again. The prices for switch-adapted toys in catalogs no longer seemed so unreasonable.

Finally, I took a class on adapting toys taught by Margaret Shuping, an instructor of computer technology in the Department of Special Education and Rehabilitation Counseling at the University of Kentucky. When I successfully adapted my first toy, I was empowered. Thus began an ongoing search for the next toy that would motivate my son to "move rocks." But the more toys I adapted, the less interested Forrest became in using switches to simply turn toys on and off.

Learning to Play
I began to realize that there was much more to this play stuff than first meets the eye. Parents of typical kids simply buy them toys and they play with them. Forrest demanded a higher level of involvement, and I discovered that I didn't know how to play with him. I hit the books and started learning about the developmental levels of play. This knowledge gave me a whole new perspective on how to play with both of my children.

Soon, Forrest and I had come up with a few simple games. One of Forrest's favorite switch activities was playing "airplane." This game involved using a flashlight that had been installed in a shoe box with red cellophane and white construction paper to create a "fasten-your-seatbelts" sign. When Forrest used the switch to activate the light, the rest of us jumped around as though we were on an airplane experiencing severe turbulence.

We also hooked a switch to a red light inside a small, plastic cup. Once strapped over Forrest's nose with elastic, he was ready for his part as Rudolph in the Christmas play. Another toy that kept Forrest's interest was a motorized water gun that we had adapted and placed on his wheelchair tray. This toy worked only as long as he could find "victims" to stand in front of his chair while he moved his hand onto the switch.

Around this time, Forrest's team of therapists and I decided to change the mounting of his switch from the wheelchair tray to under his chin. The chin switch gave Forrest a more efficient way to activate his electronic communication device.
Since Forrest no longer needed his hands to activate the switch, I mounted the water gun onto a Lazy Susan, hoping Forrest could use his limited arm movement to rotate the water gun and "aim." Due to his spasticity, however, the gun usually ended up aiming in a different direction than intended.

**Water-Gun Party**

Forrest's tenth birthday was coming up and after adapting every battery-operated car, truck and dancing bear I could find, I was fresh out of ideas. Then I saw a television commercial for “Shout N Shoot,” a hands-free, sound-activated, head-mounted water gun. Maybe this would work.

A week before Forrest's birthday, I located the water gun at the local Toys R Us. I asked the clerk if I could try it to see how much and what type of sound it required. We had tried other sound-activated toys in the past; they were either unexciting or required sounds that Forrest could not produce. I held the “Shout N Shoot” and made an "eep" sound. Water came pumping out of the gun. I made a slightly softer, lower sound and out pumped more water; then a quick sound, and nothing happened. The sound-recognition switch seemed to require only a one-second sound slightly louder than clearing one’s throat. Finally, I had found a toy that I didn’t have to adapt!

At Forrest's birthday party, he blew out the candles on his cake with his battery-operated fan and switch. Then, he opened the present from Mom. I strapped the gun onto his head and adjusted the microphone. Forrest made a short sound and out came some water.

He laughed, and out came lots of water. All his friends had been instructed that this would be a “water-gun party.” To Forrest's amazement, all his guests pulled out water guns and the fun began in earnest. Forrest quickly found he didn’t have to wait for someone to stand in front of him and wait for a soaking; all he had to do was shout and shoot!

Jean Isaacs lives in Lexington, Kentucky with her sons Fielding, 11, and Forrest, 10. Jean works for an Alliance for Technology Access center, the Bluegrass Technology Center for People with Disabilities, which operates an adapted toy lending library.

"Shout N Shoot," manufactured by Cap Toys, Cleveland, Ohio, is widely available at a suggested retail price of $15-20.
All of these toys have been used with success by children with special needs. Many are especially easy to activate and provide interesting sensory feedback. Through play, children with visual or hearing impairments can learn to make effective use of their other senses. Similarly, children with motor impairments need products that respond to and motivate active exploration. While trying to meet the special needs of children with various disabilities, we also recognize that children enjoy playing with the same products as their siblings, cousins or neighbors. Adapting ordinary toys can put their play lives into the mainstream.

Most of the toys described below are readily available at, or can be ordered through local toy stores.

**INFANTS & TODDLERS**

**Hot Tots BabyShakes** (Eden, $6.50)
Soft-fabric rattles can be attached to baby's wrist or feet. All babies are fascinated to discover their limbs; these add-ons can help them refine more purposeful motions.

**Listen & Learn Farm Animals Ball**
(Texas Instruments, $24.95)
This popular 12-sided ball is activated by pushing the picture of an animal. Children are rewarded with the animal's sound and name in English. This toy can motivate kids to crawl and can develop hand-eye coordination along with naming skills. Note: this toy also comes in a bilingual (English & Spanish) version.

**Activity tip:** With older kids, you can use this toy for a playful game of “I Spy.” Tell the child you spy an animal that has four legs and barks. Child must find and push the dog button. Switch roles and have the child make up the riddles while you find the animal.

Or play “Who said that?” by putting a towel over the ball, pushing a button and asking the child to identify the animal who makes that sound.

You can also build auditory memory and sequencing skills with “Play what I play.” Push buttons corresponding to two animals and have the child push the same buttons in the same order. Build up to sequences of three or more.
Sounds Around Video (BoPeep Productions, $19.95)
This live-action video features children exploring the musical, mechanical, animal and human sounds of everyday life. Cast is multi-cultural and includes a child with Down syndrome. Besides being fun, this video fosters sound awareness and auditory discrimination. It also helps a child build a vocabulary to describe the sounds he or she hears.

Activity Tip: Without using anything but hands, feet, mouth and other body parts, how many different sounds can you and your play partner make?

Play About Walker (Little Tikes, $35)
More stable than most push-about activity toys, this sturdy toy leaves enough foot room so toddlers won't trip on the softly clicking wheels. Simple spinners, clackers and other activities can also be enjoyed by a baby who can sit up.

Adaptation idea: For added sensory interest, or for a child with visual impairment, add textures to the push handle and activity panel.

Activity tip: Older tots will like rolling this back and forth or using it as a tunnel through which a smaller vehicle or ball can be rolled.

Little Smart Table Talk (V-Tech, $39.99)
You can personalize this electronic activity table by putting photos of Mom and Dad behind the peek-a-boo door slide. There are musical notes, a chime roller and plenty of easy-to-activate interactive buttons. This table needs little in the way of adaptation for younger kids. Tots will enjoy seeing the results of their actions. Preschoolers can build auditory memory skills and language with various games.

Activity tip: Play an "I Spy" button game by giving your child a clue—"I spy a button that says 'woof, woof.'" Let the child try to find the button with the dog. Once your child knows the sounds on the toy, play the game with "no peeking." The first player listens without looking while the second touches one button. Based on the sound, the first player must identify the button.

Sesame Street Spin Around Play Park (Playskool, $25)
Children with differing abilities enjoy this easy-to-activate merry-go-round and Ferris wheel that produces good sound and action with the push of a big plunger. Only the Elmo figure is removable; this avoids the frustration of having too many pieces to manipulate.

Adaptation ideas: Glue fabric textures onto plunger for children with visual impairments. The base of this toy fits a wheelchair tray and can be attached with suction cups.

Activity tip: This toy can help children work on concepts like start-stop, in-out and up-down. It may also teach them to take turns or play side by side. For extra play interest, a puppet on your hand can be one of the turn takers.

Other soft toys can "ride" on the merry-go-round; to keep them from flying off when the plunger is pushed, add Velcro dots to their undersides and the insides of merry-go-round seats.
Table Toys ($69-299)
The Table Toys company makes a variety of play tables for building with Lego or Duplo blocks. Their standard tables are 20" high to accommodate a stool or chair. Their newest model comes with adjustable legs which can make the surface high enough for a wheelchair. While the standard table has a storage bag in the middle, the new table uses cut-outs and bags in the corners so children don't have to reach as far. Building with colorful plastic Duplo and Lego blocks is fun for most children; it may also enhance color-matching, counting and size-discrimination concepts.

Radio-Control Raceway (Fisher-Price, $79.95)
This is a welcome new choice for kids who can't go chasing after a radio-controlled car or manipulate the small buttons on a standard racing set. This radio-controlled raceway has two chunky cars that can zip along the track which comes complete with under-and overpasses. A large single button controls each vehicle. Along with fun, this toy can build eye-hand coordination. It doesn't look babyish, although it is much easier to operate than typical racing sets.

Adaptation ideas: Controller button can be covered with Velcro and used by a child who is wearing a Velcro mitt. For more control, tape the button to a fixed surface. Cars can be set to go at two different speeds for beginners and more skilled drivers.

Adaptive Equipment for Dolls With Disabilities (Lakeshore Learning Materials, $18.50 and up)
Now your child’s favorite 15-16” doll can be fitted with realistic, doll-sized adaptive equipment. Choose from:
- Walker & accessory bag ($33.50)
- Two leg braces and two forearm crutches ($29.50)
- Wheelchair ($44.50)
- Guide dog, harness & cane ($18.50).

Press ‘N Dress Fashion Doll (Constructive Playthings, $29.95)
The Press ‘N Dress Fashion Doll, now available in an African-American version, is the modern version of that favorite toy of yesterday—the paper doll. Each 13” fabric-covered doll comes with six Velcro-backed, cloth outfits that “slip on” with the press of a finger. Three additional sets of three outfits each are available ($14.95 each).

Mickey Press ‘N Dress Doll (Pockets of Learning, $30)
Both boys and girls will enjoy playing with Mickey Mouse, another version of the Press ‘N Dress doll. The Mickey doll uses Velcro-backed clothes that are easy to change. Wardrobe, stand and doll are stored in a zip-up carrying case.
Radio-Control Bubble Fire Truck ($30)
A single button makes this fire truck go forward and then turn. It has flashing lights, but no annoying sounds. If you "gas it up" with bubble solution, it leaves a trail of bubbles as it moves. This toy will be very easy for most children to operate with no adaptations.

Little Tikes Place Wheelchair and Ramp (Little Tikes, $12)
The Little Tikes Place ($70) is a big, open doll house ready for dramatic role-play. Chunky furniture is easy to manipulate, and so are the family figures. Add the wheelchair and ramp to make this doll house accessible!

Little Smart Driving School (V-Tech, $39.95)
All the fun of a steering wheel with electronic horn and other automotive sounds. It also includes a telephone and typewriter keyboard that says every letter a child presses for plenty of auditory feedback and reinforcement. The toy has a friendly quiz mode that will be fun for kids who are learning the names of letters.

Activity tip: Play "Find the sound I'm saying"— "Can you find the letter that you hear at the beginning of these words: monkey, mommy, mountain?" Or, for older kids who are working on alphabetical order— "Can you find the letter that comes after T? Before G?"

Talk 'N Dress Baby Bop (Playskool, $34)
Children who are working on dressing skills and following directions will enjoy buttoning, snapping and helping to dress Barney's popular pal, Baby Bop, who talks when her "belly" is squeezed. For a child with visual impairment, Baby Bop has a variety of textures—velour, fuzzy fur, satin and cotton.

Adaptation idea: For children who cannot squeeze the doll's middle to make her talk, the sound box can be removed and placed on a table where it will respond to a touch.

The Oppeheim Toy Portfolio is an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS; it also publishes a quarterly newsletter. Both publications include useful sections on adaptting products for kids with special needs. These sections are done in conjunction with the National Lekotek Center, a nonprofit organization serving special needs children and their families (See page 46).

For more information, contact the Oppeheim Toy Portfolio, 40 E. 9th Street, Suite 14M, NY, NY 10003, (800) 544-8697.
Sometimes, children with disabilities miss out on the fun and games of childhood. Parents, teachers and friends may mistakenly assume that children with disabilities cannot participate in the same activities as other kids. Or parents may be so absorbed in getting a child to appointments for special services that they simply forget to make play a priority.

That’s why a special education teacher founded the National Lekotek Center in 1980—to provide children who have mental, physical and emotional disabilities with opportunities to play, learn and, most importantly, to have fun. The first Lekotek center was modeled after a similar program in Sweden, where the word “lekotek,” loosely translated, means “play library.” Today, in addition to its national headquarters in Evanston, Illinois, Lekotek serves many hundreds of children through more than 50 affiliate centers in 20 states (and one in South America). Many Lekotek programs are offered on a sliding-fee scale, with scholarships often available. For Lekotek centers that do not offer sliding fees, yearly membership costs $50-180 a year.

Lekotek offers a family-centered approach to play. Children with special needs—along with their parents, siblings and sometimes, grandparents, other caregivers and neighborhood friends—attend monthly play sessions. Specially-trained “Lekotek leaders” introduce children to toys, games and computer software that are appropriate and challenging for their developmental level.

If necessary, toys are adapted to allow the child with a disability to use them independently. For example, a child with only limited use of his arms might not be able to operate a battery-propelled car with a control button requiring fine-motor skills like the flick of a finger. But when the car is connected by wire to a Velcro-fastened wrist band that houses a special “flip switch,” the child only has to flip his wrist over to make the car move. In this way, the child experiences all the fun of a battery-operated toy while refining motor skills that will help him in other areas of life as well.

After a play session is finished, children are loaned their favorite playthings to take home for the next month. Nationwide, Lekotek toy libraries have more than 50,000 toys available to children and families. Participating families appreciate the cost savings of having access to a wide range of appropriate play materials for their children.

Lekotek’s Compuplay program, available at 21 locations nationwide, also offers individualized computer training and playtimes using software appropriate to an individual child’s developmental level with adaptive technology as needed. Some centers loan computers and software. Costs for Compuplay sessions range from $30-200 depending on the length and type of session and whether the particular program is subsidized by an outside agency.

Lekotek offers special programs, too, like summer computer camps, ability-integrated play groups, preschool inclusion assistance and various family support services. In addition, year-round training programs are offered to teachers, parents and daycare providers. Toy-building manuals and videos are also available. Call (800) 366-7529 for a free catalog.

Today, the Lekotek movement is growing rapidly as parents express the need for Lekotek services in their own communities. The National Lekotek Center offers some basic guidelines for parents and professionals interested in starting a new Lekotek program:
• Contact the National Lekotek Center at (800) 366-7529, or write to 2100 Ridge Ave., Evanston, IL 60201, for the new “Lekotek Start-up Kit” ($15, covers duplication and shipping) which gives a step-by-step account of how to start a Lekotek Center in your community.
• Contact other parents, professionals and community leaders and tell them about the Lekotek program. Once you have a few individuals willing to advocate for the program, a community needs assessment can be done to determine whether there would be a demand for Lekotek services.
• Contact community organizations such as the National
Meeting Street Center

- Early Intervention
- School Program
- Outpatient Rehabilitation
- Meeting Street Institute
- Assistive Technology Program
- Employment Services Program
- Services to Individuals with Deaf/Blindness

Committed to working in the community in partnership with people with disabilities and special needs, including their families, in order for everyone to achieve their highest quality of life and maximum independence.

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(401) 438-9500 (401) 438-3760 FAX (401) 438-3690 TDD
Attention: Lynn Barlow

Meeting Street Center is the local affiliate for the National East Asian Blind Society

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Easter Seal Society affiliates, United Cerebral Palsy centers, schools, libraries, hospitals or civic groups, and propose the addition of a Lekotek Center to their existing services.

- **Attend a Lekotek “Leader Training Seminar.”** Twice a year, the National Lekotek Center in Evanston, Illinois hosts intensive certification training seminars. The training dates in 1995 are February 6-10 and July 10-14. Contact the National Center at 1-800-366-7529 for details on training and certification requirements.

### Lekotek and Compuplay Sites

**ARIZONA**
- Arizona Easter Seal Society Compuplay (C)
- Easter Seal Society for Disabled Children and Adults of Arizona
  - 903 N 2nd St
  - Phoenix, AZ 85004
  - (800) 626-6061
- Children's Lekotek and Compuplay of Phoenix (L, C)
  - Southwest Human Development
  - 3033 N 24th St
  - Phoenix, AZ 85016
  - (602) 956-2711
- Easter Seal Lekotek of Southern Arizona (L)
  - Arizona Easter Seal Society
  - 5740 E 22nd St
  - Tucson, AZ 85711
  - (520) 745-5222

**CALIFORNIA**
- Easter Seal Society of the Bay Area Lekotek (L)
- Easter Seal Society of the Bay Area
  - 2645 Pleasant Hill Rd
  - Pleasant Hill, CA 94523
  - (510) 939-7353
- Lekotek Family Resource Center (L, C)
  - 2701 Cottage Way, #27
  - Sacramento, CA 95825
  - (916) 979-1121
- Lekotek of San Francisco (L)
  - The Easter Seal Society of the Bay Area
  - 6221 Geary Blvd
  - San Francisco, CA 94121
  - (415) 752-4868
- Easter Seal Lekotek (L)
  - Easter Seal Society of the Tri-Counties
  - 977 Pismo St, Box 795
  - San Luis Obispo, CA 93406
  - (805) 543-4122

**COLORADO**
- Lekotek of Northern Colorado (L)
  - Footills Gateway Rehabilitation Center
  - 301 Skyway Dr
  - Fort Collins, CO 80525
  - (970) 226-2345

**DELAWARE**
- Delaware Curative Lekotek (L, C)
  - Delaware Curative Workshop
  - 1600 Washington St
  - Wilmington, DE 19802
  - (302) 656-2521

**GEORGIA**
- Lekotek of Georgia (L, C)
  - 1955 Cliff Valley Way, Ste 102
  - Atlanta, GA 30329
  - (404) 633-3430
- Marcus Center Lekotek (L)
  - Marcus Center
  - 1605 Chantilly Dr
  - Atlanta, GA 30324
  - (404) 727-5437
- Egleston Gwinnett Lekotek (L)
  - Egleston Children's Health Center
  - 9202 Satellite Blvd
  - Duluth, GA 30096
  - (404) 497-6319
- Lekotek of Georgia-Rome (L)
  - 52 Twickenham Rd
  - Rome, GA 30161
  - (706) 324-2004

**ILLINOIS**
- Easter Seal Lekotek of Southwestern Illinois (L)
  - Easter Seal Society of Southwestern Illinois
  - 1719 Washington Ave, Box 219
  - Alton, IL 62002
  - (618) 462-8897
- East Central Illinois Lekotek (L)
  - 1304 W Bradley Ave
  - Champaign, IL 61821
  - (217) 351-1008
- Lekotek in West Humboldt Park (L)
  - c/o Chicago Commons
  - 1633 N Hamlin
  - Chicago, IL 60647
  - (312) 772-0900
- El Valor Lekotek (L, C)
  - El Valor
  - 1125 Division St
  - Chicago Heights, IL 60411
  - (708) 481-6740

**EXCEPTIONAL PARENT / OCTOBER 1994**
USA Toy Library Association

The USA Toy Library Association (USA-TLA) is a national network of nearly 400 toy lending libraries serving children with and without disabilities. Depending on the particular program, families may borrow both commercially-available and specially-adapted toys. Yearly costs for using toy libraries range from $0-35.

USA-TLA assists individuals and organizations in establishing and promoting toy libraries in local communities. The organization also distributes information on toy repair and discounts, and provides research material on play, toys and early learning. In addition, they offer books, videos and a quarterly newsletter.

For information on any of these services, or to locate the toy library nearest to your home, write to USA-TLA, 2530 Crawford Ave., Suite 111, Evanston, IL 60201.

Lekotek of Evanston (L, C)
National Lekotek Center
2100 Ridge Ave
Evanston, IL 60201
(708) 329-0001

Lekotek in Flossmoor (L)
Good Shepherd Center
2220 Carroll Pkwy
Flossmoor, IL 60422
(708) 957-5700

WSSRA Lekotek (L)
West Suburban Special Recreation Association
2915 N Maple St
Franklin Park, IL 60131
(708) 455-2100

Galesburg Public Library Lekotek Center (L)
Galesburg Public Library
40 E Simmons St
Galesburg, IL 61401
(309) 343-5956

Southern Illinois Lekotek (L)
112 N Gum
Harrisburg, IL 62946
(618) 253-5561

Easter Seal Lekotek-Kankakee (L)
Easter Seal Society of Mid-Eastern Illinois
895 S Washington Ave, Box 84
Kankakee, IL 60901
(815) 932-0623

Parents Infant Center Lekotek (L)
Special Education District of Lake County
Parent-Infant Center
1585 N Milwaukee Ave, Ste 4
Libertyville, IL 60048
(708) 549-0662

DuPage/West Cook Lekotek Center (L)
DuPage/West Cook Regional Special Education Association
1500 S Grace
Lombard, IL 60148
(708) 629-7272

Lekotek Center Of West Central Illinois (L)
Easter Seal Foundation
1504 13th Ave
Moline, IL 61265
(309) 762-9552

Easter Seal Lekotek Center-
Normal (L)
Easter Seal Society
206 S Linden, Ste 4A
Normal, IL 61761
(309) 452-8074

Southwest Cooperative
Compuplay (C)
Southwest Cook County Cooperative Association
for Special Education
6020 W 151st St
Oak Forest, IL 60452
(708) 587-6495

LaSalle County Easter Seal Lekotek Center (L)
LaSalle County Easter Seal Society
1013 Adams St
 Ottawa, IL 61550
(815) 434-0857

Easter Seal Lekotek Center-
Peein (L)
Easter Seal Society
320 E Armstrong Ave
Peoria, IL 61603
(309) 671-5884

Rockford Lekotek Center (L)
Fairview Early Education Center
512 Fairview Ave
Rockford, IL 61108
(815) 229-4230

Clearbrook Lekotek (L, C)
Clearbrook Center for the Handicapped
3765 Pleasant Dr
Rolling Meadows, IL 60068
(708) 392-2812

Easter Seel Lekotek at McKinley (L)
850 E 170th St
South Holland, IL 60473
(708) 333-7614

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DynaWrite™ is a revolutionary new software package for the DynaVox® augmentative communication aid. One that can help people compose longer, more complex messages, faster and easier than ever before. So if you know someone who might benefit from it, we urge you to contact your therapist. Or give us a call, at 1-800-344-1778.

We Hear You.

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"  
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

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Switch on the Fun

The Scanning 2-XL™ Talking Robot. Innovative, interactive, educational—and fun. Most importantly, it is accessible using a single switch through scanning. Developed with the exceptional child in mind, it's the perfect playmate for learning and entertainment. The 2-XL tells stories and jokes, plays your child's favorite audio cassettes, asks questions and waits patiently for your child to scan and select the correct answer. A great gift for the holiday season. Order soon, as quantities are limited. Call or fax InVotek today for a free catalog and pricing.

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Providing Independence Through Technology

Switch on the Fun

The Scanning 2-XL™ Talking Robot. Innovative, interactive, educational—and fun. Most importantly, it is accessible using a single switch through scanning. Developed with the exceptional child in mind, it's the perfect playmate for learning and entertainment. The 2-XL tells stories and jokes, plays your child's favorite audio cassettes, asks questions and waits patiently for your child to scan and select the correct answer. A great gift for the holiday season. Order soon, as quantities are limited. Call or fax InVotek today for a free catalog and pricing.

1-800-576-6661

Providing Independence Through Technology
DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

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DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the #1 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dieters and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call (800) 333-0003.

Free educational material, call... (800) 333-0003.

The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.
NEW PRODUCTS: TOYS

RUBBER JACKS & BALLS
Metal and plastic jacks that hurt little hands can now be replaced with slightly oversized jacks made of rubber! These colorful jacks give under pressure so children can pick them up safely. Eye-hand coordination and grasping skills can be enhanced with these eight jacks and rubber ball.
Chime Time, Atlanta, GA 30340-1562

MODULAR FRAME: ADJUSTABLE WEDGE
This oak board tilts up to 90 degrees for full access to its three single-activity modules. Each module is Velcro mounted for removal and repositioning. Activities include tactile, visual, auditory and/or fine motor skills—pick from a list of activity options to suit your child’s abilities and interests!
Danmar Products, Ann Arbor, MI 48103

K’NEX
Twenty-two basic shapes with an infinite number of possibilities. The K’Nex color-coded construction sets let children build anything from simple flat designs to three-dimensional models and vehicles. The interlocking pieces snap together and can even be connected using only the sense of touch. Shapes hold the attention of all children. Sets available for cars, trucks, flying saucers, roller coasters and more. Edges are rounded for safety.

REALITY DOLLS & WHEELCHAIR
The Reality Dolls are soft, washable dolls designed to build the self-esteem of children with disabilities and to increase awareness of disabilities for children without disabilities. The dolls are featured with hearing aids, crutches, prostheses and white canes. A doll-size wooden wheelchair is also available.
Antoni Toys and Products for the Physically Challenged, Portland, OR 97214

SENS’; BALLS
These bright yellow, inflatable balls are covered with tiny rounded protrusions that are sure to stimulate tactile sensations. Available in three sizes for various types of recreation and therapeutic play. The smallest are sold in pairs and are only 10 cm in diameter—perfect for little hands.
Ball Dynamics International, Inc., Denver, CO 80202

REALITY DOLLS & WHEELCHAIR
The Reality Dolls are soft, washable dolls designed to build the self-esteem of children with disabilities and to increase awareness of disabilities for children without disabilities. The dolls are featured with hearing aids, crutches, prostheses and white canes. A doll-size wooden wheelchair is also available.
Antoni Toys and Products for the Physically Challenged, Portland, OR 97214

INTELLIPICS
This educational software program allows adults to create activities for children to explore the fun of learning. Graphics, quick-time movies, animation, recorded sound and synthetic voices are used to teach shapes, colors, numbers and letters. Animals, music, dinosaurs and more help to keep children interested. For use on Macintosh computers.
IntelliTools, Inc., Richmond, CA 94804

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (301) 587-1967, FAX.
Sibling Concerns
by Donald J. Meyer

This article is an excerpt from SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS (Paul H. Brookes, 1994). This is the second of four excerpts EXCEPTIONAL PARENT will publish. SIBSHOPS is available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910.

Given that most brothers and sisters harbor a wide range of feelings toward their siblings, it is not at all unusual to learn that siblings of people with special needs also experience ambivalent feelings about their brothers and sisters. After all, a relationship in which one sibling has a disability or illness is still a sibling relationship. Adding a special need to the equation appears to enhance the inherent ambivalence...

It is difficult to make generalizations about siblings who have brothers and sisters with special needs, because this is only one aspect of their lives. Disabilities and illnesses affect people from all walks of life, and siblings will experience these conditions in innumerable ways. However, in listening to brothers and sisters, we hear recurring themes, despite the diverse backgrounds of these siblings... No one brother or sister will experience all of the concerns discussed below, but all will share some...

**Overidentification:**
Overidentification occurs when a sibling wonders whether he or she shares—or will share—a sibling’s problem... The risk of overidentification is one of the many reasons that brothers and sisters need accurate information about their siblings’ disabilities and illnesses. Information that may be obvious to adults may not be to children. For instance, younger children need to know that they cannot “catch” their siblings’ disability...

**Embarassment:**
A sibling with a disability or illness can be a source of embarrassment for typically-developing brothers and sisters...
Developing strategies to spare a typically-developing child embarrassment first requires analyzing the cause of the embarrassment. Is it something that can be changed, such as an age-inappropriate bib on a sibling who drools, or a behavior, such as singing during the sermon that could be changed through a carefully considered behavior program? If changeable, then the family can work toward decreasing the sibling’s embarrassment and improving the life of the person with special needs at the same time.

However, it is equally likely that the source of embarrassment is something about which little can be done. In these instances, there are two strategies parents may wish to consider. First, they should remember that most children go through stages when they are easily embarrassed, and these experiences may be unavoidable.

Early adolescents have a particularly strong need to conform. It can make a teenager miserable to be seen with her parents, much less with a sister who looks and acts differently... During this time of raging conformity, the best strategy may be to give the typically-developing child “space,” psychological and otherwise. Given permission to walk on the other side of the shopping mall or attend a different church service, most siblings will eventually re-integrate their brother or sister...

A second strategy is to acknowledge the embarrassment... Denying siblings “permission” to be embarrassed by their sibling (as in “He’s your brother, you shouldn’t be embarrassed by him!”) is more likely to invoke guilty feelings than to reduce embarrassment. It also will send a message that children cannot bring their concerns to their parents. Acknowledging that a sibling with special needs is sometimes difficult to live with not only reflects reality (after all, what sibling—special needs or not—is always easy to live with?), but it also sends a message that brothers and sisters can feel free to talk about their feelings with their parents...

Luckily, for most siblings, embarrassment is transitory... Most brothers and sisters have a remarkable ability to re-frame difficult situations in a more positive light...

**Guilt:**
... Siblings of individuals with special needs are far more likely to experience guilt than siblings of individuals with-
Exceptional Parent / October 1984

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Tarzana CA 91357

Isolation, Loneliness and Loss:

...A sibling's disability or illness can cause brothers and
sisters to experience various feelings of loss and isolation.

Especially if there are only two children in the family,
typically-developing siblings may miss having a brother or
sister with whom they can seek advice, or share their
thoughts, hopes and dreams. They may also long for the
rough-but-loving relationship many siblings
share...

When parents are con-
sumed with a child's dis-
rability or illness,
typically-developing broth-
ers and sisters can feel
neglected and isolated from
their parents. These feelings are
especially keen during times of
stress for the family, such as
diagnoses or hospitalizations...

Of course, when a child is
facing a health or developmental cri-

sis, it may be impossible for parents to
meet all their children's needs for
emotional support. During trying
times, many families enlist the sup-
port of a favorite relative or adult friend who provides the
healthy child with time, attention and an "open ear."

Donald J. Meyer is the director of the Sibling Support
Project at Children's Hospital and Medical Center in
Seattle. Don is the younger brother of two siblings who
have epilepsy. He is married and the father of four chil-
dren. His book, SIBSHOPS: WORKSHOPS FOR SIBLINGS OF
CHILDREN WITH SPECIAL NEEDS, details the program that
won the 1992 National Award for Innovation from the
Association for the Care of Children's Health.
The Biggest Game
by Bill Abbott

One afternoon, I was reading articles from EXCEPTIONAL PARENT magazine to my husband, Bill. When I finished the FATHERS' VOICES section, I looked up to see tears rolling down my husband's rugged face. “It's a good thing,” he said, and walked out of the room, seemingly embarrassed by his show of emotion.

Several hours later, I was intrigued to find my husband frantically writing away in a tattered notebook. Our two children kept vying for his attention, but Bill was completely focused on the project at hand. Finally, he took a deep breath and pushed his chair back from the table. Handing me the notebook, he said, “This is my story.”

My husband has never been big on words or expressing his feelings. After reading his story about his relationship with our son, Gregory, tears rolled down my face also.

“This is wonderful!” I said. “Let me send it in to FATHERS' VOICES.”

Bill told me that he didn’t care if I sent it in or not. He said it just felt good to express his feelings.

I have enclosed my husband's story. I will also keep it for Gregory to read when he is older.

—Cara Abbott

While waiting for my child to be born, I was like any other expectant father. I dreamed of the activities I would share with my firstborn son. As a young child and teenager, my life had revolved around sports. I dreamed about teaching my boy to throw a curve ball and catch a football.

I will never forget the day Gregory was born. When the doctor said, “It's a boy,” I felt like I was walking on air. Then, reality knocked me to the ground. My son had sustained a brain injury after an excruciatingly long labor and nightmarish forceps birth. He was rushed to a larger hospital where he spent the next two weeks in the neonatal intensive care unit. At least he was alive, but I felt completely powerless to help him.

As the months went by, we began to realize that Gregory was not doing the same things as other babies his age. After many visits to specialists, we were given a diagnosis of cerebral palsy.

I am an over-the-road truck driver. I was in Oklahoma City, Oklahoma the night my wife, Cara, gave me the news of Gregory's diagnosis. I was angry at the world. I prayed to God and to my late father. I asked, "Why has this terrible thing happened to me?"—as if I were the one with cerebral palsy.

Now, four and a half years later, the son is teaching the dad. Gregory is my son, but he is also my best friend. There are parts of me that only he knows and understands.

Gregory has more heart and gumption than any ball player I have ever seen. The cerebral palsy affects Gregory’s right arm and leg, his speech and his balance. As I watch him try to walk and use his weak arm, I have to restrain myself from helping him. In the long run, I know it will be better if he does things by himself.

Bill Abbott, 35, has traveled across the United States and Canada as an over-the-road truck driver. He lives in Columbia, Missouri with his wife, Cara, and sons Gregory, 5, and Patrick, 8 months. He also has a daughter, Jennifer, from a previous marriage.
Five Models Available Now

The B.O.S.S.

provides freedom and independence. Fully equipped with electronic controls, these play vehicles provide an enjoyable way for a young child with a disability to learn important developmental skills.

All five models offer a variety of electronic control systems each designed to meet the particular needs of the young driver. For maximum safety, an optional remote control override switch enables a parent or other adult to supervise vehicle operation. Special seating and other safety equipment is available. Cars operate on two rechargeable 6 volt batteries. Call us for additional information and orders.

1-800-950-5185
Innovative Products, 830 S. 48th, Grand Forks, ND 58201
Photo used by permission Hedstrom Corp. of Bedford, PA
Circle # 42

I could talk about my son all day. It is a big thrill for any parent to see a child take his first steps. But when your child wears ankle-foot orthotics and is two and a half years old, seeing him take his first step is a miracle.

I would gladly trade places with Gregory; I'd do anything to make his life easier. However, my son has shown me I don't have to worry about his future. I know he has the drive to accomplish whatever he decides to do.

I have always dreamed of being a coach. Well, I got my wish. Encouraging Gregory to become independent will be the biggest game I will ever coach. Teaching him to stand in one spot without taking a tumble, teaching him to successfully navigate the bathroom, teaching him to pull his pants down and back up again—these are much greater rewards than winning any Super Bowl or World Series.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, 16120 E. Eighth Street, Bellevue WA 98006, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families lives.
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Step by step
Creating no-step entrances may be easier—and less expensive—than you think by Eleanor Smith

This article was adapted from ENTRYWAYS: CREATING ATTRACTIVE, INEXPENSIVE NO-STEP ENTRANCES TO HOUSES to give basic guidelines for adapting an existing home with no-step entrances. ENTRYWAYS provides in-depth instructions on how to build no-step entrances when building a new home.

ENTRYWAYS, published by Concrete Change, costs $8. Concrete Change also offers BUILDING BETTER NEIGHBORHOODS, a $24 video about why universally accessible housing is necessary and practical. Contact Concrete Change at 1371 Metropolitan Ave. S.E., Atlanta, GA 30316 or call (404) 378-7455 (voice) or Disability Action Center at (404) 687-9175 (TTY only).

Access All Around
Eleanor Smith remembers being a teenager at a party in the ’60s. Unable to get her wheelchair through the narrow bathroom door, she slid off the chair and prayed no one would see her scooting through the doorway in her fancy party dress.

Now, at 51, Smith is helping to lead the fight for barrier-free homes. Smith, founder of the Atlanta-based Concrete Change, says creating accessible housing for people with disabilities must go beyond adjusting only the homes of people with disabilities. All homes, she says, must be “visitible.”

“The most important thing for visiting is being able to get in the house, and get through the interior doors,” says Smith, who was paralyzed by polio at age three.

Unless children with disabilities have access to the homes of friends and relatives, Smith says, they’re likely to miss out on many important childhood experiences.

“I know I was left out of certain things because of architecture, like the birthday parties because the mother didn’t think she could handle me getting in the house,” Smith recalls. Or like being stranded in a backyard while all her friends ran into the house to play. Or being able to visit only five stores in her hometown of Eureka, Illinois, because the other stores’ entrances had steps.

Smith says people must demand that their homes be barrier-free—whether or not they know someone with a disability.

“Cost is not the issue,” says Smith, refuting myths that barrier-free homes are too expensive to build. “The issue is habit—what builders are willing to do and what the public is willing to demand and ask for.”

Although Concrete Change has no formal membership, Smith says hundreds of people around the country are either using its concepts or starting their own Concrete Change chapters.

“This is about action,” Smith says. “If you walk away from a builder who won’t build a wider bathroom, then you’re a part of Concrete Change.”

—M.S.M.

No-step entrances built with attractive materials and landscaping can be a well-integrated asset to the design of any house. The no-step entrance should be the entrance primarily used by family members and guests, both for convenience and for the symbolic welcoming tone. However, the lot’s terrain is a relevant factor. For example, don’t construct a no-step entrance in front if terrain realities make it a great deal easier to create an entrance at the side or back. In all cases, using the land to advantage is the key.

The no-step entrance must be a gentle slope, no steeper than 1:12—meaning one foot in rise per 12 feet in length. If a slope is too steep, it is unusable.

The slope can be steeper than 1:12 only if the rise is 11 inches or less.

The length of the sloped sidewalk, ramp or walkway that provides the no-step entrance often can be shortened by using the land. The elevation of the incline’s starting point should be as close as possible to the elevation of its arrival point.
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Whether it's a sidewalk, a bridge or a ramp, its surface should be level side to side so it does not tilt the user. Most building codes require railings if a structure is more than eight inches above the ground. If railings aren't required, 2x2s nailed along the outside edges of the ramp or walkway can prevent wheels from rolling off the side.

