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ABSTRACT

Developed by the Florida Parent to Parent Support Program, two manuals provide materials for developing local parent-to-parent support groups for parents of children with a broad range of special needs, including those with sensory, physical, or learning disorders; developmental disabilities; emotional disturbances; and those at high risk for or with developmental delays due to prematurity, environment, or some unknown cause. The project staff conducts education and awareness seminars for parents and professionals. From those workshops a core group is identified to develop a local support group. The first manual, a "Leader's Guide," includes six training modules which cover: (1) an orientation introducing program objectives and assisting participants to assess and evaluate their own feelings and experiences as parents of special needs children; (2) factual information on specific developmental disabilities and other special needs; (3) peer counseling skills; (4) concerns about providing support including contacting new parents, the grieving process, and the issue of acceptance; (5) awareness of resources provided at the community, state, and national levels; and (6) the referral and community outreach process. The guide also includes a bibliography, list of films, and resource directory. The second volume, "Materials for Parent Training," contains items to be distributed to participants during the workshops. (VW)

1 of 2

Parent to Parent
OF FLORIDA

A Leader's Guide For Developing A Parent to Parent Support Program

and
Materials for Parent Training

Parent to Parent of Florida
621 Kraft Avenue
Panama City, Florida 32401
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Parent to Parent
OF FLORIDA

A LEADER'S GUIDE FOR DEVELOPING A PARENT TO PARENT SUPPORT PROGRAM FOR PARENTS OF SPECIAL NEEDS CHILDREN.

PREPARED BY:

SUSAN M. DUWA

LORI L. LUPPINO

PARENT TO PARENT OF FLORIDA IS A PROJECT FUNDED BY THE DEPARTMENT OF HEALTH AND HUMAN SERVICES, ADMINISTRATION ON DEVELOPMENTAL DISABILITIES AND THE FLORIDA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL.

THIS TRAINING MANUAL IS DEDICATED TO ALL OF THE SPECIAL PARENTS WE HAVE COME TO KNOW AND FROM WHOM WE HAVE LEARNED SO MUCH. THEIR COURAGE, STRENGTH, COMMITMENT AND NEVER-ENDING CARING AND SHARING MAKES PARENT TO PARENT SUPPORT A REALITY.

FOREWARD

The main objective of the Parent to Parent of Florida project is to develop support programs in Florida's communities for parents of special needs children and, subsequently, form a statewide network of these programs. The project staff conducts education and awareness seminars to parents and professionals and from these workshops a core group is identified to develop a local parent to parent support program.

The Parent to Parent of Florida Leader's Guide provides a step-by-step systematic approach in developing local groups and is available to the core group. The Leader's Guide includes six training modules, a bibliography and a resource directory. When core groups are ready to begin training, the project provides parent training materials for each parent in addition to a certificate of completion and identification card upon completion of the training. The Project staff is available to assist groups in arranging the training through utilization of community resource persons, local funding and support. A parent to parent support group has parent leadership with one or more professional advisors. The course of development in each group is unique except for one very important similarity: each group had very strong parent involvement and interagency support resulting in a positive parent/professional partnership.

The Leader's Guide provides a systematic approach to training designed to enable parents to reach out and be available to talk with other parents as soon as they learn their child has special needs or at any time of difficulty. The Leader's Guide does not require exact replication to be implemented. Each community is different and the program should be geared to the needs and resources of the area they will serve. The Leader's Guide is a guide that will be strengthened by your ability and willingness to explore new avenues to make your program unique to your community. A supplement to this Leader's Guide, Parent Training Materials, is available to be used by parents during the training.

Parent to parent support programs are parent owned programs. They utilize total parent involvement from the organizational and planning stage to the actual delivery and receipt of services. Parent to Parent of Florida is keenly aware of the need for parent support and involvement at all stages of a child's growth and development. A well trained, sensitive cadre of parents will enable your organization to successfully locate "new" parents and most importantly, team them with another parent to provide them with strength, hope and encouragement.

We hope this Leader's Guide will result in many special families giving and receiving support and understanding and, therefore, enriching not only their lives but their child's life as well.

PARENT TO PARENT OF FLORIDA PHILOSOPHY

Parents of special needs children who have come to accept and understand their child's disability are one of the best sources of information and emotional support for other parents of children with special needs who may be experiencing difficulties. By virtue of having "been there" a unique bonding occurs between parents establishing an almost immediate rapport and sharing of common feelings and experiences.

A supporting parent's skills are enhanced through their participation in parent to parent support training; however, it is their willingness and ability to share their experience that qualifies them to positively interact with other parents. Supporting parents are not trained to be professional counselors or therapists but are parents who have successfully met the challenges of parenting a special needs child and, hence, are viewed by parents as capable helpers. Parent to Parent of Florida defines special needs as any sensory, physical, or learning disorder, developmental disabilities such as cerebral palsy, autism, epilepsy, mental retardation or spina bifida, children with emotional disturbances, and those children who are high risk or developmentally delayed due to prematurity, environment or some unknown cause.

As a result of parent to parent interaction, parents are better able to approach their child's ability to grow, learn and develop to his or her potential with an optimistic attitude and within a supportive environment. Early success in relating to this life experience will positively affect family relationships and future decisions made on behalf of the child.

We believe parent to parent support should be available not only at the time of the initial crisis but throughout the child's life. The areas of concern are endless and range from coping with the initial diagnosis to a myriad of specific issues such as sexuality and guardianship.

Parent to Parent of Florida believes that the benefits of parents helping other parents facilitates the developmental growth of families through heightened awareness, knowledge, and acceptance of their child's special needs. Parent to parent support should be easily accessible within the local community to all parents of special needs children.

PARENT TO PARENT SUPPORT SERVICES

The services of Parent to Parent of Florida and it's chapters are unique in the following aspects:

- They are family centered rather than child centered.
- They actively involve both parents and professionals in organizing and maintaining each chapter by promoting parent/professional partnerships.
- Provides a cost-effective resource for both parents and professionals.
- Parents are the nucleus of each chapter.
- Each chapter is a community funded and supported organization.

Services available from Parent to Parent of Florida include:

- Leader's guide for group development
- Parent to Parent training materials for one to one support
- Consultation and follow-up support
- Parent to Parent Training
- Information and referral
- Computerized one-to-one matching for rare disorders
- Quarterly newsletter
- Education and awareness presentations
- Continuing education for chapters
- Legislative updates to chapters
- Statewide conference for parents, professionals and policy makers
- Provides a central networking office and clearinghouse for information.

Services available from local Parent to Parent chapters include:

- One-to-One parent support
- Administration of Parent to Parent referral services
- Resource information
- Group meetings for education and socializing
- Advocacy coalitions
- Sibling and Grandparent support
- Speakers bureau
- Technical assistance and parent perspective for boards, committees, other organizations
- Newsletters
- Disability information
- Inservice training to professionals on such topics as emotional and service needs of parents, parenting the special needs child, etc.
- Teaches parents to be effective and confident case managers.

ACKNOWLEDGEMENTS

This training manual was produced by Parent to Parent of Florida. For additional copies, call or write:

Parent to Parent of Florida
621 Kraft Avenue
Panama City, Florida 32401
(904) 769-6606

Parent to Parent of Florida is a project funded by a grant from the Florida Developmental Disabilities Planning Council. This grant was awarded to United Cerebral Palsy of Panama City where the Parent to Parent of Florida office is located.

The staff of Parent to Parent of Florida would like to thank the following individuals and organizations for their generosity in sharing materials, many of which are reproduced in this manual, and for their support and interest in this project.

The Parent to Parent of Florida Training Manual is meant to be a compilation of the excellent existing parent to parent resource material available. We have tried to acknowledge the source of materials throughout the manual by placing the name of the source on the page or phrase of the appropriate reproduced material. Complete information on each of our sources is listed below. These are all excellent publications and are highly recommended for your use.

1. First Steps: A Guide for Parents of Children With Developmental Disabilities.
   Published by the Florida Developmental Disabilities Planning Council
   1317 Winewood Boulevard
   Building 1, Room 309
   Tallahassee, Florida 32301
   (904) 488-4180

2. The Parent to Parent National Project
   University Affiliated Facility/University of Georgia
   850 College Station Road
   Athens, Georgia 30610

3. Parent to Parent of Georgia, Inc.
   1447 Peachtree Street, N.E., Suite 522
   Atlanta, Georgia 30309

4. Pilot Parents Program
"A Design for Developing a Program for Parents of
Handicapped Children" by Fran Porter
Sponsored by the Omaha Association for Retarded
Citizens
3212 Dodge
Omaha, Nebraska 68131

5. "Reaching Out to Parents of Newly Diagnosed Retarded
Children" by Jeff Bassin, A.C.S.W. and Diane D. Kreeb, M.S.W.
St. Louis Association for Retarded Children
1240 Dautel Lane
St. Louis, Missouri 63141

6. Project HOPE (Helping Other Parents through Empathy)
A Parent Support Network
Family, Infant and Preschool Program
Western Carolina Center
Enola Road
Morgantown, North Carolina 28655

7. Special Parents
Directory of Resources for Persons With Developmental
Disabilities
409 Dixie Road
Milton, FL 32570
(904) 432-4513

8. * "We've Been There...Can We Help?" Joanne M. Travers, M.A.
Project COPE
Association for Retarded Citizens, Ontario-Pomona (OPARC)
9160 Monte Vista Avenue
Montclair, CA 91763

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CHAPTER I

INTRODUCTION TO PARENT TO PARENT SUPPORT PROGRAMS

"Be proud of your child, accept him as he is and do not heed the words and stories of those who do not know better. The child has a meaning for you and for all children. You will find a joy you cannot now suspect in fulfilling his life for and with him. Lift up your head and go your appointed way."
Pearl S. Buck, in *The Child That Never Grew.*

CHAPTER I

PARENT TO PARENT SUPPORT PROGRAMS

Parent to Parent is a peer support program that is being developed throughout the State of Florida. It is a program in which parents of children with developmental disabilities help other parents who have recently learned that their child, too, has special needs.