The route from the street or driveway to the no-step entrance must, like the incline or walkway, be no steeper than 1:12. Even when grading is done with access in mind, sometimes a steep lot requires a driveway much steeper than 1:12. In that case, someone can at least arrive by car or be helped up the driveway and then enter the house by means of a level or gentle slope leading from the driveway to the entrance.

Unless the incline is extremely gradual (at least 20 feet long for every foot of rise), it must end in a level platform so that a wheelchair user can open the door without struggling to keep from rolling backward down the incline. A garage floor, sidewalk or porch can serve as the platform.

Ramps: Design Considerations

When designing a ramp, keep in mind:
- A ramp does not have to stick out at right angles from the house. Often the best route is a ramp that runs parallel to the side of the house and ends in a level platform as in the porch. A ramp parallel to the house is often the easiest way to take advantage of the natural lay of the land so that the ramp can be as short as possible and still be gentle enough.
- A ramp does not have to begin at the point closest to the wheelchair user's approach. The person can travel a few yards farther to get to the appropriate beginning point of the ramp. The ramp should generally start on the highest point of land near the entrance at which it is practical to construct a ramp.
- When evaluating the best place to add a ramp, ask: Can an existing porch rail be cut out? Can existing bushes be removed and replanted along the ramp?

Eleanor Smith is the founder of Concrete Change, an Atlanta-based volunteer organization fighting for universal basic access to houses.
PART THREE
Regular professional cleaning and dental treatment are important for preventing dental problems. This is especially true for children with disabilities who may be at greater risk of dental disease because of oral conditions related to a specific disability, physical limitations which interfere with oral hygiene or the use of medications that may cause decreased saliva flow or gum inflammation. Children with disabilities may require more frequent dental visits than children who do not have disabilities—possibly four times a year depending on the child’s needs.

Finding the Right Dental Office
Some dentists are trained to treat children with special needs. Call your local dental society—the number is in the phone book—for a referral to a nearby dentist who treats children with disabilities. Other resources are listed at the end of this article.

The dental office that you select should be “prevention-oriented.” An office with this orientation will usually have a registered dental hygienist who specializes in preventing gum disease and tooth decay. The dental staff also should practice infection-control precautions for all patients, meaning dentists and hygienists should wear gloves, protective eyewear and masks.

Before making an initial appointment for your child, you may want to discuss the child’s special needs with office staff. This is the time to talk about seating, positioning and access issues. You may want to ask if someone is available to assist you if necessary when arriving or leaving. You may also have questions about parking or public transportation. It is a good idea to visit the dental office by yourself, before the child’s first appointment.

You may also want to ask for suggestions about preparing the child for a visit to the dentist. Usually, it helps to reduce fears of the unknown and increases cooperation when children know what to expect in a situation with a new professional.

The First Appointment
At the first appointment, the dental hygienist or dentist should take the child’s complete medical and dental health histories. They need to know if the child is currently under a doctor’s care. They also need to know about any medications the child takes on a regular basis.

After a health history is taken, a dental professional should give the child a thorough head-and-neck examination. This will include examination of the child’s teeth and gums. If necessary—and possible—x-rays will be taken at this time.

Before any treatment is started, you should be told what was found during the exam, what treatment will be needed, how many appointments need to be scheduled and approximately how much it will cost. This is a good time to ask questions or voice concerns.

The dentist or hygienist should spend some time during the first appointment discussing ways to improve the child’s oral health. The dental professional can advise about the child’s needs, including nutrition, and can show you the best way to clean the child’s teeth at home. The dentist may also recommend additional protection against cavities such as fluoride and sealant treatments. (Fluorides protect the sides of the teeth. Sealants are thin plastic coatings that cover and seal the

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to his private practice, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman also devotes much energy and time to the Special Olympics as clinical director of their “Special Athletes, Special Smiles” program. Dr. Perlman lives in Swampscott, Massachusetts.
chewing surfaces of the back teeth. Together, fluorides and sealants are highly effective against cavities. Sealants are used only on permanent teeth, so they are not recommended for children under the age of six.)

It is important that the office staff be “right” for your child. Make decisions based on the actions of the dentist, dental hygienist and other personnel in the office and the way the child reacts to these individuals. Does the dentist/hygienist:

- Allow time for the child to familiarize himself with the environment and become comfortable?
- Speak to the child appropriately—using simple language if necessary?
- Calm the child by using a pleasant, reassuring voice?
- Praise the child when praise is appropriate?
- Introduce actions, instruments and procedures slowly?
- Provide motivation to brush and cooperate at home?
- Appear confident and comfortable in his or her approach to the child?

**Tips for Success**

- When making an appointment, remind the office staff if special considerations are required due to your child’s disability.
- Schedule visits at times when the child is least tired and less likely to be irritable.
- Call the office before you leave for your appointment to find out if the day’s appointments are running on schedule. This can help avoid unnecessary waiting.
- Arrive on time.
- Be organized: Bring the names, addresses and phone numbers of other professionals involved with the child. Know the names and dosages of any medications the child is using.
- Don’t feel embarrassed by the child’s behavior or other aspects of his or her disability. Your child has the same right to good dental care as any other child.
- Ask questions about terms or

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**Helping Children Cooperate**

Usually because they are fearful and/or do not understand why the dentist is doing things to them, children can have difficulty being cooperative—and this makes it difficult, or even impossible, to provide high quality dental care. Behaviors that may interfere include hyperactivity, resistive movements and refusal to open mouth or keep it open long enough. Some children become physically resistant to treatment; they may kick, scream or grab the dentist's hands and instruments.

Sometimes, children also have physical limitations that make dental treatment more difficult. Some children cannot open their mouth wide enough or hold it open long enough. Uncontrollable movements can also interfere with dental treatment.

Dentists commonly use several techniques, sometimes called behavior management techniques, to gain the cooperation of child patients, to control disruptive behavior or to prevent patients from causing injury to themselves due to uncontrollable movements. The dentist should discuss this subject with parents before treatment begins. The following recognized techniques may be used individually or in combination depending on the child's needs:

- **Tell-Show-Do**: Children have less anxiety when they know what to expect. With this technique, the dentist uses simple words to tell the child what is to be done. Then, the dentist uses a model to demonstrate the procedure. After "telling" and "showing," the dentist performs the procedure. The child is praised when he cooperates.
- **Positive reinforcement**: This technique rewards the child who displays any desirable behavior. Rewards may include praise, compliments, a pat on the back, a gentle hug or a prize.
- **Voice control**: When a child exhibits disruptive behavior, the dentist regains his or her attention by using an abrupt change in tone or volume of voice. What the dentist says is less

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important than the sudden nature of the voice change.

Hand-over mouth exercise: The dentist tells a child who is screaming that he is going to place his hand over the child's mouth. When the dentist has placed his hand over the child's mouth, he speaks directly into the child's ear and tells the child that if the noise stops, he will remove his hand. When the child stops screaming, the dentist removes his hand from the child's mouth and the child is praised for cooperating. If the child begins screaming again, the exercise is repeated. At no time is the child's airway restricted. It is important to emphasize that this technique is never used as a punishment, but as a means of gaining the child's attention and encouraging cooperation.

Mouth prop: This is a device that is placed in the child's mouth to prevent involuntary mouth movements or accidental closing. This prevents injury and allows jaw muscles to relax for ease of swallowing so the dental professional can complete the procedures safely and efficiently.

Physical restraint by dentist or assistants: Dental staff restrain the child from undesirable movement by holding down his hands or upper body, stabilizing his head and/or controlling his leg movements.

Papoose Board: This is the most common of several safety devices used to limit disruptive movement. The Papoose Board prevents injury and enables the dentist to safely provide the necessary treatment.

Hospital Dentistry

For some children with medical complications or in rare instances where conscious sedations are ineffective, a child's dental treatment may be accomplished in a hospital operating room under general anesthesia. But because general anesthesia may be considered a risky procedure itself, its use should be considered only as a last resort. Often, a combination of behavior management techniques can be an alternative to general anesthesia.

Other Resources

If you need additional information or help in locating a dentist who works with children who have disabilities, several groups may help you:

- Academy of Dentistry for Persons with Disabilities
  211 East Chicago Ave.
  Chicago, IL 60611
  (312) 440-2560

- American Academy of Pediatric Dentistry
  211 East Chicago Ave.
  Chicago, IL 60611
  (312) 337-2169

- American Dental Association
  211 East Chicago Blvd
  Chicago, IL 60611
  (312) 440-2500

- American Dental Hygienists' Association
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Remember to tell them you saw their ad in EXCEPTIONAL PARENT.
with having two children who have the same chronological age but different developmental ages. We are also interested in finding out the types of strollers or other transportation devices parents used to get out with their children.

How do other mothers of multiples with special needs get support? Have any of you, for example, joined a mothers of twins club? If so, what was your experience with it? I feel blessed to have connected with a few mothers in similar situations, but overall, I feel there is a tremendous lack of information on this subject in much of the literature and resources on raising twins. Mothers of twins, let's unite!

D.C., California

Self-Catheterization

My friend's 10-year-old daughter has spina bifida and receives orthopedic services through a fine hospital that is km away for providing services to children with spina bifida. However, staff members at this hospital seem to be at a loss when it comes to teaching this young girl how to catheterize herself. This is a tremendous frustration to the family because it prevents their daughter from enjoying spontaneous activities with friends or other family members. It is impossible to plan all activities around the function of one's bladder, nor do all activities take place in a clean, clinical setting. Surely, other young women with spina bifida have had to jump this hurdle towards independence. Can anyone offer some help?

D.R., Oregon

Buying a Used Van

I am the parent of a young man who uses a wheelchair for mobility. He is deaf, blind and has physical disabilities. I am interested in purchasing a used Plymouth Voyager or Dodge Caravan mini-van that has been converted with a hydraulic lift or ramp.

I'd love to get some ideas on how to locate a used vehicle of this type. I would also like information and opinions about the various hydraulic lift systems and ramps that are available; I don't want to make an expensive mistake!

W.M., New York

Russell-Silver Syndrome

I am the parent of a five-year-old girl with Russell-Silver syndrome. I would like to hear from parents of children with the same diagnosis to compare notes. I have a lot of questions, and most of the doctors we've seen can't tell us much.

Megan is basically a healthy child. She grows steadily, but remains below the fifth percentile for her age; one side of her body grows at a slower rate than the other. She also has a severe delay in speech development.

My main concern is to make sure she gets an appropriate education. Russell-Silver syndrome is rare, and I'd appreciate any information I can get.

W.W., Illinois

EDITOR'S NOTE: Contact the Association for Children with Russell-Silver Syndrome, 22 Hoyt St., Madison, NJ 07940, (201) 377-4531. They can provide you with more information about the syndrome and can put you in touch with other families.
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- 1:2 staff to student ratio
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Contact: Carolyn MacRae,
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Arborway School
147 South Huntington Avenue
Boston, MA 02130
(617) 893-6000

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A co-ed residential camp for the:
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Special Force Family Ministries oper-
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Special Force Family Ministries
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EXCEPTIONAL PARENT
SUPPORT GROUPS

- **Pen-Parents** is a free support network for parents who have experienced pregnancy loss or the death of a child. Members receive a list of parents who have experienced similar losses and contact lists for single or divorced parents, adoptive families and sterile or infertile parents. Grandparents are invited to join Pen-Grandparents.

- Pen-Parents publishes **Optional**, a quarterly newsletter. Annual subscription is $12. PAILS of Hope, a bimonthly newsletter for parents going through subsequent pregnancy, is $10 a year. Contact Pen-Parents, P.O. Box 8738, Reno, NV 89507-8738, (702) 826-7332.

- **Schwachman Syndrome** is a digestive and respiratory disorder that can result in short stature, problems with bone growth, chronic diarrhea and persistent respiratory and skin infections. A new support group is forming for parents who have children with this syndrome. Contact Joan M. Mowery, 44 Meadowlark Rd., Vernon, CT 06066, (203) 870-5454.

Follow the Fairy Tale Trail

The Fairy Tale Trail is a Halloween house that is accessible and fun for all children. Started five years ago by Lekotek, a resource center for families with children who have special needs, Fairy Tale houses are springing up all over the country.

Visitors to one of these houses follow a “fairy tale trail” through eight storybook-theme rooms, interacting with costumed characters, trick-or-treating and enjoying sensory-stimulating and accessible activities. “At the Fairy Tale Trail, children with and without disabilities can share in the fun of the holiday together—side by side,” said Judy Hynes of the Auxiliary Foundation of the Women’s Club of Evanston, Illinois, co-chairman of this year’s Evanston event.

Lekotek and the Auxiliary Foundation offer a 50-page guide on how to build the house in other communities. The guide costs $15. Contact Lekotek, 2100 Ridge Ave., Evanston, IL 60201, (800) 366-7529.

VACC Camp 1995

The Miami Children’s Hospital hosts a free, week-long overnight camp each spring for ventilation-assisted children (children who need oxygen, trachs, ventilators and/or CPAP) and their families. VACC Camp ‘95—the tenth anniversary session—will be held April 1-7, 1995. Application deadline is January 6. The program includes swimming, field trips, campsite entertainment, structured games and more. An around-the-clock medical staff is available. For more information, contact Cathy Klein, VACC Program Coordinator, Ventilation Assisted Children’s Center, Division of Pediatric Pulmonology, Miami Children’s Hospital, 3200 S.W. 60 Court, Suite 203, Miami, Fla. 33155-4076, (305) 662-8222.

Video Lending Program

A free video-lending program offers more than 150 informational videos on disability-related subjects to individuals with disabilities and their families. Videos deal with a variety of subjects including assistive devices, home modification, computer accessibility, family life, employment, health concerns, travel and wheelchair skills. Further information is available from SCI Video Access, Spinal Injury Network International (SCINI), 3911 Princeton Dr., Santa Rosa, CA 95405-7013, (800) 548-2673.
Accessible. Means bath time is child’s play.


AdjustEase. One-hand adjustable washchair. Widest size and height range anywhere. Durable, rustproof. Many other features and options.

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FIND OUT ABOUT OUR 350+ BATH ACCESS PRODUCTS FOR EVERY BODY.

Every Child’s Dream - A Bike on Christmas Morning!
cover issues regarding the adoption of children with disabilities. Adoptive Families, 3333 Highway 100 North, Minneapolis, MN 55422, (800) 372-3300.

- The National Association for Parents of the Visually Impaired (NAPVI) sells several books that may also be of interest to parents of children with disabilities other than visual impairment. How to Pack 'Em In: A Guide to Planning Workshops is full of handy tips for staging a meeting, from the very first idea to the end result—a successful workshop ($5). The Legislative Handbook for Parents is written by parents to help other parents get involved with the legislative process on the local, state, and national levels ($7).

Your Child's Information Journal provides parents with a format for maintaining careful records of important information about a child's development and medical/educational histories. Journal pages fit in a three-ring binder ($7.50).

For 1-3 books, add $2 for shipping. For 4 or more books, add $5. NAPVI, P.O. Box 317, Watertown, MA 02272, (800) 562-6265.

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Home is where the heart is, but sometimes children with multiple disabilities need special help beyond their parents and school districts. Financing multi-year private school placements can be costly too. But now a school known for its successful individualized education programs is offering an extended assessment and treatment program. That school is Heartspring.

Curt came to Heartspring not because he needed a long-term, intensive program, but because his skills had plateaued, and problematic behaviors were unmanageable. He needed a program with a fresh perspective. With Heartspring's team approach, Curt has the resources he needs: specialists in the areas of special education, audiology, physical, occupational, and speech/language therapies, pediatric development medicine, psychology, and behavior management. Together, they will address his complex needs in a comprehensive, interdisciplinary program designed to continue after he returns to his home environment.

Just think! Curt enrolled this spring, and he'll be going home before school starts this fall. When he does, a Heartspring staff member will return home with him and stay a few days to make reintegration as smooth and effective as possible.

Home is where the heart is, and Heartspring is where the hope is. Let us build a program for your child. Call today.

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... helps keep an exceptional child's legs in place and warm by completely wrapping them comfortably. Two styles available.


Rotten Roada... more than a hug!

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to repeat instructions or modify assignments at times, it would have made things much more difficult.

At first, it was very hard to see Laura struggle with OCD. With her learning and hearing problems, it seemed like she already had enough to cope with, but it has been very encouraging to see the progress that she has made. You really do cheer for the small victories!

M.S., Indiana

My eight-year-old daughter was diagnosed with OCD in March 1993. She also takes medication daily. She has made nice progress and we are very pleased.

You might want to get in touch with the OCD Foundation, P.O. Box 70, Milford, CT 06460. They have a newsletter for parents, and a special newsletter for children.

K.S., New York

Adoptive Parents

M.W. (August 1994) is the adoptive mother of a three-year-old girl who has multiple disabilities—including cerebral palsy, developmental delays and a visual impairment—caused by "shaken baby syndrome" when she was seven months old. Because her daughter has multiple disabilities, M.W. has been unable to find appropriate support groups. She wanted to correspond with other adoptive parents of similar children.

My husband and I also have adopted a daughter who has cerebral palsy. She was born very prematurely—at 24 weeks gestation. She has developmental delays and a visual impairment. She is bright and cheerful.

I also have had trouble with support groups—adoption support groups cater to parents of "normal" kids, but members of support groups for parents of children with disabilities seem to lose interest in us when they find out that Chelsea is adopted. I remember being at a meeting where some mothers were talking about their problems with Medicaid. One mother asked me what kind of insurance Chelsea had. After I said "adoption Medicaid," I could feel that they were looking at me differently. It seems they don't see me as a "real mom."

M.W., Georgia

Gift Subscriptions

As we approach the holiday season, we suggest that readers purchase gift subscriptions for other parents, care parents, caring therapists, educators and libraries. Also consider a gift subscription for your favorite clergy-person in time for the December issue on religious education.

SCHOLARSHIPS AVAILABLE

Up to five college scholarships are being offered for the fall of 1995 for a four-year period. Each scholarship provides $3,000 per year ($12,000 total) to each student. Only current high school seniors and college freshmen will be considered.

Applicants should be physically challenged, in a wheelchair, and could not attend college without this help.

All young men and women will be considered without regard to race, color, creed, or state of residence. A private interview is not required.

We require a 500-word "statement of need" explaining your physical condition, educational background, and financial status. For scholarship application, write to:

"Doc" and Alicia Keim, Chairscholars
Silver Dollar Ranch, No. 38
Odessa, FL 33556
(813) 920-2737

Deadline Jan. 15, 1995

"Helping physically challenged students in chairs go to college."
Networking
Information from The National Parent Network on Disabilities

NPND Holds First National Conference Call

More than 75 people from 17 Parent Training and Information Centers and other organizations participated in NPND's first national teleconference held on August 24, 1994.

The 90-minute teleconference, broadcast from NPND's national office in Alexandria, Virginia, focused on the detrimental effects of legislative amendments to the Improving America's Schools Act of 1994 (IASA)—previously known as the Elementary and Secondary Education Act—and the Individuals with Disabilities Education Act (IDEA).

A panel provided an analysis of amendments dealing with violence and weapons in school, regulations of the Perkins Vocational Education Act and nullification provisions of IASA. Panelists included Patricia McGill Smith, NPND's executive director; Lucy Watkins of the Center for Law and Education and Larry Searcy of NPND. Paul Marchand, director of governmental affairs of the Arc, joined the panel from his Washington, D.C. office.

NPND plans to hold future teleconferences.

NPND Establishes Electronic Bulletin Board

On September 6, NPND started its own electronic bulletin board on SpecialNet. Known as NPND.update, the board features up-to-the-minute summaries of federal legislative activities from a parent-and-family perspective as well as information regarding other NPND activities. The board can be found under NPND.update in the SpecialNet opening menu.

Because the NPND bulletin board is a read-only board, comments about information on the board can be sent through e-mail to NPND.DC.

NPND Holds Congressional Briefing

As Exceptional Parent was going to press, NPND was planning to hold its first parent briefing for members of Congress and their staff. The briefing was planned for October 3, at the Rayburn House Office Building to discuss the reauthorization of IDEA. After the briefing, which is being sponsored by Rep. Major Owens, D-NY, NPND members were planning to meet with their local legislators to discuss the needs of children with disabilities.

Join NPND today!

NPND members and friends gathered at the White House July 27 for a celebration of the fourth anniversary of the Americans with Disabilities Act with President Bill Clinton, Hillary Clinton, Vice President Al Gore and Tipper Gore. [From left to right] Connie Hawkins of New Jersey; Patricia Smith, NPND executive director; Janet Myers of Alaska; Joanne Butts of Washington; Judith Raskin of New Hampshire; Terri Dawson of Wyoming and Debra Johnson of Idaho.

[From left to right] Joseph M. Valenzano, Jr and Kim Schive of EXCEPTIONAL PARENT; Tom DeLuca of Toys "R" Us; Nona Wells of Boston; Patricia Smith, NPND executive director; Jeanne McIntosh of Toys "R" Us; Pam Steneberg of California and Martha Ziegler of Boston.
NPND Honorees

As Exceptional Parent was going to press, NPND was planning to honor four people at its annual meeting on October 1:

- Carol Rasco is the chief domestic policy advisor to President Clinton. For more than 20 years, Rasco, the mother of a son with disabilities, has provided leadership through her first-hand experiences, volunteer activities and professional life to gain services for children with disabilities. In her current position, Rasco has led the fight for the Family Leave Act and universal health care coverage, among other things.
- Justin Dart was a national leader in gaining passage of the Americans with Disabilities Act. In addition to serving as chairperson of the President’s Committee on the Employment of People with Disabilities and the federal Commissioner of Rehabilitative Services, Dart is a constant source of motivation and inspiration for the disability advocacy community.
- Pam Steneberg has provided leadership on the national level and in her home state of California. As the parent project coordinator of the Disability Rights and Education Fund (DREDF), Steneberg has provided assistance to countless parents and parent organizations throughout California. For several years, Steneberg has led the fight for people with disabilities as secretary of NPND’s board of directors and as chairperson of the NPND Legislative Committee.
- Charles Lazarus, chief executive officer of Toys “R” Us, has provided national leadership to the corporate world through his efforts to test and market toys specifically to families of children with disabilities. In conjunction with NPND, Toys “R” Us published and distributed 700,000 copies of the *Toy Guide for Differently-Abled Children*. The guide, the first of its kind, has had a tremendously positive impact on children with disabilities and their families.

NPND’s annual meeting reception was being sponsored by the National Association for Medical Equipment Services.

Parent Training and Information Center News

The Parent Network Center in Buffalo, New York has received a state grant to train parents throughout the state to provide support, information and other services to parents. The center has also received expanded federal funding to continue its services. Congratulations to Joan Watkins, the center’s executive director, and her crew for all their good work.

NPND invites you to join

**Mission:** The National Parent Network on Disabilities (NPND) was established to provide a presence and national voice for parents of children, youth, and adults with special needs. NPND shares information and resources in order to promote and support the power of parents and resources to influence and affect policy issues concerning the needs of people with disabilities and their families.

**We would like to join the NPND.**

| NAME: | | |
| ORGANIZATION: | | |
| ADDRESS: | | |
| CITY: | STATE: | ZIP: | |
| HOME NUMBER (_____) WORK NUMBER (_____) | |
| DO YOU WANT TO BE ON THE NPND FAX TREE? (_____) (your fax number) | |

Please return this form with your check made payable to: NPND, 1600 Prince St., Suite 115, Alexandria, VA 22314, (703) 684-6763, FAX: (703) 686-1232

| Membership fees | |
| Parent Coalition | $ | Sliding Scale |
| Voting (Call NPND for details) | Affiliated organization 100 |
| Parent group 50 | Parent/Individual with a disability 25 |
| Professionals 40 | Contributor 1000 |
| Corporation 1000 | Sustaining 3000 |

The National Parent Network on Disabilities Board of Directors

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- Disability Rights Education & Defense Fund, Berkeley, CA, Secretary
- Janet Vohs
- Federation for Children with Special Needs, Boston, MA
- Patricia Sladky
- Executive Director
Finally, education on video tape to help parents help their children with special needs.

Through this ad parents will receive over 40% discount from the clinical catalog prices. The following tapes can now be purchased by parents for $39.95 through Exceptional Parent.

### Potty Learning For Children Who Experience Delays,
by Susanne R. Hays, M.S., R.N., C.R.R.N.
This video presents a unique developmental approach to supporting the child in learning independence in the management of “bathroom” skills. Specific areas covered include readiness for potty learning, parent responsibilities, child responsibilities and how to implement a successful program. **ED 077OD**

### Effective Intervention For Self-Feeding Success,
by Christine A. Nelson, Ph.D., OTR.
Learn this step by step, reverse chaining method of teaching feeding to mentally retarded & physically limited children. An effective and easy to follow program for parents which provides the tools needed to be successful in moving your child toward independent self-feeding. Applicable to children of all ages. **ED 078OD**

### Massage For The Infant With Developmental Disabilities,
by Susanne R. Hayes, M.S., R.N., C.R.R.N.
Certified Infant Massage Parent Instructor.
This video will show parents how to stroke their infants and children with special attention to methods which honor the infant’s individual concerns. A valued resource for every parent to assist their child’s development. **ED 079DD**

### Near Normal Feeding For Infants With Oral-Facial Anomalies,
by Susanne R. Hays, M.S., R.N., C.R.R.N.
Nippling for infants born with cleft lip and/or palate can be very difficult. Because of this anomaly of oral structure the normal feeding process is affected. Infants can fail to thrive very soon. This video outlines the common variations of oral defects, feeding concerns inherent with each type and easy intervention strategies parents can follow. **ED 080OD**

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Tibby's, Duncan, BC, Canada V9L 3W8

Circle # 276

**FANLIGHT EDUCATIONAL AND AWARENESS VIDEOS**
Documentary-style videos feature children and adults with disabilities who show the potential each individual possesses. The stories focus on people who put emphasis on their abilities, not their disabilities. Find out how deaf children learn to communicate; see how kids with disabilities play; learn about autism; share the experiences of children with cancer at camp and hear from siblings of children with lung disease. Each video sold or rented separately. Many are open/closed-captioned.

Fanlight Productions, Boston, MA 02130

Circle # 279

**11P TRAY/DESK**
Perfect for the student wheelchair user! This full-size clear plastic wheelchair tray with stomach cutout lifts to reveal a storage desk with various compartments. Easily installed and removed by means of telescoping support arms suitable for most wheelchairs. A keyed lock is available to protect items in the desk.

Consumer Care Products Inc., Sheboygan, WI 53082

Circle # 277

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A better choice in incontinence pants! These side-closing or pull-up pants are ideal for children with light to heavy incontinence. The pants have a disposable insert liner made of a patented material that is attached to a thin, comfortable cotton pant. Plastic-free (no rustling noise!), these are not diapers, so kids can feel better about wearing them. Ask manufacturer for a free liner sample.

C.P. International Inc., New York, NY 10177

Circle # 280

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Safe and Sound Homecare, Lincoln, NE 68502

Circle # 278

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Support Engineering Associates, Garden City, NJ 11530

Circle # 281

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, VTDD, (301) 588-9284, VTDD or (301) 587-1967, FAX.
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EDITED BY J.G. TOURAEG
Over 1,000 pgs. Contains information on approximately 700 disorders.
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Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP02401 $24.95

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Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB0860D $32.00

THAT ALL MAY WORSHIP
An Interfaith Welcome to People with Disabilities
GINNY THORNBURGH
An Interfaith handbook to assist congregations in welcoming people with disabilities to promote acceptance and full participation.
ND08400 $10.00

TROUBLE WITH SCHOOL
A Family Story About Learning Disabilities
ALLISON & KATHRYN DUNN
This book takes a clear look at the warning signs and common problems associated with LD.
WB028LD $9.95

INJURY

WHEN YOUNG CHILDREN ARE INJURED: Families as Caregivers in Hospitals and at Home
J. HALTPNANGER & M. LASH
A book about the family's role in caregiving when a young child is injured.
EP065ML $7.50

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
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SPEAKEASY
People With Mental Handicaps Talk About Their Lives in Institutions and in the Community
KARIN MELBERG SCHWIER
People labeled mentally handicapped speak honestly and powerfully about their lives in institutions and in the community.
PE044PR $16.00

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OR CALL (800) 535-4910

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...continued on next page...
My 12-year-old stepbrother Forrest, Forrest’s dad, my mom and I all got married one year ago. We were all part of the wedding, so Mom says we all got married into a family. I kind of like that idea now, but at first I didn’t. You see, Mom and I were together for seven years—just the two of us. Whenever I wanted some attention from her, I got it. Now, I have to share Mom with Forrest.

Forrest has Down syndrome. Many people don’t understand him when he talks or acts out his feelings in public. Kids who have Down syndrome are all different; my brother doesn’t seem to have it as bad as another kid in our school. My mom had to tell my grandma that Forrest is not the way he is because of his real mom and dad, that Down syndrome could happen in any family. She had to explain that to a lot of other parents, too. People really don’t understand about Down syndrome until someone explains it.

Sometimes I get a little upset because I think Mom praises Forrest more than me—like one time when Mom let Forrest and me walk to the post office by ourselves and Mom told Forrest she was proud of him for looking both ways before crossing the street. My feelings were hurt until Mom explained that she knows I look both ways before crossing the street, but she had never seen Forrest do it before. Her explanation made sense because Mom taught me a long time ago that I should look both ways before crossing, but she just started teaching Forrest.

At school, some kids tease me for being Forrest’s little brother. When that happens, I do what Mom told me to do—I put my hands on my hips and say, “You don’t know Forrest!” Then I walk away.

Sometimes, kids tease Forrest, too. Mom is teaching him to say, “I’m mad at you,” and then walk away. Most kids in school really like Forrest and me. We don’t get teased too much.

Forrest is fun to play with. We make all sorts of things together. We like to go gang up and tease Mom. Forrest plays basketball really well, better than a lot of other kids. And he sure can bat when we play baseball. He makes home runs every time! He bats and I run.

Forrest is a real cool brother. I love him very much.

The Children’s Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to:

Children’s Page
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-5005
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Imagine not being able to express one’s own thoughts so that others may understand.

Now with a Canon CC-7S or CC-7P Communicator, anyone’s dream of being heard can come true.

These electronic aids allow people who are hearing and speech disabled or motor handicapped to effectively communicate in their daily lives.

Designed for easy use, all of the Canon Communicator’s operations can be accomplished by using the keyboard to type and then print out messages onto thermal tape for easy readability.

With the Canon CC-7S Communicator, you can record a total of 240 seconds of speech under 26 locations—alphabet keys—using the supplied microphone. Playback is accomplished through the built-in speaker.

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The single-key operation mode helps those who found striking specific keys difficult. Keys can be selected by simply designating the row and column which intersect at the desired key using the indicator lamps on the keyboard’s right and bottom edges. All of the Communicator functions can be used in this special mode.

And because each Communicator can be strapped on to a wrist, a wheelchair, a bed rail, with a battery pack or AC cord, they can be used wherever they may be needed.

In addition, there are Canon Factory Service Centers throughout the world. And the Canon Communicator gets first priority whenever it is brought in for service. Because Canon knows that no one should be deprived of the power to speak their mind and to be heard.

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During the school year, 18-year-old Nhi Ducmg uses a home computer and the Internet to keep in touch with friends she made during the DO-IT (Disabilities, Opportunities, Internetworking and Technology) summer session at the University of Washington in Seattle. Nhi, a senior at Evergreen High School in Seattle, has multiple sclerosis and is legally blind. Born in Vietnam, Nhi moved to the U.S. in 1984. A story about the DO-IT program begins on page 33. Photograph by Mary Levin, University of Washington.

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Attention readers! Prepare yourselves for an emotionally bumpy trip through our 12th Annual Technology Issue. Incredible and wonderful things are happening as more and more children and adults with disabilities access the powers of modern technology. But be prepared for a mixture of feelings—so much of this technology still feels so far out of reach, and so much remains expensive.

It can be overwhelming to consider the pace of change and the impact of technology in our lives. Bob Williams, commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services (“Too Few Exceptions to the Rule”) and this issue’s Role Model, Robert Walsh, both emphasize the importance of technology to full participation in community life. They show how important it has become to learn to harness the power of technology in our everyday lives. Yet many of us may wonder if we actually have the energy to learn any of this stuff.

We appreciate the work of Jackie Brand, executive director of and long-time driving force behind the Foundation for Technology Access, in pulling together the stories you will read in “Real People, Real Technology, Real Solutions.” Sheryl Burgstahler’s article about the DO-IT program provides even more examples of the way technology access can help children with disabilities overcome many of the attitudinal barriers unnecessarily imposed on their aspirations. These stories are exciting! It is incredible to see how children with disabilities—infants, toddlers, school-age kids and teens—are learning to use technology! It is also frustrating and frightening because so many still do not have access to these opportunities.

In our first Technology Issue back in 1983, we noted that “an estimated $83.5 billion per year is spent to provide financial support for adults with disabilities who are dependent on public funds for food, shelter, medical care and other services. We have no way of knowing how many of these people might be able to care for themselves or even hold jobs with the right aids and training, but it is clear that widespread application of the latest technology could accomplish a great deal.”

Looking back, we can see how much has already been accomplished. Yet as Bob Williams reminds us, we must work to assure that people like himself or Bobby Walsh are no longer exceptions, and that every child with a disability may share the opportunities of technology.

In the spirit of giving

On rare occasions in the past 23 years, this column has mentioned a specific manufacturer; this is one of those occasions. In an advertisement in our October issue and in several other publications, wheelchair manufacturer Kuschall of America announced a plan to make holiday gifts of 20 new wheelchairs to individuals in the United States and Canada who might not otherwise be able to obtain them. Within one month after this announcement, the following companies had joined Kuschall of America in this venture: Freedom Design, Jay Medical, Kid-Kart, LaBac Systems, Pindot Products, Prime Engineering, Rhamdec, Roho and Special Health Systems. Together, these companies will donate holiday gifts with a retail value of more than $200,000. Exceptional Parent will join this effort by donating a gift subscription to each recipient of a holiday gift from this program.

I can appreciate that many consumers may have mixed feelings about this type of corporate gift-giving. Yet, to my knowledge, this has never happened before in any season. I congratulate the participating manufacturers for demonstrating that one person and one company can make a difference.

Happy Thanksgiving.
Outcomes: Posture, function, and mobility improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children’s seating.
Inclusion Article Misleading

I read “Making Inclusion Work” (September 1994) with interest. Mrs. Hart is to be commended for her accomplishments with her daughter, Angela. My son is an inclusionary student as well, and I know that the amenities afforded to the Harts—like 30-member “circle of friends” meetings and four-times-per-year child study team conferences—are not available to the average family. My husband and I couldn’t persuade our child study team to meet with us at all, except for the annual review.

I find it difficult to believe that one could persuade Brownie leaders, soccer coaches, a principal and others to care enough to attend a meeting about coordinating all aspects of a child’s life. Obviously, the Harts have been successful in this endeavor, but I cannot imagine this as a realistic scenario for most families of children with disabilities. For most children with disabilities, positive extracurricular experiences are rare. Usually, the child is not accepted or wanted by other children, the achievement-oriented parents of these children and the facilitators of the activity. Participation in sports is reduced to the child donning a uniform and being permitted to attend practices and games as a sort of team mascot.

The article does not accurately reflect the struggles of most families who have a child with a disability. Please include articles in your magazine that will help average families deal with the special education system. The reality of the system includes continually decreasing funding and child study teams that are overloaded with cases. Most children will not get the attention afforded to Angela Hart. This misleading article will result in disappointment and disillusionment for families trying their best to cope.

J.R., New Jersey

Tell us about...

...your experiences with the IEP process.

(What changes would you make?)

Write to: IEP Meetings, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax).

A sampling of reader responses to this question will appear in a future issue.

Fluoride Rinse

In regard to the article on dental care for children with disabilities (“Brushing, Flossing and Rinsing,” September 1994), I am concerned with Dr. Perlman’s suggestion to use a fluoride rinse on a child who cannot spit or rinse without swallowing. As suggested by my dentist, I used a fluoride rinse on my three-year-old’s teeth; within five minutes, he vomited. I find it best to brush his teeth with a small amount of toothpaste and rinse using my finger covered by a wet washcloth.

Fluoride rinses carry a warning that they should not be swallowed. So, I advise caution if there is a chance your child may swallow even a small amount.

E.M.C., New York

EDITOR’S NOTE: Dr. Perlman’s article did not recommend that fluoride rinse be used in the usual manner for a
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L. Sasso-Lundin, Occupational Therapist, Shriners Hospital, Portland, OR

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S. Bolzer, Physical Therapist, Cottonwood, AZ

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Methodist Hospital, San Antonio, TX

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M. Miller, Parent, Lombard, IL

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Children's Hospital of Philadelphia, Philadelphia, PA

"My daughter has a shunt in her head. ProtectaCap protects it really well. It's wonderful."  
C. Vanderpool, Parent, Bellingham, WA

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Professional Praise
This letter is long overdue. I am a professional who, since 1965, has been involved in training all levels of staff who deliver services to individuals with developmental disabilities. In addition, I recently became the facilitator for a parent support group.

I cannot stress the importance of the assistance I have received from Exceptional Parent. The articles, letters from parents and special departments in each issue have been invaluable. I find more helpful information in this magazine than I do in the professional journals I read.

Please keep up the good work. Parents who subscribe call the magazine their "bible."

M.K.M., Georgia

Spreading the Word
As usual, I read the September issue cover to cover. When I saw your request to spread the word about the magazine, I wrote an article which will be published in my daughter's school newsletter. It begins like this: "Like all busy parents, you probably do not find much time to read. However, as parents of children with special needs, there is one monthly publication I would encourage you to make time for. It is called Exceptional Parent..." I went on to describe the regular features of the magazine and give subscription information.

I wanted to share this idea as an example to other parents who also may wish to spread the word about Exceptional Parent through their child's school publication.

Thank you very much for your excellent magazine.

E.K.L., New York

EDITOR'S NOTE: Thank you for sharing your idea with us. We continually hear from new readers who say they don't know why they hadn't heard of the magazine sooner. Thanks for helping to get the word out.
Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

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Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.

Circle #16
Non-Organic Failure to Thrive
My two-and-a-half-year-old son has been diagnosed with non-organic failure to thrive. At first, doctors said he was experiencing a behavioral feeding difficulty. I had a hard time accepting this. Eight months ago, he had complete gastrointestinal and endocrine evaluations that were inconclusive, except for finding the parasite giardia. He has been fed with an NG-tube for the last six months but has experienced little growth; currently he has a Mic-Key G-tube. I would love to hear from anyone with a similar child.

C.C., Washington

Stepparent Seeks Insurance Information
I am the stepmother of a five-year-old boy who was born with multiple disabilities. Born prematurely (at 34 weeks gestation) after an otherwise normal pregnancy, Chris has been diagnosed with cerebral palsy, spina bifida, dual lower-eyelid coloboma (clefts), hydrocephalus, two-three toe syndactyly, dual hernias, a high double-grooved palate and a multi-cystic kidney. He has some seizure activity at birth. No syndrome has been identified. All chromosomes are normal.

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146-6006
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Bt 37, P.O. Box 8823, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see “National Resources for Specific Disabilities and Conditions” in Exceptional Parent's 1994 Resource Guide (January 1994).

We are trying to get health insurance coverage for Chris. At the time of his birth and related surgeries (the last one was in May 1992), Chris was covered under the U.S. military medical plan, but my husband is no longer in the military. Despite the fact that Chris' birth problems have all been corrected (to the extent that they can be), we have been unable to find insurance that will cover Chris with his "pre-existing conditions." We want coverage only for "normal" childhood illnesses and injuries. Does anyone know of an insurance plan that looks favorably on children with disabilities?

Chris' father and I have been raising him since he was two years old (my husband has full legal custody). Chris lives with us during the school year and visits his mother and stepfather during the summer months. In spite of his lengthy list of disabilities, Chris has progressed remarkably well. He is enrolled in a public school special education kindergarten class and enjoys the activities of other children his age. He also spent two years in an early intervention program and Head Start. His medical conditions have all been resolved. Chris looks "different," but after the initial stares by other children, they accept him like any other child. He is extremely outgoing.

I would be very interested in corresponding with parents who have a child with similar conditions, or other stepparents of children with any disability.

M.S., California

Pfeiffer Syndrome
We are the parents of an outgoing, energetic two-year-old named Bryson. He has Pfeiffer syndrome (a craniofacial disorder) and hydrocephalus.

Bryson has had seven surgeries including one shunt placement.

We are interested in the genetic aspects of Pfeiffer syndrome. How many children in the United States have it? Is it linked to a chromosomal abnormality? If so, which one? Could it be diagnosed with amniocentesis?

We also are interested in exchanging letters with other families of children who have Pfeiffer syndrome.

B.H. & M.H., North Carolina

Down Syndrome and Blind
I have a daughter who is a little over one year. At birth, Morgan was diagnosed with Down syndrome and several heart problems. This was unexpected and devastating news. But before it even had time to sink in, Morgan was also diagnosed with a cancerous brain tumor (astrocytoma). Morgan was two and a half months old when she was admitted to the hospital for a long stay in which she fought for her life. It is a miracle she made it. As a result of the cancer, however, she is completely blind.

I have been unable to find anyone else dealing with this combination of problems. Is there anyone out there who has a child like mine?

A.R.G., North Carolina
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Circle #119
Ventilator Dependence

D.S. (August 1994) wanted to know how other parents caring for a child who is ventilator-dependent "deal with everyday life." D.S. is the parent of a two-and-a-half-year-old who has a form of muscular dystrophy.

As a result of congenital cytomegalovirus (CMV) infection, our seven-year-old daughter, Jennifer, has been ventilator-dependent since birth. The number of children like ours is increasing, but I suspect that all parents like us have felt isolated and desperate at those times when even a trip to the grocery store becomes impossible.

Over the years, there have been important elements that have helped our family. First, you need to have a reliable respiratory care company, a good relationship with a hospital pediatric pulmonary rehabilitation department and an available physician. These professionals must be people who know what a tremendous responsibility you have and understand the stresses you may feel. They need to be able to teach you how to care for your child and be available to help you troubleshoot technical problems that occur.

Second, you need to train additional family members and friends to take care of your son. Although we may think we can provide 24-hour-a-day vigilance, we must also find time for ourselves. Teaching others about your son's needs may seem difficult, but make it an important goal.

We have had many adventures with Jenny and her vent. Our van was stolen once, along with her spare ventilator. I wasn't worried about the car—it was the vent I wanted back! In retrospect, it seems that patience, perseverance and a sense of humor have allowed all of us to survive.

Whenever I have been ready to give up, I have realized Jenny wasn't giving up, and that has encouraged me. She has become a delightful little girl, ventilator and all!

E.M.A., Colorado

Community Involvement

J.R. (September 1994) has a nine-year-old son with attention deficit hyperactivity disorder (ADHD), auditory processing disorder and secondary autistic tendencies. He recently completed a year of supported inclusion in the second grade. His social life during that year was difficult, though J.R. and her husband did all they could. J.R. wanted suggestions from parents who have been successful in involving their children in their communities.

Our 16-year-old son, J.R., was diagnosed with borderline Tourette syndrome, dyslexia and ADHD when he was very young. He had low self-esteem and no self-confidence. He was very shy. Over a nine-year period, he took four different medications. Some helped; others didn't.

Since starting school, J.R. had been in self-contained special classes. The only community involvement we could find was Special Olympics. We tried Cub Scouts, baseball, soccer, basketball and football. None of our efforts were successful.

In 1990, J.R. tried Taekwon-do, the Korean art of self-defense. Within three months, he was off his medication and learning self-control.

Today, J.R. is 6'2", 175 lbs. and a three-time national
pion in the sport. He has been a member of the U.S. National Taekwon-do Federation (USNTF) Junior National Team for two years. In April 1995, he will compete in Seoul, Korea, as he states, "show that 'made in the USA' is better than 'made in Korea.'"

Taekwon-do gave our son self-confidence, higher self-esteem, honesty, self-control and discipline. It also gave him a new meaning in life. I hope you will try it for your son and I hope it works as well for you as it has for us and many other parents who have tried it with kids with ADHD. Don't expect miracles overnight; it will take time, but the rewards are incredible.

Any reader is welcome to get in touch with me to learn more about Taekwon-do. I have asked Exceptional Parent to publish my address. It is:

Susan West, 5015 East 25th Place, Tulsa, OK 74114.

Werdnig-Hoffman Disease
B.O. (September 1994) is the mother of five-year-old Daniel, who has been diagnosed with Werdnig-Hoffman disease (spinal muscular atrophy, type I) and a seizure disorder. He has a feeding tube and has been hospitalized frequently due to aspiration pneumonia. He cannot roll over, sit up, crawl or walk, but uses an electric wheelchair and is very mobile. He retains control of his arms and hands and is exceptionally bright. B.O. wanted to hear from others with information about or experience with this condition.

Like your son, I have spinal muscular atrophy. My 19-year-old sister has it, too. We weren't diagnosed until I was about 19. In 1977, the doctors told our parents that we had Werdnig-Hoffman disease, but they never said what type we had.

My mother says that my sister and I both seemed fine at birth. My sister was doing everything a "normal" child would do until she had her first DPT shot; it seemed to make the disease speed up. I also was fine until I had my first shot. By the time I was 12, I had to get a wheelchair. I was just too weak to hold myself up.

My condition is not as bad as my sister's. I can move around. I can get out of my wheelchair and transfer myself to the couch or bed. But Heather has had to have metal rods put in her back because of scoliosis. She was hospitalized several times when she was younger because of pneumonia. Doctors told my parents that my sister would not live to the age of five. Now, she is almost 20. She is doing great. She graduated from high school and is now attending a local college.

As for me, I'm now 24, married and have two beautiful, "healthy" daughters.

S.C., Tennessee

Undiagnosed
D.T. & B.T. (August 1994) were looking for a diagnosis for their five-year-old daughter, who remains undiagnosed. Katie has hypotonia, microcephaly and mental retardation. She is non-verbal, makes inconsistent eye contact, drools and walks with a wide gait. Her parents thought she...
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Special
might have Angelman syndrome but have been told that is not possible.

My daughter, Emily, was diagnosed with Angelman syndrome (AS) when she was three. I was struck by the fact that you were told AS was not a possibility. We were told the same thing. Emily had all the tests you describe plus an even closer look at the 15th chromosome where most people with AS have a deletion. Our doctor, a geneticist, ruled out AS based on factors I later discovered were erroneous. Most doctors are unfamiliar with or not up-to-date on the syndrome.

On my own, I sent a tape to the Angelman Research Group at the University of Florida. Based on the videotape alone, the doctor there felt an AS diagnosis was likely. A subsequent methylation test showed the chromosomal deletion. We found out that there are labs across the county which can do a DNA probe for AS which provides a better test than even the high resolution g-banding that had been ordered by our doctor. Also, a significant percentage of children are clinically diagnosed with AS, but do not show a deletion. So being “deletion-negative” would not necessarily rule out AS.

Some of the hallmark characteristics of AS which you specifically mentioned in your letter include having a happy disposition, irregular sleep patterns, high level of sociability, hypotonia, petite stature, microcephaly, wide gait, drooling and stronger receptive than expressive language skills. You also mentioned that Katie likes having her hands rubbed. I've never seen that in AS literature, but my daughter is the same way. It relaxes her and helps her fall asleep. Emily also tends to fixate on things she really loves, like water, balloons and "Barney" videos.

I wonder if Katie's inconsistent eye contact might be the result of a vision problem—another common AS characteristic. My daughter, like many people with AS, has strabismus and is near-sighted.

I strongly recommend that you contact the Angelman Syndrome Foundation (5050-77 SW 20th Ave., Gainesville, FL 32607, 904/332-3303) and the Angelman Research Group (University of Florida/Genetics, Box J-296, JHM HC, Gainesville, FL 32610-0296, 904/392-4104). If I had followed my doctor's advice that AS was not a possibility, Emily would still be undiagnosed. I urge you to have your daughter evaluated for AS by those who are the most current on the syndrome.

My husband and I found that one of the most valuable benefits of having a diagnosis is the ability to connect with other families who are facing similar educational and behavioral issues and professionals who are addressing these challenges successfully. Even if Katie is not diagnosed with AS, she has so many AS characteristics that you might benefit from being part of our organization.

M.M., Kentucky

EDITOR'S NOTE: D.T. and B.T. received a number of similar letters from parents whose children were positively diagnosed with Angelman syndrome after the first doctors they had seen had told them it was not a possibility.
Four-year-old Samantha Diaz shows off her dino-sized charm in a costume she chose herself—"Barney's" friend, Baby Bop. Samantha, who has Down syndrome, was one of the first students with a disability to be included in regular classes at her public school in Yonkers, New York.

"Sister" Mary Chikasuwe, now 13, enjoys trick-or-treating with brother John, 12, in Honolulu, Hawaii. Mary, who has developmental delays, attends Kaimuki Intermediate School and competes in ramp bowling in the Special Olympics. Mary's family lives on a mountainside overlooking the ocean. They say that getting her wheelchair door-to-door is their favorite Halloween sport.

Last Halloween, Keri Ann Seminaris was an island princess—Staten Island, New York, that is. Keri, 6, attends P.S. 37. Each year, Keri celebrates her birthday and Halloween within a few weeks—no wonder October is her favorite month!

Two-year-old Corey Graham rode a devil of a hayride during the Halloween carnival at his early intervention program last year. Corey lives with his parents, Melissa and Jon, in Oxford, Mississippi. He loves going to school, especially when a party is part of the schedule! Corey has developmental delays.

This witch casts quite a spell on everyone she meets! Kerah Moss, 4, lives in Marietta, Georgia with her parents, Palmer and Marsha, and brother Corey, 13. Kerah, who has cerebral palsy, attends Timberlake Elementary School.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 208 Hanover Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
CARNITOR® (levocarnitine) is now available for reimbursement by Medicaid in all 50 states and Medicare in many states.

CARNITOR® is the only prescription formulation of levocarnitine available and "...should not be confused with dietary and health supplement L-carnitine products.... Such supplements have not undergone review by FDA for safety and effectiveness."1

"Unless these dietary supplements...have been approved...recommendations/requirements by State Medicaid agencies would be inappropriate for the treatment of systemic carnitine deficiency."2

"The data from this and previous studies indicate a lack of quality control in the manufacturing process of tablets and capsules in products sold as food supplements, resulting in gross inconsistencies in the properties of the tablets to disintegrate under physiological conditions within a reasonable time. Furthermore, there is evidence that many of the products contain significantly less than the stated amount of the active substance, suggesting also a lack of quality control in the formulation of the product."3

"Only the prescription form of levocarnitine is indicated for the treatment of carnitine deficiency. Over-the-counter and health food store products should never be substituted."4

The Only Prescription Formulation: Available in Tablets, Oral Solution, and Ampoules for Intravenous Use... And Now Available for Reimbursement!
CARNITOR® (LEVOCARNITINE) Tablets and Oral Solution

For oral use only. Not for parenteral use.

CARNITOR® (Levocarnitine) Tablets (330 mg) CARNITOR® (Levocarnitine) Oral Solution (1 g per 10 mL multidose)

Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:
CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency.

Tablets and Oral Solution are also indicated for the acute and chronic treatment of patients with an inborn error of metabolism which results in a secondary carnitine deficiency.

CONTRAINDICATIONS: None known.

WARNINGS: None.

PRECAUTIONS:
General: CARNITOR® Oral Solution is for oral/intestinal use only. Not for parenteral use. Gastrointestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3-4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility: Mutagenicity tests have been performed in Salmonella typhimurium, Saccharomyces cerevisiae and Schizosaccharomyces pombe which do not indicate that CARNITOR® is mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy: Pregnancy Category B

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There is, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers: It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion:


Pediatric use See Dosage and Administration.

ADVERSE REACTIONS: Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D-L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uraemic patients receiving L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE: There have been no reports of toxicity from carnitine overdosage. The oral LD50 of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea.

DOSAGE AND ADMINISTRATION:

CARNITOR® Tablets: Recommended adult dosage is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution.

Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED: CARNITOR® Tablets: supplied as 330 mg, individually foil-wrapped tablets in boxes of 90.

Store at room temperature (25°C/77°F). CARNITOR Oral Solution is supplied in 118 mL (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection

For Intravenous Use Only

CARNITOR® (Levocarnitine) injection 1 g per 5 mL CARNITOR® (Levocarnitine)

Before prescribing, please consult complete product information, a summary of which follows:

INDICATIONS AND USAGE:

For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

CONTRAINDICATIONS: None known.

WARNINGS: None.

PRECAUTIONS:

Carcinogenesis, Mutagenesis, Impairment of Fertility: Mutagenicity tests performed in Salmonella typhimurium, Saccharomyces cerevisiae, and Schizosaccharomyces pombe indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine.

Pregnancy: Pregnancy Category B

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There is, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers: It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, it is a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Metabolism and excretion:


Pediatric use See Dosage and Administration.

ADVERSE REACTIONS: Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D-L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uraemic patients receiving L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

OVERDOSAGE: There have been no reports of toxicity from carnitine overdosage. The oral LD50 of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea.

DOSAGE AND ADMINISTRATION:

CARNITOR® (Levocarnitine) Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 200 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter), and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discolouration prior to administration, whenever solution and container permit.

HOW SUPPLIED: CARNITOR® (Levocarnitine) injection, 1 gram per 5 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton. Store ampoules at room temperature (25°C/77°F) in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

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**Ask the Doctor**

by David Hirsch, M.D.

**"Flu" and "Pneumonia" Vaccines**

Q My three-year-old has spastic diplegia (a form of cerebral palsy involving two extremities, usually the legs) and mild developmental delays in motor and speech. She is in a preschool program where she gets speech and physical therapy. She has been fairly healthy, usually getting only a few colds each year. The rest of the family is healthy also. Should she get a “flu” shot?

A Your daughter does not have one of the “classic” indications for an influenza vaccine—age over 65; chronic cardiovascular (heart) or pulmonary (lung) disorders, including asthma; chronic metabolic diseases such as diabetes; any condition or treatment causing immunosuppression or a weakened immune system; kidney disease; conditions which hamper the production of blood; long-term aspirin therapy or residence in a nursing home or long-term care facility. However, I believe she should be vaccinated against influenza.

The vaccine is very safe, only occasionally giving local tenderness and fever. The only true contraindication (reason not to give the vaccine) for the influenza vaccine is an allergy to eggs or egg-containing products. One cannot get influenza from the “flu” vaccine. While the vaccine will not protect your daughter from the common cold or other respiratory viruses such as parainfluenza (a virus which causes “croup,” colds, pneumonia and bronchitis) or R.S.V. (respiratory syncytial virus, the most common cause of bronchiolitis and viral pneumonia in young children), it will significantly reduce the risk or the severity of an illness that would make her miserable for one to two weeks and cause her to miss school and therapy.

Check with your daughter’s doctor about the best type of influenza vaccine for her. You’ll need to get her immunized as soon as possible. And because the influenza viruses change from year to year, the influenza vaccine needs to be given each year.

Q Our son has epilepsy which is controlled fairly well with an anticonvulsant. He also has asthma and is on inhalation treatments and occasionally steroids. He gets a "flu" vaccine each year. Do you think he also should get a "pneumonia" vaccine?

A The “pneumonia” vaccine is actually a vaccine that gives protection against a number of strains of a bacteria known as *Streptococcus pneumoniae* (pneumococci). Individuals for whom the “flu” vaccine is recommended—those over 65 years old and those with chronic pulmonary disorders, including asthma; immunosuppressive problems or other chronic medical conditions—should receive this vaccine also. It also is recommended for children over two years old who have chronic illnesses which may cause an increased risk of pneumococcal infection.

Unlike the influenza vaccine, the pneumococcal vaccine usually needs to be given only once. Side effects such as redness and pain at the injection site are common, but typically very mild. Please contact your son’s physician for more information about this vaccine.
The Alliance for Technology Access is dedicated to redefining human potential through the imaginative and empowering application of technology for children and adults with disabilities. Now numbering 77 centers in the United States and Canada (see list beginning on page 26), each center provides opportunities for people with disabilities, their families, friends, advocates and service providers to get hands-on experience to learn more about the ways assistive technology can enhance independence, achievement, productivity and quality of life. Working in collaboration with 75 technology developers and manufacturers, each ATA center is equipped with the latest information about available products and services.

Technology is no longer a luxury in our society. Information about and access to technology, including products and information services, has become crucial to educational achievement, employment and participation in the world. Each ATA center is ready and eager to help potential users of technology become familiar with today's exciting technology tools. Through demonstrations, consultations, seminars and a myriad of other activities, more than 100,000 people each year are discovering tools and services which significantly enhance their lives. In these pages, you will meet a few of those people...

When I was asked if I wanted to write a short story about my son, Michael, and his use of assistive technology, I was very excited. I'm thrilled to be able to spread the word about how assistive technology has turned Michael into the independent
John
Assistive technology helps one child prove the “experts” wrong
BY JOHN DUGANNE

I was born with cerebral palsy in 1971. My first public school program was a development center for children with severe disabilities. Unlike the other kids, I couldn’t control my movements and I couldn’t talk. The teachers told my parents I was not learning. The school psychologist tested me and said that I was mentally retarded.

Luckily, my parents didn’t believe it. They believed I needed friends and support to be able to do things my body wouldn’t allow me to do. My stepfather began building switches and other gadgets, and my mother began to advocate for me to be included in everything with kids my age—school, play groups and church. I left public school and began attending a private alternative school where I was the only kid with a disability.

But I still had trouble learning. After two years, the teachers at the private school suggested I return to public school where there would be special education teachers to help me. But my IQ test followed me; people saw my wheelchair and inability to talk before they saw me. Again, I ended up in a class for students with severe disabilities.

Then I got my first computer. It was 1978, and I was seven years old. This was the beginning of real life for me. There were no adaptive devices at that time, so my family’s first invention was to put plastic wrap over the keyboard so I wouldn’t drool on it. They taped a pencil into my hand to touch the keys. My family and I saw that the computer could be a learning and communication tool for me. And we have been working at making it perform for me ever since.

When Michael was born six years ago, he was without oxygen for at least 18 minutes during and after birth. As a result, he does not sit, stand or walk. He has speech problems and has not yet been able to feed himself independently.

When Michael was about 18 months old, his early intervention teacher noticed that although Michael could not use his hands very well, he consistently used his left foot to manipulate objects, especially his favorite books. Michael was introduced to a computer by the time he was two years old.

Michael is the first child with multiple disabilities to be fully included into a regular first grade classroom in our school system. Michael’s Intellikeys keyboard has become his tool for completing written work on his personal computer in the classroom. During reading lessons, Michael sits with his classmates at the reading table using an adapted chair.

I cannot imagine that Michael’s integration would have been as successful if assistive technology had not given him a way to express his thoughts and ideas. Just the other day, Michael’s teacher commented that he has become a real “chatterbox” in class. I don’t think she realized how happy that made me feel—not that I want Michael to talk out of turn, but his teacher’s comment showed me how many friends he has made at school.

I hate to think about how limited Michael’s life would be without all this equipment to help him interact with his peers, family and community. Assistive technology has unlocked my son’s intellect. It has allowed him to express himself—not only to me, but to the rest of the world. Assistive technology has already empowered his young body and mind. I can only imagine the possibilities in store for his future.
During a 1981 visit to the home of 10-year-old John Duganne, Dusty became fascinated with everything John could do with his Apple computer. (See John's story on page 21.) At that time, control was a big issue for Dusty, because she had Down syndrome and very little control over things in her life. With John's computer, she could push a button and make things happen. Dusty's parents had to drag her home from that first encounter with technology.

Dusty, then six, was attending a regular kindergarten class. Her teachers told her parents that she did not pay attention well and would not stay on task. Dusty's mother knew the trick would be to find a task Dusty wanted to stay on.

Through her research, Dusty's mother learned that children with Down syndrome tend to be good visual learners. That clinched it. At Christmas, her parents bought Dusty an Apple computer and some software programs that would be both educational and fun. Dusty learned the keyboard quickly and began to practice counting without being asked.

Dusty's mother had no prior experience with computers or other technology. She did not consider herself "mechanically inclined," but she and Dusty learned together. As a way to get Dusty access to a computer at school, her mother volunteered to teach computer use to other students in Dusty's class. As the students played with the computer, Dusty's teacher began to realize Dusty could be included in computer activities, like everyone else.

The computer was an invaluable tool for Dusty as she moved through the educational system. As a student at her local high school, Dusty used a Macintosh computer with large print, a talking word processor and a word-prediction program. Using these tools, she wrote children's books in her English class, then read these stories to the children in the daycare center where she worked.

Dusty's mother says, "Technology gave Dusty confidence in her ability as a learner. She began to feel good about herself. She has always been able to do the things without the technology that she does with it. But without the computer, her work appears to have been done by a six-year-old. With the computer, it looks as if it were done by a person her age. Before technology, writing was something of a 'Catch-22'.

Dusty's mother adds, "Technology is highly motivating, and can bring out the best in a child. As a parent, I think it can help you discover the ways your child learns best because it gives you so many exciting avenues to explore. It's a feel-good thing—fun for the whole family. It's also a good integrator. For us, it attracted kids from around the neighborhood who wanted to come over and play."

Dusty, now 19, attends a transitional program at the College of Marin, a community college in northern California. A version of Dusty's story appeared in the book COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES.

ATA Update
by Jacquelyn Brand

In addition to the services offered at each ATA center, some of the Alliance's key national initiatives include:

Universal design
The ATA is working closely with mainstream hardware and software developers to build access into their products. One company in particular, Broderbund Software—the successful publisher of such well-known educational software as Kid Pix, Print Shop and the Carmen Sandiego games—has approached this topic with concern, interest and heart. The Alliance has been working with Brøderbund to identify key universal design elements. The ATA also tests Brøderbund software products to make sure they are compatible with common assistive technology devices. These results are published each year in Brøderbund's catalog of educational software, making appropriate software selection that much easier for parents and educators.

Creating accessible school computer labs
The ATA is collaborating with the Mattel Foundation and IBM in the implementation of a major national initiative—the Computer Learning Lab Project—which brings IBM Writ-
ATA Update continued

ating-To-Read labs to elementary schools across the country and around the world. ATA trainers travel to schools that have been selected by the Mattel Foundation to receive these labs, and provide extensive training and follow-up for teachers in the use of a variety of software solutions, adaptations and strategies to allow students with disabilities to be full participants with peers. We have learned that labs can be accessible to all students once teachers become comfortable with the tools at their disposal. Working together, Mattel Foundation, IBM and the ATA are demonstrating that all means all.

Accessing Computer Technology in our Neighborhoods (ACTION)
The Alliance has just concluded a three-year pilot project designed to reach out into communities and neighborhoods which have been traditionally underserved by technology. In five communities across the country, ATA centers conducted technology fairs, visited shopping malls, HeadStart programs, churches and other key community locations to introduce people to the possibilities of technology.

While one segment of our society becomes more and more sophisticated in using new technologies, the ATA is very concerned about the growing gap between technology “haves” and “have-nots.” The ACTION project was designed to develop and implement strategies for reaching communities which have not yet had opportunities to learn about technology. An outreach manual is currently in development.

Coming soon...
The Alliance is developing a series of seminars on the role of technology in the transition from school to work. Supported by a grant from Citibank and the J.M. Foundation, the ATA will be training students, parents, educators and rehabilitation professionals to look closely at the laws pertaining to transition and the use of technology. The seminars will also focus on technology implementation strategies which may lead to employment.

Jacquelyn Brand is the executive director of the Foundation for Technology Access.

Peter Cameruca is a beautiful four-year-old with cerebral palsy. Peter cannot use his hands, but thanks to assistive technology, he can read a book, play a game and color a picture. He is unable to talk, but he can communicate. Peter cannot walk, but he races around the neighborhood with his friends.

Peter was introduced to assistive technology by the local toy library and began using adapted toys around his first birthday. With toys run by switches, he could play and explore like any other child.

Peter's greatest love is to have someone read to him. His desire to participate in book-reading sessions created his next need for assistive technology. At 18 months, Peter received his first communication device, a Prentke Romich IntroTalker. This first augmentative communication device gave Peter a way to tell the person reading to him when to turn the page and when to read it again. He could also talk about what was happening in the story. By his second birthday, Peter was using augmentative communication to talk to a large number of people about many things.

Next, Peter needed a way to participate in activities with his older brother, David, and other children. This created his third need for assistive technology. A Macintosh computer and a variety of games adapted for switch input gave Peter and David an activity in which both could participate on an equal basis.

Children in Peter's neighborhood tend to play in large groups. In the course of a day, kids travel from house to house and yard to yard.

Peter's desire to participate created his fourth need for assistive technology. Now, a power wheelchair enables him to be part of the group.

With assistive technology, Peter can go across the street to visit a friend, play games with his brothers and talk about his favorite books with his mom. Assistive technology allows Peter to do the usual in unusual ways.

Peter Cameruca lives in Columbus, Ohio with his parents and two brothers, David and Joey. Melinda Peters Todaro, the author of this piece, is Peter's aunt.

Continued on page 25
You Asked DynaVox To Do Even More...

"I more talk."

"I want to tell a story."

"I want to spell and talk faster."

Now, It Offers 3 Powerful Software Solutions.

DynaVox Was Just The Beginning.

When we first introduced the revolutionary DynaVox* augmentative communication aid, the response was overwhelming.

Because people found that DynaVox's modern dynamic-display system was much easier to learn than traditional devices. So much easier, in fact, that most people could begin using the DynaVox in less than half an hour.

But ease of use is only one part of the DynaVox story. Another, equally important part, is communication flexibility.

The Choice is Yours.

Now DynaVox users can choose between 3 powerful software systems, each designed to serve a different range of needs.

DynaSym 2000 is the comprehensive language-based system that provides users with nearly two thousand symbols, many of which are electronically animated. But it's not just a collection of pictures, it's a complete, clinically-designed visual language that follows the basic rules of human speech. It helps promote rapid learning and spontaneous self-expression.

DynaWrite* is the software package for those who prefer to spell their messages and employ "word prediction." DynaWrite analyzes as you write, learns your words and offers choices for the next word - based on grammar rules, recency and frequency, a built-in 40,000-word dictionary, and more.

People can then select the word they want with a single keystroke, and compose messages much faster than ordinary letter-by-letter typing.

Finally, DynaWrite/DynaSym* combines all the benefits of both programs into one fully-integrated package. It offers a long-term solution for those who are making the transition to literacy - or who are literate and appreciate the power of symbols.

Dedicated To Communication.

And because the DynaVox is a totally self-contained communication device, you get all this capability without having to buy a separate computer and speech synthesizer.

No other single device can offer the complete spectrum of communication - from symbols, written words, and advanced word prediction, to the highest quality synthesized speech. So no other device can offer the value DynaVox can.

A Lasting Commitment.

And that's no accident. It's a direct reflection of our commitment to you. Because we know it takes more than just technology - it takes a thorough understanding of language, and practical, affordable solutions - to keep pace with your growing needs.

So if you know someone who might benefit from DynaVox, give us a call at 1-800-344-1778. Or see us at the ASHA convention.
or the first few years of their lives, Zach and Mallory Holler could walk, talk, see, hear and play like other children. Then, due to a rare condition called Rosenberg-Chutorian syndrome, each began to lose much of their hearing and vision, as well as the ability to walk and use their arms. Mallory also lost most of her speech when her hearing diminished.

Zach and Mallory Holler
Regaining independence and control
by Kim and Greg Holler

We experienced intense frustration when our children could no longer write their names, color pictures or even talk with friends. But now, thanks to assistive technology, Zach and Mallory are beginning to do things they haven't been able to do for several years.

At a recent assistive technology camp, Zach, now six years old, was able to write his name independently on a touch-window with a homemade head pointer. His beautiful face filled with joy as he said, "I wrote my name all by myself!" At home, he uses an Intellikeys keyboard to play computer games. Soon, he will be using it for spelling and other schoolwork. His kindergarten teacher plans to incorporate computers into the curriculum so Zach can participate in the same activities as his peers.

Mallory will soon be four, and her biggest need for technology has been in the area of communication. Fortunately, she has regained some speech and has also found many other ways to communicate with her family. But to help her communicate with the rest of the world, Mallory began using the Liberator, an augmentative communication device. Because of her hearing loss and muscle weakness, it was difficult to find an appropriate method for her to access this device. Now, with a homemade head-pointer like her brother’s, Mallory is learning to successfully communicate and play. She also enjoys working on the computer.

Zach and Mallory also have switch-activated toys. We are waiting for several funding sources to come through so we can install switch-activated environmental controls for their use. Assistive technology has given our children some measure of independence, and we know it will continue to play a major role in their futures.

Zach and Mallory Holler live in Dayton, Ohio with their parents, Kim and Greg.

My adopted 13-year-old son, Joshua, has extensive brain damage as a result of accumulated hydrocephalic pressure. Born in Korea with hydrocephalus, Joshua did not receive his first shunt until considerable brain damage had occurred. Because of his problems with long- and short-term memory, most professionals believed his functioning would be extremely limited.

For example, I was told that Joshua would probably never learn. Frustration mounted as he tried to memorize math facts.

Then, we introduced him to the computer and everything changed. Computer games provided learning opportunities that held Joshua's attention, even with repetition. "Impossible" addition became second-nature. Subtraction followed quickly.

Multiplication brought a return to frustration until we found a software program called Number Munchers. Now, Josh knows his multiplication tables perfectly too.

As Joshua's knowledge increases, we face new challenges. We constantly search for computer games that will provide the needed stimulation and excitement to help him continue to advance academically. Reading-comprehension software for older children is a special challenge.

Joshua
Using technology to do the "impossible"
by Helen Smalley-Bower

Joshua can read out loud on a sixth-grade level, but his comprehension lags several grade levels behind. So far, we haven't found an exciting reading game for kids his age. But we're still looking!

Economic reality can limit access to technology. In the beginning, we bought several pieces of software that—as we learned only after bringing it home—did not meet Josh's unique needs. We knew we couldn't afford to make this kind of expensive mistake. Fortunately, the software lending library at our local ATA center (ALOHA Special Technology Access Center) has helped to solve the problem. Now, we borrow software programs and try them out at home for two weeks. This way, we can see if they suit Joshua before we make a purchase.

Joshua's progress has already surprised many people. I know that as we continue to find new software and technology suited to his unique needs, Joshua will continue to learn and grow.

Joshua Bower lives in Honolulu, Hawaii with his parents, Helen Smalley-Bower and Scott Bower.
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<td>Santa Monica, CA 90403</td>
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Key to Services
- 1 Hands-on computer demonstrations
- 2 Guided exploration and problem-solving
- 3 Formal technology-needs assessments
- 4 Assistance in obtaining assistive technology funding
- 5 Software lending library
- 6 Loans of computers and hardware
- 7 Toy lending library
- 8 Loans of assistive devices
- 9 Videotape lending library
- 10 Constructing/adapting switches and devices
- 11 Technical assistance to IEP teams
- 12 Teacher training
- 13 Parent/family training
- 14 Augmentative communication training
- 15 Workshops
- 16 Early childhood/ preschool programs
- 17 Computer camps/After-school programs
- 18 Transition training for young adults
- 19 Technical assistance to employers
- 20 Newsletter
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Too Few Exceptions to the Rule
A vision of true technology access for all
by Bob Williams

One does not have to look far to understand why access to technology is vital. Of course, this access is important to all Americans. But, it is especially important to those of us with significant disabilities. In fact, I would not be writing this piece today if I had not been given access to my very first piece of assistive technology when I was seven years old—some 30 years ago—an IBM electric typewriter.

Years later, I learned that at that time, my teacher did not believe I would ever learn to read. In fact, I am convinced that if I had not been given the typewriter, that teacher’s perception would have become a self-fulfilling prophesy. This has happened for many of my contemporaries with cerebral palsy. These people, despite their typical intelligence, face significant difficulties with reading, writing and comprehending the printed word.

Learning is not a passive act. Learning requires a great deal of communication and feedback. Having a typewriter not only enabled me to convince others that I could read; but equally importantly, it enabled me to see that reading and writing had a real purpose and would have real consequences in my life.

Real power

Now that I head a multi-million dollar federal agency, many say I have power. Perhaps so. However, I can tell you that my real power stems not from my position, but from the fact that I have always somehow beaten the odds. I beat the odds by getting a college education—something most Americans with disabilities still have not been able to do. I beat the odds by growing up in a family that helped me to set and achieve some lofty goals. And perhaps most importantly, I have beaten the odds by being able to access the full range of personal assistance and assistive technology I need to live the life that I want to lead.

For me, this includes a great deal of assistance from my wife and best friend, Helen, and others with everyday tasks such as bathing, dressing, eating and managing the paper flow which constantly threatens to overtake my desk. Or the help I receive from my assistance dog, Decoy, in getting up from the floor or walking across a uneven patch of ground. Or the assistance and productivity I demand from my Liberator (an augmentative communication device) and other assistive devices. To me, personal assistance includes any sort of assistance we individuals with disabilities rely on to make our lives more personally and professionally productive.

An exception to the rule

Unfortunately, I am very much an exception to some very important rules in our nation. I say this with little pride, but with a great deal of outrage—outrage that my friend, Vi, went to her grave without ever getting the assistive technology, training or ongoing support she needed to effectively express herself. Outrage that such technology, training and support is still seen as a luxury rather than the necessity it is. And outrage that as a nation, we continue to spend an estimated $240 billion each year to keep people with disabilities needlessly dependent.

I hope you share these feelings of outrage, because your job and mine is not to produce a few more “exceptions.” Instead, we need to change the rules of the game.