Young children with special needs are a heterogeneous group. More and more families have children growing up with chronic illnesses or any one of a myriad of handicapping conditions. As methods of medical care have improved, many children who formerly died at birth survive today, but they survive with various kinds of physical and mental impairments. For the purpose of this manual, special needs children or children with developmental disabilities will be defined as children with sensory, physical and learning disorders, children with diagnosed developmental disabilities such as cerebral palsy, autism, epilepsy (seizure disorders), mental retardation, or spina bifida, children with emotional disturbances, and also those children who are high risk or developmentally delayed due to prematurity, environment, or some unknown cause.

Parents may be told their child has special needs at the time of birth, in the child's early developmental years, at the time the child enters school, or at the time of an accident or trauma later in life. Whatever the disability or age of the child, the parents needs are similar. The program's main purpose is to provide supportive experienced parents to guide new parents through the initial difficulties of accepting that their child has special needs, learning about these needs, and finding the appropriate service to aid their child in his or her development. Supporting parents are parents who have met the challenges and crisis of parenting a disabled child successfully, and hence are viewed by new parents as capable of understanding and empathizing.

For most parents of special needs children, the initial period is indeed an emotional crisis. Parents feel guilty, angry with each other, depressed, unable to explain why one of life's happiest events has apparently been irreparably spoiled. Mothers of children born early or handicapped frequently speak of a period of unshakeable gloom and self-pity in which it was a great effort for them to care for their children. Fathers, always excluded somewhat from the interaction of mother and child in infancy, edge farther away, unable to talk about the child they are not sure they can accept. Relatives, who are usually so helpful at the time of childbirth, don't call because they don't quite know what to say. The result, frequently, is that the parents are left alone, caught in a vicious circle of anger, depression, and disbelief. One couple described their family in that early period as "an island with no contact with the outside world".

Parents who experience this "crisis of acceptance" can be helped in a unique way by parents who have overcome the difficulty of accepting that their child has special needs. The experienced parents offer something that other support systems--friends, clergy, physicians--cannot provide: the fact that they are intimately familiar with the emotions and real problems that having a special child presents to the new and often bewildered parents.

Supporting parents are themselves parents who have learned to accept their special child. As supporting parents, they have no magic answers to impart to troubled new parents. What they do impart, however, is acceptance and a willingness to talk about the problems and pleasures of raising a special needs child. They convey positive attitudes toward their own child who usually has a developmental disability similar to the child of the new parents. Ordinarily, supporting parents are matched to new families by the similarity of the child's needs, as well as similarities in family background. A new family with an epileptic child, for example, will usually have a supporting parent whose own child has epilepsy. Thus the supporting parent can be a source of information to the new family about the particular disability and about the location of appropriate services for the child.

New parents can be referred to the Parent to Parent Program through a number of sources and, as the program grows and becomes better known, the sources become more varied. Family physicians, obstetricians, and nurses in obstetrics and pediatric hospital wards frequently alert parents of newborns with special needs to the existence of Parent to Parent. Social service agencies also refer families to the Program as do new parents themselves who are often highly enthusiastic supporters of the Parent to Parent Program.

The Parent to Parent Program contacts a new family only when the Program Coordinator learns that the family is interested in talking with a supporting parent. The Program does not solicit new parents, nor is it forced on an unwilling family.

When the Coordinator learns by referral or a call from a new family that they would like to talk to a supporting parent, he or she initiates a three stage process:

1. The Coordinator gathers general and family background information from the new family in order to match as closely as possible the supporting parents who will visit them.
2. The Coordinator selects an appropriate supporting parent who is urged to make the initial telephone contact within 24 hours.
3. When the supporting parent visits the new family for the first time, he or she gives the new family pamphlets, brochures and booklets that pertain to the child's needs. These are brief and easy to read and satisfy one of the new family's most urgent needs...information about their child's disability, possible medical needs, and the need for special services.

After the initial meeting takes place, the relationships between the supporting parents and the new parents will develop in a direction largely set by the needs of the new parents. Occasionally a new family will want or need no more than the initial meeting. Ordinarily though, the relationship develops through frequent contacts spurred by the insistent questions of the new parents, a good sign that they are trying to deal with the child's real present and future needs. The supporting parents assist the new parent through this crisis period by frequent contacts, answering their questions, and encouraging them to participate in social activities. Most of all, they assist by being patient and available friends who will listen and who will share their experiences in coping with the same feelings and frustrations.

What new families gain from the supporting parents is not so much answers as much as attitudes and expectations. New parents of developmentally disabled children are apt to view their child's special needs as a catastrophe, a permanent blight on their family's future. In supporting parents, however, they see people who have raised a child with a similar disability and who take pride and feel joy in their child's achievements. Supporting parents demonstrate a particular kind of courage that new parents want and need to see:

the courage to accept the child as he or she is, the courage to put away doubts and fears and to raise the child with love. Finally, the new parents have an opportunity to meet the supporting parents' special child, who is frequently an older child with the same condition as the child of the new parents. For many new parents, this opportunity marks a decisive moment of attitude change.

The Parent to Parent Program has many ways to assist new parents. In addition to facilitating the relationship with the supporting parents, the Program encourages new parents to attend morning coffees, films on various disabilities including that of their own child, and growth groups. These activities not only offer the new parents the opportunity to learn more about their child's needs, but also introduces them to other families whose experiences may be similar to theirs. Many strong friendships have developed out of the many social activities of the Parent to Parent Program.

As new parents become more sure of themselves, they no longer require the strong support necessary at the beginning. The supporting parents gradually ease away, leaving the new parents on their own. By this time---and it might be six weeks, three months or one year---the new parents have gained knowledge and understanding of their child's disability, have made arrangements for appropriate community services, and are able to face the future in a positive way.

Parent to Parent is aimed not only toward helping parents cope with the initial crisis, but also aids the parent of a special needs child to deal with problems or crises that are faced throughout their child's life. At every point, parents reach out for the kinds of information which will help them with their children. Parents may need help coping with initial dianosis, educational planning, their child's adolescence and sexuality, workshop and group home exploration, guardianship, and other legal issues. Parent to parent contacts can provide support and information which help families to deal with such issues as well as with concerns of siblings, relationships with parents and other family members, advocacy, and a myriad of specific issues such as feeding or dressing. The areas of concern are endless. The parent to parent contacts provide the vehicle for parents to express feelings they have little chance to express in their daily lives. This is true not only of parents who have recently faced the reality of having a developmentally disabled child, but also for parents who have lived with this reality for many years.

The role of a supporting parent can be very demanding. However, the inner satisfaction and the benefits the supporting parents receive from their association with the new parents is well worth the time and effort. Not only do the parents grow from the association with the program but the supporting parents grow as well. The philosophy regarding the role of a supporting parent may best be summarized in this statement by a supporting parent: "We have unique and valuable skills and expertise in our roles as parents of children with handicapping conditions. By sharing our skills and our caring with parents who are newly experiencing the traumas, we are enriching our own experiences. We are not therapists. We are not counselors. We are empathetic, sensitive, skilled listeners who can offer friendship and a shared experience".

It is our belief that our Parent to Parent Support model is a viable one that may be adapted to a variety of agency settings wishing to be of assistance to families at the time they discover that their child has special needs. Although our implementation of the model focuses on families with developmentally disabled children, we feel that other disabling conditions may be successfully adapted to the approach as set forth in the following chapters.

It is our intent that this manual will promote and encourage the implementation of programs aimed at providing support, information and services to families with very young developmentally disabled children. Early success in relating to this life experience is bound to positively effect family relationships and future decision making on behalf of the child. We have observed this in our own program.

The manual is subdivided into chapters designed to guide you in recruitment of potential parent volunteers, training of supporting parent volunteers, community outreach and follow-up of parent referrals. We have concluded with a list of helping organizations and a selected bibliography of written resources. These may be used for background material or in actual training sessions. An emphasis has been placed on the actual process of training parent volunteers. This is the most crucial component, upon which the success of the program rests. A well trained, sensitive cadre of parents will enable your organization to successfully locate "new" parents and most importantly, team them with another parent to provide them with strength, hope, and encouragement.

CHAPTER II

GETTING STARTED

"Courage is not the absence of fear; it is the making of action in spite of fear." M. Scott Peck, in The Road Less Traveled.

CHAPTER II

GETTING STARTED

ESTABLISHING A PROGRAM - AGENCY SUPPORT

A Parent to Parent Program may be established by any number of people, anywhere. A parent of a special needs child, realizing the need for such a program in his or her community, may advocate for its development. The staff member of a service agency, aware of the value of the program to parents of special needs children, may advocate among parents to organize a program. Or perhaps a group of parents may band together with professionals to establish a program.

The Parent to Parent program believes in a parent/professional partnership to maximize the effectiveness of parent to parent groups. This can best be accomplished by utilizing the staff and resources of an established agency such as United Cerebral Palsy, Association for Retarded Citizens, March of Dimes, etc. Some of the advantages of such an affiliation are:

1. Availability of professional staff to develop and implement training for parent volunteers and act as resource persons.
2. To conduct a needs assessment with agency parents. (Attachment IIA)
3. To set up planning meetings to explain Parent to Parent to local service providers who will help you select parents.
4. Professional staff availability to consult with volunteers and help them with any problems they might encounter in their parent to parent contacts.
5. A central office to maintain records, coordinate the program, and use of office equipment.
6. A not-for-profit status of an established service agency to qualify for funding to maintain the program.
7. Assistance with public relations.
8. A Parent to Parent telephone line to receive referrals.
9. To absorb start-up costs for the program until that time when the group begins to solicit funds (i.e. postage, brochures, pamphlets, film rental, copying, clerical help, etc.)