Dreams deferred

I continue to learn more about assistive technology—about its power, about its potential and most of all, about its dreams deferred. A few years ago, I met a contemporary of mine who also has cerebral palsy, a woman named Kathy. At that time, Kathy was living in Clover Bottom, an institution.

As soon as I met her, Kathy used her communication board to point to the symbols for “I want to go.” My wife and I asked the staff what she meant. They replied that Kathy wanted out of Clover Bottom—forever.

I initially talked to Kathy using my manual communication board. Later, as we were leaving, I spoke to her using my Liberator. Kathy made it clear that she was interested in obtaining a similar device. When I told her the law said she should get what she needs, Kathy cried inconsolably, and with good reason.

Kathy is like many others. The greatest crippler she faces is not her disabilities, but others’ severe ignorance and profound underestimation of her abilities. Access to supports like personal assistance and assistive technology is critical. In fact, for individuals like Kathy and myself, it’s often the only thing that can begin to tear down the walls of myths and stereotypes.

Kathy finally moved out of Clover Bottom and into a group home. It’s not perfect, but it’s a beginning. However,
although the state obtained a communication device for her some time ago, she has yet to receive any of the support and training she needs to learn how to use it.

Like my friend, Vi, and millions of other Americans with significant disabilities, Kathy seems to have a strange attraction to the proverbial monkey wrench. Or maybe it’s just plain inertia—not inertia on Kathy’s part, but a lack of urgency and sustained effort by the system.

Where the rubber meets the highway
We all talk a good game about the power and potential of assistive technology. And it is all very true. But—speaking both as an individual and a federal executive—I continue to see the need to change the system. That is where the rubber meets the information superhighway. That is where we transform power and potential into everyday realities for real people.

Creating true access to assistive technology means much more than creating access to devices, hardware and software. It means building in training, ongoing support, opportunities for self instruction and troubleshooting. In fact, I have a staff person, Ron, who spends about a third of his time as my technology troubleshooter. This is important because I rely on my Liberator for more than just communication. It is my principal management tool. I use it to access my computer, e-mail and the Internet. And Ron is there to anticipate problems and to solve glitches as soon as they occur. Frankly, I cannot afford to be nonproductive, not even for five minutes or a half hour—certainly not for an entire day.

America can no longer afford nonproductivity either. Those people who are “exceptions to the rule”—like me—are exceptions because we have had access not only to assistive technology, but to the training and ongoing support we need to make it work. And it does not only improve our own lives; it also makes a critical difference in the lives of our families, our communities and our nation. America can no longer afford to have only a few of us “exceptions” hanging around.

Looking toward the future
We need to figure out the best ways to get ongoing technology training, assistance and support to individuals. We must reach out, and reach beyond the traditional ways of responding to the challenges—and opportunities—presented by disability. The disability community must work with those of us in the Clinton Administration to infuse universal access as a pivotal element in the national information infrastructure.

It begins with working with young Americans—those with and without disabilities—especially those who are left out and left behind at the very margins of the American community. It begins with preparing a number of these young men and women to come together to form what might be called a “national personal support infrastructure,” offering all individuals with significant disabilities ready access to the same kind of ongoing training, support and troubleshooting that is now available to me.

Access to technology of every sort will increasingly become a prerequisite for learning, working and simply living in twenty-first century America. This will be true for all Americans, but it will be particularly true for Americans with disabilities.

Bob Williams is Commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services. Williams has cerebral palsy and uses augmentative communication. He is well-known for his leadership on disability issues.

Prior to assuming his current position, Williams was a policy associate with the United Cerebral Palsy Associations and served as a co-chair of the Consortium for Citizens with Disabilities Task Force on Personal Assistance Services. A writer and poet, Williams’ best-known works are included in his first volume of poetry, In a Struggling Voice.

This piece was adapted from a keynote speech given at a July 1994 reception hosted by USA Today, IntelliTools, and the Foundation for Technology Access, to celebrate the publication of the Foundation’s new book, Computer Resources for People with Disabilities.
Disabilities, Opportunities, Internetworking & Technology = DO-IT!
Gaining access to science, engineering and mathematics
by Sheryl Burgstahler

High school sophomore Randy Hammer was a good student who loved to participate in sports. Blind since birth, he was interested in foreign languages and science. However, all printed materials needed to be produced on tape or in Braille or read to him—all slow processes. He wondered if he would be able to keep up with academics if he went to college. Then, Randy became a “scholar” at the DO-IT (Disabilities, Opportunities, Internetworking and Technology) program at the University of Washington (UW) in Seattle.

In this program, Randy gained access to a portable computer system with voice output, a scanner with optical character recognition, a Braille printer and a wealth of human and information resources on the Internet network. Using the Internet, he read a newspaper by himself for the first time in his life. He met engineers, scientists and university students on the net; some of them with similar disabilities. “My computer and access to the Internet have become my eyes to the world,” Randy reports.

In live-in summer programs at the university, Randy participated in science and engineering labs and discovered career options. He also had a firsthand taste of dorm life. “I learned what college life is all about and, most importantly, I learned that the early bird catches the shower,” Randy says.

Technology opens doors
Only a few years ago, careers in science, engineering and mathematics might have seemed like pipe dreams for individuals with disabilities. However, because of developments in adaptive technologies, more extensive use of computers and networks in these fields and an explosion of electronic resources, opportunities are growing.

Still, challenges remain. DO-IT provides students with the tools needed to face these challenges so they can pursue science, engineering and mathematics programs and careers. Funded primarily by the National Science Foundation, DO-IT began in 1992 in UW’s College of Engineering and department of Computing and Communications.

The DO-IT Scholars program allows sophomore or junior high school students with disabilities to study science, engineering and mathematics; experience campus living; develop self-advocacy skills; interact with mentors and use technology to pursue academic interests. The only comprehensive program of its kind in the nation, it admits students from Washington, Oregon, Idaho, Montana, North Dakota and Alaska.

Internetworking
DO-IT scholars learn to use computers and the Internet to explore academic and career interests. Computers and adaptive technologies are selected for each participant; local Internet connections are established and in-home training is provided.

Although Duchenne muscular dystrophy has slowly taken away one scholar’s ability to walk, dress himself and manipulate a fork, adaptive technologies have allowed him to interact with hundreds of people on the Internet. “I don’t see myself as disabled,” he says. “I see myself as playing football and baseball even though I don’t... Sometimes when I’m e-mailing somebody, I think of myself as being ‘normal.’ It kind of puts you on equal footing.”

Mentoring
DO-IT scholars use electronic communications and personal meetings to connect with post-secondary students and career “mentors” to facilitate academic, career and personal achievements. Mentors study or work in many fields, including computer programming, post-secondary education, statistics, physics, engineering, computer science, computer consulting and biology. Mentors “provide us with useful contacts in academics, career and personal areas... They help participants find their talents and inte-
ests, and confirm their goals," one scholar says.

Experienced scholars learn communication and leadership skills as “peer mentors” for new program participants. A parent reports that her son, a scholar with attention deficit disorder (ADD) and a learning disability has helped another child with ADD “by taking the boy to register for high school and showing him around so he will know where things are on the first day of class.”

Summer study
At live-in programs held during two consecutive summers at UW, scholars study science, engineering and math through lectures, labs, computer applications and the Internet network. Subjects include oceanography; heart surgery; chemistry; virtual reality; geophysics; material sciences; civil, mechanical and electrical engineering; mathematics; biology; physics and astronomy. As new scholars spent time getting to know students with disabilities different than their own, many were not sure where they would fit in. “Across disabilities there were some very exciting things to see, where students realized they could complement each other,” one instructor recalls.

In a computer lab held during this year’s summer session, an observer would see 33 students working:
- A student with no use of his hands types by talking into a headset-mounted microphone.
- A scholar who lost both arms in a farming accident types with a device attached to his one remaining elbow, at 20–25 words per minute.

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program. Back at home, scholars log-on to the Internet to continue their conversations and friendships. "It's kind of like going to summer camp," says one scholar, "but to a certain extent I don't ever have to go home."

Special Projects and Events
Scholars also have opportunities to pursue special projects, including collecting scientific resources, administering systems, editing the DO-IT newsletter and teaching in the summer program. Scholars as well as other pre-college and college students with disabilities and their families, teachers, counselors and service providers can participate in special events, including the UW Computer Fair booth, presentation and reception; the UW Engineering Open House and the UW Health Sciences Open House. Events attract children with disabilities and their parents who, after meeting DO-IT participants, are encouraged to use technology and to pursue science, engineering and mathematics interests.

Signs of success
It is too early to measure the ultimate impact of the DO-IT project, but evidence has begun to appear in the successes of many DO-IT scholars:
• Four scholars who graduated from high school in 1994 are pursuing college programs in genetics, computer programming, electrical engineering and general studies in preparation for more advanced scientific studies.
• One scholar won a four-year NASA scholarship to attend UW; she became aware of the scholarship program during a DO-IT summer study session.
• One scholar won an award for his essay about the Internet in a national contest sponsored by the National Science Foundation, National Center for Education Statistics and NASA; he was subsequently invited to speak at the Washington State "Governor's Technology Conference."
• One scholar works part-time at Microsoft and in UW's Adaptive Technology Lab.

For the scholars, the most important two words in their vocabulary may be "do it." One scholar with health, mobility and speech impairments says DO-IT gives him the skills "so I can do what I want to do."

DO-IT Resources
DO-IT has created two videos:
• DO-IT Scholars follows many of the program participants through 1993's summer session (Free).
• Working Together: Faculty and Students with Disabilities helps college and university faculty become aware of the academic potential and access needs of students with disabilities ($20, includes written materials).

To obtain either video, or for more information about DO-IT, contact:
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Tips for Parents, Schools and Employers

Many small steps taken locally can have a substantial impact and move us closer to a world where people with disabilities have equal access to opportunities in science, engineering and mathematics:

- Give students with disabilities access to computers, electronic communications and network resources at an early age.
- Make facilities, computers, science equipment and programs accessible to people with disabilities.
- Assure that scientific and mathematics publications are available in appropriate alternative formats.
- Encourage students with disabilities to take high school and college math and science classes.
- Establish positive, motivational and lasting interactions between high school and college students with disabilities and engineers and scientists who have disabilities.
- Facilitate transitions to college and employment.
- Help educators and employers appreciate the potential of people with disabilities and create learning and working environments where skills can be developed and productivity can be maximized.

The historical impact of technology on people with disabilities cannot be overestimated. Computers and networks help them to access resources, communicate with others and perform academic tasks independently. Such tools are required if individuals with disabilities are to compete with their peers without disabilities.

"In the beginning, when they let us work, persons with disabilities were pigeonholed into positions involving basic manual skills such as basket weaving and chair caning; then we got computer smart," says one DO-IT mentor who is blind. "Now we have the information superhighway and we reach out to connect with each other and with the world."

Sheryl Burgstahler is the director of the DO-IT Project. With a Bachelors and Masters degree in mathematics and a Ph.D. in higher education, Burgstahler is an assistant director in the Computing and Communications Department and a research assistant professor at the University of Washington.
Robert Walsh
Making the journey to communication with assistive technology

Robert Walsh became a ward of the state as an infant when his birth mother felt unable to care for him because she was unwed and he had cerebral palsy. Unable to communicate, walk or use his hands, Walsh was initially thought to be mentally retarded. After a series of tests when he was four, however, the professionals realized he was probably brighter than average.

Walsh lived in various foster homes and institutions before being adopted at age 11 by Joseph and Catherine Walsh, a couple who had known Bobby since he was very young (their daughter worked and still works at Saint Joseph's Children's Center in Scranton, PA where he was born).

Walsh graduated from West Scranton High School in 1992—and ranked 26th in a class of 197. Not only was he a National Honor Society member, but he was also voted homecoming king and most popular boy in his class.

Now 23, Walsh is a junior majoring in Computer Information Systems at Marywood College in Scranton. While taking 12 credits each semester, Walsh's current grade point average is 3.04. Walsh's success is likely to continue after college; by his sophomore year, he already had received two post-graduation job offers.

Currently, Walsh is enjoying a new power wheelchair which he is able to control with head movements. "The new chair gives me even more mobility and independence," Walsh says. "This I like."

I was born with cerebral palsy. Not being able to talk, walk or use my hands, I felt like a prisoner in my own body. Although the lack of communication was just one of the many disabilities that had overcome my body at birth, it was the most devastating. People do not realize that nearly every minute of our waking lives is spent talking. For the first eight years of my life, I tried very hard to communicate verbally, but I could not speak.

I had to find alternative methods. I tried to communicate with my eyes. Have you ever tried to talk to someone with your eyes? Many times, the people I was trying to communicate with just ignored me; maybe they thought I had a nervous eye condition. People had a hard time understanding what I was trying to tell them—I became very frustrated.

My hands were another problem. I learned to understand sign language by watching others, but this didn't help me because I am unable to use my hands. However, I never gave up on trying to use my eyes. When I wanted to communicate with someone, I would just drive that person crazy with my eye movements until, eventually, they would start asking me questions.

The learning years
When I was 10 and a student at The Home of the Merciful Savior School in Philadelphia, I received my first word board. Finally, the doors of communication began to open. At last, I could ask for a drink or express my feelings. I communicated by shifting my eyes toward a group of numbers that were on the board; each number corresponded to a series of words. Eventually my board became too small because my vocabulary had grown so rapidly.

When I was 11, I was adopted by Joseph and Catherine Walsh. Around this time, I was evaluated for the Express 1, a new augmentative communication device that included synthetic voice output. With all the bureaucracy involved in getting financing for this machine, by the time its purchase was approved, the more advanced Express 3...
was about to make its appearance on the market. After a series of articles in a local newspaper, Scranton residents along with the Kiwanis Club bought me the Express 3.

My Express 3 helped me get accepted to the sixth grade at the West Scranton Middle School. After being placed in a "physically handicapped and learning disabled" class, I accomplished six years' worth of learning in one year. My teachers were astounded at what I had accomplished in such a short time.

**Full inclusion with technology**
A special education supervisor eventually contacted an assistive technology center to set up an evaluation for me. The evaluation team felt I was a good candidate for a Light Talker, another augmentative communication device. One of my teachers received a grant to purchase the device. The school got an Apple computer for me.

With this technology, my learning abilities became unlimited. I was able to enroll at West Scranton High School and was mainstreamed for all my classes. I took French, Latin, algebra and trigonometry.

During my senior year in high school, the local vocational rehabilitation office bought me a Liberator, a highly advanced augmentative communication device which I still use. I access my Liberator with a head pointer—it's like my third hand. When I am not hooked up to my Liberator, I use the head pointer to turn book pages and strike keys on my IBM computer. Technology has also helped

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me in other ways. I have many books on tape, a dictionary in my IBM computer and an encyclopedia set that I can use by logging on to Prodigy, an on-line service.

**Entering college**

My fears about making the transition from high school to college resulted in many sleepless nights. I applied at and was accepted by four local colleges. I decided on Marywood College in Scranton.

Before starting school, I worried that my disability would interfere with my education. I was concerned I wouldn't be given the same opportunities as other freshmen. But three days after entering Marywood, I realized this was the right place for me. My fears slowly diminished, and I made up my mind that I was going to work to the best of my ability.

My classes were all in the morning so I was able to come home each day and prepare my work for the following day of classes. This helped me keep up with the work and not fall behind. Sister Francella Shaughnessy, my academic advisor, found me a note-taker for each class. I also tape record each lecture.

Taking tests also was an issue, but it has been dealt with fairly and efficiently by my professors. Some professors give me extra time, or in some instances, I take my tests at special times without the rest of the class. Using my Liberator, I take other exams, like true-false or multiple-choice tests, along with the class. These accommoda-

Dancing with the bride: Bobby was the ring bearer at the 1983 wedding of his adoptive sister, Cathy.

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Bobby Walsh says his head pointer is like a "third hand." He uses the head pointer to access his augmentative communication device, to turn book pages and to strike keys on his computer.

Toons give me an opportunity to earn the grades I deserve.

I have an IBM computer at home and at school that I can use with my Liberator. This is important, because this is how I do all my writing. With the IBM, I have more accuracy on tests. If I use the printer on my Liberator, I might accidentally hit the wrong key—once it is printed out, it cannot be corrected.

In my first semester at Marywood, I put my Liberator through a lot of work and learned a great deal in my Writing Skills class. Sister Immaculata Norton had us write in a journal every day. I stored each journal entry in my Liberator, reading it out loud in class like every other student.

In my second semester, I took classes that were required for my major. I really enjoyed my Computer Tools class. Although I thought I already knew all there was to know about computers, I received a rude awakening in this class. I learned WordPerfect, Lotus 1-2-3 and dBASE III+.

One of the requirements in my Principles of Management class was to give a 10-minute speech on any subject. I chose "Disabilities in the Work Force." I gave the speech with my Liberator. My 10 minutes turned into 15. I must have been a great hit because the class gave me a standing ovation.

Attending Marywood College has given me an opportunity to show the world that just because a person has to use augmentative communication,
this does not mean he cannot fulfill his dreams.

People with disabilities have to prove to the world that they are human beings and can be productive people in society. The only way a person with a disability can achieve his or her goals is through education. College can help a person with a disability lead a full and productive life. You have to ask yourself, "Do I want to have a decent job in the future and lead an independent life, or not?"

Kids with disabilities should be given a chance in regular classes. It will mean a great deal in their lives. Don't judge people by the way they look. So many times I was discouraged by professionals because I didn't look or act like an average kid. Little did they know that I had a brain—maybe a better brain than the average kid without a disability. I did get the chance. Thank God, someone listened to me!

Everyone can make a difference in making this a better world. I can do it, and so can every kid with a disability. One of my goals in life is to help people with disabilities. I know the experience of not being able to communicate. But with the help of friends, families, educators and technology, all the doors of communication have been opened for me.

---

Throwing items, turning over furniture, pulling hair... the list continues. For Adam, summers mean more than hayrack rides and swimming. They mean concentrated training, lifeskills, and measurable gains through Heartspring's new Summer Intensive Behavior Program.

Adam, 10, has autism and during his first few days of this year's summer program at Heartspring, he averaged about 45 acting-out episodes a day. Heartspring staff members developed a plan to interrupt destructive and aggressive behaviors, and to teach Adam more appropriate ways to communicate his needs and frustrations.

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NOVEMBER 1994 / EXCEPTIONAL PARENT • 41
Using Ordinary Toys for Kids with Special Needs
by Joanne and Stephanie Oppenheim

The products on these pages have been used with success by children with special needs. Most are readily available at, or can be ordered through local toy or book stores.

PUZZLES, GAMES & MANIPULATIVES

**Elephant Parade (Tag, $38)**
This cleverly-designed, circular puzzle board spins like a Lazy Susan with big, wooden, colored elephant puzzle pieces to fit in and take out. It’s ideal for children who can’t reach far, and the big pegs on each puzzle piece make it easier to grasp. There is space under each elephant to hide “treasures” for a child to discover—like crackers, colored plastic chips or smaller toys.

*Activity tip:* Create a game in which each player chooses his own color. Spin the puzzle; if your color stops in front of you, you take one of three colored chips hidden under your elephant. The winner is the first to collect all three chips.

Or mark a die with a different color on each face. Players throw the die, then find the elephant of the same color. If they choose correctly, they get to take a cracker from under that elephant.

**Touch ‘N Play Lotto (Guided-aft, $32)**
Developed with a teacher for children with visual impairments, these four handsome wooden playing boards and matching lotto pieces have raised, textured geometric shapes that give sensory feedback through the fingertips. For extra contrast, put boards against a dark background. This game may develop sorting, matching, counting and language skills.

*Activity tip:* For extra fun, put playing pieces in a bag and have players match shapes by feel.

The playing pieces can also be placed face-down for a concentration-type game. Players turn over two pieces at each turn and feel for matching shapes.

**Soft Stuff Potato Head (Playskool, $13.99)**
For kids who found the traditional peg-in-the-hole Mr. Potato Head hard to use, this all-fabric body with Velcro features is ideal.

*Adaptation idea:* Make choices easier for a child with a play board. Glue colored felt on the lid and sides of a sturdy box. Potato Head’s features will adhere to the felt. The box can be used to store pieces when the toy is not in use.

*Activity tip:* Try a game of “Name that part” as each is pulled out of a bag and placed on Potato Head’s body.

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This is the second of two articles adapted from the new 1995 edition of THE BEST TOYS, BOOKS & VIDEOS FOR KIDS (HarperCollins, $12) by Joanne and Stephanie Oppenheim. The book (available through EXCEPTIONAL PARENT LIBRARY, 800/535-1910) is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens. The 1995 edition includes an expanded chapter on adapting toys for children with special needs; it also includes books and videos of special interest.
**TERRIFIC ART MATERIALS**

**Wax Works** *(Chenille Kraft Company, $4.95)*

This is an inexpensive and new modeling material that's not messy! Skinny sticks of colorful wax can be used in a variety of ways. Kids can twist them around pencils, puzzle pieces and other objects. Wax sticks can be shaped into letters and numbers or used to make pretend eyeglasses or sculptures.

---

**Big Handle Paint Brushes** *(Alex, $8 for three)*

These extra-large brushes have handles shaped like bulbs. They're perfect for young artists with fine motor difficulties.

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**NOTABLE BOOKS**

**What Happens Next?**

by Cheryl Christian

*(Checkerboard Press; available only through EXCEPTIONAL PARENT LIBRARY, 800/535-1910, $6 incl. shipping and handling.)*

This mystery book for toddlers provides visual clues like a picture of a little girl in pajamas with her clothes laid out on the bed. What happens next? Open the flap, and the little girl is dressed. Photos include a child with Down syndrome.

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**Where's Chimpy?**

by Bernice Rabe

photos by Diane Schmidt

*(Whitman, $13.95)*

Misty, a little girl with Down syndrome, does not want to go to bed without Chimpy, her toy monkey. With help from Dad, she solves the mystery of the lost monkey by recalling the events of the day. A warm, charming story for ages 3-7.

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**Handsigns**

by Kathleen Paine

*(Chronicle, $13.95)*


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**My Buddy**

by Audrey Ososky

illustrations by Ted Rand

*(Holt, $14.95)*

A school-aged child with muscular dystrophy tells about his special relationship with his service dog, a Golden Retriever named Buddy. Ages 5-10.

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**Patrick and Emma Lou**

by Nan Holcomb

*(Turtle Books, $6.95)*

Three-year-old Patrick, who has cerebral palsy, is very excited about walking with his brand new walker. But he finds that it isn't quite as easy as it looks! He gets discouraged as he takes a couple of embarrassing tumbles, but his six-year-old friend, Emma Lou, who has spina bifida, helps him to get over his upset feelings. Ages 3-7.

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The Oppenheim Toy Portfolio is an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS; it also publishes a quarterly newsletter. Both publications include useful sections on adapting products for kids with special needs. These sections are done in conjunction with the National Lekotek Center, a nonprofit organization serving special needs children and their families. For more information, contact the Oppenheim Toy Portfolio, 40 E. 9th Street, Suite 14M, New York, NY 10003, (212) 598-0502.
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Song of Light
by Susan L. Gengerke

He was no Merlin, no super sorcerer. Ah, no. In fact, it could be said that he wasn't even your average enchanter; though he did not lack ability. He was just a wistful wizard of small-scale spells and minor incantations, content to amuse himself and make his life easy, for he was basically lazy. He remained mostly apart from other magicians and their kind, separated by his furry appearance and thus more at home with other inhabitants of the forest. Yet he was an enchanter of the soul, drawing to him the affection and gentle kindness of people who recognized his unique value and learned to appreciate him.

These were the first words of a children's story—really my first "song"—for my son, Tony, who sings without words and lives in innocence. This story is my second song for Tony, who is both the "darkness" and the "light" of my life.

Anyone who sees Tony knows instantly that he isn't what the world calls "normal." He sits in the bottom of the grocery cart, making discordant and incomprehensible sounds. Sometimes he lets loose with a gleeful, piercing shriek and hugs me so emphatically he nearly pulls me into the cart. At other times, he screams and thrashes so hysterically he has to be removed to the car, which rocks with the intensity of his rage. It is impossible to explain "what's wrong with him" to the casual questioner because Tony has such complex disabilities.

As far as the experts are concerned, he is "multiply handicapped" with a "bleak prognosis." He's been diagnosed as autistic, profoundly retarded and epileptic, with multiple and severe visual, aural, kinesthetic and sensory "deficits." The rest of the world, which likes neat categories, usually accepts the experts' definitions. I am also expected to accept this dismal vision, if I wish to receive the tolerance granted to parents who are "realistic."

An "unrelieved tragedy"

The world has a tendency to view my son's condition as an unrelieved tragedy for both of us. Most people eye us with pity, convinced that Tony's life is irrelevant at best and that mine is wasted in a warped excess of maternal devotion. When I encounter these attitudes, I want to scream, on Tony's behalf, the words of the poster in his room—"See me for what I am, not for what I lack."

But don't mistake me for some quixotic Pollyanna or saint. It's impossible to romanticize the pain and problems our family faces; real life brutally shatters such illusions.

The truth is that life with Tony brings a mixture of extreme emotions. It is exhausting to spend years as the primary caregiver for an ever-growing "baby." As you struggle for every step of progress, your body is drained of energy and your spirit is drained of dreams. Yet it is incomparably exhilarating to watch the first steps of this "baby," who had been sentenced by experts to a wheelchair.

It is painfully beautiful to be oh-so-gently kissed by this child, who cringed at every touch during the first two years of his life. And after experts told me he would neither understand nor communicate, it is another miracle to hear him say "Mama" with a joyful grin, and to watch him create his own sentences in sign language.

It is incessantly discouraging to have to explain why I love my child, and to justify my faith in him, year after endless year. But more important than the pain is the profound satisfaction of honoring my commitment to someone I love so deeply.

It can be terrifying to try to empathize with him; I know the restrictions and confusions of his life. But how can I do less, as I watch with awe the courage of a child who persistently climbs mountains which I can only imagine?

I can understand, if not accept, the inherent prejudices of society. "Normal" people learn an impressive range of skills and ideas not possible for my son. Tony may never read or write, and he will probably never speak more than a few words. But the unintentionally insensitive arrogance which accompanies normal learning assumes that those who lack it are deprived of a real life. Thus, if you cling to the normal view of what constitutes a full life, it is an
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Learning from Tony

Tony will never understand Mozart. For one former friend, this was sufficient proof of the devastating emptiness of his life. Yet Tony's pleasure in music is as deep as mine—or hers—while the range of his musical appreciation is uninhibited. Free of intellectual bias, he can delight equally in the music of seagulls, kazoos, crying babies, metal pans and Mozart. His "limits" enrich his pleasure in music, while our "superior understanding" limits ours.

Tony can't ride a bike or play softball, but his thorough enjoyment of such overlooked items as doorknobs leads me to wonder just who is deprived! Tony doesn't understand holidays or presents either. But he delights in the paper and ribbons—their color and texture; sometimes even their smell and taste—as much as he enjoys the gift inside. And though the concept of holidays eludes him, he is free of their materialism as well.

Tony has no intellectual or philosophical comprehension of joy. Yet he experiences it abundantly, and in expressing it, shares it exuberantly with those around him. In his gleeful teasing and mischief, he is a funny, exasperating pixie; yet he is honestly without malice. He awards his affection like the prize that it is. His laughter is free, unrestrained and easily contagious.

Tony understands emotions with an instinctive clarity most of us never achieve. He loves without condition or manipulation. He forgives without hesitation and holds no grudges. He accepts each of us without judgment, affirming us as we are—whether or not we accept him.

Tony's "song of light" is a unique and invaluable gift to the world. Those who possess the wisdom to learn from this child receive gifts of lasting insight into what is fundamental, joyful, beautiful and truly important.

Tony, now 23, participates in a home-based program and continues to participate in outside therapies. Susan recently became involved with Partners in Policymaking, a national leadership program which provides advocacy training to families and people with disabilities. Tony and Susan have lived in California and Rhode Island, and currently live on Long Island, New York.
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More Sibling Concerns

by Donald J. Meyer

This article is an excerpt from Sibshops: Workshops for Siblings of Children with Special Needs (Paul H. Brookes, 1994). This is the third of four excerpts Exceptional Parent will publish. This month’s excerpt continues the October excerpt’s discussion of some unique concerns of siblings. Sibshops is available through Exceptional Parent Library, (800) 535-1910.

Since the 1980s, we have learned one simple yet far-reaching lesson from the hundreds of parents and siblings we have met, and it is this: Siblings’ experiences parallel parents’ experiences. Brothers and sisters will encounter joys, concerns and issues regarding the person with special needs that closely correspond to those of their parents. And, although brothers and sisters have the longest-lasting relationship in the family, siblings (as we see again and again) have, compared to their parents, far fewer opportunities to gain access to programs, services and professional support.

Nowhere is this more evident than in the area of peer support. Many parents count on sharing the good times, the not-so-good times and helpful information with a peer who is also the parent of a child with special needs. Some parents connect with other parents through common-sense efforts in programs such as Parent-to-Parent, fathers’ programs, or mothers’ groups. Many parents maintain informal contact with other parents of children who have similar special needs. For most parents, the thought of “going it alone,” without the benefit of knowing another parent in a similar situation, is unthinkable. Yet this happens routinely to brothers and sisters...

Like their parents, brothers and sisters appear to benefit from groups in which they can voice their fears, hopes and doubts. Groups specifically for brothers and sisters demonstrate that somebody cares about the issues facing them and values the important role they play in the family. Brothers and sisters, while they have unique concerns, are not the at-risk population once described in the research literature. Like their parents, the vast majority of brothers and sisters of people with special needs do well despite challenges brought about by their siblings’ disability or illness. Consequently, programs for brothers and sisters should reflect siblings’ and families’ strengths while acknowledging their concerns...

Unequal treatment and excessive demands

When we listen to brothers and sisters at Sibshops or during sibling panels, they frequently complain that their siblings “get away with murder.” Family rules about behavior, chores, bedtime routines and so forth often do not apply to the child with special needs. Brothers and sisters frequently insist that their sibling could comply with many of the family’s rules and requirements “if only my parents would make him [or her] do it.”

Siblings’ views deserve to be heard, even if, as children, they lack a parent’s understanding of the “bigger picture.” Their alternative perspective—which almost always focuses on what they believe their sibling can do—can provide parents and service providers with fresh insights regarding a child’s actual abilities. “My brother never has to unload the dishwasher because he has Down syndrome,” one brother told us. “But he can do it. I know he can, because when my parents aren’t home, I make him unload the dishwasher....”

Planning for the future

In families where there is a child with developmental disabilities, frequently there is an assumption—often unspoken—that brothers and sisters will someday become guardians of their sibling. An especially poignant concern for many adult brothers and sisters regards their siblings’ future and the role they will play in that future...

When parents fail to involve siblings in planning for the future for the person with the disability, resentment is likely to occur. “My parents won’t consider letting Bobby try a group home,” one sister told us. “That’s all well and good now, but what happens when they die? Will he have to come live with me?”

...It is reasonable to expect that adult siblings of the baby-boom and post-baby-boom generation will be more involved in the lives of the brothers and sisters with disabilities than any previous generation. Unless parents and service providers involve siblings in the planning for their children’s future, many adults with disabilities will soon have sibling guardians who are both ill-prepared for the job and resentful of the responsibilities placed on their shoulders...

Increased responsibility

Research suggests some general guidelines for assigning domestic chores to siblings of children with special needs. First, the type of chores assigned should be considered. Are child-care demands resulting in conflict? If so, parents may wish to consider offering siblings a choice in the type of household responsibilities they assume. Par-
One size does not fit all!

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Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation"—the highest distinction—awarded by the Joint Commission on Accreditation of Healthcare Organizations.
During the week of June 27, a project six years in the making was finally completed. Just 16 miles outside of Baltimore, Maryland, Future Home is a home overflowing with state-of-the-art technology designed to help people with disabilities and the elderly. The home was built by the Volunteers for Medical Engineering (VME), a non-profit agency made up of volunteers from the fields of engineering, medicine and rehabilitation.

There are doors that open automatically when a wheelchair approaches, lights that come on when someone enters a room and kitchen cabinets that raise and lower with a flick of a switch. Switches are coded in Braille. Devices can be voice-activated. Parents of children with disabilities clamored to know how the equipment in Future Home could help them. They wanted to know how much it would cost.

Jeffrey Jerome, Future Home’s technology expert, explains, “We see in Future Home how new technology for the home—coupled with barrier-free design—can help children live more independently and help their parents cope with the daily demands of child care. There are many devices that help achieve that end without spending a whole lot of money.”

However, Jerome warns against giving a shopping list of prices. “It’s all well and good to give a price for the equipment, but proper design for the individual and installation must be considered. A system must be designed based on individual needs and capabilities. And prices can vary depending on the layout of the home.”

**Future Home’s technology**

With that in mind, we offer a list of some of Future Home’s technology. The list is not at all inclusive. Among the least expensive items are remote controllers and X-10 devices which allow users to turn things on and off without touching a switch.

For $100 or less, a cordless phone can make life easier. Big button switches can be purchased. Keyboard and telephone hands-free positioning arms are also available for under $100. Swing-clear door hinges which won’t block any part of the doorway can be used by people in wheelchairs.

For $500 or less, there’s a toiletting system which acts as a bidet with a drier. You can also buy a voice recognition system for your computer which enables it to respond to verbal commands. Other devices within this price range are keypad door locks, wireless microphones, sensors to open the doors when a wheelchair approaches and a CD-ROM drive with sound card that will allow you to play compact discs and educational software on your computer. Most software packages for children with disabilities are available for less than $500.

For $1,000 or less you can purchase a whole-house telephone/intercom system which allows children to call for help or dial parents at work; a security system that children can work; television cameras to monitor children (with or without sound) or a whole-house infrared system that allows a remote controller from one room to work devices throughout the home. Sinks can be equipped with push buttons on the side of the counter which control the water and prevent scalding.

Less than $3,000 will buy some power doors that can be opened with a hand-held control. Some stairlifts also are obtainable for this price. Automatic lighting which comes on a few seconds after someone enters a room is available. Individual heating and cooling systems for each room are available, as is a wheelchair-accessible shower. Motorized cabinets which are adjustable in height can also cost less than $3,000, as adjustable countertops which lower to accommodate children in wheelchairs. There are also tables with tops which adjust in height to the proper size of the child as he grows. A small wearable transmitter can monitor the...
The Disabled Opportunities Center

When a 1986 accident left Tim Connole's 16-year-old stepson, Dominick, a quadriplegic, Conno le became determined to provide Dominick with a barrier-free environment.

Connole, a successful building contractor and developer, built a new home, gathering assistive devices and adaptive equipment from around the world. Connole then devoted himself to designing and constructing other homes and facilities for people with disabilities.

Soon, hundreds of people were flocking from across the country to view Connole's home. The attention prompted him to open the Disabled Opportunities Center (DOC) in 1993.

The DOC, in the Kearny Mesa area of San Diego, houses a full-scale model home and model office with equipment from various manufacturers. Visitors can try out devices ranging from a ceiling lift to specialized dishes. A centralized voice-activated computer can open, close and lock doors and windows; turn on the stereo and television and set the alarm system. Cabinets and sinks are height-adjustable with a touch or voice command.

On-site occupational therapists provide individual assessments and training on how to use adaptive equipment. The DOC also offers consultation on the Americans with Disabilities Act (ADA) to help businesses and individuals work in compliance with the law.

For more information, contact Disabled Opportunities Center, 7323 Engineer Road, San Diego, CA 92111, (619) 573-0800 (Voice), (619) 573-1801 (TTY), (619) 573-0886 (fax).

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Dental Care for Children with Disabilities

Common Pediatric Dental Problems

by Steven P. Perlman

PART FOUR

Though children with some disabilities may be more prone to certain dental problems (see “Special Children are at Greater Risk,” August 1994), they must also deal with the more common dental problems of childhood. This article will help parents recognize and obtain appropriate treatment for some common pediatric dental problems:

• A dark (blackish-bluish) front primary tooth may indicate a change in the vitality of its nerve, usually due to a past history of trauma to the tooth. Your dentist should be consulted.

• Facial or gum swelling most often indicates an abscessed (infected) tooth. This is usually caused by a deep cavity, or occasionally is related to past trauma to the tooth with subsequent nerve damage. In primary teeth, the usual treatment is extraction; in permanent teeth, the normal treatment is tooth pulp therapy, more commonly known as a “root canal.” Your dentist should be consulted immediately to help prevent the spread of infection.

• Cavities, or dental decay, must be treated in both primary and permanent teeth.

• An over-retained primary tooth is a “baby tooth” that is still in position when a permanent tooth is erupting into the same space. The over-

Steven P. Perlman, D.D.S., M.Sc.D., specializes in dental care for children with disabilities. In addition to his private practice, he teaches pediatric dentistry at the Boston University Goldman School of Graduate Dentistry and serves as vice president of the Academy of Dentistry for Persons with Disabilities. Dr. Perlman is clinical director of the Special Olympics “Special Athletes, Special Smiles” program. He lives in Swampscott, Massachusetts.

retained tooth should be removed immediately, so the permanent tooth can take its rightful position.