Agencies may have limited funds to provide for Parent to Parent but may be able to provide space and staff. They may also assist Parent to Parent groups in soliciting donations, planning funds raisers, applying for small community based grants, and provide consultation.

Other possible sources of funding which may be explored are university affiliates, private foundations, local philathropists, or United Way funds. Human service agencies, developmental disabilities offices, and other organizations may be useful sources of information about funding and grant sources. Many films, brochures, and pamphlets are free of charge. These are obtainable from the U.S. Government Printer and the various developmental disabilities agencies. Meeting space will frequently be donated by banks, churches, libraries, and community organizations who have available space. Various mental health professionals are often happy to address a Parent to Parent group if the subject is within their area of knowledge. Students will sometimes donate their work on audio/visual presentations, brocures, etc., in exchange for experience and credit. In short, the resources for an active program are available, if you ask.

STRUCTURING THE PROGRAM

There are many ways in which a Parent to Parent program may be structured. The method you choose will depend on the resources available to you, the commitment of your group and the needs of your supporting agency.

MODEL ONE

The first structure model this manual will outline is for an agency staff person, such as the Social Worker or Parent Trainer Coordinator, to assume responsibility for the training and coordination of this group. The role of the Parent to Parent Coordinator would include the following responsibilities:

1. Conduct all meetings.
2. Arrange for speakers for training sessions.
3. Arrange for meeting rooms.
4. Liason between sponsoring agency and committee.
5. Obtain names of, and contact, prospective supporting parents.
6. Maintain records regarding operation of the program.

To fill this role of Parent to Parent Coordinator and staff liason, the person needs a knowledge of developmental disabilities, awareness of community resources, knowledge of group dynamics, ability to work with media, and familiarity with interpersonal communication skills. Most important, the group leader needs to be able to model empathetic skills. They need to be able to express this by actively listening to what each parent has to say. Each leader acts as a supporting, helping person who leads the group toward new knowledge and understanding. The Coordinator must also establish a functional communication network with community agencies and resource persons to increase their awareness of the needs of special families and to secure the referrals of such parents. Visibility and acceptance of the Program Coordinator and sponsoring agency lends credibility to the program.

Qualities of a Good Parent to Parent Coordinator/Trainer

1. Is supportive of participant efforts.
2. Respects feelings and is free to express his/her own.

3. Is responsive and undefensive when criticized.
4. Is interested in the content.
5. Provides useful and timely feedback on performance.
6. Reinforces learning.
7. Is nonjudgemental.
8. Does not impose his/her own values or opinions.
9. Encourages participants to try new behaviors.
10. Listens carefully and accurately.
11. Normally directs activities with quiet authority.
12. Directs activities with stern commands when that will move the learning past frustration.
13. Is patient.
14. Stimulates interest and suggests new possibilities.
15. Is capable of showing a wide range of genuine human emotions.
16. Models desirable attitudes and behaviors.
17. Counsels with individual participants.
18. Is flexible, open to change.

For the parents and community to assume ownership of the Parent to Parent support program is very important. The Program Coordinator should emphasize the importance of the parents themselves taking responsibility for the ongoing implementation of the program, primarily the community education efforts. There should be volunteer parents responsible for the following in each community:

1. Publicity
2. Social Events
3. Community Education and Awareness
4. Fund Raising

The supporting parents and Program Coordinator will also work closely with the Advisory Committee. An advisory committee of parents and professionals representing a variety of disabilities and interests enhance a support group. It is easier to obtain an invitation to speak to a physician or hospital group if an advisory committee member is a well-known and respected physician. Establishing successful relationships with relevant professionals will facilitate referrals of new families to the program and increase the longevity of the program.

The Committee may consist, for instance, of a physician, a social worker, a parent of a child with handicaps and an educator. The Committee may include parents representing different disability areas and additional health care professionals. The Advisory Committee members are contacted as required for individual expertise, to meet needs of the group, and may meet as a whole only to plan for each year's activities.

An advisory committee's interest and support is invaluable for ongoing resource development. Committee members need to know, prior to serving, how the program intends to utilize their expertise and how often meetings will be called. Permission must be obtained from committee members for their names to appear on printed materials such as the project brochure.

MODEL TWO

In lieu of having an agency staff person and advisory committee, the following structure may be used to begin a Parent to Parent support group. In this model, the first step is to form a steering committee after recruiting a sponsoring agency and conducting a needs assessment. It is essential that the majority of this committee be volunteer parents who assume responsibilities in areas such as the following:

1. Chairperson
2. Publicity
3. Assignments
4. Social Events
5. Secretary
6. Educational materials

The roles of the steering committee members are as follows:

Chairperson:
1. Conduct all meetings.
2. Arrange for speakers for training sessions.
3. Arrange for meeting rooms.
4. Liaison between sponsoring agency and committee.
5. Obtain names of, and contact, prospective supporting parents.
6. Maintain records regarding operation of the program.

Publicity:
1. Arrange for all publicity for the program.
2. Contact radio and television stations.

3. Contact newspapers, local and organizational newsletters.
4. Arrange for parents to participate in all publicity.
5. Maintain records of all publicity used, media contact persons, etc.

Assignments:

1. Receive all referrals.
2. Match, select and contact parents regarding referral.
3. Assist supporting parent with referral if necessary.
4. Maintain detailed records of referrals, assignments, and follow-up.

Social Events:

1. With assistance from other supporting parents, arrange all social events involving the supporting parents and new parents.
2. Maintain records of events, contributing organizations, costs, donors, etc.

Secretary:

1. Record minutes of all meetings.
2. Mail minutes to steering committee and supporting parents.
3. Answer correspondence.
4. Maintain minutes of meetings, correspondence, etc.

Educational Materials:

1. Review and select all reading materials, films, etc., used by the Parent to Parent Program.
2. Maintain records of materials reviewed and used.

In some communities, the committee may consist of only two or three parents. In such cases each person would take charge of several areas of responsibility. Naturally the more persons on the committee the more can be accomplished, if the roles and responsibilities of each member are sufficiently clear.

The steering committee, as a whole, plans the training program, assisted by the additional members of the steering committee, who may be professionals in the field, or perhaps interested citizens. Professionals such as doctors, ministers, social service representatives, parent group liaison person, etc., may offer valuable assistance in the development of the training for supporting parents and in the design of the Program. They may also be a major source of referrals to the Program. Interested citizens may be a valuable source of information for the publicity campaign carried on by the committee. They, too, can contribute to the Program's overall development.

As the Program develops and grows, the time may come when the volunteers no longer are able to meet the increasing demands of operating the Program. To facilitate further growth, the steering committee may consider hiring a coordinator. With the addition of a coordinator, the steering committee will be relieved of many of its duties, and take on an advisory role.

This manual has presented two different models for developing a Parent to Parent program. We want to emphasize that these are only suggestions and the individual qualities of your community and the persons interested in starting a support group will determine the structure adopted. Starting a Parent to Parent support program that is successful, visible, and meets the needs of families with special children seems like a huge task. Nevertheless, the need the parents feel for such a program and the energy put forth gives great impetus to its establishment.

Structures adapted from Pilot Parents

SAMPLE NEED ASSESSMENT FORM

DO WE NEED A PARENT TO PARENT PROGRAM?

We are trying to set up a referral system in which parents of special needs children help other parents who have just learned of their child's special needs.

1. If such a system were offered to you when you became aware of your child's special needs, would you have used it?

2. When did you realize something was wrong with your child?

3. How long after was your child professionally diagnosed?

4. What were your feelings then?

5. What was the profession of the person who informed you of your child's special needs?

6. Was he or she helpful?

7. Was any support offered to you at this time?

8. Would it have been helpful to talk with a parent who had been through a similar experience?

9. What options were suggested to you for caring for your child?

10. Now that you have been through this experience, do you feel you could help another parent?

CHAPTER III

RECRUITMENT

"Sometimes we are apt to regard as limitations qualities that are actually the other person's strength." Eleanor Roosevelt in <u>You Learn By Living</u>.

CHAPTER III

RECRUITMENT

The beginning task in implementing a parent to parent program is the recruitment of potential parent volunteers. Being a parent of a special needs child alone does not qualify a person to be a supporting parent. However, it is a prerequisite. You want to identify parents of special needs children who are both interested in the concept of reaching out to other parents and willing to participate in parent training sessions to help them acquire skills needed to provide effective parent support and information to new parents.

A diversified group of parents is essential to a well-rounded program. One must consider and involve as much as possible families from all social groups and economic levels, as well as parents from every type of family--two parents, single parent, divorced, foster and adoptive.

Fathers are vital to the program and whenever possible should be encouraged to participate as supporting parents. Too often, fathers are overlooked or allowed to stand apart from parenting groups, when in fact the father's acceptance of, and positive relationship with, his child is a major factor in the child's development. The father's active involvement in the program benefits the child directly and in the long run enhances the stability of the entire family.

The sponsoring agency may already be familiar with parents who have expressed an interest in such a program which could help to form the core of your first training group. Other community agencies who provide services to special needs children, such as special education schools, public health nurses, other parent groups, developmental centers, etc., can be approached to send home letters explaining the program to solicit referrals of appropriate parents. Confidentiality usually prohibits these agencies from releasing parents names; however, they will usually send the information if requested to do so. Attachments III A and B are sample letters you may use.