This problem occurs most commonly with the lower front teeth, but it can also happen with the upper front teeth. Older children (ages 7–13) may retain primary teeth in the molar and cuspid region. The presence of baby teeth in the middle teenage years indicates a potential problem such as a congenitally absent permanent tooth or an impacted permanent tooth.

• If a primary tooth is accidentally knocked out of the mouth, leave the tooth out and seek care immediately. Bring the tooth to show the dentist. If the tooth is intruded (pushed up into the gum) due to an injury, it can often be left to re-erupt, but must be carefully monitored.

• If a permanent tooth is accidentally knocked out of the mouth, prompt treatment is essential. The longer the tooth is out of the mouth, the less likely it is that treatment will be successful. Handle the tooth by the top (crown), not the root portion. Try to stick the tooth back into the socket—normally, it will fit quite well—and hold it firmly in place until help is obtained.

If you are unable to replant the tooth in the socket, place it in milk. If milk is not available, have the child hold the tooth in his mouth or place it in water. Do not store the tooth in the child’s mouth if there is a possibility he will swallow it.

The dentist will attempt to replant the tooth. The dentist will replace the tooth in the socket and keep it stable by splinting it to adjacent teeth for several weeks.

• If primary or permanent teeth are displaced (knocked to the side but not out of the socket), reposition them as soon as possible and seek professional care immediately.

• Vague pain in gums may be caused by canker sores. These are very common in children and can occur in any soft tissue area. Medication can be given to relieve pain. Avoiding hot and spicy foods and drinks will diminish discomfort.

• Fractured permanent incisors (front teeth) require prompt treatment. Children with some disabilities are more prone to accidents that can fracture teeth. Seizure disorders and poor motor coordination can lead to falls. If the incisors protrude, they are more likely to be damaged.

Fractured incisors can be restored with a bonding technique or crown. If the nerve is exposed, it will be removed or treated before the bonding treatment is undertaken.

• Erupting wisdom teeth (third molars) may sometimes cause pain. An infection called pericoronitis may occur if the tooth does not erupt fully. If this occurs, swelling will occur in the face and/or gums. Immediate care is necessary to prevent the spread of infection.

• Bruxism, the grinding or gnashing of teeth, occurs more frequently in children with disabilities. Bruxism usually occurs when the child is sleeping, but some children may also grind their teeth throughout the day. This habit, continued consciously or unconsciously over a period of time, can cause tooth abrasion and loss of tooth structure. In permanent teeth, bruxism can lead to periodontal disease (bone loss) and/or temporomandibular joint disorder (TMJ) in which the upper and lower jaws are out of alignment resulting in headaches and facial pain. However, most of the time, bruxism will not cause such problems.

Bruxism can be diagnosed at a routine dental visit. Treatment may include bite adjustments or a bite-guard appliance. However, treatment is usually not necessary and the habit is outgrown.
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A Whole New Ballgame

Reflections on a year of Fathers' Voices

by James May

In The Fathers' Book, Harvard professor David Bell remarks, "Despite the things we [men] did learn from our fathers, we usually did not find out how to balance full participation in work and in family. Now we are exploring uncharted territory, with all of the missteps and false starts that such exploration requires."

Fathers of children with special needs understand the discomfort and joys of this exploration better than any other men I know. Daily, they ask themselves hard questions: How do I come to terms with my child's future when it so often seems hopeless and confusing? How do I cope with the feelings of anger and helplessness that continually creep to the surface? How do I help my employer understand the special circumstances of my family without jeopardizing my job? Where do I find enough time in the day to work, to nurture the relationship I have with my spouse and to be a vital part of my child's life?

"Unnatural" Change?

Like many other men, fathers of children with disabilities are making family the priority in their lives. Increasing numbers of men are showing up at therapy sessions, doctor's appointments, even circle time. Indeed, the philosophy of family-centered care declares there must be more than one "designated expert" when it comes to the well-being of a child. In The Nurturing Father, Yale professor Kyle Pruett captures the essence of these changes when he notes that "the uninvited, uninvolved, unwelcomed, inept father is moving towards obsolescence. But let's not delude ourselves. Such change is frequently unwelcome, highly suspect, and often seen as 'unnatural.'"

But to whom is such change unnatural, and why? Several Fathers' Voices pieces have spoken of fathers' ongoing struggles to win recognition for the pivotal roles they play in the lives of their children. In "Fathers Are Caregivers, Too!" (August 1994), Steve Fischer reminds other dads that "we have a long way to go in educating our health care providers about the emotional needs of fathers who have children with disabilities. We fathers must take the lead in educating medical professionals and advocating for ourselves. We must support, encourage and share with each other. We must remind our health care providers that fathers are caregivers, too."

Likewise, Bob Craig, in "I'm Bryan's Dad and Part of His Team" (February 1994), implores men to "stay involved! It's important for you as a parent. It's important for your child with special needs. And it's an important statement to professionals on behalf of all the fathers who will come after you."

A whole new ballgame

Fathers of children with special needs are re-thinking their values and priorities. In doing so, they are discovering that parenting is a whole new ballgame. Bill Abbott ("The Biggest Game," October 1994), an over-the-road truck driver from Columbia, Missouri, dreamed of teaching his then-unborn son to "throw a curve ball and catch a football." After Gregory was diagnosed with cerebral palsy, the game plan changed. Bill wrote, "I have always dreamed of being a coach. Well, I got my wish. Encouraging Gregory to become independent will be the biggest game I will ever coach. Teaching him to stand in one spot without taking a tumble, teaching him to successfully navigate the bathroom, teaching him to pull his pants down and back up again—these are much greater rewards than winning any Super Bowl or World Series."

In "The Silent Ringmaster" (November 1993), Robert Greenwald wrote to his son of a wish...

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Learning from our kids

Many men have written about how a child can become the father's teacher. In "Dreams" (April 1994), John Cox wrote, "All children are a gift to their parents, grandparents, teachers and everyone who comes into contact with them. And they all teach us something that we would not have learned without them. For me, it was to slow down so I could take pleasure in the details of my children's lives. I learned to take an active part in all my children's activities and cherish each of their accomplishments. I am richer for the experience of having a child with a disability. I would not wish it away."

In "What's a Tough Guy to Do?" (June 1994), Thomas Nolan's moving commentary on life with a son who has a life-threatening condition, Nolan notes that the experience of parenting a child with special needs helped him to "become a more caring father for both of my sons. All those 'womanly traits' I was so shocked to find within myself have helped me to
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Ending the isolation
In this first year of Fathers' Voices, I have found myself deeply moved by the willingness of men to communicate their thoughts and feelings. Fathers have written about shattered dreams, anger and fear. But above all else, they have written of their delight in and love for their children. No one will ever convince me that men don't have strong emotions; they might not always exhibit their emotions for the world to see, but for those inclined to take the time to observe and listen, men's feelings are clear and evident.

I feel blessed in having met these terrific fathers who have been willing to share their stories, passions, strengths, laughter and tears. And I know readers have enjoyed meeting them, too. Many men (and their wives) have written to thank me for lifting the mask of personal isolation, for helping them know that their feelings and emotions are normal and "okay." They speak of finding renewed hope in knowing they are not alone—"Thanks to Exceptional Parent and Fathers' Voices for the information, support and inspiration."

Men, do continue to send us your reflections on the many meanings of fatherhood. Help us continue to rejoice in the freedom to love, care for and nurture our families. As John Huffacker declares in the Father Times newsletter, "The reward for this courageous 'coming out' will be immeasurable for men, women, children and a society that desperately needs this kind of repair within the family."

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.
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Phone( ) __________ Fax( ) __________

B. Annual Household Income (include all family members)

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<tr>
<th>Income Range</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>Less than $30,000</td>
<td>1</td>
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</tr>
<tr>
<td>$30,001 - $40,000</td>
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<tr>
<td>$50,001 - $75,000</td>
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<td>$100,000+</td>
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C. Do you live in a(n):

<table>
<thead>
<tr>
<th>Type</th>
<th>Yes</th>
<th>No</th>
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<tbody>
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<tr>
<td>Apartment</td>
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<td>Own Rent</td>
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<td></td>
</tr>
<tr>
<td>10 Rent</td>
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D. In all, how many automobiles do you and others in your household own or lease?

<table>
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<tr>
<th>Number of Automobiles</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
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<td>One</td>
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<tr>
<td>Two</td>
<td>14</td>
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<td>Three or more</td>
<td>15</td>
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E. Do you plan to purchase a product or service advertised in Exceptional Parent within (check one):

<table>
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<tr>
<th>Time Period</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>one month</td>
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<tr>
<td>three months</td>
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<td>one year</td>
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**Expiration Date:** February 28, 1995

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A There are some wonderful communication devices available for children these days. They can enable a child with a severe communication disability to communicate effectively, thus creating a foundation for education, social activities and future employment. The problem, as you already know, is that some of the devices may be expensive, and insurance companies don't always cover the costs.

The first issue in dealing with an insurance company on a problem such as this is to determine whether there is a specific policy provision that excludes reimbursement for communication equipment or "durable medical equipment." If there is no such policy provision, there's a great deal you can do to ensure that the device is paid for by your insurance company.

It's important to remember that insurance policy rules are usually very specific and extremely precise. If a product is described inaccurately, or a claim does not include all of the necessary paperwork—or "documentation"—the insurance company may not pay for it, even if the item is covered by the policy. And, in some cases, an insurance company may phrase the reason for the rejection of the claim in technical or bureaucratic terms that are difficult for a consumer to understand.

Communicating with consumers

Most insurance companies, I think, try very hard to communicate effectively with consumers. However, companies are very careful about how they phrase things these days because of potential legal implications. In addition, insurance companies generally process claims by computer, and there are only a certain number of coded sentences that can reasonably be placed on a computer.

Thus, the reason for the claim rejection printed on the EOBs ("Explanation of Benefits Statement") is likely to be in very general technical language. If an insurance company wants a letter from a medical doctor before it will pay a claim, for example, the EOBs may contain a statement such as "Documentation Incomplete" or "Not Medically Necessary."

A phrase such as "Not Medically Necessary" may sim-
ply mean that the insurance company cannot further process the claim until the documentation is complete. In the meantime, the claim will be coded as "Not Medically Necessary" in the computer, since the company can't verify that the equipment is medically necessary without complete documentation.

Your next step should be to find out the specific reason for the rejection of your claim. Insurance company representatives are usually quite willing to help consumers understand the claims process. If the insurance company representative who answers the phone isn't able to help, ask to speak with a supervisor. Most supervisors have been with a company for a long time, and are usually quite knowledgeable about the details of the claims process.

Prentke Romich Company, a manufacturer of communication devices, publishes How To Obtain Funding For Augmentative Communication Devices, an excellent booklet on filing insurance claims. The booklet, which costs $5, includes definitions of basic terms and sample letters from doctors and therapists. For a copy of this booklet, contact Prentke Romich Company, 1022 Heyl Road, Wooster, OH 44691, 800-262-1984.

Alternate sources of funding

If your insurance policy does specifically exclude communication devices or "durable medical equipment," there's really not much you can do to persuade the company to pay for the device. However, alternate sources of funding may be available.

Since communication is essential for education, for example, the local public school district may be willing to purchase a communication device for a child with a disability as long as the need for the device is noted in the child's IEP ("Individualized Educational Plan"). State agencies or charitable organizations may also be willing to purchase such a device.

I think the most important thing is not to give up until you've thoroughly explored all of the possibilities. A child's right to communicate effectively, in spite of a disability, should not to be denied for financial reasons.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 509 Harvard St., Suite 303, Brookline, MA 02146, or fax questions to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To insure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.

EXCEPTIONAL PARENTS TALK ABOUT M.O.V.E.

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Canoga Park, California

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Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:
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Technology Resources

• The Electronic Industries Association (EIA), a 70-year-old trade organization representing all facets of electronic manufacturing, offers Extend Their Reach, a 24-page pamphlet about assistive technology. Written as a general introduction to assistive technology, the pamphlet includes information on computers; environmental controls; telephone and communication services and funding sources to help people pay for assistive devices.

Single copies of the pamphlet are free; each additional copy is 90 cents. Extend Their Reach, EIA, 2001 Pennsylvania Ave., NW, Washington, DC 20006-1813, (202) 457-9752.

• Unlocking Tomorrow is a 56-minute documentary video on assistive technology. The video shows individuals with disabilities using a full range of assistive technology—from very simple to sophisticated adaptations—in recreation, education and employment.

The video, produced by Georgia Public Television (GPTV) with support from the Texas Planning Council for Developmental Disabilities, has closed captions and DVS (audio description for people with visual impairments).

Texas residents can obtain the video at no cost by calling (800) 262-0334 (toll-free in TX only). For all others, the video costs $30; contact GPTV Tape Sales, 1540 Stewart Ave., SW, Atlanta, GA 30310, (404) 756-4700.

• Teens with hearing impairments and their hearing friends socialize on the PC Pals Teen Network, a computer bulletin board on American Online (AOL), a commercial online service. PC Pals, a joint venture of the Alexander Graham Bell Association for the Deaf and Oticon, offers a special interest place for teens from across the country to discuss topics ranging from summer jobs to movies and books. There’s also a chat group where up to 40 teens can “talk” to each other at the same time. Currently, the chat group meets on Sundays at 7 p.m. EST.

To use PC Pals, you will need a computer, modem, telephone line and subscription to AOL. To order an AOL starter kit and free software, call (800) 827-6364, ext. 6751. There is a monthly charge of $9.95 for five hours of connect time per month; additional usage is $3.95 per hour. AOL can also be accessed through some schools and libraries.

To find the PC Pals board, sign on to AOL and enter the keyword “deaf” to go to the deafness and hard of hearing area. Then, scroll down to and select “PC Pals Network.”

For more information, contact the Alexander Graham Bell Association, 3417 Volta Pl., NW, Washington, DC 20007, (202) 337-5220 (Voice/TTY).
Movin' On

Movin' On is a 24-minute, close-captioned video about successful people with disabilities. Among the six individuals profiled are a hospital administrator with cerebral palsy, a chemist who has a hearing impairment, an Indiana State University undergraduate who is blind and hopes to become a lawyer and a pediatrician with spina bifida.

The video is free, but requires a $5 shipping and handling fee.

Contact the Riley Child Development Center, c/o James Whitcomb Riley Hospital for Children, 702 Barnhill Dr., Indianapolis, IN 46202-5225, (317) 274-8167.
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Thames Valley Children's Centre, London, ONT, Canada N6C 5Y6

Circle # 155

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Carica, Inc., Surrey, British Columbia, Canada V4P 1M7

Circle # 156

**THE WRITING BIRD**
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North Coast Medical, Inc., San Jose, CA 95125-1042

Circle # 157

**ACTIONVOICE**
Up to 18 natural voice messages with up to two minutes total recording time can be recorded on this portable (about 13 ounces!) supplemental communicator. Adapted devices and toys can be connected to the unit with two built-in switch closure outputs. Kids can use the built-in keypad, single-switch scanning or optical pointing access when combined with accessories.

Ability Research, Inc., Minnetonka, MN 55345-0721

Circle # 158

**CLICKIT!**
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IntelliTools, Inc., Richmond, CA 94804

Circle # 159

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Magic Laboratories, Inc., Redwood City, CA 94061

Circle # 160

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 listings of products for persons of all ages who have a physical, sensory or cognitive disability. The products above were chosen for inclusion on this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. For more information on assistive devices, or to submit product information for inclusion in the database (and possible inclusion on this page), please contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, VTDD, (301) 588-9284, VTDD, or (301) 587-1967, FAX.
You can order any of the books listed here with the coupon below or by calling (800) 535-1910.
JOSEPH  by Teresa Schubert

My brother's name is Joseph. He is 11 years old. Joseph goes to Parkwood Elementary School. He is in fourth grade. Joseph has a special need. He learns slower than we do. He is in a special class. He sits in a special chair when he eats.

Joseph is fun to play with! He likes to roll a ball, swing in his swing and play with balloons. But most of all, he likes to snuggle.

Seven-year-old Teresa Schubert is a second grader at Saint Thomas More School in Chapel Hill, North Carolina. She enjoys dancing and drawing. Teresa lives in Durham, North Carolina with her parents, Peter and Margaret, sister Christina, 9, and brother Joseph, 11. Joseph has trisomy 18.

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005
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JUST LIKE EVERYBODY ELSE
Jim Pierson; foreword by Joni Eareckson Tada

On a zoo outing, Derek and his granddaddy encounter a number of people with disabilities. Derek is reluctant to approach them, but he is put at ease by Granddaddy's friendly interaction with them. Later, when a disabled girl joins his class at school, he is able to welcome her "just like everybody else."

This lovingly illustrated story also includes suggestions for parents and teachers to answer kids' questions about disabilities.

DESIGN FOR TEACHING LEARNERS WITH DISABILITIES VIDEO SET

"This Design for Teaching video is the first thing I recommend for anyone involved in disabilities ministry," said Connie Hutchinson, a disabilities ministry director in California. "It covers everything you need to know to successfully include a child with a disability in your Sunday School class."

This powerful teacher training program shows how to include a severely disabled child in a classroom — while increasing learning opportunities for the whole class!

REACHING OUT TO SPECIAL PEOPLE
Jim Pierson and Robert E. Korth, Editors

This helpful book will equip your church to begin a ministry for people with disabilities. It features a Bible-teaching program with 52 lessons for those with mental retardation. It also deals with visual and hearing impairment, emotional disturbances, learning problems, and much more. One of the best ways to minister to people with disabilities is to simply be a friend. "Reaching Out to Special People helps you do just that.

Available from your local Christian bookstore, or call Standard Publishing toll free 1-800-531-3353.
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In this issue, we celebrate religion, educational religion and spirituality and illustrate the progress many faiths are making in including children and adults with disabilities and their families in community congregational life. Sadly, the important role that religious participation can play in the lives of families is rarely discussed in meetings between parents and education and health care professionals. Many professionals do not appreciate the ways a family's religious faith and participation can meet some important needs of children with disabilities and their parents.

Similarly, professionals tend not to see members of the clergy as valuable allies and collaborators in efforts to advocate on behalf of children with disabilities. Such advocacy efforts are often aimed at the goal of creating more opportunities for children with disabilities and their parents to participate in day-to-day community life—but community life includes activities within local churches, synagogues and mosques.

We invited a committee of members of different faiths to help with this issue. The committee, chaired by the Rev. Bill Gaventa, included Marilyn Bishop, Becca Hornstein, Ginny Thornbur and Dr. Brett Webb-Mitchell—each a dedicated leader in his or her faith's efforts to include people with disabilities. Committee members wrote articles and reached out to encourage individuals to share stories about the ways members of local faith communities have included and empowered children and adults with disabilities. We are very grateful to this committee and to all the other wonderful, giving people from so many faiths who contributed to this issue.

Because of all the powerful material about religion to be included in this issue, we did not have space to run an important article by Sen. Tom Harkin about health care reform efforts in the past year, the senator's article (which we will publish in February) shows that the voices of parents have been heard by some key members of Congress; there is still hope that needed changes will occur. With the help of our readers, and advocates like Sen. Harkin, we hope that the many new members of Congress will learn to listen to and appreciate the input of parents and people with disabilities on this critical issue.

Special thanks
We appreciate the hard work of Tawanda Brocket-DeVance in setting up the photo shoot for this issue's lovely cover of Veronica Chloe and her mother, Sandral. Thanks again, Tawanda.

Looking back, looking ahead
We have been delighted by reader feedback about new departments begun in 1994—Father's Voices, Familiar Faces, Role Models, Ask the Doctor, Health Insurance Troubleshooter and Research. This month's Father's Voices, Edward Sample's "A Few Miles on the Ol' Rocker," is a powerful example of why so many readers look forward to these departments.

It has been gratifying to hear so many favorable comments from readers about how much our magazine has improved this year. Because her dedication and talent have played such a key role in the "new" Exceptional Parent, I am pleased to announce that Kim Schive has been promoted to associate editor.

Our editorial office has also moved to a larger space at the same address. New staff members include Marc S. Malkin, a graduate of Boston University with several years of experience as a newspaper reporter, and Leslye Sneider, a former president of the UCLA Union of Students with Disabilities.

We extend our best wishes for the holiday season and the new year to all our readers.
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S. Bolzer, Physical Therapist, Cottonwood, AZ

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Methodist Hospital, San Antonio, TX

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M. Hiller, Parent, Lombard, IL

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Children's Hospital of Philadelphia, Philadelphia, PA

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C. Vandorpol, Parent, Bellingham, WA

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We are the parents of a child who is blind and has multiple disabilities. We live in Malta—that little island in the Mediterranean—and were first introduced to Exceptional Parent two years ago.

First of all, let us congratulate your editorial team for your comprehensive overview of the worries, joys, struggles, triumphs and day-to-day care which form part and parcel of raising our special children. Not only have I learned a lot from your magazine, it has been a source of ever-needed support to us.

Our six-year-old daughter, Henar-Marie, was born at 28 weeks gestation and has retinopathy of prematurity and mild cerebral palsy. She also has a right leg, above-knee amputation. I believe she is a unique case in Malta; as such, we have not found much professional advice regarding the hundred and one complex questions that we must tackle to enable our girl to develop her full potential.

Limitations of facilities and expertise are disadvantages of living in a country with such a small population (approximately one-third of a million people).

Reading about the accurate assessment of children, and learning of all the technological advances and aids in your magazine makes us wish to just fly over to the USA to seek help for our daughter, but we certainly can’t afford it. We worry that we are not providing her with the services and environment needed to enhance her development, though we know she is getting the best possible care under the circumstances. Such feelings are quite disheartening. Nevertheless, we carry on in our search for answers both locally and abroad.

This is why we consider Exceptional Parent our lifeline to the USA.

S.B., Malta

Inclusion and Ideology

It was with dismay, disappointment and disillusionment that I read Albert Shanker’s Inclusion and Ideology (September 1994). I am a parent who looks forward each month to your magazine. Usually, it gives me information to help me with my child’s school, health and social life. Reading this magazine has always given me a sense of hope because it lets me know I am not alone.

Instead, you chose to reprint an old editorial from Albert Shanker’s Inclusion and Ideology. I respect the viewpoints of other people and do not expect everyone to agree with me all the time. I respect the opinions of professionals who are trained in certain areas and who are experienced in working with children who have disabilities. I especially respect the opinions of parents because I believe they know what is best for their child and family. If any of these people had written an article on inclusion, I would have read it with interest and tried to learn from it. Instead, you chose to reprint an old...
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Two Children with Spina Bifida?

After reading the response to D.H. & D.H. (August 1994) about the family who had a second child with spina bifida, I felt compelled to write.

In the United States, one in 1,000 babies is born with a neural tube defect—spina bifida is the most common. If a mother already has one child with a neural tube defect, her risk of having a second child with a neural tube defect increases to one in 30.

The most important news about neural tube defects is that they can usually be prevented. Recent studies have shown that mothers who take the B vitamin—folic acid—immediately before pregnancy and during the first two months of pregnancy, dramatically reduce the risk of these defects in their babies.

If you are a woman who has already had a baby with a neural tube defect, and who hopes to have another child, you should take 0.4 milligram of folic acid daily. This amount of folic acid is available in many brands of non-prescription multi-vitamins or can be taken separately. During the time you are actively trying to become pregnant, change the supplement to four milligrams of folic acid each day. This must be obtained as a prescription from your doctor. Do not try to increase the folic acid dose by taking additional multi-vitamin tablets; this may cause you to receive a dangerous overdose of other vitamins.

If you become pregnant, continue the four milligrams of folic acid until your first pregnancy visit, at which time your doctor can advise you about pregnancy vitamins.

—D.M., South Carolina

EDITOR'S NOTE: The advice in D.M.'s letter has been reworded and confirmed by medical experts.

article written by a union official who does not work with children who have special needs and who is absolutely opposed to any type of inclusion program.

My child has severe mental retardation. He has been included for two years and is doing things that we never thought would be possible. The biggest gain has been for the other children in his classes. They have accepted Ben as they would any other child. He is invited to their parties and their homes, they come to his home and they all get along. These children will grow up to be better adults because of their experiences with Ben. They will be more accepting of everyone, regardless of their differences. Isn't that what inclusion is all about?

Your magazine is very important to parents; please use more consideration in the future. Yours is the only magazine that gives us the opportunity to hear each others' voices—that is what is most important. Articles about education programs should be written by qualified professionals who care about our children or parents who can speak from experience. I believe this is the least we should expect from your excellent magazine.

—J.C., Virginia

EDITOR'S NOTE: Our goal in the September issue was to provide a range of perspectives from leaders in the field of education. —S.D.K.
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Seventh Chromosome Deletion

My five-year-old daughter, Vanessa, has two larger diagnoses and some smaller ones as well. When she was born, doctors told us she had intrauterine growth retardation (IUGR). Almost three years later, we found out that she has a seventh chromosome deletion (band 7q 36.2). She has also been diagnosed with attention deficit hyperactivity disorder (ADHD).

Vanessa is not adjusting well to the medications for her ADHD. On some of the medications she has even become very dangerous to herself and to others around her. When her medication is working, she is a sweet little girl; when her medication isn’t working, she hurts herself, screams, hits others, bites and throws things.

Right now, Vanessa weighs about 23 pounds and is 35 inches tall. She does not see or hear very well. She has very poor muscle tone. She has a high palate and poor teeth. She does not sit still for more than a minute or two, but she is very cute.

I don’t have very much information on IUGR and doctors tell me there is no other child in the world with a similar chromosomal deletion. I know Vanessa will be very tiny and will have developmental delays. I know that her vision and hearing will deteriorate and that she will have small changes in the formation of her hands, feet, ears and toes. But there are so many questions I have unanswered. Is there anyone out there who has a child like my daughter? Can anyone recommend a source of information?

T.T., Minnesota

Chronic Guillain-Barre Syndrome

I am the mother of 12-year-old identical twin daughters. One of the girls, Melissa, has chronic inflammatory demyelinating polyneuropathy, also called CIDP or chronic Guillain-Barre syndrome. Her sister is healthy.

Melissa is doing quite well now, but has had four exacerbations of CIDP during the last five years. The weakness and paralysis come on rather suddenly, usually within 24 hours. Each time, she has been unable to walk for five to 10 weeks. Gradually, the paralysis leaves. The muscle weakness is often accompanied by a burning, tingling, pins-and-needles type of pain, particularly in her feet. She also experiences migraine headaches, extreme fatigue and a distorted sense of touch and temperature. Between relapses, her health and strength are normal. Her residual problems include difficulty with prolonged walking and standing, low stamina and some foot and leg pain. Melissa has no deep tendon reflexes; she also has some atrophy in her feet.

I am interested in hearing from other families who have children with CIDP. I want to help develop a national registry of these children so some significant research could be conducted on this rare disorder.

P.S., Nebraska

Congenital Fiber-Type Disproportion

Our three-year-old daughter, Alisha, may have congenital fiber-type disproportion. Doctors tell us she has not been given a formal diagnosis because this condition varies with each child.

Because Alisha has overall muscle weakness, she has had numerous bouts with pneumonia. She also has scoliosis. She is not able to walk or crawl, but can sit unaided. In addition to occupational and physical therapy every week, we work with her at home. At times, Alisha seems to regress and then, after a period of time, she comes out of the regression. We have no idea what causes these periods.

We are grateful that she is very bright. There is nothing wrong with her mental capabilities or speech. We would like to hear from other parents who have children with this diagnosis to hear how they are doing.

J.H. & J.H., Illinois

Deafness and Motor Impairments

Our beautiful five-year-old daughter, Eleanor, was born with profoundly hypotonic muscle tone and right-side hemiplegia (cerebral palsy), but has always been exceptionally visually alert and socially aware. She has made steady progress in motor skills but has not developed language; this was always attributed to the neurological impairment. In July, we learned that she is profoundly deaf. We have been working with her educational program to address her deafness and lack of language, and our family is learning sign language. We know parents of other deaf children, but they all are able-bodied and were diagnosed much earlier than Eleanor. Eleanor uses a wheelchair; she has limited use of her right hand and decreased coordination with
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her left hand. Hearing aids do not seem to help. She has the language skills of an infant, but appears to have good potential to learn.

We would love to hear positive stories (only positive!) about children with motor impairments and deafness, especially when the deafness was diagnosed late. We want to know about sign language acquisition by and resources for deaf children with multiple challenges.

T.K., Montana

Loud Noises in Public
Our six-year-old daughter, Kaitlyn, has severe intellectual disabilities. She has a combination of very different characteristics that do not seem to fit any one syndrome. We do not feel she is autistic. Rett syndrome has also been ruled out.

Kaitlyn does not talk. However, at times, she makes loud noises and high-pitched screams. She has been toe-walking since age three. She does not like to make eye-contact directly, but prefers to look from the side. She is happiest wandering around, picking up objects and dropping them. She has no interest in playing with others or with toys. She does not like anything that requires a lot of effort. Kaitlyn has a constant need to touch objects and put them in her mouth—this started when she was five years old. When frustrated, she will bite the closest object. She can feed herself with a spoon and drink from a cup, but is very messy. She shows no interest in potty training.

Our main concern is the loud noises she makes, especially in public and around large groups. We do not know how to get them down to a reasonable pitch, and are especially concerned about how this will be handled when she goes to kindergarten next fall. We want to hear from anyone who has dealt with a child who has similar characteristics, especially the loud noises.

G.W. & J.W., Indiana

Therapeutic Recreation
Our community is working to establish a recreational program that includes children with disabilities. We are looking for information on established therapeutic recreational programs and how these programs have been funded.

E.W., Georgia
Augmentative Communication Aids

D.F. (October 1994) is the parent of a boy with a physical disability affecting only his gross motor skills; his fine motor skills are good. D.F. was looking for information on augmentative and alternative communication (ACC) devices because her son has just started school.

As suggested in the Editor's Note following your original Search letter, the article in the June 1994 issue of Exceptional Parent magazine is a good place to start your search because it gives an overview of the factors you should consider when selecting an ACC device. Our experience may also be helpful to you.

My seven-year-old son has multiple disabilities and is nonverbal. Due to significant physical disabilities, sign language was never a viable option. Ryan's first exposure to an ACC device came in preschool. However, he was unable to activate the device used in his classroom because he could not press the pictures hard enough.

After my repeated requests, he got a Prentke Romich IntroTalker, a device commonly used with preschoolers. Although Ryan could activate the device, he did not seem to relate to the recorded voice, that of an adult female. And because the number of items on the device was limited to eight, he quickly lost interest in using it.

Finally, a friend referred me to a voice output device called the Dynavox (manufactured by Sentient Systems, 2100 Wharton St., Ste. 630, Pittsburgh, PA, 412/682-0144). As soon as I saw this device, I thought it might be something my son would like. I was right. The key seemed to be that Ryan was motivated by the voice output, which sounds very much like a boy of his age. He finally had a voice. Now, I worry that my nonverbal son talks too much!

Perhaps you can visit an ACC center that has a variety of devices for you and your child to look at and try out. Professionals are helpful in identifying appropriate devices, but remember, you know your child best and should not hesitate to use that knowledge in selecting a device. It's also important to find a device that motivates your child; if the child does not like the device, its "appropriateness" really doesn't matter.

We chose the Dynavox for a number of reasons—we found it easy to program (all the picture symbols are already in the computer), it was easy for my son to use and it will grow as his language grows. But most of all, we chose this device because he loved it.

R.C., Maryland

☐ My five-year-old son, Frankie, has cerebral palsy and is non-verbal. Like your son, Frankie has great fine motor skills even though his gross motor skills are not so good.

We recently purchased the AlphaTalker from the Prentke Romich Company (1022 Heyl Road, Wooster, OH 44691, 800/262-1984). This device is wonderful! It has enabled him to express his wants and needs, and the whole world now views him differently.

We tried several different devices, but this was definitely the easiest to program. The Prentke Romich staff is very helpful; they even helped us get funding to buy the device. Their payment and rental policies are great; you can trade in used devices for credit as your child's needs change.

M.D., Massachusetts

Down Syndrome and Nonverbal

K.E.'s (October 1994) seven-year-old daughter, Jennifer, has Down syndrome. Jennifer was able to say about 75 understandable words by the time she was two and a half, but stopped talking a year later after frequent ear infections. Jennifer, who has received ongoing, intensive speech therapy, vocalizes but says nothing understandable. She has learned some sign language, but her signs are poorly formed and inaccurate. She has begun to use an augmentative communication device, but uses it mostly to respond rather than to initiate conversations or make requests. K.E. wanted advice and support.

I also have a child with Down syndrome, but unlike your daughter, my six-year-old son talks all the time. I thought you might find it helpful if I tell you some of the things I have done with him.

My first recommendation is to avoid the rush to words! If we pressure a child to talk before she is ready, it will actually discourage her. Your daughter must first enjoy being with people, and prefer this to being alone. Play and interact with her as much as you can. Stop what you are doing frequently, just to spend some time with her. It doesn't have to be a lot of time, just do it often when you are both at home. It's important that children with language delays play and interact with others as often as possible, so they don't become "socially isolated."

Second, I suggest you don't talk too much! We parents are often told to "bathe" our child in language. But sometimes we end up "drowning" our children with words they can't yet say! Instead, keep your language short and simple. In the beginning, use just one or two words that she can try to say during an interaction. Then wait and give her a chance to do or say something. And I mean something—just whatever she can do or say, even if it is unintelligible at first. This will teach her turn-taking.

This waiting sounds very easy, but it's not. Most adults have a very difficult time waiting for a response from a child who has a language delay, but it is important that you do this; otherwise your daughter may become just a passive observer of everyday life, like so many children with developmental delays. Help her become a real participant by waiting for a response each time you say or do something.

Third, follow her lead in whatever she is doing, as often as you can. In other words, don't become the "director" of each interaction! If she is playing with her toys, quietly join in. Imitate her actions and sounds, then add simple ones of your own. Play and talk in ways she is able to imitate, not in ways that are too difficult for her to try.

Fourth, keep her interacting. By that, I mean don't let her leave an interaction right away, but try to keep her with you for a few more turns each day. It really isn't that hard if you can make yourself more fun and interesting than whatever is distracting her. (And turn off the television if she spends a lot of time watching. TV won't help her learn to communicate!)

continued on page 15
CARNITOR® (levocarnitine) is now available for reimbursement by Medicaid in all 50 states and Medicare in many states.

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CONTRAINDICATIONS None known.

WARNINGS None.

PRECAUTIONS General CARNITOR® Oral Solution is for oral/intestinal use only. Not for parenteral use. Gastrintestinal reactions may result from too rapid consumption. CARNITOR® Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day (every 3-4 hours, preferably during or following meals) to maximize tolerance.

Carcinogenesis, Mutagenesis, Impairment of Fertility Mutagenicity tests performed in Salmonella typhimurium, Saccharomyces cerevisiae, and Schizosaccharomyces pombe do not indicate that CARNITOR® is mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy Category B Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or whether to discontinue the drug, taking into account the importance of the drug to the mother.


Pediatric use See Dosage and Administration.

ADVERSE REACTIONS Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D, L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uricemic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient complaints.

DRUG INTERACTIONS In animal studies, levocarnitine has not resulted in embryotoxicity. No drug interactions have been observed in humans using CARNITOR® (Levocarnitine) Tablets and Oral Solution.

DOSAGE AND ADMINISTRATION CARNITOR® Tablets: Recommended adult dosage is 900 mg two or three times a day using the 330 mg tablets, depending on clinical response. Oral Solution: the recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution. Recommended dosage for infants and children is 50-100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should start at 50 mg/kg/day and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

HOW SUPPLIED CARNITOR® Tablets are supplied as 330 mg, individually foil-wrapped tablets in boxes of 90. Store at room temperature (25°C/77°F). CARNITOR® Oral Solution is supplied in 118 ml (4 fl oz) multiple-unit plastic containers packaged 24 per case. Store at room temperature (25°C/77°F).

CARNITOR® (LEVOCARNITINE) Injection For Intravenous Use Only CARNITOR® (Levocarnitine) Injection 1 g per 5 mL.

DOSAGE AND ADMINISTRATION CARNITOR® Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q6h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter), and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

Pediatric use See Dosage and Administration.

ADVERSE REACTIONS Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying disease condition.

OVERDOSAGE There have been no reports of toxicity from levocarnitine overdosage. The oral LD50 of levocarnitine in mice is 16.0 g/kg. Large doses of levocarnitine may cause diarrhea.

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Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

HOW SUPPLIED CARNITOR® Injection, 1 gram per 5 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton. Store ampoules at room temperature (25°C/77°F) in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.
And one last, very important thing—don't ask too many questions. Questions can put children with language delays "on the spot" because they have a difficult time answering. Don't use questions as a way to start an interaction or conversation. Instead, try making a comment on something you see or something your child is doing, then give her a chance to respond.

I'm sure if you try some of these ideas, you will see more communication from your child!

B.M., Ohio

**Identical Twins Who Are Different**

D.C. (October 1994) is the mother of 10-month-old identical twin boys. Due to a complication of pregnancy called twin-to-twin transfusion, blood intended for one twin (the donor) was diverted to the other (the recipient). They were born seven weeks prematurely. One twin (the donor) has been diagnosed with spastic quadriplegic cerebral palsy and a vision impairment. The other twin is developing normally. D.C. wanted suggestions for coping with the problems that arise from having two children with the same chronological age but different developmental ages.

My sons, Levi and Luke, are four-year-old fraternal twins. They were born seven weeks prematurely. Luke, the second-born, was breech and had more difficulties than his twin.

When the boys were 11 months old, both were diagnosed with cerebral palsy—Levi, "mild," and Luke, "severe." Now, however, Levi shows no signs of cerebral palsy, while Luke is moderately affected.

I believe Levi has been a continual motivator for Luke to do as much as he can. We have made a special effort to include Luke in everything, no matter how difficult. I've tried to keep the boys together as much as possible.

It was very difficult for us when Levi was achieving various developmental milestones and Luke was not. At this point, Levi crawls and walks with a walker. Both boys have started asking "why" questions.

I belonged to a Mother of Twins Club and found it to be useless. I was the only mom with differently-developing twins. A group called Mothers United for Moral Support (MUMS, c/o Julie Gordon, 150 Custer Ct., Green Bay, WI 54301) may be able to help you find other mothers of differently-developing identical twins. I have found this group to be a great resource.

L.A., Minnesota

**EDITOR'S NOTE:** MUMS makes an effort to match members who are dealing with similar situations and disabilities. The organization's most recent parent-to-parent list of disorders includes 11 families of twins in which one twin has cerebral palsy.

I had been meaning to write my own Search letter. Then, I saw yours, stopped everything and got out paper and pen.

We are also very proud parents of identical twin boys. Like you, I had complications with my pregnancy. Five months into the pregnancy, an ultrasound revealed twins, but doctors were concerned that "twin B" was much smaller. After a month, his growth had fallen further behind. At the very end of my sixth month, I went into the hospital for a "routine" ultrasound and was admitted 15 minutes later for toxemia.

The next day—10 weeks before my due date—our boys were delivered by emergency cesarean section.

The boys are now 27 months old. Like your "donor," twin A has cerebral palsy and a cortical visual impairment. His brother, "twin B," was in the hospital for 14 months and is now at home. He is fed through a g-tube and is on a ventilator with 22-hour-a-day nursing care. Mentally, they are both pretty sharp. "Twin A's" physical condition keeps him from doing what his mind is capable of. "Twin B" has about a 30-word vocabulary in sign language and is starting to crawl, however his vent and his many tubes limit him.

I am 17 months ahead of you. I wish I could tell you differently, but it really doesn't get much better. I joined the Mothers of Twins club even before the boys were born. Their support has been great, however, they all have "normal" lives and "normal" children so there is a lot we don't have in common.

Believe me, I know how you feel. It's very lonely not fitting in anywhere. I just get up every day and do the best I can to make my kids the best they can be—just like any other mom.

J.F., Washington

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The parents of two-year-old Jordan Arkontaky call her their "bundle of joy." Jordan, who lives in Hawthorne, New York, where winter outings require serious bundling up, has multiple disabilities including low muscle tone and cortical blindness. She enjoys listening to music and being tickled by big sister Justine.

Megan Jane Carroll, 11, enjoys nothing more than "borrowing" mom Judy's makeup, jewelry, and clothes. On one such occasion, Megan's "best buddy" and former teacher, Barbie Nelson, used Judy's camera to snap a picture. Mom was pretty surprised when she picked up the photos from that roll of film! The hat, incidentally, is Megan's own creation—made of painted newspaper, sunflowers and lace. Megan has Rett syndrome and lives in Dothan, Alabama.

Despite being a bit young for a license, three-and-a-half-year-old Matthew Scott Newquist loves to "drive" just about anything—like this tractor at a friend's house. His imagination and infectious laugh have earned him the nickname "Charmer." Matthew, who lives in Big Creek, California with parents Mark and Lisa, has cerebral palsy.

Brothers Billy and Christopher Stoddard, ages two and three, enjoyed a visit to the San Diego Zoo with their father Jack. The boys didn't get to pet any lions or tigers as they had hoped, but they still had fun wearing their parents out. The Stoddards, who live in Las Vegas, Nevada, were in San Diego for an appointment at a clinic specializing in metabolic disorders. Billy and Christopher have been tentatively diagnosed with Leigh disease.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!
Back and forth, in and out of conventional hospitals and treatment programs. Because complex behavioral issues frustrate treatment of a young child's neurological deficits. Our unique medical and behavioral approach can break the cycle of multiple failures.
Admittedly fearful of speaking in public, Edward Sample of Janesville, Wisconsin chose to vocalize his thoughts as his wife, Roberta, wrote them down.

Most of you have met someone like me. I was the boy in your class at school who you thought never knew the answer. When the teacher called on me, I cleared my throat and squirmed, but never could answer. Until the third grade, I knew the answers, and until the third grade, my teachers called on me. But in third grade, a label appeared on the bottom of my school record. After that the teacher stopped calling on me. She stopped dropping by my desk to show me how to do things. I could still answer the questions, but I couldn't do most of my homework. I couldn't read. I never understood what happened in the third grade. For a long time, I thought the teacher just didn't like me. Then I saw my school record. I read the label—I knew why she stopped working with me.

I didn't finish high school, but I did learn to read. I taught myself with the help of a doctor that I worked for while I was in the Army. Now, I can read, but I still have trouble reading out loud. I still stumble over words, so I write my words down. Even if I cannot speak, you will have my thoughts because Roberta said, "Just share what it is like for you. Tell them what it is like to be Dad when your children have some special needs."

I can't really tell you anything about what medical people call "special" about my children. The children have "cerebral palsy." I don't know what that means in medical terms. But I do know what that means to Dad. It means that some people see me and my family with a label. It means that some people only see what is "wrong" with my children. It means that some people only get excited if they think they can "fix" what is wrong.

It means that some people want to know why the children are broken, who broke them and how to get me to do something called "accept." It means that some people get the words "accept" and "give up" confused. It means that things really haven't changed very much since I was in third grade. And it means that some people make me mad as hell!

If you look at us this way you are going to miss my real family. You'll never hear the children laugh. You'll never see us go to the park to fly our kites. You'll miss seeing my wife trying to mount a horse—from the wrong side.

Being Dad is pretty much the same for me as it is for any other Dad I know. I love my children. I want the best for them. They make me laugh, and sometimes they make my cry. "Disability" is not what we are or who we are. Disabilities for us are just like... having blue eyes, brown hair or freckles.

One advantage of being Dad is nobody expects to see much of you. I remember the first time my wife and I took Edward to a place that examines slow babies.
They schedule appointments 9 a.m. to 5 p.m., Monday through Friday. I took the day off from work.

I drove.
I parked the car.
I carried the diaper bag.
I went and got the parking sticker.
I gave the insurance information.
I signed the forms, and then I went to look for my family.

By the time I found them, the examination was over.
All of the people who had examined my son came into the room to tell what they had found.
They asked my wife the questions, even though I was the one who had taken “maternity leave.”
Since I was the one who had been feeding him, I told them it took 45 minutes to give him two ounces.
The one lady said, “We found nothing wrong.”
The doctor said, “Have your wife show you how to hold him.”
Several days later someone called for more information...
They asked to speak to my wife.

Most dads I know are in pretty much the same boat.
What is different for me is that special needs do not go away.
There are more and more appointments.
More and more strangers digging in your life.
More and more labels for your child and your family.

Then one day the boss says, “Listen fella, I’m sorry for your problems, but I can’t keep giving you days off.”
Even when the boss is understanding, bill collectors are not.
So one day—I don’t remember when—
I stopped going to appointments.
I didn’t understand much of what was said.
Most of the words—like “fine motor” and “gross motor”—
were foreign to me.
Now I know this was the beginning of our family’s long, slow process of drifting apart.
One day I realized that mother and children were living one life, and I was living another.
Grown-up men are not supposed to say how afraid they are.
So I watched my wife grow more distant, more irritable, more tired.

I never told her how lonely I was.
I never told her how worried about the bills I was, but I nagged about the wash being stacked up, the house being messy and her never having time for me.
I nagged until she cried.
Then I left...

I am ashamed of having left my family.
Every time I left them, I knew it wouldn’t help.
All the time I was gone, I loved them and supported them and knew I would come back.
But still I left—until the last time.
As I was putting my things in the car, I overheard my eight-year-old screaming.
“Please God, my Dad, him’s leaving cause my brain’s broke.”
I held him in my arms.
We both cried.
Mom and Sarah joined us.
We were all wrapped up in our sadness.
Then Robbie asked, “Did our dog die?”
There’s laughter in our family, too—lots of it.

For too long I sat quietly in the third grade.
My thoughts and feelings trapped inside me.
My son’s fear, my family’s tears helped change that.
This family is the best thing in my life.
Each of us is of equal worth and importance.
Each of us will share in the other’s life.

Because we want to and we need to.

I keep reading that there are very few fathers involved in their children’s programs.
Everybody seems to think this is some great new event.
That dads are somehow not interested in their children.
I cannot speak for all dads, but if I had the chance...
I would ask the dads who are doing some of that research to take a look at their own lives.
How many of them visit the doctor with their children?
How many of them could take four days a month off from work?
How many of them can visit their child’s program each day?
Does not being there, not knowing, have anything to do with the kind of dad they are?
No.
And it doesn’t for me either.
I hope that someday the people who are looking for us dads will remember where many of us have to be.
If you want to see us, you only need to make it possible for us to be a part of our family, without letting our family down.
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- Lists of religious materials.

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Fathers’ Voices is a regular feature of Exceptional Parent magazine. This column, coordinated by James May, Project Director of the National Father’s Network, focuses on fathers’ experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers’ Network (NFn) or to receive their newsletter, write or call: National Fathers’ Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-1004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children’s and families’ lives.
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Circle # 168 893
"Tell me your church and synagogue stories."

I'll never forget the answers I got the first time I asked that question at a relatively large gathering of parents and advocates. This was in the late '80s, at a South Carolina conference for parents of children with Down syndrome.

One mother told me she and her husband had used their congregation as an arena where their daughter could begin to develop her own sense of identity and independence. The parents trusted their church community enough that they could, as the mother said, start letting go. Now a young adult, their daughter lives in a supported apartment.

Another said, "We took our minister to our IEP meeting at the school. It was wonderful. We got everything we wanted."

After a pause she added, "They thought he was our lawyer."

Everyone laughed, but the point was made. Think what could happen if clergy or congregational advocates regularly went with families as supports and friends during what can be very anxious planning times.

The discussion reminded me of one of those times—16 years earlier—when I sat with an interdisciplinary diagnostic team in North Carolina as they tried to figure out where a young boy with developmental disabilities could get some desperately needed socialization and recreational experiences. Though this rural area of the state had few specialized programs, an obvious possibility was a community in which the rest of the family was involved—their church and its Sunday school. However, as a young chaplain-in-training, I was too intimidated by all the discussions of highly professional diagnostic tests and interviews to mention the family's church as a possible resource.

What's changed? Along with shifts in public education and systems of care, the International Year of the Disabled in 1980 and the Americans With Disabilities Act in 1992, religious denominations and faith groups have developed a number of resources to stimulate and encourage congregational inclusion of children and adults with disabilities. Almost every faith group now has an office which deals with religious education and ministries with people with disabilities, either on a full- or part-time basis. Interfaith networks and programs connect many others, and share resources through magazines, newsletters or journals. Models of congregational ministry and services include both specialized and inclusive religious education programs, creative ways to facilitate participation in worship, congregational respite care, group homes run by religious groups, disability awareness materials, daycare, camps and congregation-based circles of support.

The resources and models are there, although finding them may require looking beyond the boundaries of your own denomination, faith tradition or local religious bookstore. Learning about services provided by other faith groups can lead you to ask one of the most effective questions for initiating new congregational awareness and inclusiveness—"If they can do it, why can't we?"

**Congregation benefits**

But tapping the potential in congregational supports also means taking a hard look at the painful experiences of families and people with disabilities when the doors to their congregations seem to close. Many recent studies have testified to the importance of personal faith and spirituality in sustaining parents and families of children with disabilities. But when these same families were asked if they had received much support from their congregations, most gave answers of "no" or "very limited."

These studies come alive when we listen to families share their own individual stories—stories that can compel congregational change. One mother told me about her family's efforts to find a new church home after a move from out of state. They tried including their daughter—labeled "moderately retarded" and "microcephalic"—in a church youth group without advance preparations. Someone in the group said something that hurt the girl's feelings, and she refused to go back to church. The mother admonished her daughter that the church was God's unique opportunities

Today, however, many parents, professionals and religious leaders realize that religious education and congregational life offers unique and wonderful opportunities for children with disabilities. Besides giving children an opportunity to learn and grow in their faith tradition, participation in congregational life may allow them to realize that they, too, are part of God's people with gifts to be celebrated and needs to be shared.
PATION FOR ALL

house and that, as a family, they needed to be there. Her daughter listened to this explanation, then said simply, "Well, it may be God's house, but He's not home."

The loss in these stories is not just to the family and the child, but also to the congregations. Many congregations who have worked to include children and adults with disabilities will testify to their belief that in the long run, the congregation is the greatest beneficiary of the experience.

Creating stories to celebrate

What needs to happen now, so more of these stories become stories we can celebrate? Challenges and opportunities exist on many levels:

- Families, parents and people with disabilities need to knock on the door of their faith community—sometimes with others acting as advocates or guides on their behalf—with resources, models, hopes and needs in hand.
- Clergy and congregations need a vision of hospitality, a commitment to the importance of including every individual and his or her gifts, the wisdom to know that it takes time to build trust, understanding that the first prayers may be ones of lament or anger and an awareness that an effort to include one person or family will touch many people. And they need to know that they do not have to become a special educator in order to help. They simply need to let families know that they are welcome in that place called a "sanctuary," and that God is home.
- Professionals and advocates can use their understand-

ANDREAS YUAN

"Please don't bring Andreas to Special Religious Education anymore."

I heard the words in dismay. Although he was 15 years old, my son was preparing for First Communion.

"Andreas' volunteer teacher is all right with him, but the other teachers in the group have said they will quit if he doesn't stop coming."

The week before, Andreas had taken me by the hand and quietly led me into the special prayer room. With a sense of awe, he'd taken me up to the altar to show me the candles and Bible.

"The real reason is, he's disruptive of our process of coming closer to God."

It took me several months to get over my hurt and bitterness. In the end, it was Andreas' eagerness to go to church that led me back. Although he couldn't speak, whenever we passed a church, Andreas would wave his hand back and forth in his own sign for singing. This time, however, I approached our own parish in the town where Andreas was fully included in high school.

Immediately, a group formed to prepare Andreas. It included one of his high school classmates, our priest, the director of religious education and several other members of the congregation. Every Sunday, we stayed after the service and had a "mini-Mass" with Andreas. We explained each part repeatedly and practiced receiving communion. Following the consecration of the bread and wine, Andreas would shout out in acclamation. These shouts had become so much a part of the Mass that the priest normally waited for them before continuing the service.

Our biggest stumbling block was the texture of the host (unleavened bread). Like many people with autism, Andreas is very sensitive to texture—and he had decided this was not his idea of bread! One week, we brought a bag of unconsecrated hosts home to give Andreas some time to get used to the texture. Later, when I discovered the bag missing, I found Andreas very solemnly putting host after host on the outstretched tongue of the family dog!

Finally, the big day arrived. His sisters came home from their distant colleges; a close family friend, who happens to be Jewish, also attended the service. When the big moment arrived, Andreas walked to the front of the sanctuary, surrounded by his entourage of family and friends. Suddenly he realized someone was missing! Andreas returned to our pew and taking our Jewish friend by the arm, brought him forward to join the group. Then Andreas opened his mouth and happily ate the host. The congregation erupted in cheers! Andreas belonged—and we all came closer to God, together.

—Susan Yuan
"As a parent, I want to know what's going on."

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☐ Civil Rights (Americans with Disabilities Act) ☐ Personal Assistance Services
☐ Family Support - keeping your child at home and your family together
☐ Telecommunications (using the information superhighway)
☐ Technology (wheelchairs, computers, communication devices)
☐ Impact of health care reform on people with disabilities and their families
☐ Other, please specify:

Name: ___________________________ Address: ___________________________
Phone: __________________________ Fax: ___________________________

Age of family member with disability: __________________________

Please mail this form to: United Cerebral Palsy Associations, Governmental Activities Department, 1522 K Street, NW, Suite 1112, Washington, DC 20005 or fax it to (202) 842-3519.

Advancing the independence of people with disabilities
ing and skills in direct ways in congregational settings, but they should also realize that they can teach and guide others. Just as a job coach facilitates integrated employment, we need more people willing to be “church and syn-
agogue coaches”—people who believe in and are able to tap an existing reservoir of good will and desire to help.
• Everyone needs to realize that a church or synagogue can take the first steps without starting a formal “ministry” or “program.” Often, specialized programs are the established way of doing things, but it’s important to realize that a congregation’s initial effort can focus on the life of one child and one family.

**It’s important to realize that a congregation’s initial effort can focus on the life of one child and one family.**

It’s important to realize that a congregation’s initial effort can focus on the life of one child and one family.

Telling our stories

In the pages of this issue, you will hear about some national and local efforts, see some of the resources and feel some of the faith, hope, pain, and love. And in the months ahead, *Exceptional Parent* has expressed its willingness to host a dialogue between families and religious leaders in many traditions through occasional articles.

So what are your stories? What’s worked for your family in your faith tradition? What hasn’t? Write to me in care of *Exceptional Parent* (209 Harvard St., Ste. 303, Brookline, MA 02146). Help us tell the stories!

Bill Gavента is an ordained American Baptist clergyman and chaplain. Since 1973, he has been involved in ministries involving people with developmental disabilities and their families. He currently serves as director of Community Training and coordinator of Congregational Supports for the University Affiliated Program of New Jersey. He lives in Princeton, New Jersey with his wife, Beverly, an associate professor at Princeton Theological Seminary, and their son, Matthew, a high school student.

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**VERONICA CHLOE**

When Veronica Chloe played an angel during a Christmas play at the Ebenezer African Methodist Episcopal (AME) Church in Fort Washington, Maryland two years ago, Christmas took on a new meaning for many—especially her mother, Sandral. For her, Veronica became the perfect image of an angel, Sandral recalls.

Seven-year-old Veronica, who has cerebral palsy, was three years old when the church began its Exceptional Child Ministry, a program for children with disabilities. Sunday school classes are the primary focus of the program, but it also offers opportunities to participate in social activities like movie nights, monthly outings and the Christmas play.

In Sunday school, children with disabilities study the same curriculum as other children in the church. However, they are taught at their own pace and in whatever format is necessary, including Braille and sign language. After each class, the children join the rest of the congregation for worship in the sanctuary.

Veronica, one of the program’s original participants, has benefited greatly from the socialization opportunities church activities have provided. Easily startled as an infant, Veronica has grown so accustomed to the singing and clapping of hands in worship service that she no longer jumps at sharp noises. This has also affected her behavior outside of church.

“Veronica is a very sociable child,” says Sandral. “She is very attentive to the ministers and perks up when she hears their voices on the radio.”

Veronica also becomes noticeably animated when the congregation begins singing The Lord’s Prayer, a prayer she knows and loves.

Marion Crayton, president of the Exceptional Child Ministry, says when you “come into Veronica’s presence, something happens. She has a radiance around her.”

Veronica’s “gift of smile,” her mother says, has garnered many new friends and won the hearts of her pastors and congregation.

—Jennifer M. Koerber
CATHOLIC LIFE FOR CHILDREN WITH DISABILITIES

by Marilyn E. Bishop

Just ten years ago, Catholic parishes tended to come up with quick solutions when a child was diagnosed with a disability involving learning deficits. The child's parents were either advised that their child was an angel and did not need the saving grace of the church's sacraments, or they were told that a separate class or tutor could prepare the youngster for receiving eucharist (communion) or confirmation. Today the picture is very different.

Sometimes a child with a disability is included in regular religious education classes without obvious modifications. In California, Mary Brosseau, director of the Department for Special Religious Education, surveyed 44 parishes and discovered that "common sense" was the primary method used for including children. "In speaking with directors of religious education, I have found that many do not realize the level of assistance that they are providing because it simply seems common sense," Brosseau said in her newsletter, News Notes from the Department for Special Religious Education. "In other words, they are doing a better job at making adaptations than they realize."

In other parishes, the welcome mat for children with disabilities is more organized and deliberate. At St. Luke Church near Dayton, Ohio, the catechists (Sunday school teachers) were trained in curriculum adaptation and cooperative learning techniques. The teachers were told that the learning goals were not the same for everyone, but that all the children would discover that community means that all belong.

And when the child is accepted, his or her family feels that same welcome. "Our family was now a part of a bigger family," said Debbie Pollard, whose children—

GIDEON GOLDSTEIN

Having Prader-Willi syndrome means always resisting the urge to eat what's in front of you. Keeping Kosher requires the same type of resistance to eating without restriction and thoughtful consideration. For Gideon Goldstein, each set of dietary rules reinforces the other.

Gideon, 14, is a high school freshman whose command of the Hebrew language is remarkable. While he may struggle with math assignments and physical education classes, Gideon is always welcomed as a full participant in the Orthodox Jewish "minyan" (prayer group). In this setting, Gideon is not viewed as a teen struggling with the challenges of his disability, but as a young man who often provides the obligatory "tenth man" needed to begin morning prayers. Faced with fine motor problems that make writing a frustrating exercise, Gideon is able to manage the intricacies of "laying tefillin" (see photo) in preparation for prayer, winding the leather straps in a specific pattern around his hand and arm and wrapping another strap and box across his forehead.

In 1985, Gideon became one of the charter members of a new special education program at Temple Chai religious school in Phoenix, Arizona where he received an individualized program of Judaic and Hebrew instruction in both resource and regular classes. When he stood before the congregation for his bar mitzvah, the glow of his pride and happiness transformed the sanctuary. No one who attended will ever forget that service.

Part of a close and loving family, Gideon enjoys reading, music, animals and attending sporting events. As traditional observant Jews, his family spends Shabbat (the Sabbath) together in prayer and study. Gideon relishes this weekly escape from daily stresses that have accompanied his entrance into high school. Parents David and Carol and younger brother Noah also find great joy in this day of rest when labels like "able" and "disabled" disappear, and each family member comes together to share equally in the study of Torah (the scriptures).—Becca Hornstein

Gideon Goldstein begins each day with the morning davening (prayer).
with spina bifida and one with cerebral palsy—were included in a regular weekly religion class at St. Luke. When Debbie’s daughter, Megan, was hospitalized at Christmas time, she was eager to return home—not to play with her toys—but to go to church. Megan told the doctor, “I have to go home because tomorrow is church.”

Debbie believes that Megan’s positive experience with the church is important for her future. “That will see her through the trials she’s got ahead of her in life,” she said.

**Parish advocates**

It would be inaccurate to imply that Catholic students with disabilities have no barriers to enrollment in religious education. For example, one priest declared such training unnecessary for Claire, who is deaf, blind and mentally retarded. But her mother insisted that Claire could benefit from sacramental preparation. The director of religious education agreed and located a tutor from the nearby Catholic university, the University of Dayton. With support from the university’s Center for Ministry with Disabled People, the tutor was trained to successfully instruct Claire. Such staff support is provided in various ways in different parts of the country.

In the Archdiocese of Boston, for example, people with disabilities are identified and supported by “parish advocates.” Of the 400 parishes in this archdiocese, 75 have trained people to provide resources and support to adults and children with disabilities. Pat Friel, director of the Office for Persons with Disabilities for the Boston archdiocese, is concerned with making people with disabilities feel welcome in local churches. “How do we word our invitation to welcome children with disabilities? How do we teach the appropriate response to pastoral care needs?” she asked. Her answer was to initiate a 30-hour certification course to provide volunteers with information about communication skills, various disabilities and advocacy techniques. (Training materials are available. For more information, contact the Office for Persons with Disabilities, Archdiocese of Boston, 240 Adams St., Dedham, MA 02026, 617/254-0100.)

**Inclusive parochial schools**

One of the needs a parish advocate may discover is the desire to enroll a child with disabilities in the regular parish parochial school. “The calls that are most disturbing to me are the calls I get from parents whose children are rejected by parish schools because those schools have not thought of ways to include all children,” said Mary.
Jane Owen, director of the National Catholic Office for Persons with Disabilities in Washington, DC. A common reason for denying admission to a student with a disability is that the educational needs of the student demand resources—especially financial resources—that the school does not have.

Owen believes parents may need to pursue legal means for helping their parish schools get the money necessary to serve students with disabilities. She cites the precedent-setting 1993 Supreme Court decision in the Zobrest case as hopeful. This decision declared that public funds could be used to pay for interpreter services for a deaf student attending a Catholic high school. The important issue in this case was that the child—rather than the school—was the recipient of the services paid for with public funds.

But funding is not the only issue. Like many public school teachers, Catholic school teachers often feel their skills are inadequate to teach children with learning differences. The newly-formed Network of Inclusive Catholic Educators at the University of Dayton is alleviating those anxieties by training teachers to use alternative strategies like cooperative education, curriculum modifications, peer tutoring and teacher-to-teacher mentoring. The network hopes to begin using computers to share information among educators and professionals as the number of inclusive schools grows beyond the 30 currently identified.

This movement toward inclusive Catholic schools is encouraged by the National Catholic Educational Association (NCEA). In 1995, NCEA's national convention will offer at least three workshops on inclusion.

A nudge and some guidance

The policy of the Catholic church is inclusive. But, as Mary Jane Owen aptly described the situation, "The words are there, but the actions do not always follow the words." The guidelines on page 33 ("Advocating for Access") offer parents some pointers on helping their church communities become more accessible. Though more and more churches are making efforts to welcome all to their community, some may need a nudge and some guidance to set the wheels in motion.

Marilyn E. Bishop is the director of the Center for Ministry with Disabled People at the University of Dayton. She established the center in 1980. The purpose of the center is to link the resources of the university with people who have disabilities to support their spiritual enrichment. Marilyn has a B.A. in communication and is an M.A. candidate in religious studies.

“Now I can see my beautiful daughter flourishing and making progress that I never thought possible! Thank goodness for a place like this school.”

—Parent

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Just 20 miles from Boston
A JEWISH EDUCATION FOR EVERY CHILD

by Becca Hornstein

“Educate each child according to his ability.” —Proverbs 22:6

I just wanted what any Jewish mother wants for her son—I wanted Joel to have a bar mitzvah. The problem was that Joel has autism and in 1983, most religious schools made no accommodations for children with significant learning difficulties.

On the face of it, my desire for Joel to have a Jewish education may have seemed preposterous. Joel had lost the little bit of spoken language he had possessed when his autism surfaced at 21 months. A self-taught reader, Joel could read and write by his second birthday and quickly learned sign language, too. But he didn’t begin to verbalize phrases until age eight. Why, then, was I pursuing a goal which would require years of study in both English and Hebrew and would culminate in Joel speaking before a sanctuary filled with people?

As any parent of a child with a severe disability knows, the diagnosis of a child’s disability creates a tremendous sense of isolation, along with sporadic anger and grief. For many, the logical source of comfort and renewal is within one’s religious community. Although I had wrestled with my own anger at G-d’s when Joel was diagnosed, by the time he was nine years old, I had made my peace and craved the support, warmth and spiritual renewal of my religion. My desire for Joel to prepare for a bar mitzvah was part of the healing process. I wanted to be able to formally declare to family and friends that Joel was a person of value and dignity, an asset to his community and a blessing to his congregation. Most importantly, I wanted Joel to know he was accepted by his fellow Jews.

Responding to parents’ requests

Jews have been referred to as “the people of the Book.” But what can they offer to the child who cannot read, hold or see the Book? Presented with children or adults who had developmental, communicative and learning disabilities, rabbis of the past centuries were at a loss. Communities provided for the safety and welfare of Jews with special needs, but formal religious instruction could not take place until new systems of adapting teaching materials and methods were developed.

In the late 1970s, federal legislation began to change the face of public school education for children with special needs, Jewish educators began to respond to parents’ requests for religious education, like mine for my son, Joel. Until the mid-1980s, very little was available outside of New York City, where Orthodox Jewish communities had already instituted some special classes and schools. At that time, the Coalition for the Advancement of Jewish Education began to offer teacher training workshops at their annual national conferences. The Conservative and Reform movements began to look at curriculum modifications, disability-sensitivity workshops and ways of creating a network for families who have children with special needs.

In 1985, the Reform movement held the first national conference on special needs and began publishing the Likeyot Connection, a national newsletter devoted to disability issues. In the Orthodox community, the Otsar (meaning “treasure”) organization was founded by parents of children with diverse developmental disabilities to provide educational and recreational programs for people of all ages.

Exciting opportunities

Without a lot of fanfare, Jewish special educators began creating exciting opportunities for children, teens and young adults with mild to severe disabilities. In Chicago, the Keshet program initiated a wide variety of programs, including a Sunday school which now has a dozen classes with a high staff-to-student ratio and individualized experiential curriculum. For day school students, Keshet provides a special education program on four regular Jewish day school campuses. This affords students some integrated classes in addition to specialized Judaic and non-religious studies. By using volunteers in both classrooms and recreational activities, Keshet continues to provide disability awareness in the community.

Other Jewish communities—including those in Akron, Houston and San Francisco—employ a special education consultant who visits day and after-school religious education programs to provide teacher training, classroom observation, curriculum modification and behavior management techniques. With this assistance, religious schools can offer inclusion to many students with significant learning differences.

Self-contained Jewish day schools for children with mental and physical disabilities are unusual outside cities with large Jewish populations. However, good examples can be found in Baltimore’s Gesher Latorah and greater Washington, DC’s Shema V’Ezer schools. Whenever possible, students attending these schools are integrated with students in nearby Jewish day schools.

Many religious schools have added resource rooms for children having difficulty in learning to read or write Hebrew. Some religious schools, like Temple Chai in...
When Eyal David Sherman took the pulpit on the Saturday morning of his bar mitzvah, read from the Torah (scriptures) and led the prayers, the congregation heard him—silent and clear.

Nearly 1,000 worshippers at Temple Adath Yeshurun in Syracuse, New York, read Eyal's lips as video cameras projected the text and his face onto large screens mounted at the front of the sanctuary.

"Even though my bar mitzvah is different or awesome or radical, being high tech, I never really thought about that," Eyal said in his speech. "I just knew that when I reached age 13, I'd be up here on the bimah (pulpit) and have a bar mitzvah just like any other kid."

Nine years ago, Eyal suffered a stroke after surgery for a brain stem tumor. It left him a quadriplegic who—technically speaking—cannot walk, talk, breathe or eat "on his own." But that's not how Eyal sees it.

That Saturday, in front of the doctors and nurses who saved his life; the public school-teachers who helped bring him into regular classrooms; his mother, Leah, who first began teaching him Hebrew at home and his father Rabbi Charles Sherman, the spiritual leader of the congregation, Eyal performed the ritual marking him an adult in the Jewish community. And being an adult, he said, means "taking responsibility" for your own life.

After Eyal's bar mitzvah, a woman whose son has a neurological disorder, told Rabbi Sherman, "Now I know my son can have one, too." A public bar mitzvah sends a message to children with disabilities that "you're not shunned; you're not isolated," said the rabbi, who believes it is the clergy's moral obligation to give every child a religious education according to his or her abilities and a chance for religious expression in his or her own voice.

In his silent voice, Eyal gave a message of his own back to his community. As his father explained, "With all the horrible things in this life and all there is to complain about, you see that a kid can still ascend the pulpit and thank God for what he has."

—Andrea Kamens

Phoenix, have developed a continuum of educational options ranging from small self-contained classes, to pull-out, resource-room Hebrew classes, to inclusion with or without one-on-one assistance.

Since learning is a lifelong experience, programs such as Chaverim in greater Los Angeles offer a wide variety of classes as well as social and recreational activities for adults with disabilities. Their annual retreat now draws participants from as far away as San Francisco.

**Bar mitzvah boy**

Joel will soon be 21 years old. After several years in Temple Chai's self-contained class, he stood before 200 people for his bar mitzvah in May, 1987. Joel led the congregation in prayer and chanted his Torah portion (selection from one of the first five books of the Hebrew scriptures) and Haftarah portion (selection from the Prophets). On that day, surrounded by family and friends, teachers and classmates, Joel was special—no, not "special needs" and not "special education"—Joel was special because he was the bar mitzvah boy. His achievement reflects the rapid growth of Jewish special education and the benefits it has brought to both families and congregations.

Becca Hornstein is the executive director of the Council For Jews With Special Needs in Phoenix, Arizona. Becca lives in Scottsdale, Arizona with her husband, Barry, an instructor in special education at Glendale Community College, and their two children, Joel and Shana.
TOWARD A MORE INCLUSIVE PROTESTANT SUNDAY SCHOOL
Making religious education accessible to all
by Brett Webb-Mitchell

This is a story of a good struggle that led to new ways for children with disabilities to be included in a Sunday school program in an East Coast, suburban, Protestant church. For a time, this church was the scene of a struggle. On one side of the debate were parents of children with disabilities, who wanted them included in regular Sunday school classes. On the other side were parents of children without disabilities, who disagreed.

After many months, the stalemate was unexpectedly broken by something the children did—someone finally noticed that when the children with disabilities and the children without disabilities shared time together on the church's playground, the atmosphere was one of mutual caring and fun. On that playground, the children played happily together and helped each other enjoy the playground equipment. They were truly living Jesus' commandment to "love your neighbor as yourself."

With the eyes of the congregation now open to the lessons of the children, they were able to appreciate a story shared by one of the Sunday school teachers about Jimmy, an eight-year-old boy with mental retardation. During a Sunday morning worship service at the end of Vacation Bible School, Jimmy had walked to the front of the sanctuary. He wanted to hold the Bible for the worship leader. He wanted to be included in worship—doing something, anything—and his assistance was welcomed.

TYLER HOLGREEN

When Tyler Holgreen was diagnosed as a baby with 49,XXXXY syndrome, a rare variant of Klinefelter syndrome which causes intellectual and physical limitations, doctors said he would probably never participate in the same activities as other kids. At 12 years of age, however, Tyler Holgreen is usually just "one of the gang."

"Oh, the other kids know his problems," says his father, Lynn, "but they work with him and walk him through things."

Things like an after-school game of touch football. Or his responsibilities as a deacon in his Syracuse, Utah congregation of The Church of Jesus Christ of Latter-day Saints. With the church's worldwide educational and ministerial structure comprised entirely of volunteers from local congregations, Tyler's role as a deacon is a significant responsibility.

But of greater significance to the church is Tyler himself, says Doug Hind, manager of Special Curriculum at church headquarters in Salt Lake City, Utah. Hind's job is to see that those with disabilities enjoy "the same opportunities for growth, friendship and recognition" as any other member.

The church provides a number of services to give members with disabilities equal access to religious activities and education. Tyler Holgreen, for example, who normally wouldn't begin Seminary—a demanding four-year program of religious study offered to Latter-day Saint youth worldwide—until ninth grade, benefits from a two-year head start for children with disabilities. Tyler's father, Lynn, comments that Tyler often receives one-on-one tutoring from his leaders and his pals—in the chapel and on the line of scrimmage in his neighborhood backyard football "league."

And that's the way it should work, says Lynn—support from church leaders enhanced by individual concern. "These people are very aware," he says. "And they are very willing to help."

—Clayton Newell
The congregation was also able to appreciate the abilities of Sandra, a 10-year-old girl with Down syndrome who loves to play with the other children on the playground. She gets all the other children—children with and without disabilities—to participate in the fun and games. The Sunday school teachers call her a “natural leader,” as she effortlessly orchestrates playground games that all can enjoy.

As this congregation began to recognize the potential contributions of children with disabilities, teachers and parents started working on strategies to include all children in the Sunday school program, putting an end to segregated classes. This congregation has come to understand that inclusive Sunday school classes give everyone an opportunity to share the God-given gifts of all young church members.

**This congregation has come to understand that inclusive Sunday school classes give everyone an opportunity to share the God-given gifts of all young church members.**

Segregation and the “public school paradigm”

Gestures of caring, openly practiced by the youngest members of this congregation, helped open a door that had long remained shut. Yet few “mainline” Protestant churches recognize the power of such gestures. Instead, in most Protestant churches, educating children in the Christian faith still means reading, writing and rote memorization of Bible stories, along with group discussions where participation requires a certain level of verbal fluency.

Among religious educators, this method is known as the "public-school paradigm," and like many public schools where children with disabilities are still segregated, many children with disabilities are also kept out of regular Sunday school classes. Many Protestant churches have developed specialized curricula for people with mental retardation or teachers who used a whole-language approach. He was also helped by classmates who offered models of reading and correct spoken language along with their friendship and encouragement. Most of all, however, Ryan learned to read because he really was ready to learn.