An introductory meeting for prospective Parent to Parent supporting parents should be held to explain the program and discuss plans for training. For these parents who make the decision to volunteer, the first training session will be an orientation meeting. (Attachment IIIF).

Another recruitment technique is to approach the communication media. The local newspapers, as well as television and radio stations, will run public service announcements concerning the program and the introductory meeting. These announcements serve not only as a recruitment tool, but to prepare the community for the eventual availability of the Parent to Parent Program.

An extremely important factor to be taken into account throughout the process of recruitment is the consideration of what characteristics typify good candidates for supporting parent volunteers. Some of these characteristics are:

1. An acceptance of their handicapped child and some degree of healthy resolution of feelings within their family system.
2. An interest in devoting time to the actual parent to parent contacts as "new" families are referred.
3. A receptivity to participate in all the scheduled parent training sessions.
4. An open-minded attitude and tolerance of values and feelings which differ from their own.
5. A willingness and ability to share their experiences with referred parents and interested persons.

Further qualities desired are explained in the screening instrument. (See Attachments IIIC). This tool may be used to determine the readiness of the prospective supporting parent to work in the Program. The use of the screening tool is optional and one may prefer to use his or her own judgement or the recommendation from another community agency. Many parents may be known to the sponsoring agency or have been recommended by another community agency staff person. Basic information is gathered pertaining to the parents when they apply to become supporting parents (See Attachment III E.) This information is retained for use when matching supporting parents with new parents who are referred to the Program. The Parent to Parent Fact Sheet (Attachment III D) can be used to explain the program to interested parents.

Recruitment and screening of potential supporting parents is often a simple process, for those parents who are most confident about their ability to help will volunteer and those that are still working through this experience will remain uninvolved. However, in discussing their own crisis, some parents may realize they are not ready to help others. In this case, the Coordinator should offer alternative ways to participate in the program such as fundraising, educational meetings, developing program materials, support meetings, social events, and clerical help. The parent may have other skills that could benefit the program and allow them to be part of the group and gain the benefit of the group's support and its sense of belonging. It is probably for these benefits that such parents joined the program.

Attachment IIIA

Dear Agency :

Enclosed you will find a letter to prospective parents inviting them to participate in a Parent to Parent Program we hope to develop in this area. We are seeking your assistance in identifying those parents who would be best suited for this purpose.

The Parent to Parent Program is based on the philosophy that parents of developmentally disabled children experiencing crisis can be helped by parents who have made an adjustment to their own handicapped child and who have the willingness to help others by sharing their experiences. These parents also share their belief that offering support and factual information about a child's handicap enables parents to view, in a positive manner, their child's ability to grow, learn and develop to his or her fullest potential.

In order to accomplish these goals, supporting parents offer:

1. Emotional support and understanding.
2. Factual information about developmental disabilities and handicapping conditions.
3. Information about services, educational programs, and support and advocacy agencies.
4. Introduction and access to people and groups who share their concerns and interests and who can help them meet their needs as well as those of their child.

In addition, the developmental growth of parents participating in Parent to Parent will produce a positive change in attitudes, values, capabilities, concerns, and involvement creating a common bond that draws closer the parents, their families, and the community.

We feel this program will be a valuable resource for the community and help to meet the needs of parents with handicapped children.

We know there are many parents in the community who would make excellent supporting parents. Please read the handouts enclosed and send a copy of the parent letter to those parents you would recommend as supportive parents. If confidentiality allows you to do so, you may send me a list of names to contact.

If you have any questions, comments or suggestions, please contact me at (telephone) .

Sincerely,

Attachment IIB

Dear Parents:

The United Cerebral Palsy Child Development Center and March of Dimes are very interested in developing a Parent to Parent Program in this area. We have asked that this letter, inviting you to participate, be given to parents.

The Parent to Parent Program is an opportunity for parents of children with a disability to provide emotional support and information to parents who have just learned that their child has a disability. This is accomplished by matching parents with similar backgrounds so that informal and personal assistance can be offered by one parent to another.

Supporting parents not only offer support but also provide information on specific services and programs that are so essential to helping the child develop to his or her fullest potential. They can also talk about the pleasures as well as the problems of parenting a child with special needs and most importantly can just "be there" at a time of crisis.

Supporting parents will be prepared for this sharing experience by a series of training sessions to be held at the United Cerebral Palsy Center.

If you are interested in learning more about Parent to Parent and perhaps becoming involved as an organizer or as a supporting parent, please attend a meeting to be held Tuesday, January 22, 1985 at the United Cerebral Palsy Child Development Center at 621 Kraft Avenue, Panama City, Florida at 7:00 p.m.

Sincerely,

PARENT TO PARENT SCREENING INTERVIEW

Explain the following to prospective supporting parents:

1. Purpose of Parent to Parent support.
2. Screening process.
3. Training sessions.
4. Work with new parents, including contact within one day.
5. Monthly meetings.
6. One year commitment.

Interview Questions:

1. Tell me about your special needs child.
2. What were your feelings when you found out your child was handicapped?
3. How has (child's name) affected your family?
4. What does the future hold for (child's name) when he or she grows up?
5. Do you think you can be involved with other people without having it hurt you?
6. Are you involved in any parent group or voluntary association?
7. Do you feel you have time to be involved in Parent to Parent?
8. Why would you like to be a supporting parent?

Interview Checklist:

1. Complete the checklist based on the prospective supporting parents' answers to the interview questions.
2. If there were two interviews, checklists are to be compared and responses reconciled between the interviewers.
3. Checklist includes a determination of acceptance to become supporting parents.
4. Regardless of determination, checklists are to be kept and filed.

Notification of Outcome of Screening Process:

The Parent to Parent Coordinator notifies the prospective pilot parents of the results of the screening process.

Attachment IIIC

PARENT TO PARENT SCREENING INTERVIEW CHECKLIST

Name of Prospective Supporting Parents: ____________________

Interviewer: ____________________ Date: ____________

For each quality/ability, check yes if parents seem to have reached the described level; check no if not.

QUALITIES/ABILITIES	YES	NO
<u>Acceptance of handicapped child</u>		
View handicapped child as a valuable person.		
Accept child's strengths and weaknesses and have expectations which seem realistic for the child.		
Believe child can learn and view learning opportunities as important.		
Participate actively in services provided to own child (are seeking or have obtained services, participate in and monitor services and advocate for change as needed).		
Have successfully worked through any anger regarding child being handicapped and professionals involved.		
<u>Acceptance of other people who have disabilities</u>		
Accept other people who have handicaps.		
View all people as valuable.		
Interested in helping other people.		
Believe disabled people have rights, including the right to live in the community.		
<u>Ability to provide support to other parents</u>		
Willing to share own experiences.		
Concerned about other people.		
Not judgemental of other people.		
Would view role as supporting other people in their decisions, not assuming a decision-making role.		
Are coping with own family problems well.		
Can identify other people's feelings.		

QUALITIES/ABILITIES	YES	NO
Ability to cope with other people's problems		
Willing to become personally involved with other people's problems.		
Can cope with other people's problems without being hurt by them.		
Can handle confidential information without the need to discuss with other people.		
Ability to communicate		
Express selves adequately.		
Are good listeners.		
Maturity		
Able to accept rejection by others without being personally offended.		
Can work without a lot of praise or recognition.		
Willing to give to others without expectation of returns.		
Time		
Have time to be involved in Parent to Parent (based on the judgement of the prospective parents).		

Comments and Recommendations

Parents should be accepted to become supporting parents.
(Yes rating in all of the above areas.)

If not recommended for acceptance into Parent to Parent, what other areas were discussed (voluntary association or services):

Adapted from Pilot Parents

PARENT TO PARENT OF FLORIDA

FACTS ABOUT PARENT TO PARENT SUPPORT PROGRAMS

1. THE PURPOSE of parent to parent support programs is to match trained support parents with parents who are experiencing a time of crisis or seeking information.

2. SUPPORTING PARENTS is the term for trained volunteers who are personally well adjusted and who have successfully integrated a child with special needs into their family and are willing to share their feelings and experiences with other parents. Supporting parents are open-minded and non-judgmental.

3. SPECIAL NEEDS are defined as any sensory, physical or learning disorder, developmental disabilities such as cerebral palsy, autism, epilepsy, mental retardation or spina bifida, children with emotional disturbances, and those children who are high risk or developmentally delayed due to prematurity, environment or some unknown cause.

4. SUPPORTING PARENTS are trained to be peer support parents by successfully completing a series of workshops on communication skills, developmental disabilities, local, state and national resources, community outreach and the referral process.

5. REFERRED PARENTS is the term for parents who are experiencing a time of crisis related to their child's disability or seeking information. These situations may include the time of the initial diagnosis, hopsitalization, the educational process, sexuality, group home exploration or guardianship issues.

6. INITIAL CONTACT by a supporting parent is made within 24 hours of a request being received, or as soon as possible thereafter. Contact is made either by phone or in person. The amount and kind of continued contact depends on the needs and desires of the referred parents.

7. PARENT TO PARENT makes contact with referred families only when these families express an interest in talking with a supporting parent. Contact is never made without the referred parent's consent and confidentiality is maintained at all times.

8. SUPPORTING PARENTS do not provide formal counseling but do offer encouragement, emotional support and information on an informal and personal basis. Supporting parents model appropriate early accessing of resources.

9. SUPPORTING PARENTS do not give advice, particularly medical advice. They may give general suggestions or outline options, but they leave decisions to the referred parents.