Ryan's inclusion at St. Peter's extends beyond the classroom. He's on the basketball team, in the scout troop and a frequent guest at birthday parties. He is an altar server and has been a prayer leader at Mass.

Now, St. Peter's hardly remembers a time when Ryan wasn't part of the community. When asked recently if she'd do it over again, principal Sister David Ennis replied, "I'd do it again in a minute. Ryan has been a gift to our school. His hunger to learn has inspired us all. His special needs have helped us remember how much we all need. Thanks to him, our school is a better place."

---

**Ryan Reed**

As a public school student, Ryan Reed’s test results indicated he would never learn to read. He was assigned to classes focusing on non-academic skills.

But Ryan’s mother, Mary Jo, believed she could recognize many signs of reading readiness in her son. When public school teachers and administrators refused to modify his educational goals or class placement, she turned to the Catholic school in her parish.

Parochial schools often respond to a request like Mary Jo’s by saying, “We can’t do what the public schools can. We don’t have the money or the resources.” But Ryan needed only good teachers and a good learning environment.

This is not to say that Ryan’s family or teachers at St. Peter’s School in Rockford, Illinois took lightly the inclusion of a child with Down syndrome. There were plenty of skeptics and nay-sayers. And even those who felt Ryan’s inclusion could succeed, recognized the need for careful planning and preparation.

When 11-year-old Ryan entered fifth grade at St. Peter’s, he was reading at a pre-primer level. By the end of the school year, he had achieved a second-grade reading level. He entered seventh grade last fall reading third- and fourth-grade materials.

He learned to read from good teachers who used a whole-language approach. He was also helped by classmates who offered models of reading and correct spoken language along with their friendship and encouragement. Most of all, however, Ryan learned to read because he really was ready to learn.

Ryan’s inclusion at St. Peter’s extends beyond the classroom. He’s on the basketball team, in the scout troop and a frequent guest at birthday parties. He is an altar server and has been a prayer leader at Mass.

Now, St. Peter’s hardly remembers a time when Ryan wasn’t part of the community. When asked recently if she’d do it over again, principal Sister David Ennis replied, “I’d do it again in a minute. Ryan has been a gift to our school. His hunger to learn has inspired us all. His special needs have helped us remember how much we all need. Thanks to him, our school is a better place.”

—Margaret R. Bowman
other disabilities that may be taught in special classes outside of the "normal" Sunday school program. Many of these same churches go so far as to advocate a separate worship service for people with disabilities.

**Toward greater inclusiveness**

Even within the structure of most Protestant Sunday school programs, greater awareness and small modifications may allow children with disabilities to be included. Here are some practical suggestions:

- **Teach children about differences.** Invite children and their parents to learn about differences in abilities that may affect what people can and cannot do in church, at home or in the community. Focus on the fact that we all have different abilities and limitations.

- **Focus on what children with disabilities can do.** Let parents and their children with various disabilities teach Sunday school classes what a child with a disability can do in the context of church activities. One focus might be on alternative forms of communication—like signing songs, painting responses rather than verbalizing, or dramatizing a Bible verse rather than reading it.

**Focus on the fact that we all have different abilities and limitations.**

- **Create a "least-restrictive" Sunday school environment.** Minor modifications—both in the physical layout of a class and the structure of its schedule—can make a Sunday school class more accessible to a child with a disability. If a child is in a wheelchair, the class layout can allow plenty of space for that child to move around. If a child has a visual impairment, someone can be responsible to tell that child about things he or she cannot see. If a child has a hearing impairment, it will be important for the teacher and other students to know the best way to communicate with that child.

Such changes in the Sunday school—even within the limitations of the "public-school paradigm"—can open up doors for people with disabilities to participate. It will also help others to see anew the diversity of gifts in the church.

Brett Webb-Mitchell, a visiting assistant professor in Christian Nurture at Duke Divinity School, is also the president of the Religion Division of the American Association on Mental Retardation. He is the author of *God Plays Piano, Too: The Spiritual Lives of Disabled Children* and *Unexpected Banquet: Welcoming People with Disabilities into the Church*, both published by the Crossroads Publishing Company.

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**ADVOCATING FOR ACCESS**

By Marilyn Bishop

Parents have long been the prophets and organizers for education, services and employment. They may also find that some of that personal organizing ability will be needed to create a church community that responds with love to their children with disabilities.

If you are searching for a faith community that will welcome you and your child, here are several strategies to consider:

- **Be specific when you ask for a service for your child.** Requesting "membership" is too vague. Decide on the services your child needs, then come up with a plan. If your child is of preschool age, consider preschool or nursery school classes at your church or synagogue. If your child is older, ask for age-appropriate religious education that is integrated with the other children. If your child wants to be part of a youth group, watch for an opportunity to sign up for a specific activity in which the child has had some experience.

- **Ask the right person for the service you need, and ask for it at the right time.** Although the priest, minister or rabbi is the key to a faith community, a request for special services may confuse him or her and lead to a response that is less than you expected. If you are seeking religious education, ask the education coordinator during a quiet moment. Better yet, call for an appointment and take your child with you. It's hard to refuse when the child is sitting there. And the opportunity to meet the child in person may reduce fears and misconceptions.

- **Check with nearby members of the same faith to see if other congregations are offering the services your child needs.** You may decide to move your membership to a church or synagogue that provides these services, or you may be able to meet with the personnel involved in a model program to get some strategies for taking the first steps in your own faith community.

- **Don't give up if the response is not immediate.** Ask again, and the second time bring along some resources that will help church or synagogue personnel learn about similar services provided elsewhere.

- **Call some of the national faith group resources listed in the directory beginning on page 49.** Many serve as interdenominational or interfaith resources and offer curricula and materials.
THE SPECIAL OLYMPICS CHRISTMAS ALBUMS

Featuring The Pointer Sisters  Eurythmics  Whitney Houston
Bruce Springsteen and the E Street Band  The Pretenders  John Cougar Mellencamp
Sting  RUN D.M.C.  U2  Madonna  Bob Seger & the Silver Bullet Band
Bryan Adams  Bon Jovi  Alison Moyet  Stevie Nicks
Jimmy Mulzet
A dream of meeting the pope comes true

On a clear summer night more than a year ago in Denver, Colorado, "Jimmy" Mulzet's dream of meeting Pope John Paul II came true. Mulzet not only spoke during a Mass celebrated by the pope at World Youth Day, but he was also hugged and blessed by the pontiff.

"The day I met the pope in Denver I really wanted to ask him, 'Why did God make me handicapped?"' Mulzet says. "I wanted to talk to him. But the Mass had to go on."

Mulzet, 37, grew up on the Upper East Side of New York City. The son of the late Frank and Hazel, he was educated in special education programs within the New York City public schools. Mulzet, who was diagnosed with cerebral palsy and developmental delays when he was three years old, is a mailroom messenger at the City University of New York.

"I am one of God's special children," Mulzet says. "He wants me to go out and help people because God helps those that help themselves."

When Cardinal Terence Cooke of New York died, Archbishop John O'Connor came to take his place. At the time, I was working at City University, where there was a welcoming party for O'Connor. I didn't know O'Connor or Monsignor John McCarthy, O'Connor's right-hand man. They came to the party in a big black limousine. That was the first time I met my friend—John O'Connor.

I had my picture taken shaking hands with my new friend. There were a lot of people there that day, but I was the only one that got his blessing. Only me—but then no one else asked him!

When the cardinal left I helped him put on his coat and I walked with him outside and talked to him about Cardinal Cooke. I was happy he was here, but I was sorry that Cardinal Cooke died. I opened the door and helped him into the limousine. Ever since that day, me and Cardinal O'Connor have been good friends.

The first Mass
In October of 1989, Cardinal O'Connor told one of the sisters at Catholic Charities he wanted someone to read at the special Mass for the handicapped. She asked me to do it. One of the sisters at Catholic Charities practiced with me. I could not read it right away. One sister said, "You've got to read this right because the cardinal said he wants you to." I went home and practiced.

I was not scared on the day of the Mass. I waited for my time and I read it and it was beautiful.

Midnight Mass
A few days later, a sister from Catholic Charities called, "Jimmy, the cardinal wants you to read again at Midnight Mass for Christmas at St. Patrick's Cathedral." I practiced and practiced.

I was not a good reader at the time. I did not learn reading very well at school.

The night came. My hands were sweaty. The cardinal was there. As soon as I saw him, I knew everything was alright. I was so happy.

When it was my turn, I wasn't nervous. I took my time. I started to read and did it without stopping! I know I made the cardinal happy. After Mass, we all went to his residence and had a little party.

continued on page 36
"I'd like to meet the pope"

Two or three weeks later, I went right up to the cardinal and said, "Your Eminence, can you do something for me?" I told him I'd like to meet the pope and tell him about my disability. He said, "We will see."

I know the cardinal and Mon- signor McCarthy tried to find a way to send me to Rome. But there was no one to take me. I called Mon- signor McCarthy every week to ask about the pope.

Then one day we found out the pope was going to Denver for World Youth Day (WYD) in August 1993. I asked Cardinal O'Connor if I could go. A few days later I got the call; I was going.

Most of the people I was going with told me, "We're just going to WYD. We're not going to meet the pope. If you want to meet him, you'll have to talk to Cardinal O'Connor or make some other arrangements."

Meeting the pope

I got a call from the WYD office. Cardinal O'Connor recom- mended that I speak in Denver at the candlelight vigil with the pope. I was so excited. My face lighted up.

That is when everyone started contacting me. I was in the New York Post and on the radio and television. Everyone wanted to interview me. It made me feel very special.

On Friday morning, I was taken to Chero- kee State Park where we rehearsed for the candlelight vigil.

The next day—the biggest day of my life— was Saturday, Aug. 14. There were a lot of people at the candlelight vigil; more than 200,000. I was on the stage with the priests, cardinals and bishops. I saw three helicopters coming. The pope was in one. They landed in a field. And then the pope's car pulled up to the stage's back entrance. The crowd was yelling like he was a king.

I was the fourth person who was going to talk about their faith in God. We were told we only had two minutes.

When it was my turn, I walked out and I saw the pope sitting there. I spoke for exactly seven and a half minutes. I had to say how much I loved God. Then I turned and bowed to the pope. He picked up his hand and told me to come to him.

There were three steps up to his seat. Someone helped me up the stairs. When I got there, the pope gave me such a big hug. The biggest hug that you ever saw!

A few people got to touch the pope, but he did not give them a big hug. When I gave him a hug, I patted him on the back and hugged him. And then the pope hugged me back. I never thought that would happen to me.

SCHOLARSHIPS AVAILABLE

Up to five college scholarships are being offered for the fall of 1995 for a four-year period. Each scholarship provides $3,000 per year ($12,000 total) to each student. Only current high school seniors and college freshmen will be considered.

Applicants should be physically challenged, in a wheelchair, and could not attend college without this help.

All young men and women will be considered without regard to race, color, creed, or state of residence. A private interview is not required.

We require a 500-word "statement of need" explaining your physical condition, educational background, and financial status. For scholarship application, write to:

"Doc" and Alicia Keim, Chairscholars
Silver Dollar Ranch, No. 38
Odessa, FL 33556
(813) 920-2737

Deadline Jan. 15, 1995

"Helping physically challenged students in chairs go to college."
the back and that is when he handed me rosary beads and a cross. That is when I wanted to stand up there and tell him about my disability. But I could not chit-chat with him. Maybe I can one day in Rome.

The Pope said, "God loves you." That made me very special and very blessed.

"In the peace of Christ"

When Cardinal O'Connor went over to Rome after that, he brought back a letter and a picture of me and the pope hugging. It was signed, "In the peace of Christ."

I have realized why God made me the way I am. He wants me to go out and share the Gospel. It is like God gave me a special gift that no one else has. I am one of God's special children.

My soul feels very peaceful now, lots more than it did before this wonderful experience ever happened to me. My body is calmer. I don't get excited like I did before. I just let things come to me with the love of Christ. I know whatever God wants me to do he will tell me in his own special way. Now I want to tell everybody, "Whatever you want to do in life, do not give up. Pray to God and God will help you because He loves you."
This directory has been adapted from one in Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and their Families, a Bibliography and Address Listing of Resources for Clergy, Laypersons, Families and Service Providers, 1994 Edition. This vast 60-page bibliography was compiled and published by the Religion Division of the American Association on Mental Retardation (AAMR) in cooperation with The University Affiliated Program of New Jersey/UMDNJ, Building Community Supports Project. The complete bibliography may be purchased for $10 from AAMR Religion Division, 31 Alexander Street, Princeton, NJ 08540.

Using this directory For ease of use, resources are listed by denomination and/or faith group. Interfaith/Interdenominational resources are listed at the end. However, please note that many denomination-specific organizations also serve as interdenominational or interfaith resources; those in this category are identified by an asterisk (*) following the group’s name. Therefore, individual readers may find useful resources throughout the list. The numbers following each organization’s listing correspond to services listed in the key and provided by that group.

Updates to come The compilers of the bibliography have not yet identified resources for children and adults with disabilities in some faith groups. Exceptional Parent is updating the directory will be updated.

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<th>RELIGION</th>
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<td>FAITH GROUP RESOURCES</td>
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### Resources

**American Baptist Churches, USA**  
National Ministries Resources*  
PO Box 851  
Valleymere, PA 19482-0561  
(610) 678-2464  
(610) 678-2470 (FAX)  
2,5,6,7,8

**Christian Church (Disciples of Christ)**  
National Benevolent Association  
11780 Borman Dr, Ste 135  
St Louis, MO 63146-4157  
(314) 993-9000  
(314) 993-9018 (FAX)  
3,4,5,6

**Christian Reformed Church**  
Committee on Disability Concerns*  
2850 Kalamazoo Ave SE  
Grand Rapids, MI 49506  
(616) 246-0837  
(616) 246-0834  
1,2,3,4,5,6,7,8

**Church of the Brethren**  
Association of Brethren Caregivers*  
141 1 Dundee Ave  
Fign, IL 60020  
(600) 323-8039  
(708) 742-5100, ext 275 (TTY)  
(708) 742-6103 (FAX)  
2,4,5,7,8

**Church of Christ**  
Christian Church Foundation  
for the Handicapped*  
PO Box 9969  
Knoxville, TN 37940  
(615) 579-0863  
(615) 579-0942 (FAX)  
1,2,3,4,5,6,7,8

**Church of Jesus Christ of Latter-day Saints (Mormons)**  
The Church of Jesus Christ of Latter-day Saints Special Curriculum*  
Church Office Bldg  
50 E North Temple, 24th Fl  
Salt Lake City, UT 84150  
(801) 240-2477 (Voice/TTY)  
(801) 240-1727 (FAX)  
1,2,4,5,7,8

**Church of the Nazarene**  
Children's Ministries*  
6401 The Paseo  
Kansas City, MO 64131  
(816) 333-7000  
(816) 333-4439 (FAX)  
1,2,3,4,5,6,7,8

**The Episcopal Church**  
Diocesan Office on Ministry with Persons with Handicaps  
c/o St James Episcopal Church  
3225 E Minnehaha Pkwy  
Minneapolis, MN 55417  
(612) 729-5322  
2,3,5,8

**Evangelical Covenant Church in America**  
Covenant Resource Center  
3200 W Foster Ave  
Chicago, IL 60664  
(800) 338-4332  
(312) 478-2622 (FAX)  
5,6,8

**Evangelical Lutheran Church**  
Disability Ministries  
Division for Church in Society  
8765 W Higgins Rd  
Chicago, IL 60668  
(800) 638-3522, ext 2692  
(800) 442-3522 (TTY)  
(312) 380-2797 (FAX)  
2,3,5,8

**Jewish**  
Association of Jewish Special Educators  
Special Education Center  
PO Box 3333  
Agoura Hills, CA 91301  
(818) 707-5664  
(818) 707-2391 (FAX)  
1,2,3,5,7,8

**LCHU**  
PO Box 3333  
Agoura Hills, CA 91301  
(818) 707-5664  
(818) 707-2391 (FAX)  
1,2,3,5,7,8

**United Synagogue of Conservative Judaism**  
155 5th Ave  
New York, NY 10010  
(212) 533-7800, ext 2300  
(212) 533-9439 (FAX)  
2,3,6,8

**Mennonite Churches in USA & Canada**  
Mennonite Mutual Aid*  
Advocacy and Educational Resources Department  
1110 N Main Street  
Gothen, IN 46526  
(800) 348-7408  
(219) 533-9439 (FAX)  
2,3,5,7,8

**Moravian Church in America**  
c/o Linda Marsh*  
2718 Winslow Lane  
Winston-Salem, NC 27103  
(910) 768-8923  
2,6

**The Presbyterian Church, USA**  
National Ministries Division, Health, Education, and Welfare Association  
100 Witherspoon St  
Louisville, KY 40202-1396  
(502) 569-5800  
(502) 569-8034 (FAX)  
2,3,5,7,8

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**KEY**

1. Specialized curricula for religious education  
2. Disability awareness materials  
3. Newsletter or other periodical  
4. Consultations to local non-religious organizations  
5. Consultations to local congregations  
6. Referrals to other resources  
7. Serves people from other faiths/denominations  
8. Serves all disability groups  
9. Serves specific disabilities only
CHRISTOPHER BOUSLOG

Christopher is nearly three years old now—he walks, talks and loves to play! He has an infectious laugh and hugs everyone he meets. Christopher also has Down syndrome.

When an amniocentesis revealed that Christopher would be born with Down syndrome, his father left his mother, Teri, to await Christopher's birth alone. Fortunately, Teri was a member of a church with an active Disabilities Ministry. Because this was a difficult pregnancy, Teri was put on bedrest early. The church's Disabilities Ministry secured a place in the church preschool for Christopher's older brother, and took him to and from school every day. Volunteers cleaned Teri's house, prepared meals and did the laundry.

During these first years of Christopher's life, the volunteers and staff of the Disabilities Ministry have provided Teri with free, quality respite care and supported Christopher's successful inclusion in Sunday school. They have also supplied funds for Teri and her boys to attend retreats designed specifically for families that have a member with a disability and helped church members understand the challenges of raising a child with a disability.

Christopher has become the darling of the preschool set, and has won the hearts of the whole congregation. Most importantly, Christopher is an accepted and appreciated member of his large church family, and has taught pastors and peers alike the meanings of perseverance, patience and unconditional love.

—Jane L. Simmons

National Council of Churches of Christ Committee on Disabilities

Recognizing that persons with disabilities bring unique gifts to the life and ministry of the church, the National Council of Churches of Christ (NCCC), Committee on Disabilities seeks wholeness in the church by promoting full inclusion and participation of all persons.

The NCCC Committee on Disabilities is a consortium of representatives appointed by their denominations to serve as a "think tank" in the area of disabilities.

The committee also engages the expertise of consultants who voluntarily assist its work in the areas of inclusive education, bio-medical ethics, seminary/parochial education, family issues, legislative issues and research and evaluation.

The collective work of the committee encourages denominational commitment. It broadens the information base through sharing and evaluating resources, program models, research studies, denominational priorities and policies. The committee enables denominations to participate in joint projects such as leadership conferences, media development and consultations.

For more information contact: National Council of Churches, Ministries In Christian Education, 475 Riverside Dr. Room 504, New York, NY 10011 (212) 870-2897.
RAISA PUHACZ

My eight-year-old daughter, Raisa, has tuberous sclerosis. She has seizures. She cannot walk or communicate. She needs someone to take care of all her personal needs. Despite these obstacles, I've always wanted Raisa to participate in the same activities as her peers.

My husband, Ihor, and I are members of St. Josephat's Ukrainian Catholic Church in Bethlehem, Pennsylvania. Three years ago, an announcement in the church bulletin encouraged all parish families to enroll their children in religious education classes.

I wanted Raisa to be a part of those classes. I wanted her to make her First Communion—just like her cousins. But I wasn't sure what our pastor, Father Daniel Gurovich, would think.

I called him to ask if Raisa could be included.

"I just assumed you'd enroll Raisa," he said quite simply. "And if you didn't, I was going to call and insist she attend."

Then I began to worry about the children in Raisa's class. Would they like her? Had they ever been around a child with a disability? I prepared a speech to introduce Raisa to the other children. As the first day of class approached, I became more and more nervous. As executive director of The Arc of Lehigh and Northampton Counties, I give speeches all the time. But this one was making me more nervous than I'd ever been.

When I began speaking, a youngster raised his hand and said, "I know all about disabled kids; I go to school with them." I didn't need to say another word—Raisa was a part of the class.

When I picked Raisa up after that first class, her teacher said, "Remember that boy who said he knows all about kids with disabilities? At closing prayer, Andy said, 'Thank you, God, for giving Raisa such a nice smile.'"

When I reached the car, tears filled my eyes. I cried all the way home.

Last May, Raisa made her First Communion with her classmates. She was treated like a typical kid—all we'd ever wanted.

—Stephanie Hnatiw

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Let me tell you about our son Peter. He is 34 years old and just over six feet tall. He has dark hair and thoughtful eyes. My husband, Dick, and I agree that Peter is the most handsome of our four grown sons. He is an avid baseball fan and roots for both the Pirates and the Phillies. He lives with a roommate in an apartment in Harrisburg, Pennsylvania, and attends church regularly.

Maybe what I appreciate most about Peter is his quiet, uncluttered faith. Three years ago on Christmas Eve when my mother, Dick, Peter and I were seated around the dinner table, I decided it would be a good idea if we each took a turn and talked about what Christmas meant to us.

"Peter, what is important about Christmas?" I asked. There was a long silence. Finally Peter spoke. "Jesus," he said. That was all.

What's so surprising about any of this? Nothing, really, except that Peter has severe mental retardation.

When Peter was four months old, he was in a car accident. His mother—Dick's first wife—was killed. His two older brothers, John and David, sustained minor injuries, but Peter suffered extensive brain damage.

When I married Dick in 1963, Peter was almost four years old, still wearing diapers. He did not speak or walk. Beneath his scalp, a large section of his skull had been removed to prevent additional pressure on the brain. He was on medication for seizures and was susceptible to infections. He required constant care, but I was a young, energetic former schoolteacher, full of optimism.

We lived in Pittsburgh at the time, and we enrolled him in a private preschool for children with special needs, where the teachers gave us useful techniques for working with him. When he woke in the morning and after naps, Peter was a great babbler. So we put a tape recorder beside his crib. Then, the school's speech pathologist used these sounds as building blocks to develop Peter's speech.

One morning when it was still dark, Dick woke me up. "Listen!" he said. Peter was calling his first word, "M-ah-ah-m." Mom.

**What about Peter?**

Peter was six and a half when our fourth son, Bill, was born. Until then, we had always had a babysitter at home for Peter when we went to church. Now with Bill home too, members of the congregation began to ask, "When are we going to see that beautiful new baby of yours in the nursery?" What about Peter? I thought. Why don't they ask about Peter?

I was hurt and angry. Peter had a right to come to church too. "We need to welcome everyone, including children with mental retardation," I told the congregation.

We created space in the church for a classroom. We found a woman with a special education background, who volunteered to teach. We put a notice in the church bulletin and placed an ad in the local paper. Finally the first Sunday came up. Only one child showed up—Peter.

I cried and cried. I felt humiliated. What was all our hard work for? Did other parents of children with mental retardation feel so alone? Were they so accustomed to being excluded that they couldn't even imagine a welcoming church?

With Dick's encouragement, I recruited children from Peter's preschool for our church school. We also became involved with our county chapter of the Association for Retarded Citizens. At one meeting, I was surprised when an older mother said ominously, "Be prepared. The day will come when you'll have to fight for your son."

**Pot holders**

That day came when, at age eight, Peter was ready to enter the public school system. I made an appointment to visit our district elementary school and learn about their program for children with disabilities. On a dark rainy
Each child was unique in God’s sight. They couldn’t be ignored. I wouldn’t let it happen.

Becoming an advocate

Joining forces with other volunteers, I set out to see what conditions were like in our state’s institutions. To our dismay, the conditions we found were wretched.

At one of the state’s oldest institutions, we discovered residents deemed unmanageable being kept in cages. One adolescent boy was cramped in a metal box so small he couldn’t stretch his legs. The investigation that followed our visit in 1973 resulted in the firing of the institution’s superintendent, the banning of cages and state funding for upgrading facilities and retraining staff.

At another facility, residents were dying from accidents and injuries at an alarming rate. The day before our visit, a young man who required a diet of pureed food had choked to death on a chunk of meat. We headed straight for the school’s kitchen and seized a sample tray, including a portion of gristly meat, which we later presented to members of the state legislature at an emergency meeting.

Some called us troublemakers, but gradually Pennsylvania established itself as a leader in institutional reform and placement of people with mental retardation.

One day I was called as a witness for a hearing about a state-licensed facility I had visited. As the interrogating senator kept interrupting me, demanding yes or no answers, I became flustered. I felt my cheeks become hot and tears fill my eyes. The worst moment came when the senator in charge leaned into the microphone and said patronizingly, “There, there, Mrs. Thornburgh. We don’t want to upset you. You may be excused.”

Outside I vowed, This work is too important. I will never cry in public again. And with God’s help, I haven’t.

In 1979, Dick was elected to the first of two terms as governor of Pennsylvania. That’s when I began to grasp that the advocacy work I’d done was little more than a drop in the bucket. Every day I responded to letters requesting help, not only for people with mental retardation but with other disabilities as well.

When Dick’s appointment as attorney general took us to Washington, I continued my advocacy work as director of the Religion and Disability program of the National Organization on Disability. Although people with disabilities face architectural and communication barriers, I soon learned that the most insurmountable barrier is prejudice.

“You have to remember, Ginny,” Dick would remind me at the end of a long day, “not everyone has a Peter Thornburgh in her life.”

Peter changed my life

The culmination of my work, and the tireless advocacy of countless others, came on July 26, 1990. On that brilliant summer day, in an outdoor ceremony on the South Lawn of the White House, President George Bush signed the Americans with Disabilities Act into law.

Standing in the warm sun, holding Dick’s hand, I thought of Peter. While still severely limited, he had become much more independent—riding city buses, going to church, sharing pizza and laughter with friends in his supervised apartment. He had come so far. But then I was struck with the most amazing thought—So have I.

Because of Peter, I learned how to fight for what I believe. I learned how to speak out and stand up to injustice. While trying to nurture his gifts, I discovered my own gifts for communication and organization. Peter changed my life. And for that I’ll be forever grateful.

Ginny Thornburgh is the director of the Religion and Disability Program at the National Organization on Disability (NOD) in Washington, DC. A graduate of Harvard University’s Graduate School of Education and Wheaton College in Norton, MA, Ginny is the editor of LOVING JUSTICE: THE ADA AND THE RELIGIOUS COMMUNITY and That ALL MAY WORSHIP. She has received many awards and nine honorary degrees for her years of community service.

Thornburgh’s husband, Dick is counsel to the Pittsburgh-based law firm of Kirkpatrick & Lockhart in its Washington, DC office. With a public career spanning 25 years, he has served as governor of Pennsylvania, attorney general of the United States and undersecretary-general of the United Nations. The Thornburges have four sons and five grandchildren.

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A Comprehensive Look at Disability Laws and the Religious Community

Loving Justice: The ADA and the Religious Community, edited by Ginny Thornburgh, is a companion volume to That All May Worship (see sidebar below). Both $10 books are available through Exceptional Parent Library, (800) 535-1910.

Reviewed by Robert C. Anderson:

The much-anticipated companion volume to That All May Worship is now available—and worth the wait! Loving Justice: The ADA and the Religious Community builds upon the foundation of its predecessor with particular emphasis on the ADA (Americans with Disabilities Act of 1990) and other relevant disability laws as they relate to the religious community.

This work is a collaborative product of disability leaders and lawyers from Christian and Jewish traditions. The groups are concerned with increasing the religious participation of persons with disabilities. In addition, the core information will be published under the same name, Loving Justice, through denominational offices of the Roman Catholic, United Methodist, Evangelical Lutheran and Episcopal faiths.

Key concepts, ideas and implications

Because our government honors the separation of church and state, places of worship and other religious institutions have historically received exemption from governmental control while remaining subject to the bounds of the law itself. This delicate tension preserves our religious liberties while protecting the rights of the individual from the freedoms of other citizens. This relationship is not breached by the ADA, although its provisions must be noted by religiously-related entities.

For example, religious institutions may be subject to the employment provisions of ADA if they operate residential housing, daycare, health care or formal educational programs which provide services to the community. There are also a number of other instances where ADA provisions apply. Congregations and religiously-affiliated groups which provide facilities for school groups, blood drives or health clinics may have compliance factors to consider. Religious groups which operate senior citizen meal programs or homeless shelters may also have compliance concerns if they operate under the scope of a municipal program or receive federal, state or local subsidies.

Similarly, religiously-affiliated colleges or
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Dana Davidson Blair, RN, MA
Writer and Lifestyle Adjustment Consultant, Options Consultants

"It is about time that a resource such as this is available. The journal has articles which WILL LEAD ONE TO GREATER UNDERSTANDING AND CARE: WITH, OF, AND FOR PERSONS WITH DISABILITIES... The journal will not have a place on my shelves but will be on my desk and reading table."

-Rev. David O. Kyllo, DMin, Director of Chaplaincy, Rehabilitation Institute of Chicago

The journal keeps religious professionals up to date about developments in the field of disability and rehabilitation in order to help them enhance the lives of those with disabilities and those who care for them.

Call for Papers: Potential authors are encouraged to request an "Instructions for Authors" brochure from either William Blair or Dana Davidson Blair, Journal of Religion in Disability & Rehabilitation, 6473 Pine Tree Lane, Pinson, Alabama 35216; Tel: (205) 681-1457.

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other educational entities are generally exempt unless students receive federal grants or guaranteed loans. In other instances, the responsibility for providing accessible accommodations and services rests with the state or political jurisdiction. For example, congregations which occasionally serve as polling sites for elections are not specifically responsible for compliance regulations; rather, the state or local government must ensure that the polling sites they select are accessible.

One issue frequently raised by congregations is that they don't have any persons with disabilities who come to their facility. That may be true simply because they cannot get inside, or do not feel welcomed when they enter. As with the general public, 17 percent of congregational members have one or more significant disabilities.

Congregations which voluntarily comply with ADA requirements are simply doing the right thing.

Theological and Moral Imperatives

The heart of the matter is not whether a religious institution can be exempted from legal compliance; the constitution, by and large, resolves this issue. For congregations to embody the mission of hope and love which they so fervently treasure, the real challenge is to be proactive, becoming as inclusive as possible. "Reasonable accommodation" is a spirit of fairness and equity already built into the ADA. As stated in the introduction to Loving Justice, "If supermarkets and bars are more accessible than altars, then we must all bear the shame."

Religious institutions do not seek to exclude or make persons with disabilities feel unwelcome, although this message is conveyed in very subtle terms—more frequently than congregations would like to admit. The religious community prides itself as the sacred bastion of God's love, where all are accepted as equals in personhood and access to the Divine. And yet many persons have no access to religious facilities. How can they honestly conclude that these places of worship (and hence God) really care about them? This double standard may be covertly at work within the faith community.

The message of this guidebook is clear: justice and love will triumph only when segregating walls are knocked down and when the barriers of architecture, communication, and attitudes are removed. Only then will people with disabilities become full participants in the celebrations and obligations of their faith.

This seminal work is a must-have for those committed to becoming more creative, caring communities of faith.

Robert C. Anderson, M.Div., is the director of Pastoral Care Services at Lakeshore Rehabilitation Hospital, ReLife Rehabilitation Systems, in Birmingham, Alabama.

This review of Loving Justice will appear in the Journal of Religion and Disability and Rehabilitation, Vol. 2, Issue 1 (Haworth Press), edited by Dr. William A. and Dana D. Blair. For information about the journal contact the Blairs, 6473 Pine Tree Lane, Pinson, AL 35126, (205) 681-1457.
Buying and Converting
What you need to know about van lifts and ramps

Janet Vohs never thought about learning to drive while she was raising her daughter, Jessica. Because Jessica uses a wheelchair, Vohs knew any automobile she owned would have to be a customized van with a lift to transfer Jessica and her wheelchair in and out of the van.

"Being a single parent, I couldn't afford it," Vohs says. As for a less expensive car, Vohs says she has never had the physical strength to lift her daughter in and out of a car.

When traveling from their Boston-area home, Vohs and her daughter would take buses, taxi cabs and accessible vehicles provided by the Massachusetts Bay Transit Authority.

However, it has not always been that simple. For example, this summer the two couldn't get a ride to the Massachusetts State House—10 minutes away by car—where Jessica was to testify at a hearing on community living for people with disabilities. Instead, the two had to make a 90-minute trip by foot and wheelchair.

Limited travel options can leave people like Jessica isolated. Between the ages of 14 and 21, Jessica attended a residential school program. But when she came home, it was hard for her to visit her best friend who lived an hour away by car.

Now, Jessica is 23 and living on her own with a live-in aide. Jessica and her aide are adventurous types, Vohs said. They want to be able to get in a car and just go—they've talked about going on a cross-country trip.

Vohs wants to buy them a van because the aide's car is not in great shape and is too small for Jessica's power wheelchair.

"We're going to have to get something secondhand," Vohs says. "I still don't know how we're going to pay for it. And we want a van so we can get the wheelchair in it."

Vohs is just one of an increasing number of people inquiring about accessible vans and equipment, says Rebecca Plank, executive director of the National Mobility Equipment Dealers Association (NMEDA), a 195-member trade group of accessible automobile and equipment dealers.

"A lot of people are finding out the equipment is out there and is available to them and they want to have their independence too," Plank says.

Finding a dealer

- About 400 equipment dealers nationwide sell and install products from any of the more than 20 equipment manufacturers. To find a local dealer, check the yellow pages under "Van Conversion & Accessories."
- Find a reputable dealer. Ask to see documented proof that the dealer has been trained by the manufacturer to install its equipment. State rehabilitation offices, the Veteran's Administration and NMEDA (800/833-0427, voice) may help you find a dealer.
- Once you are happy with a particular dealer, continue to do business there. With an ongoing relationship, it will be easier and more comfortable for you to define your needs and goals in the future.

What kind of van and equipment?

- Many mini- and full-size vans allow wheelchair users to sit in the driver and front passenger areas.
- Full-size vans may fit more than one wheelchair user.
The choice is easy...

A Columbia Toilet Support gives your child independence, privacy and secure support.

- If converting a van, the adaptive equipment, and in some cases, the medical equipment you need, should fit comfortably and securely in the vehicle. Also, make sure the van’s roof is high enough for the wheelchair’s sitting height, which is the distance between the ground and the wheelchair user’s head while seated in the wheelchair. The wheelchair user should also be able to look out the window.
- Certain vans and/or equipment may not work as well as others under different weather conditions. Some may have problems in extremely cold or hot temperatures. Manageability in severe weather conditions is another factor to consider.

Ramps and lifts

- Decide whether you want a lift or a ramp. If you do not have the strength to constantly lift your child, a fully- or semi-automatic lift may be the way to go. Fully-automatic lifts usually allow the transfer of a wheelchair user without the help of someone else because they lift and lower electronically. Semi-automatic lifts require you to do part of the job, such as unfolding and refolding a part of the lift. Many lifts come with manual back-up systems in case there are problems that prevent electronic operation.
- A ramp can be used on all vans. Some ramps can be bolted to the floor inside the side or rear door. When not in use, the ramp folds up and is stored just inside the door. Portable ramps—ones which are not permanently attached to the van—can be repositioned to meet different needs. However, portable ramps usually are not as strong and stable as bolted ones.

Price

- Health insurance companies generally do not cover the purchase of accessible vans and/or equipment, usually claiming they are "luxury" items. Medicare and Medicaid also do not cover the costs.
- Many van manufacturers offer rebates ranging from about $750 to $1,500 when converting one of their vans.
- Many equipment installers may not cut the frame of a van to accommodate specific equipment because this could void a manufacturer's warranty.

The wheelchair user should also be able to look out the window.

It is hard to say how much it will cost to buy an accessible van or convert one. "Everybody's disability is as different as their fingerprint," Plank says. "Their transportation needs are that different, too."