10. SUPPORTING PARENTS serve to model the normalization principle for families experiencing the crisis of acceptance and make them aware of the important affect their attitude will have on their child's development.

11. PARENTS are matched as closely as possible according to several relevant criteria: diagnosis or degree of child's disability, age of child, marital status, racial, religious or cultural factors, geographic location of residence, etc.

12. PARENT TO PARENT support may help to reduce the incidence of child abuse and neglect by providing an emotional outlet and reducing family stress.

13. PARENT TO PARENT support programs strengthen the partnership between parents and professionals in a local community. Supporting parents are the nucleus for each local program and receive support and assistance from at least one professional person within the community.

Date ____________

APPLICATION FOR SUPPORTING PARENTS

I. FAMILY INFORMATION

Name ______________________________ Age ________

Address ______________________________ Phone ________
City, State

Education ____________________ Occupation ____________________

Place of Employment ______________________________

Interests/Hobbies ______________________________

Marital Status ___ Separated ___ Married ___ Divorced ___ Widowed ___ Single

Spouse's Name ______________________________ Age ________

Education ____________________ Occupation ____________________

Place of Employment ______________________________

Interest/Hobbies ______________________________

How would you rate your family's income?

___ Low Income ___ Low Average ___ Average ___ High Average ___ High Income

Name of Each Child	Birthdate	Sex

II. INFORMATION REGARDING SPECIAL NEEDS CHILD

Name of your special needs child ______________________________

Describe your child's special needs ______________________________

____

____

____

____

Does your child have any other problems? ___ Yes ___ No

If yes, what are they?______________________________

Does this child live at home? ___ Yes ___ No

If not, where?______________________________

Please list the programs in which this child has participated (starting with most current program).

NAME OF PROGRAM	DATES OF PARTICIPATION

PARENT TO PARENT PROGRAM

INTRODUCTORY MEETING AGENDA

To familiarize prospective supporting parents with the Parent to Parent Program.

Presentation should include:

1. What Parent to Parent is
2. How it can function locally
3. Who it serves
4. Responsibilities of supporting parents
5. Training sessions
6. Role of sponsoring agency
7. The referral process
8. Other needs of the program parent volunteers can fulfill (i.e., public relations, fundraising, child care)

Invitation to participants to sign up for training to become supporting parents.

Suggestions:

1. Provide childcare during meetings
2. Schedule meeting time when both fathers and mothers can attend.
3. Be brief--Those parents who are interested will receive complete orientation to program at the first training session.

CHAPTER IV

PLANNING THE TRAINING SESSIONS

WHAT IS A GROUP LEADER?

A Group Leader is:
creative,
nonjudgmental,
democratic,
excited,
exciting,
sharing,
inspiring,
strong,
sensitive,
perceptive,
a member
of a team,
patient,
growing,
learning,
open,
alive,
honest,
exploring,
feeling,
YOU.

PLANNING THE TRAINING SESSIONS

The materials and information contained in this part of the training manual have been compiled and developed from many valuable sources. The information available to train parent to parent volunteers is consistently growing and being improved. What we have offered here is only a guide. You may wish to change, omit, or supplement to meet the needs of your particular training style and the needs of your group.

The training sessions are perhaps the most important component of the Parent to Parent Program. A well-planned, well-implemented training program is not only advantageous, but necessary to equip volunteers to offer the most effective support, guidance, and information possible.

The training sessions do much more than provide a solid foundation of information about developmental disabilities and available community resources. The sessions also provide an opportunity for self-evaluation; each participant can examine his feelings about his own family situation, and about his tolerance of others whose values, beliefs, and actions may vary greatly from his. Knowledge and self-awareness are both essential characteristics of a good parent outreach volunteer.

Some of the characteristics of the Program Coordinator mentioned in previous chapters, directly pertain to his or her ability to lead these training sessions. The group leader must, of course, have a good working knowledge about developmental disabilities and about services and resources available to meet the special needs of clients and their families. In addition, the coordinator must be familiar with concepts of group dynamics and interpersonal communication skills and techniques. The latter skills are necessary to assure that the process of self-evaluation, sharing feelings and concerns, are growth-producing experiences rather than threatening or destructive encounters.

The topics to be covered in the training, the format of the training and size of the group will all vary from community to community. It will take some time to plan the training sessions. This manual will outline a six session format with each session lasting approximately two and one-half hours. An alternative to this format would be a two day session lasting approximately six hours. We recommend twelve to eighteen hours of training with a group size of twelve to fifteen. This size of group has proven to be quite effective. A larger group is not conducive to the comradeship and group interaction we have observed in small groups. The time and location of the training session should be established to fit the preference of the group members. Child care should be made available to prospective supporting parents.

Attachment IV-A is a checklist designed to insure that the training sessions are smooth and purposeful. These are suggestions that may be adapted to your particular group as needed.

The topics to be covered in the six training sessions are as follows:

Training Session I - Orientation
Training Session II - Developmental Disabilities/Special Needs
Training Session III - Peer Counseling Skills
Training Session IV - Parent to Parent Support
Training Session V - Resources
Training Session VI - Referral Process and Community Outreach

Attachment IV A

Training Session Preparation Checklist

1. Read all training materials, be familiar with resources you choose to use.

2. Contact speakers for the training session.

3. Locate films and other materials pertinent to the topics selected.

4. Prepare an outline of the training sessions time and place of training and mail it to all participants.

5. Prepare agenda for each training session.

6. Prepare packets for supporting parents.

7. Prepare new parent packets. (You may want to do this as a group project)

8. Establish starting and ending times of sessions, allowing for a break time during the meeting. Also allow time for visiting before and after the meetings.

9. Confirm speakers a day or two before sessions.

0. Call all participants on day of session to confirm their attendance.

1. Check meeting room for wall plugs, light controls and extension cords.

2. Make name tags.

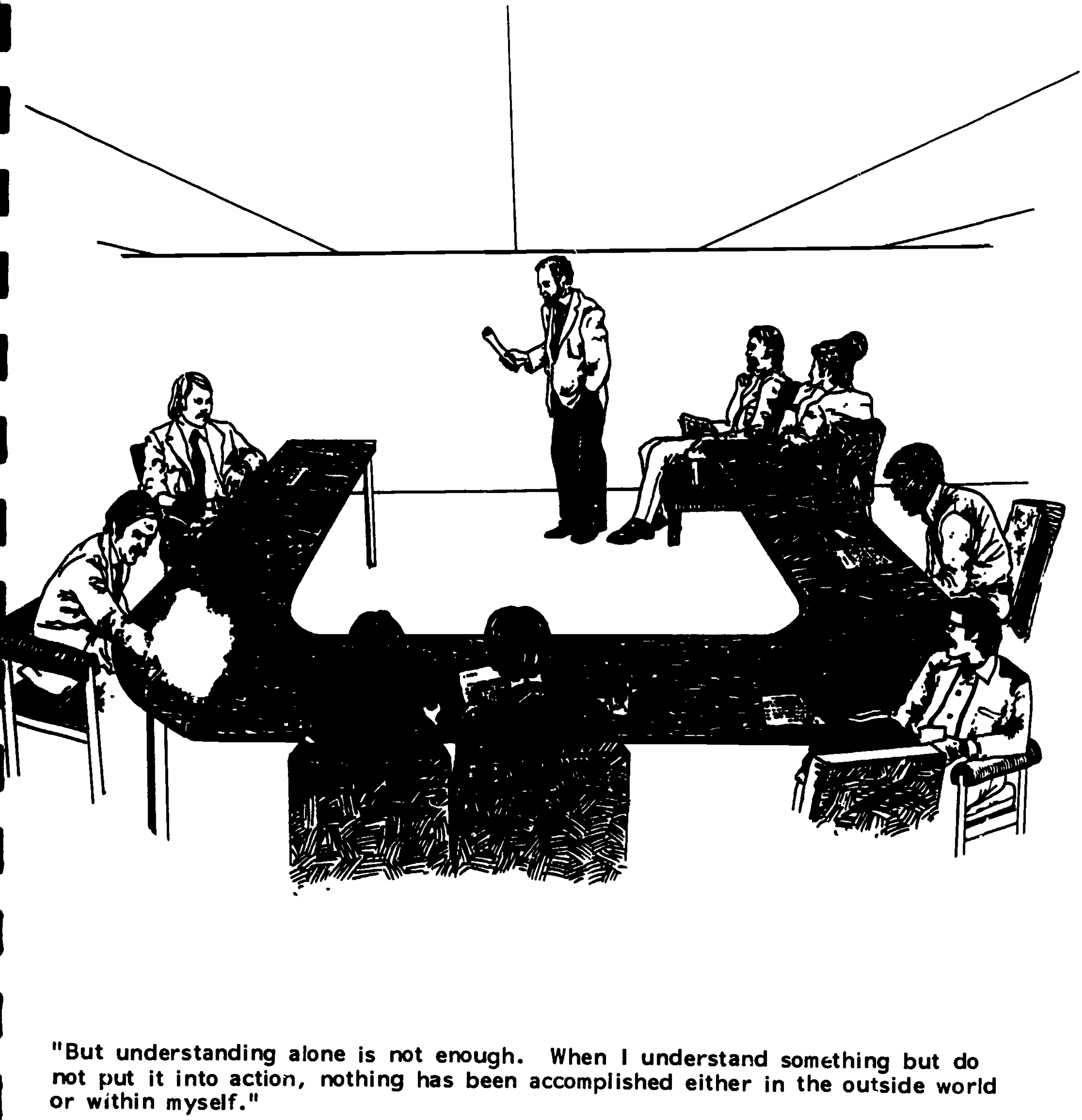
3. Make coffee and refreshments available.

4. Provide childcare if needed.

Adapted from Pilot Parents

CHAPTER V

TRAINING SESSIONS



"But understanding alone is not enough. When I understand something but do not put it into action, nothing has been accomplished either in the outside world or within myself."

Bary Stevens in Person to Person

TRAINING SESSION I

ORIENTATION

CONSIDER THESE OPTIONS

- Accept the fact that the "child of your dreams" never was and never would have been. All parents must acknowledge this sooner or later. Your problem: You must do it sooner.

- Love your child exactly as he or she is. Real love does not demand that persons change into what we want them to become before we can start loving them.

- Take advantage of the early discovery of your child's handicap. The sooner you find professionals and advocates willing to help you and your youngster, the better. Early intervention is crucial.

- Take comfort in knowing it is better that your child's birth came now, rather than thirty years ago. Today, supportive persons are available in the community; there are even parents available who have experienced what you are going through. Their number grows each year. Thirty years ago, you would have been torn between two terrible choices--keeping your child at home with no help from anyone...or sending your youngster away.

So let the child of your mind die. Let the real child live!

Robert Perske "New Directions of Persons Who Are Retarded", 1975.

TRAINING SESSION I

ORIENTATION

OBJECTIVES

The objectives of the orientation session are as follows:

1. To familiarize prospective supporting parents with the Parent to Parent Program.
2. To acquaint parents with one another and create a comfortable atmosphere.
3. To assist participants in self assessment and evaluation regarding their own feelings and experiences in parenting a special needs child.
4. To preview the six scheduled training sessions.

SAMPLE AGENDA FOR TRAINING SESSION I

I. INTRODUCTIONS

As parents arrive for the first session it is important that they are made to feel comfortable at once. Name tags should be available to facilitate easy introductions. A brief introduction and welcome by the group leader is sufficient at this time as parents will have the opportunity for more personal introductions later in the session.

II. ANNOUNCEMENTS

If the sessions are to be taped, prior permission should be obtained from each participant. Taping allows make-up for parents who are absent from a session.

There should be a statement of expectations that participants will attend all six sessions. (If attendance at any meeting is impossible, the volunteer is required to arrange an individual contact with the coordinator.)

The responsibility of parents to read all materials distributed to better prepare them to actively participate in subsequent sessions should be stressed.

It is important to assure parents that the training coordinator will be available to talk about any concerns a parent may have during the sessions.

III. OVERVIEW OF PARENT TO PARENT

This should be a brief introduction to the Parent to Parent program. Many parents may have already attended an introductory meeting and, therefore, have a basic understanding of the program. The following materials should be distributed and discussed:

A. Purposes and Philosophy (Attachment V - IA)
B. Parent to Parent Fact Sheet (Attachment V - IB)
C. Tips for Supporting Parents (Attachment V - IC)

The Group Leader should allow for a question and answer time for clarification of any materials presented.

IV. PARENT INTRODUCTION EXERCISE

Announce the introduction game by reminding participants that the success of the group is based on getting to know one another and being able to feel more comfortable in getting acquainted with a stranger. Then ask parents to find someone in the group whom they have not met and to pick a quiet spot where they can talk with one another for ten minutes. Each person is to talk about himself for five minutes while the other listens. After ten minutes, the whole group reassembles and each person then introduces his partner and relates two or three facts about the person that were of particular interest. In a large group, this game can take considerable time, so it may be necessary to limit the number of facts to be shared.[1]

V. REFRESHMENT BREAK

Ask parents to get acquainted with others whom they do not know during the refreshment break.

VI. GROUP DISCUSSION

The Group Leader begins this section with a general presentation on reactions of parents finding out their child has special needs. The group leader will hand out a copy of "Weird Times" (Attachment V - ID). The group will then break into small groups of six or eight for a discussion time. The group leader will then ask each person to answer the following questions:

A. What motivated you to come tonight?

B. What would have been helpful to you when your child was first diagnosed?

C. What concerns might you have in talking to a referred parent?

While answering these three questions, the parent shares with the group his or her past experiences and feelings. It may occasionally be necessary for the group leader to draw out the feelings and details of the experiences of some people. He or she must do this tactfully and supportively. It is important that prospective supporting parents understand, and be willing to verbalize, their feelings and experiences regarding their handicapped child. Hence, he or she should be guided to give a reasonably full account in answering the three questions. This sharing is very important for it enables the members of the group to become better

---

[1] Project COPE

acquainted with each other, and to understand and empathize with each other's feelings. From this understanding develops a cohesiveness which continues to grow as the training continues.

The group discussing and sharing points out many similarities in experience but, to the surprise of many participants, it also exposes a diversity of reactions and feelings.

VII. PREVIEW OF TRAINING SESSIONS

The group leader should give a brief overview of the upcoming training session and distribute any handouts required for the next session.

VIII. CLOSING

The group leader should summarize the sessions key points and end the session by answering any questions. Make sure all participants have completed a supporting parent form. (Attachment III E)

IX. ADDITIONAL SUGGESTIONS

A. A notebook or folder for the training parents to collect materials.

B. Show and discuss the following films:

1. Gift of Love

Available in 1/2" and 3/4" VHS videocassette
Thought-provoking interview with 4 families; 25 minutes
Free loan from: National Down Syndrome Society
70 West 40th Street
New York, NY 10018
(800) 221-4602 or (212) 764-3070

2. You Don't Outgrow Down Syndrome

Available in 35 mm slide/tape and 1/2" and 3/4" VHS videocassette

Alerts physicians and hospital personnel to need for information and support for parents of a newborn with Down Syndrome. Parents and physicians voice difficulties and problems encountered. Strongly advocates parent support groups. 1982 production, 18 minute color program.

For rent and purchase price, write:

National Association for Down Syndrome
Box 63
Oak Park, IL 60303
(312) 543-6060

3. Can We Help? We've Been There

Filmstrip, color, 15 minutes
A fine overview of Project COPE. Use at first meeting. Available through OPARC
9260 Monte Vista Avenue
Montclair, CA 91763
(714) 621-3884

4. <u>"Cry Sorrow, Cry Hope"</u>
16mm, 58 minutes

To rent: The Pilot Parent Program
3212 Dodge Street
Omaha, NE 68131
(402) 348-9220

PARENT TO PARENT OF FLORIDA PHILOSOPHY

Parents of special needs children who have come to accept and understand their child's disability are one of the best sources of information and emotional support for other parents of children with special needs who may be experiencing difficulties. By virtue of having "been there" a unique bonding occurs between parents establishing an almost immediate rapport and sharing of common feelings and experiences.

A supporting parent's skills are enhanced through their participation in parent to parent support training; however, it is their willingness and ability to share their experience that qualifies them to positively interact with other parents. Supporting parents are not trained to be professional counselors or therapists but are parents who have successfully met the challenges of parenting a special needs child and, hence, are viewed by parents as capable helpers. Parent to Parent of Florida defines special needs as any sensory, physical, or learning disorder, developmental disabilities such as cerebral palsy, autism, epilepsy, mental retardation or spina bifida children with emotional disturbances, and those children who are high risk or developmentally delayed due to prematurity, environment or some unknown cause.

As a result of parent to parent interaction, parents are better able to approach their child's ability to grow, learn and develop to his or her potential with an optimistic attitude and within a supportive environment. Early success in relating to this life experience will positively affect family relationships and future decisions made on behalf of the child.

We believe parent to parent support should be available not only at the time of the initial crisis but throughout the child's life. The areas of concern are endless and range from coping with the initial diagnosis to a myriad of specific issues such as sexuality and guardianship.

Parent to Parent of Florida believes that the benefits of parents helping other parents facilitates the developmental growth of families through heightened awareness, knowledge, and acceptance of their child's special needs. Parent to parent support should be easily accessible within the local community to all parents of special needs children.

PARENT TO PARENT OF FLORIDA

FACTS ABOUT PARENT TO PARENT SUPPORT PROGRAMS

1. THE PURPOSE of parent to parent support programs is to match trained support parents with parents who are experiencing a time of crisis or seeking information.

2. SUPPORTING PARENTS is the term for trained volunteers who are personally well adjusted and who have successfully integrated a child with special needs into their family and are willing to share their feelings and experiences with other parents. Supporting parents are open-minded and non-judgmental.

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12. PARENT TO PARENT support may help to reduce the incidence of child abuse and neglect by providing an emotional outlet and reducing family stress.

13. PARENT TO PARENT support programs strengthen the partnership between parents and professionals in a local community. Supporting parents are the nucleus for each local program and receive support and assistance from at least one professional person within the community.

PARENT TO PARENT OF FLORIDA

DOs AND DON'Ts FOR SUPPORTING PARENTS

DOs

1. Listen to what the referred parent has to say.

   Allow the referred parents to express their feelings and ask questions. Do not overwhelm them with your experiences, suggestions, and general information. Let the new parents vent their emotions.

2. Visit and take pictures with you.

   At some time during your contact with the referred parents, have a few pictures of your child from birth to the present with you. Referred parents are anxious to see how other children with the same handicap look when they are older.

3. Be sure to relate to baby or child when visiting a family.

   Hold and play with the child. If the child is obviously handicapped you may be the first to relate positively other than the family. Also acknowledge spouses and siblings.

4. Encourage parents to take pictures of their child.

   An opportunity once lost can never be regained. Regardless of what they think their child looks like, encourage parents to take pictures right from birth.

5. Take referred parents to the services if need be.

   A referred parent may need transportation to a service, or perhaps may need moral support to get there. If necessary, accompany them rather than have them miss an appointment.