—Marc S. Malkin

Thanks to the following experts and companies for their contributions to this article: ABLEDATA; Rebecca Plank, executive director of the National Mobility Equipment Dealers Association; Andrew Goodyear, owner of the Wheelchair Getaways franchise in southern Florida; Jeff Hermanson, first vice president of The Brown Corporation; KneelKar Medinet, Inc.; Crow River Industries; Independent Mobility Systems, Inc.; Ricon Corporation; Bruno Independent Living Aids; the Ford Mobility Motorizing Program; the Physically Challenged Assistance Program of the Chrysler Corporation; the General Motors Mobility Program; Care Concepts; Vantage Vans and Wheel's Van Rentals.
CHAMELEON
This three-in-one stander for infants allows parents and therapists to create numerous positions, and changes from a stander to a stroller or highchair. All positions keep the child cradled against cushioned supports. Other features include a removable tray and a folding lightweight frame. The unit's colorful upholstery is removable and washable. All materials are non-toxic.
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Produced as a tribute to Mackenzie Sara Noca, a girl with Down syndrome who died at three months of age, this video is an emotional and educational journey about parenting a child with Down syndrome. Factual information and advice is provided by William Cohen, M.D., director of the Down Syndrome Center in Pittsburgh.
Mackenzie Sara Noca Charitable Trust, Pittsburgh, PA 15239
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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 59) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TTY, (301) 588-3984, V/TTY or (301) 587-1967, FAX.
In front of an audience, Michael Phillips is pretty quick on his feet.
Information Needs of Siblings

by Donald J. Meyer

This article is an excerpt from Sibshops: Workshops for Siblings of Children with Special Needs (Paul H. Brookes, 1994). This is the final of four excerpts EXCEPTIONAL PARENT will publish. Sibshops is available through EXCEPTIONAL PARENT Library, (800) 535-1910.

Throughout their lives, brothers and sisters will have a need for information about their siblings' special needs... Siblings need information for reassurance, to answer their own questions and questions posed by others and to plan for their future. And, unless their brother or sister has a terminal condition, informational needs will be lifelong.

Throughout their lives, the types of information siblings need—as well as how it is optimally presented—will vary with the siblings' age...

Preschoolers

Preschoolers need to know that they cannot catch their siblings' disability, nor did they cause the condition. These concepts—while obvious to adults—may not be clear to a young child who has caught her sister's cold and has a preschooler's sense of causality.

Explanations of disabilities or illnesses to children at this age should be as clear as possible... One way to explain a disability is to describe it in terms of differences in behavior or routine. A four-year-old who accompanies his two-year-old sister to an early intervention program may understand his sister's disability this way: "Down syndrome means you have to go to school to learn how to talk..." While clearly incomplete, a definition like this can be the foundation for more involved explanations at later ages.

School-aged children

During their grade-school years, siblings need information to answer their own questions about the disability or illness as well as questions posed by classmates, friends or even strangers...

More so than preschoolers, school-age children may have more specific questions. They may ask: "Why can some people with cerebral palsy walk and some can't?" "What does amniocentesis mean?" "What's physical therapy? Does it hurt?"...

Teenagers

Because they can envision a life beyond their parents, teenagers and young adults require additional information about their siblings' future and what role they will play in that future. If parents have not made plans by this time, it is critical that they begin and encourage brothers and sisters to be a part of this planning...

Avoiding misconceptions

Some parents, seeking to protect their children from the sadness they are experiencing, choose to tell their children as little as possible. But when left in the dark about what is happening to a brother or sister, siblings may make up their own stories that are worse than the truth. They may even blame themselves for their siblings' conditions. Obtaining information, then, can be reassuring, even comforting...

With rare exceptions, most books and materials about disabilities and illnesses have been created for adults... Siblings are also frequently excluded from another traditional source of information—teachers, physicians, therapists, nurses and other service providers... Relegated to waiting rooms, siblings report feeling ignored or isolated...

Some siblings are reluctant to ask questions, having witnessed their parents' sadness about the disability or illness. When a child does not ask questions, parents may assume he or she has no interest in the topic. Sisters and brothers tell us that parents must be proactive in offering information...

If children's questions about siblings' special needs are answered in a forthright manner, and if they are made to feel glad that they asked, they will not only gain a growing understanding of their siblings' special needs but will also become confident that they may approach their parents whenever they have questions...

Into the loop

Inviting—but not requiring—siblings to attend meetings with service providers can benefit all parties. When included, siblings can obtain helpful, reassuring information about a sibling's condition, and can contribute by providing information, and unique, informed (and frequently unsentimental) perspectives on issues such as barriers to inclusion with neighborhood age peers, or a sibling's ability to accomplish household and self-care responsibilities...

When invited to meet with service providers, siblings are brought "into the loop." A message is sent to family members and service providers alike that brothers and sisters are valued members of the child's "team." Including them acknowledges the important roles they play in their siblings' lives and, for many, roles they will have as adults...

Donald J. Meyer is the director of the Sibling Support Project at Children's Hospital and Medical Center in Seattle, Washington.
Transition to Oral Feedings; Felbamate

Q My four-year-old son has a syndrome called Cornelia de Lange. As a result of this condition, he was born with low birth weight and anomalies (defects occurring during fetal development) of his arms and hands. He has a small jaw. He is also moderately mentally retarded. He has had significant feeding difficulties from the beginning. In spite of considerable effort by my husband and myself, we had to place a gastrostomy "button" at about six months of age. However, over the last three years we have continued efforts to feed him orally. Now, he is able to take some of his feedings orally but he shows significant defensiveness and aversion when oral feedings are attempted; he tries to avoid the food by turning his head and refusing to open his mouth. I am afraid he might aspirate (breath in) some of his food because he is fighting instead of swallowing. Do you have any suggestions on how we should proceed? What else should we watch for?

A First of all, congratulations on getting as far as you have. It certainly can be very difficult going from enteral (tube feeding) to oral feedings especially after a few years. About 75 percent of children with Cornelia de Lange syndrome, sometimes called Brachmann-de Lange, have significant problems with feeding. They typically have marked retardation of growth which makes adequate nutrition even more important. However, your child's weight should not be a concern unless it is unduly low for his height.

You have taken the right steps in attempting to feed him orally at his own pace. Speech and occupational therapists and a dietitian can help you develop a feeding program specifically for your son.

With regard to aspiration, this is more often a problem in infants with Cornelia de Lange than in older children with the syndrome, although precautions need to be taken anytime there is a potential risk. Children with this syndrome also have a higher incidence of other gastrointestinal problems such as esophageal dysmotility (the esophagus does not propel food to the stomach properly), gastroesophageal reflux (the stomach contents come back up the esophagus), hiatal hernia (a small portion of the stomach protrudes through the diaphragm) and esophagitis (irritation of the lining of the esophagus). Before continuing with more aggressive oral feedings, your pediatrician may want to evaluate your son for these or other potential feeding problems by ordering radiographic (x-ray) studies or by consulting with a pediatric gastroenterologist. Appropriate medical intervention for these problems can make the transition from enteral to oral feeding easier on your child and yourself.

Feeding aversion or oral defensive-ness are potentially significant problems. A child who has not eaten orally for a long time and has "forgotten" how to eat or who has experienced unpleasant reactions to oral feedings, such as choking or reflux (severe heartburn caused by abnormal backflow of stomach contents), may develop an avoidance reaction or aversion to oral feedings.

Many people believe that children who are tube-fed never have a sense of "hunger." In my experience, this is not true. Their stomachs still empty and they feel "hungry" (unless they are fed continuously or with "drip" feedings). However, the satisfaction of tasting food will not be there with tube-feeding so you will want to encourage this feeling by offering foods that typically taste good and that have a texture your son can handle.

You might want to make sure that everyone feeding your son is aware of his transition to oral feedings and is patient with him, but still able to feed him within a reasonable period of time—usually 30 to 45 minutes and never less than 20 minutes.

Experienced speech pathologists, occupational therapists and dietitians can be very helpful with your son's transition to oral feeding. Again, go at your child's own pace to avoid exacerbating these problems.

More information about your son's condition may be obtained by contacting the Cornelia de Lange Syndrome Foundation, 60 Dyer Ave., Collinsville, CT 06022-1273, (800) 223-8355.

Ask the Doctor is a regular department of EXCEPTIONAL PARENT in which questions are answered by David Hirsch, M.D., a pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch mentions specific products or medications, he is illustrating his suggestions; he is not endorsing any specific products.

To submit a question, write or fax: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8748.
Q: My eight-year-old daughter has a form of epilepsy called Lennox-Gastaut. It is a complicated type of epilepsy for which we have tried many types of anticonvulsants (medications to control epilepsy) without very good results. About 10 months ago, my daughter's neurologist put her on a new medication called Felbamate. Her seizures have significantly decreased and, more importantly, her quality of life has improved. Recently, however, her neurologist advised me that some potentially serious side effects of the drug have been reported. He recommended that she be weaned off the medication. Is there anything else that can be done?

A: This is really an unfortunate situation. Felbamate, sold under the brand name Felbatol, seemed to be a medication that was effective in reducing seizures, especially in children with Lennox-Gastaut and other types of complex or difficult-to-control seizure disorders. In spite of extensive evaluations and clinical trials which showed Felbamate to be safe and effective, and approval by the Federal Drug Administration (FDA), an unexpected but marked increase in the occurrence of aplastic anemia (a very severe blood disorder) and/or liver failure has been associated with the use of the medication. The FDA has decided to continue to make Felbamate available because of its effectiveness for certain conditions, especially Lennox-Gastaut.

Listen to the advice of your daughter's neurologist. Never stop a medication without consulting the physician who has prescribed it. He or she, in conjunction with your own observations and feelings about what is best for your daughter, will help you make the best decision.
Children & Teens

Scott Richards: Age 9, male. Has brother with Coffin-Lowrey syndrome; likes rock-collecting and karate. Wants to hear from anyone.
RR #1, Box 1889E, Whitefield, ME 04353

Marsha Lynn Yarmus: Age 18, female. Has cerebral palsy; enjoys board games and loves hockey, especially the New York Rangers. Wants to hear from males aged 19-23 with cerebral palsy in the New Jersey area.
124 Somers Ave., Bergenfield, NJ 07621

Ivan Perge: Age 18, male. Has cerebral palsy. Participates in the New York State Games for the Physically Challenged, competing in track and field, swimming and wheelchair basketball. Likes music, plays bass in a band. Wants to hear from young adults (ages 17-20) with or without disabilities.
24 Townsend Pl., Sposset, NY 11791

Noa Elimelech: Age 7, female. Has a four-year-old brother with developmental delays. She is in the second grade. Wants a pen pal who understands her situation.
18356-B Collins St., Tarzana, CA 91356-2406

Betsy Edwards: Has 16-year-old son with mental retardation and autistic tendencies and an adult brother with mental retardation and mild cerebral palsy. Collects postcards. Wants to hear from anyone, especially divorced parents of children with special needs.
107 Cloverbloom, Victoria, TX 77904

Catherine Haynes: Has a five-year-old son with cerebral palsy and severe mental retardation who walks with help, rolls over and sits up. He is non-verbal. Wants to hear from parents around her age (22) who have a child like hers.
516 Rasco Road West, #1, Southaven, MS 38671

Justin and Laurie Laurenzi: Parents of 20-month-old boy, who has congenital myopathy and hypotonia. He is fed through a g-tube, has a trach and is on a ventilator while sleeping. He is very bright and can sit up, but cannot walk or crawl. Want to correspond with families with similar children. Hope to start a local support group.
238 A Fairmount Ave., Blackwood, NJ 08012

Darlene French: Mother of two teenagers: one who is microcephalic with severe mental retardation, the other with learning disabilities and diabetes. Enjoys sewing, reading, crafts and animals. Wants to hear from "those who enjoy the challenge of life's experiences."
HC 63 Box 17, Dornsife, PA 17823

Pen Pals

Send Pen Pal requests to: Pen Pals, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. All requests should include a daytime phone number (to reach you, not for publication), three sentences introducing yourself and the type of pen pal you want. Children's requests must also include their age and sex and a parent's signature indicating permission to publish the child's request.

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Medicaid and HMOs

Q Because of his disability, my son has been covered by Medicaid since shortly after birth. He has seizures, microcephaly, cortical blindness, low muscle tone, brain damage and a possible metabolic disorder.

We have always had him on our private insurance in addition to the Medicaid coverage. Until recently, we have had a traditional 80/20 insurance plan with a deductible. While we were on this plan, all claims were first sent to our private insurance company. Any remaining balance was paid by Medicaid. We had no expense for Medicaid-authorized procedures or services. Our only cost was the private insurance premium.

Due to the cost of that premium, we recently switched to an HMO that covers 100 percent of most expenses once the co-pay is met. Like before, we still pay our son's HMO premium. But now, in addition, we have started receiving bills for past-due co-payments for my son's medical treatments. The "co-pays" add up rather quickly because of my son's frequent hospitalizations and doctor visits.

We carry our son on our private health insurance policy because we feel it is our financial responsibility to pay the insurance premium we would pay if he did not have a disability. It seems that Medicaid should prefer that we pay the private insurance premium for our son, leaving them responsible only for the co-pay amounts. In fact, they should be happy we are now part of an HMO that pays a higher percentage of his medical bills. Instead, Medicaid seems to be penalizing us. Apparently, they don't look at it from a financial standpoint. In my conversations with Medicaid personnel, they seem to be encouraging us to drop our son from our private insurance policy.

Should we take this drastic step? If so, he would be left with only Medicaid, and they would be responsible for all of his medical bills. Would dropping him from our private insurance policy cause us problems with Medicaid? I don't want to make a mistake and end up being responsible for all of my son's medical bills if Medicaid decides not to pay.

A.L., Nebraska

In theory, when a child is covered both by Medicaid and private insurance, Medicaid will act as secondary insurer. This means Medicaid considers paying any co-pay amounts remaining after the primary insurer has paid its portion of the bill.

However, although Medicaid is a federal program, many of its very specific rules are set at the state level. Medicaid programs in many states work successfully with both traditional insurance and managed-care programs, including HMOs. In those states, switching from a traditional insur-
An insurance program to a managed care program as primary insurer would probably not lead to any difficulties.

But in some states—including Nebraska—the situation is somewhat different. According to a Nebraska Medicaid representative, when a traditional insurance program is a primary insurer for a Medicaid recipient, that insurer usually itemizes the claim, listing the amount it has paid and the amount remaining as co-payment. Nebraska Medicaid rules allow payment of any remaining amount, up to the maximum allowed.

Some managed-care programs, however, require consumers to pay the co-payment amount prior to the provision of services. In this situation, the Nebraska Medicaid program does not cover co-payments. This is because, technically speaking, a co-payment made prior to services rendered does not represent an amount remaining after the primary insurer's payment. It seems like a minor difference, but it's significant in terms of the Medicaid rules in Nebraska.

Possible changes

More than 1,000 Medicaid recipients in Nebraska are affected by this situation. That number is likely to grow as managed care becomes more widespread.

Medicaid officials in Nebraska are aware of the problem and are considering a series of rule changes, including a request for a federal Medicaid waiver that would allow for the payment of co-pay amounts even when the primary insurer requires co-payments to be made prior to services. Still, it's likely to be quite a while before any changes go into effect.

Explore your options

Review options with your attorney, a state Medicaid caseworker or an attorney at the local legal services office so you can make a reasonable decision.

Since Nebraska's Medicaid rules may change, however, the decision you make at this point may provide only a temporary solution. Follow the situation closely, and be prepared to make appropriate changes in the future.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. Fax questions to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To ensure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.
Are They Ready to Teach Our Kids?

A national survey shows a widespread lack of confidence in the readiness of regular classroom teachers to educate children with learning disabilities.

Parents of children with learning disabilities are convinced that regular classroom teachers aren’t adequately trained to teach their children—and almost half the teachers agree, according to a recent survey conducted for the National Center for Learning Disabilities (NCLD).

This situation poses a serious threat to the education of the 10 percent of American children with learning disabilities, warns the NCLD, a leading organization for people with learning disabilities.

The survey of classroom teachers, special educators and parents of children with learning disabilities suggests a critical need for changes in teacher preparation practices. Conducted among parents and teachers who were members of NCLD and the Learning Disabilities Association of America (LDA), more than 1,500 of the original sampling of 5,000 responded.

The findings

Only 53 percent of regular classroom teachers surveyed feel adequately trained to teach youngsters with learning disabilities compared to 89 percent of special educators.

However, 98 percent of parents of children with learning disabilities are convinced that general educators are not trained to teach children with learning disabilities. Both regular and special educators overwhelmingly expressed a desire to reverse this negative trend, with 80 percent wishing to learn more about special techniques for teaching children with learning disabilities.

Of the 540 teachers who answered the question asking if “inclusion is a very supportable approach to education for all children,” 54 percent agreed; 76 percent felt general education teachers are “receptive to the logistical and teaching demands of inclusive classrooms.”

Among the educators and parents who did not feel general education teachers are adequately prepared to teach children with learning disabilities in regular classrooms, most agreed that the two top priorities for educating children with learning disabilities should be to “develop and institute a concrete plan for teacher preparation prior to the implementation of an inclusion program and to give teachers the tools to cope with children’s diverse needs.”

A significant gap exists between promising research discoveries and their implementation in the classroom. Only 50 percent of all teachers, including special educators, were aware of any research on reading disabilities that could positively influence their teaching practices.

“This alarming disparity strongly indicates that teacher training is behind the times,” said Dr. Tom Hehir, director of Special Education Programs at the U.S. Department of Education. “This is unfortunate, since approximately 75 percent of all learning disabled children identified have difficulties learning to read.”

Children with learning disabilities comprise 51 percent of children with disabilities in the American public school system. “Clearly, the improved ability of our teachers to teach reading would have significant effects on literacy levels overall,” said Dr. Reid Lyon of the National Institute of Child Health and Human Development.

These findings were obtained for the National Center for Learning Disabilities (NCLD) by NFO Research, Inc. of Greenwich, Conn. Established in 1977, NCLD is an advocacy group for people with learning disabilities. NCLD provides national and information referrals; educational programs; public awareness and understanding campaigns and legislative advocacy.

This survey was released during Learning Disabilities: A National Responsibility, a two day summit sponsored by NCLD in Washington, DC Sept. 20–21.

For more information on the survey and NCLD, contact NCLD, 381 Park Ave. South, Suite 1420, New York, NY 10016, (212) 545-7510.
DIAFOODS THICK-IT brings the joy of eating back to people with swallowing problems.

Here's the solution for the millions of young and old who need modified consistencies to enjoy eating.

DIAFOODS THICK-IT, when mixed with hot or cold, thick or thin liquids and pureed foods, produces any desired consistency quickly, easily and controllably. But it does not change the taste or appearance of the food it thickens.

DIAFOODS THICK-IT adds sixteen calories per tablespoon for nourishment but is very low in sodium for people on sodium-restricted diets. And it helps hydrate patients because it will not bind water or fluids.

DIAFOODS THICK-IT is the market-maker and the educational material is available for free. The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia. The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call (800) 333-0003.

3 selling brand of Instant Food Thickener. It is recommended by speech and language pathologists, dietitians and nutritionists in hospitals, nursing homes and rehabilitation facilities across the country.

For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call (800) 333-0003.
Just For Kids

• HiP is a new non-profit magazine for 8- to 14-year-olds who are deaf or hard of hearing. Publishers Ellen Dolich and Robin Gladstone, parents of children with profound hearing impairments, plan to publish HiP six times a year.

Features include profiles on outstanding people who are deaf and hard of hearing, movie and video reviews written from a deaf perspective, an advice column written by a deaf child and a comic strip starring a superhero who is deaf.

A free sample copy is available upon request; annual subscriptions are $14.95. HiP, 1563 Solano Ave., #137, Berkeley, CA 94707, (510) 523-4221.

• Membership in the Halo Club is free to all brothers and sisters of children with Angelman syndrome (AS). Members receive a newsletter full of cartoons, stories and pictures sent in by each other. Club friends and their parents are planning a 1995 gathering at the Angelman Syndrome Foundation conference in Colorado Springs.

To join the Halo Club, contact Ashleigh Evans, 13280 Caminito Mar Villa, Del Mar, CA 92014, (619) 481-8781.

• Children with visual impairments can now receive the monthly newsletter Young Environmentalist's Action (YEA) in Braille. Published monthly by Global Response, an international environmental education group, YEA teaches young people about environmental issues and how to protect the earth. Topics include rainforest destruction, endangered species protection, marine mammals and air and water pollution. YEA (also available in English and Spanish) is free, but donations are accepted. Contact Global Response, P.O. Box 7490, Boulder, CO 80306-7490, (303) 444-0306.

When Young Children are Injured

When Young Children are Injured: Families as Caregivers in Hospitals and at Home is a new guide for families with infants, toddlers or preschoolers who have sustained serious injuries, including traumatic brain injuries, spinal cord injuries, near drownings, major burns or other injuries that have caused a disability. The guide is intended to let parents know that they are not alone and to give families practical information for decision-making. Topics addressed in the guide include siblings; helping your child with pain and discomfort; finding support for family members; leaving the hospital and letting go once the child is home. $7.50; bulk rates available. Available from Exceptional Parent Library, (800) 535-1910.

Publications

• FAS: Parent and Child is a handbook about parenting children with fetal alcohol syndrome. The 32-page book covers sleeping, eating, developmental milestones, speech and learning problems, illnesses, sensory disorders, activity levels, behavioral concerns, friendships, family relationships, adolescent issues and parental needs. Also available in Spanish, the book is recommended for parents and professionals. $7.95; bulk rates available. Available from Exceptional Parent Library, (800) 535-1910.
The thrill of victory came three times for 17-year-old Jon Rydberg during the 1994 U.S. Open Wheelchair Tennis Championships held Oct. 8-16 at the Racquet Club in Irvine, Calif. During the first weekend, Rydberg, of Pine City, Minn. captured the Junior Open Singles title and teamed with Ricky Molier, of the Netherlands, to win the Junior Open Doubles championship.

But Rydberg would not stop there. He stayed to play with the "big boys," and reached the semi-finals in the Men's B Singles Division before losing a close match to Tennessee's Rocky LeBlanc. Rydberg later teamed up with LeBlanc to claim the Men's B Doubles title.

Rydberg "epitomizes why adaptive sports and recreation programs are vital to the physical and emotional well being of our nation's younger population who have disabilities," commented Brad Parks, founder and president of the National Foundation of Wheelchair Tennis.

included is a list of books, newsletters and support groups related to FAS. The $7.50 book is available from the Fetal Alcohol Education Program at the Boston University School of Medicine, 7 Kent St., Brookline, MA 02146, (617) 739-124.

A Spanish edition of About Hydrocephalus: A Book for Parents is now available. It is an exact duplicate of the English version which is considered to be the most up-to-date resource on hydrocephalus for families. Members of the Hydrocephalus Association can receive either English or Spanish versions free; $2 for others. Hydrocephalus Association, 870 Market St., Ste. 955, San Francisco, CA 94102, (415) 776-4713.

Kasey was bounced from school to school, program to program for most of his life. Teachers and family tried in vain to break through his aggressive behavior patterns, and curb his tendency to run away without warning. Still, one day he escaped close supervision and dashed into heavy traffic, bringing cars to a screeching halt inches away from impact.

Nothing improved for Kasey or his family until they contacted Heartspring. Here, caring professionals used an interdisciplinary team approach to gain an understanding of Kasey's needs, then tailored a program to reach him.

Heartspring has a unique approach to helping children with autism. Education teams provide 24-hour-a-day coordinated services, implementing therapies designed around your child's individual needs and personality. Specialists in the areas of education, speech, psychology, occupational therapy, physical therapy, and residential care work toward the same goals.

Recently Kasey's mother observed an incredible event: her son walked across the Heartspring campus with his personal teacher, making no effort to run away. "I watched him do other things even I couldn't get him to do," said his mother. Today Kasey is a happier person — and his family shares his joy.

When you need help reaching your unreachable child, call Heartspring. We can make a difference.
LIVING AND LEARNING
IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges
- Autism
- Hearing/Sight Impairment
- Mental Retardation
- Severe Maladaptive Behavior
- Physical Disability

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597

Circle # 27

HMS School
For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- Physical Therapy
- Occupational Therapy
- Speech and Language Therapy
- Communication Aids
- Special Education
- Music Therapy
- Special Medical Attention
- Adapted Recreational Activities

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215) 222-2566

Circle # 39

Free Product & Service Information

A SPECIAL SERVICE FOR EXCEPTIONAL PARENT READERS! This Reply Card enables you to receive FREE information about products and services seen in Exceptional Parent.

how to use this service:
1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in Exceptional Parent!

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**Expiration Date:** March 31, 1995
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ON DISABILITIES CONFERENCE
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Because many parents cannot take the time or afford to attend the annual meeting, NPND—for the first time ever—is offering highlights of the annual meeting and congressional briefing on video.

NPND members receive a 10 percent discount on all materials:

1984 NPND Annual Meeting Highlights includes presentations by Rep. Major Owens, D-NY, chairperson of the House Select Subcommittee on Education and Civil Rights; Carol Rasco, assistant to Pres. Clinton for domestic policy; leading disability rights advocate Justin Dart and Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services. ($19.95)

The 1984 NPND Congressional Briefing: The Reauthorization of IDEA: Parents’ Perspectives includes all of the parent panels. It also contains information parents must understand to protect the access of children and youth with disabilities to a free, appropriate, public education. ($19.95)

Inclusion: A Parent’s View is a compilation of parents from around the country sharing experiences regarding the inclusion of their children in neighborhood schools and communities. These vignettes will inform and inspire. ($19.95)

NPND Legislative Briefing Book is a 325-page collection of readings that provide a comprehensive understanding of inclusion. ($40)

ACB Train-the-Trainer Manual is a 160-page manual containing information helpful for working toward inclusion at any level. It describes ACB’s four phases of inclusion and includes useful forms such as the Community Assessment Tool and the Positive Student Profile. Also includes sample training outlines and references for further reading. ($25)

ACB Related Readings Manual is a 325-page collection of readings that provide a comprehensive understanding of inclusion. ($40)

ACB First National Teleconference is a video copy of the nearly three-hour March 1994 teleconference about inclusion. Also included talks with Tom Hehir, director of the Office of Special Education Programs in the U.S. Department of Education; Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services; Martha Fields, executive director of the National Association of the State Directors of Special Education and parents. ($28)

TOTAL (NPND members may deduct 10%)
NPND’s Annual Meeting is Unparalleled Success

NPND’s annual meeting for 1994 was held Oct. 1-3 in Washington, DC. Following a full-day meeting of the board of directors Sept. 30, the annual meeting included panel discussions, talk about legislation and updates on the Americans with Disabilities Act (ADA) and the reauthorization of the Individuals with Disabilities Education Act (IDEA).

Before the annual meeting officially opened, the NPND board of directors attended a working dinner of the Joseph P. Kennedy Jr. Foundation. Eunice Kennedy Shriver, Foundation Executive Director Steve Eidleman and several other foundation staff members attended the dinner. Shriver, who asked NPND board members their opinions on a wide range of topics concerning children with disabilities and their families, stressed the need for parents and other family members to become more politically active. Shriver also suggested that a meeting between the NPND board and the foundation become a regular part of NPND’s annual meetings.

National leaders open meeting

Rep. Major Owens, D-NY, chairperson of the House Select Subcommittee on Education and Civil Rights, opened the annual meeting Saturday, Oct. 1. Based on the accomplishments of the House-Senate conference that had completed its work just the day before, Owens spoke about the Families of Children with Disabilities Support Act of 1994 and the reauthorization of the Improving America’s Schools Act of 1994, commonly referred to by its previous name, the Elementary and Secondary Education Act.

Arguing that government must reprioritize its spending, Owens advised parents and advocates not to accept many legislators’ arguments that money is insufficient to adequately fund disability-related programs. Parents must continue to lead the fight for the rights of students with disabilities, Owens said.

Following Owens, Carol Rasco, assistant to the president for domestic policy, shared her experiences of raising a son with disabilities. She said her son had a special friendship with Pres. Clinton and emphasized Clinton’s commitment to people with disabilities. Rasco was given the NPND National Leadership Award after her comments.

Leading disability rights activist Justin Dart was also honored Saturday with the NPND Citizen Advocate Award. In an emotional speech, Dart described the upcoming winter as the “Valley Forge” of the disability movement while urging for more advocacy, determination and hope.

Update from the Hill

Other Saturday talks included remarks about the just-ending congressional session and predictions for upcoming legislative actions. Speakers included George Jessen, a Kennedy Policy Fellow working with the Senate Subcommittee on Disability Policy; Hans Meeder, staff to the House Select Subcommittee on Education and Civil Rights; Paul Marchand, director of the ARC Office of Government Affairs and Lucy Watkins, parent advocate for the Center on Law in Education.

Saturday afternoon concluded with a talk by Judy Heumann, assistant secretary of the Office of Special Education and Rehabilitative Services (OSERS). Heumann urged parents to become heavily involved in the reauthorization of IDEA and, in particular, to respond to the questions that her office had put forward in the Federal Register.

Bob Williams, commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services, also talked about Heumann’s office on Sunday, Oct. 2, saying he was trying to work more closely with OSERS, the Department of Labor and other agencies. Following his presentation, Williams spent time with some parents to discuss

[From left to right] NPND executive director Patricia McGill Smith chats with Eunice Kennedy Shriver and Diana Cuthbertson, outgoing president of NPND’s board of directors, at a Joseph P. Kennedy Jr. Foundation dinner Sept. 30.
Parents' Perspectives, the Reauthorization of IDEA: Differently-Abled Children.

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education department is pants about various IDEAasion with meeting partici-

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by contacting NPND.

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meeting participants

On Saturday afternoon,

work on behalf of children

the Year Award for her

Parent Leader/Advocate of his stores' Toy Guide for

founder of Toys "R" Us, was

ried in his stores' Toy Guide for

Thanks goes out to for-

now have to a free appropriate
discuss “hot topics” sug-
gested by NPND mem-

bers through a member survey conducted earlier in

the year. Topics included the legislative process; rural and Native

American issues; communica-
tion; fundraising; NPND 2000, a strategic

planning program for

NPND and the justice sys-
tem’s treatment of people

with disabilities.

A wake-up call is sounded

On Monday, Oct. 3, NPND held its first congres-
sional briefing, “The

Reauthorization of IDEA: Parents’ Perspectives.”

During the briefing, spon-

sored by the Senate Sub-

committee on Disability Policy and the House

Select Subcommittee on Education and Civil

Rights, parent panels addressed critical issues in

maintaining the rights and protections already

embedded in IDEA. Many

parents shared stories about the successful

benefits of IDEA.

Panels included Parent

Participation: The Key to

Success; Least-Restrictive

Environment; Procedural

Safeguards; Equal Justice

and Monitoring.

In addition to parents, Bobby Silverstein, chief of

staff for the Senate Sub-

committee on Disability

Policy and Maria Cuprill,

chief of staff for the House

Select Subcommittee on

Education and Civil Rights, gave compelling presenta-
tions about the magnitude of the upcoming fight to

retain the protections chil-
dren with disabilities now

have to a free appropriate

discussion. Other confer-

dence and reception contrib-

utors included Hal's Pals,

Virginia Leingang, Neil's

Outrageous Liquors and

Deli, Robert Blair Ruble, Sir

Speedy, St. James Resi-
dence Hotel, Total Audio

Visual Systems and the

Joseph P. Kennedy Jr. Found-

dation.

Board elections

An election of NPND board

members was held during

the business meeting on

Sunday. New board mem-

bers are Marta Anchondo,

Margaret Burley and Diana

Autin. Jo Butts, Sue Pratt

and Pam Stoneberg were

re-elected.

New board officers were also

elected at the first

meeting of the new NPND

board Sunday evening.

Elected were President Jo

Butts, Vice President Pam

Stoneberg, Secretary Janet

Vohs and Treasurer Joan

Kilburn.

Thanks goes out to for-

ter board members Rich

Burden, Sweet Alice Harris

and Amparo Crespo for their

hard work and dedication.

Hot topics discussed

After lunch on Sunday, small groups gathered to

NPND awards

NPND held its annual

reception and award cere-

mony Saturday night:

• Doreen “Pam”

Stoneberg received the

Parent Leader/Advocate of the Year Award for her

work on behalf of children

with disabilities and their

families in northern Califor-

nia and across the nation.

• Charles Lazarus,

founder of Toys “R” Us, was

named Corporate Leader of the Year for the produc-

tion of his stores’ Toy Guide for

Differently-Abled Children.

NPND extends special

recognition to American

Airlines and the National

Association of Medical

Equipment Services for

their generous support of

their concerns about the

SSI benefits program.

IDEA reauthorization

On Saturday afternoon,

meeting participants reviewed, edited and devel-

oped policy positions

regarding the reauthoriza-

tion of IDEA. Called The

Reauthorization of IDEA: Parents’ Perspectives, the

position paper includes

eight principles critical to a

new IDEA that will be more

responsive to the needs of

students with disabilities

and their families. This

paper is available free to

parents and organizations by contacting NPND.

Tom Hehir, director of the Office of Special Educa-

tion Programs in the U.S.

Department of Education, also addressed IDEA on

Sunday in a lengthy discus-

sion with meeting partici-

pants about various IDEA

reauthorization issues the education department is

particularly interested in.

The National Parent Network on Disabilities Board

of Directors

Marta Anchondo

TASK, Anaheim, CA

Dianna Autin

Advocates for Children of New York,

Long Island, NY

Margaret Burley

OCEHC, Marion, OH

Joanne Butts

Washington PAVE, Tacoma, WA,

President

Connie Curtin

Vermont Parent Information Center,

Burlington, VT

Diana Cuthbertson

Statewide Parent Advocacy Network (SPAN), Westfield, NJ,

Past President

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Touchstones, Seattle, WA

Paula Goldberg

PACER Center, Minneapolis, MN

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Exceptional Children’s Assistance Center (ECAC), Davidson, NC

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Pam Stoneberg

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  A Guide for Families
  B.L. Harris, Ph.D.
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- **Down Syndrome**
  A Parent's Guide
  Ed. by Karen Stay-Gundersen
  The complete guide for new parents of babies with Down Syndrome. Written by professionals and parents, this book covers everything new parents need to know.

**DISABILITY, GENERAL**

- **Activities for Developing Pre-Skill Concepts in Children with Autism**
  Tom Flowers
  Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity.

- **The Best Toys, Books, & Videos for Kids**
  Joanne Oppenheim & Stephanie Oppenheim
  A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.

- **Computer Resources for People with Disabilities: A Guide to Exploring Today's Assistive Technology**
  The Alliance for Technology Access
  Provides user-friendly support, information, and up-to-date answers.

**DOWN SYNDROME**

- **Down Syndrome**
  A Resource Handbook
  Edited by Carol Tingey
  This book, written for both families and clinicians, is personal in approach and direct in style. It discusses with compassion and knowledge the genetic, medical, social, and family aspects of Down syndrome.

**SIBLINGS OF CHILDREN WITH AUTISM**

- **Son Rise**
  The Miracle Continues
  Barry N. Kaufman
  An awe-inspiring reminder that love made tangible can move mountains.

**THE EARLY INTERVENTION DICTIONARY**

- **The Early Intervention Dictionary**
  A Multi-disciplinary Guide to Terminology
  Jeanne Coleman, M.Ed.
  Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.

**HELP! THIS KID'S DRIVING ME CRAZY!**

- **Help! This Kid's Driving Me Crazy!**
  The Young Child with Attention Deficit Disorder
  L. Abrams & J. Cady
  Information about typical behavior characteristics; suggestions on how to foster the development of appropriate behavior.

**I AM, I CAN, I WILL**

- **I Am, I Can, I Will**
  Mutis Books
  A series of audio and printed materials designed for young children with disabilities. These programs may be used to help develop a child's emotional, language, perceptual, listening and creative abilities.

**IT ISN'T FAIR**

- **It Isn't Fair!**
  Siblings of Children with Disabilities
  Edited by S.D. Klei & M.J. Schleifer
  Features chapters by parents, siblings and professionals.

**THE LANGUAGE OF TOYS**

- **The Language of Toys**
  Teaching Communication Skills to Special-Needs Children
  S. Schwartz & J. Miller
  Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.

**LITTLE CHILDREN, BIG NEEDS**

- **Little Children, Big Needs**
  Parents Discuss Raising Children with Exceptional Needs
  Don Weinhouse, Ph.D. and Marilyn Weinhouse, M.A.
  What are the concerns of parents who raise disabled children? Contains candid interviews with 60 families of children with a wide range of disabilities.

**TEACHING CONCEPTS IN CHILDREN WITH DOWN SYNDROME**

- **Teaching Concepts in Children with Down Syndrome**
  A Parents' Guide
  Ed. by Karen Stay-Gundersen
  A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
If I could give the world a gift, it would be what my brother has taught me:
My brother is patient all the time. He waits for me, even when I sometimes don’t have time for him.

My brother is always happy and smiles with a big, open-mouth smile. He always gives me a smile, even when I don’t feel like smiling or when I have had a bad day.

My brother doesn’t care if I don’t make straight A’s or score a goal in soccer; he will always love me, no matter what.

My brother only knows how to love, and this is how God wants us to be—the same way He loves us no matter what.

Joshua, 11, lives with his parents, Karen and Dennis, and his two brothers, Jordan and Jarrett, in Waco, Texas. Jordan, 8, has agenesis of the corpus callosum. Joshua, a fifth grader at Midway Intermediate School, entered this essay in a contest sponsored by the National PTA where it won first prize at the campus, council, and district levels. Joshua’s hobbies include drawing, soccer, and golf.
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