6. Be a crutch for your referred family.

   A supporting parent can be a "crutch" for the referred family by offering the support needed until they are able to cope with the situation. However, care should be taken to not allow the family to become too dependent.

7. Supporting parents help new families to make new friends.

   Many times friends will stop associating with families with a child diagnosed handicapped. Through the supporting parents and the Parent to Parent program, new friendships can be developed.

8. Commit yourself to Parent to Parent for one year.

   Support parenting can be very time consuming; therefore, a commitment for only one year is asked. However, it is not compulsory to leave and you can remain with the program as long as you wish.

9. Supporting parents are expected to attend monthly or bi-monthly meetings.

   Monthly or bi-monthly meetings are held to continue education, keep abreast with community services, and share experiences. These meetings should be held on the same evening each month, perhaps the same evening as the training sessions.

10. Encourage parents to take time out for themselves.

11. Remember to do #10 yourself.

DON'Ts

1. Do not be critical or judgmental.

   Supporting parents should not be critical or make a judgment of a family's home, furniture, housekeeping, or personal appearance. The only thing to be concerned with is the family's adjustment to their child and the obtaining of services for their child.

2. Do not give advice, particularly medical advice or advice regarding medications.

   Supporting parents are not professionals. Do not give specific instructions; give several suggestions and leave final decisions to the parents.

3. Don't be too positive in your attitudes when a family has just learned that their child is handicapped.

   When talking to a referred family, be reassuring but do not be too enthusiastic about your child. It may be some time before they will be able to accept the thought that raising a handicapped child has its pleasures and rewards.

4. Don't be too positive about specific services. Try to keep an open mind about the services.

   If the supporting parent is too positive about a specific service the parent may be made to feel they have made a poor choice if theirs is not the same. There may be unknown reasons why they cannot select the same service as the supporting parent.

5. Don't use alot of "alphabet soup"; i.e., IEP, ARC, HAB, DD.

   Supporting parents help referred parents with new medical terms and vocabulary. Assure new parents they will learn the terms in time.

6. Don't overload with too much reading material.

   Overload is different for everyone. Offer the referred parents the materials but explain to them you do not expect them to read everything.

7. Do not allow the referred family to drain you.

   If they have emotional problems, a referred family can become too dependent and demand too much from you. Discuss this with your professional resource persons. It may be they need professional help.

8. Don't worry about delay in obtaining referrals.

   Supporting parents are matched with referred families. This occasionally results in some supporting parents receiving several referrals while other have yet to be assigned one. Be patient. Your time will come. Get involved in other aspects of the program; i.e., fundraising, newsletter, educational activities, etc.

Attachment V ID

BEWILDERING ("WEIRD") TIMES

You will have them, all right. You may wonder if you are losing your mind. Probably not. But strange times will come, and getting through them takes energy and grit.

Some experts have described in detail the stages you are expected to face. The only trouble is that parents who are adjusting to children with handicaps do not follow a set course. Each parent reacts differently.

Here are a few oversimplified descriptions of stages you may—or may not—experience. And many parents could add to this list.

The Drags. It is as if your spring had run down. You feel so tired you can hardly drag yourself around. The sun may be shining, but to you the day seems cloudy. You may feel a lump in your throat or knots in your stomach. It is hard to breath, and every once in a while you may hear yourself sighing. You may even wonder if you have the flu. When these times come, you wish you could find a warm cozy hole, crawl into it, and close a lid after you.

This may be your mind's way of telling you that "out there," there is too much to take. So you slow down, withdraw, move within yourself, interact less with the world around you, and take some time out. This is OK, providing you do not stay out too long.

The Speeds. When this stage approaches, you feel as though somebody has wound your spring too tightly. You move around at a frenzied pace . . .

so much to think about
so much to do
so much ground to cover
so many places to go
so many people to see.

It is as if a combination of the Ten Commandments and St. Vitus Dance energizes your movements. Many new ideas and concepts which need to be acted upon come to your mind. It is your personality's way to "get at it," even if some motions are wasted.

The Blocks. Tough news came from the doctors. But somehow your ears refused to hear what they told you, and your eyes remained blind to the evidence they presented. The knowledge that your child possesses a handicap is hard to take. You may even talk to others as if your child has no handicap. That is OK for awhile. Parents' minds need time to change from believing their child's a superbaby to seeing that child as he or she really is. It is all right to make this shift slowly. But it is unhealthy if it is never made.

The Hurts. No professional can describe all the types of anguish and pain parents feel after learning their child has a handicap. Nevertheless, all of them hurt; they hurt badly!

Such pain can force you to become edgy and nervous: to walk floors or lie awake all night, tossing and turning; or to break down and cry—fathers included.

Bear in mind that when you do feel such pain, it may be your body and mind saying to you that you are strong enough to bear the hurt you must feel. It is my hunch that you will never suffer pain beyond what you can endure. There are many mechanisms within you to dull the senses when things become overwhelming. Some people can become stronger from enduring pain.

If you happen to be hurting while reading these sentences, you may feel anger toward the author of these words. That is OK, too. This book is not intended to bring you comfort. Its purpose is to help you grow and adjust so that you can accept, love, and act creatively on behalf of your child. You cannot do this without experiencing some hurts, enduring them, and working your way through them.

The Guilts. At times you may feel you have committed some horrible sin against God and man. You may even look deeply into your past, searching for that single horrid act that

From Hope for the Families: New Directions for Parents of Persons with Retardation or Other Disabilities. Perske and Perske. Abingdon Press, 1981. Reproduced with permission.

caused it all. But I am willing to wager that no matter how hard you search, you probably will never find such a cause.

Nevertheless, on some days you feel sure that you must be the worst human specimen on the face of the earth. Somewhere, somehow, you committed an unpardonable sin, and now you are paying for it.

Such guilt is phony. It is not the same kind of guilt you feel when you are caught with your hand in the cookie jar—or when you commit other real transgressions of greater magnitude. Therefore, you need not drag out all the black things in your life, examining them one by one. This exercise only gets in the way of adjusting to your child's handicap.

The Greats. While a few days earlier you may have felt that you were the world's worst mom or dad, now it may come to you that you are one of the greatest. You secretly may feel that God has chosen you to bear this extra burden because you are more special than other human beings.

Of course, it is more pleasant to fantasize yourself as being great. It is better than feeling you are the world's worst. So enjoy it while you can. But be careful. Sooner or later somebody will say or do something to send you crashing off your pedestal When that happens, it is to be hoped you will not fall into the guilt trap again. Instead, you may achieve a fresh stability from knowing you are not a superparent. But you aren't a superdemon either. You have your weaknesses and strengths, like everyone else.

The Hates. After hurting for a time, you may search irrationally for chances to blame others and hurt them. Almost anybody you can think of may become a target:

your spouse
your neighbor
your doctor
your minister
your children
your parents
or in-laws.

So you watch and wait. Sooner or later, someone—being human—will say or do something to "justify" unleashing your anger at them.

Fortunately, your gracious friends and relatives often remain unruffled when you blow your stack at times like these.

It is all right to feel such anger and hatred, even though it is irrational. Acting on that anger, however, can be precarious. It could make others hurt . . . then you hurt because you caused them pain . . . and the vicious circle starts over again.

The Escapes. Sometimes when you awaken at 2:00 A.M., you may wish you could close your eyes and never open them again. These wishes usually will remain secret because you will be ashamed of them. Nevertheless, many parents of children with handicaps openly confess to going through stages when they felt such an urge to escape. In spite of such in-the-wee-hours-of-the-morning urges, grit your teeth and hang on. By the time the sun rises, the situation often looks brighter.

Consider These Options

- If you feel like ending it all . . . wait. In time you will realize that such escapes are stupid. They create more problems than they solve.
- Do not divorce your mate this week. Better to wait, even though you harbor fears that your spouse has rotten genes . . . or that it is all his or her fault. (Your marriage partner may be harboring secretly the same fears about you.) It is better to contain such fears for the present and try to work together as a team.
- Shout epithets if you must. But let it come as no surprise that your curses lack the power to shake the foundations of God, nor do they wither the earth. It may be wiser, however, to utter them under your breath, in order to save wear and tear on your throat.

- Do not blame your doctor. The news that your child has a handicap will hurt no matter how he or she breaks the news to you. On the other hand, if your physician, in relating to you and your child, develops irrational blocks, guilts, and greats because of the handicap . . . get yourself another doctor.

- If you find yourself in the drags, enjoy the misery only for a limited time. Then grit your teeth and get going. Move those muscles! Work! Scrub that sink or mow that lawn. Do it even though you do not want to.

- When the speeds come on, stop. Sit down for a moment. Then talk slowly, walk slowly. Pick only one of the 241,000 things you feel you should do that day, and do it.

- Learn to admit to yourself that no matter how real these feelings may seem, they are strange and irrational. They will pass.

- Know that time is your best friend. In time, beautiful sanity can grow out of the terrible chaos.

- Look around and choose genuine support-persons—key professionals, advocates, relatives, friends—who are capable of entering your struggle in a helpful way. More are available than ever before, so do not try to "go it alone." In an international symposium on persons with handicaps, the participants asserted that although the initial pain in parents (upon learning their child is handicapped) remains high, their ability to move through those bewildering stages became easier because of the outside support they received.[1] Also, in a report to the President it was learned that child abuse in one program was nonexistent because of the many helpful family supports from the outside.[2]

- Try to keep the "unbearables" you experience from overflowing onto your child with the handicap. After all, the barriers he or she must overcome or live with are almost unbearable, too. It does not help to heap more burdens on these children when it is all they can do to carry their own.

So, there will be bewildering times in your lives. But as you hang on and move through each one, you will find precious opportunities to be strong and tender at the same time—with yourself, with your child, and with those around you.

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1. R. Perske, ed. *Improving the Quality of Life. A Symposium on Normalization and Integration A Symposium of the International League of Societies for the Mentally Handicapped* (Arlington, Tex · Association for Retarded Citizens, National Headquarters, 1977).
2. R. Perske, "A Coordinated Effort to Take the Risk Out of 'At Risk,' " *The Report to the President, Mental Retardation The Leading Edge—Service Programs That Work* (Washington, D.C · President's Committee on Mental Retardation, 1978)

TRAINING SESSION II

DEVELOPMENTAL DISABILITIES/SPECIAL NEEDS

"You can rebel, resent, resist the situation, constantly question why it happened, play the martyr, mope, and be defeated. Or you can accept the challenge, take up the gauntlet and find the blessing and victory in it, building on and appreciating the positive points, looking for and appreciating the opportunities to grow in depth and sensitivity as a person, finding deep joy in all evidence of overcoming limitation, no matter how small."

Judith L. Jogis, mother of a disabled child in "To Be Spoken Sadly".

TRAINING SESSION II
DEVELOPMENTAL DISABILITIES/SPECIAL NEEDS

OBJECTIVES:

To provide factual information and familiarize parents with developmental disabilities and other special needs that include:

1. Autism
2. Cerebral Palsy
3. Cleft Lip/Cleft Palate
4. Developmental Delay
5. Down Syndrome
6. Emotional Disturbances
7. Epilepsy
8. Learning Disabilities
9. Low Birth Weight
10. Mental Retardation
11. Speech and Language Impairments
12. Spina Bifida
13. Visual and Hearing Impairments

SAMPLE AGENDA FOR TRAINING SESSION II

I. ANNOUNCEMENTS

II. REVIEW

Review briefly last week's session and ask if there are any questions/comments.

III. INTRODUCTION

At this point in training it is important to have a knowledgeable staff person or physician present a general overview of developmental disabilities/special needs. Parents become aware of a lack of knowledge about other special needs as they become acquainted with parents whose children have handicaps different from those of their own child. The group leader should introduce the guest speaker to the parents with some background information concerning his or her qualifications. A panel of specialists could also be used for this presentation.

IV. PRESENTATION

The speaker(s) should address the following issues regarding each developmental disability/special need:

A. What it is
B. Known Causes
C. Possible range of functional limitations
D. Immediate and long-range considerations regarding care, health and growth and development
E. The future
F. Special Considerations
G. Educational Implications

V. REFRESHMENT BREAK

VI. QUESTION/ANSWER TIME

There should be time allowed for questions and answers to allow for clarification.

There are several sources of written materials on these special needs. We have included informational materials presented by several sources. In mary cases these materials are disseminated at no charge. We urge you to write or call these resources for copies to have available for your parents before this training session.

VII. CLOSING

Review next training session and distribute any lesson assignments or handouts.

VIII. ADDITIONAL SUGGESTIONS

The following films are also available on developmental disabilities:

A. Images of Epilepsy (self-awareness)
Three students - (8 year old, early detention)
(13 year old, psycho motor)
(17 year old, grand mal resentment)
Available through: Nebraska Epilepsy League, Inc.
7171 Mercy Road, Suite 129
Omaha, NE 68106

B. Something Different (Cerebral Palsy)
Available through: United Cerebral Palsy of Nebraska
P. O. Box 80103
Lincoln, NE 68501
(402) 466-8302

C. I See You As A Person (Developmental Disabilities)
Available through: Easter Seal Society for Crippled Children and Adults of Nebraska
12177 Pacific
P. O. Box 14204 - West Omaha Station
Omaha, NE 68114
(402) 333-9306

D. Bobby (Autism)
Available through: Information and Referral Services
NSAC
306 - 31st Street
Huntington, WV 25702

E. The Person With Epilepsy
Excellent portrayal of a person with epilepsy; 28 minutes, 16 mm
Free loan for a period of three days
Abbott Laboratories
Audio-Visual Services
Dept. 383
Abbott Park, IL 60064

F. Down Syndrome: New Expectations
35 mm slide/tape and 1/2" and 3/4" VHS videocassette
Highlights four persons with Down Syndrome at various life stages
For rental and purchase price, write:
National Association for Down Syndrome, Box 63, Oak Park, IL 60303

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AUTISM

Definition

According to the National Society for Children and Adults with Autism (NSAC), autism is a severely incapacitating developmental disability that usually appears during the first three years of life.

Prevalence

The rate of prevalence, or how often autism occurs in children, ranges from five to fifteen out of 10,000 births. The different estimates are based on slightly different definitions of autism.

It is four times more common in boys than girls and is rarely found in more than one child in a family.

There appear to be several causes of autism, each with distinct neurological effects. Among these causes are untreated phenylketonuria, rubella, celiac disease, and chemical exposures in pregnancy. No known factors in the psychological environment of a child have been shown to cause autism.

Characteristics

Sometimes infants show autistic behaviors from birth: they appear aloof, resist cuddling and show no interest in their surroundings. Children usually have average appearances. Typical characteristics include:

- absent or delayed speech and language, including immature speech rhythms, limited understanding, and use of words without attaching usual meanings.
- abnormal ways of relating to people, objects, and events
- unusually high or low activity levels
- insistence that the environment and routine remain unchanged
- use of toys and objects in unconventional manners
- slow development or lack of physical, social, and learning skills
- repetitive movements such as rocking and spinning, head banging, and hand twisting.

It should be noted that these characteristics may occur in children with other disabilities. Sometimes the term "autistic-like" behavior is used.

Educational Implications

Early diagnosis of autism is very important, but appropriate help given at any age can make a big difference.

The child or youth with autism appears to profit from a high degree of structure in the educational program. Such programs frequently stress social and language skills, with instruction broken down into small, sequential steps.

Although the majority of children with autism are severely delayed in learning, most can learn academic skills and social functioning in an appropriate program.

Many parents and teachers have found that behavior modification can assist the child in developing appropriate behavior.

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DeMyer, M. Parents and Children in Autism. 1979. (John Wiley and Sons, 605 Third Avenue, New York, NY 10158)

Gillian, James E. Autism: Diagnosis, Instruction Management, and Research, C.C. Thomas. 1981.

Luce, S.C., & Christian, W.P. How to Reduce Autistic and Severely Maladaptive Behaviors. 1981. (H&H Enterprises, Inc., P.O. Box 1070 A-1, 946 Tennessee Street. Lawrence, KS 66044)

National Society for Autistic Children. How They Grow: A Handbook for Parents of Young Children with Autism. 1980. (National Society for Autistic Children, 1234 Massachusetts Avenue, NW, Washington, DC 20005) Available in Spanish

Paluszny, M. Autism, A Practical Guide for Parents and Professionals. 1979. (Syracuse University Press, 1011 E. Water Street, Syracuse, NY 13210)

Park, C.C. The Siege. 1967. (Harcourt, Brace and World, 757 Third Avenue, New York, NY 10017)

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Scnopler, E. Mesibov. G. Autism, in the Adolescent and Adult. 1983. (Plenam Publishing Corp., 233 Spring Street, New York, NY 10013.

Schopler, E. Individualized Assessment and Treatment for Autistic and Developmentally Disabled Children. Incl. Vol. 1 Psycho-Educational Profile. 1978. Vol. 2 Teaching Strategies for parents and Professionals. 1979. (University Park Press)

Wing, L. (Ed.) Early Childhood Autism. 1976. (Pergamon Press, Inc., Maxwell House, Fairview Park, Elmsford, NY 10523)

Resources

Institute for Child Behavior Research
4157 Adams Avenue
San Diego, CA 92116

National Clearinghouse for Mental Health Information
National Institute of Mental Health, HHS
15C-17 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005-4599

NSAC Bookstore
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, DC 20005-4599

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Cerebral Palsy

Definition

According to the United Cerebral Palsy Association, cerebral palsy is a group of disabling conditions caused by damage to the central nervous system. "Cerebral" refers to the brain, while "palsy" describes lack of muscle control that is often (but not always) a nervous system symptom. Cerebral palsy can be mild or severe.

Damage to the brain may occur before or during birth because of illness in pregnancy, premature delivery, or lack of oxygen supply to the baby; or it may occur early in life as a result of an accident, lead poisoning, illness, child abuse, or other factors.

Incidence

Approximately 700,000 Americans (or 16 out of every 5,000) have some degree of cerebral palsy. 10,000 babies with the disorder are born each year, and another 2,000 acquire it in the early years of life.

Characteristics

Four main descriptions of cerebral palsy have been identified:

1. Spastic, the most common type, which results in tense, contracted muscles;
2. Athetoid, which is characterized by constant uncontrolled movements; and
3. Ataxic, which is typified by poor sense of balance and depth perception.
4. A combination of the types of cerebral palsy listed above.

The effects of cerebral palsy depend on the extent and location of the brain damage. One or more of the following conditions may occur:

- seizures
- problems in vision, hearing or speech
- abnormal sensation or perception
- mental retardation
- impairments in arm and leg movement

Educational Implications

Early identification of cerebral palsy can lessen developmental problems and lead to appropriate treatment when it helps the most. Special educators and physicians have discovered that early intervention can make an important difference. Early intervention programs enlist parents and other family members in working with the child in specific activities. These activities, designed by therapist, provide the child with stimulation needed to overcome slower development which is part of cerebral palsy. Other forms of treatment of children with cerebral palsy may include speech and language therapy, occupational therapy, physical therapy, medical intervention and social services.

Among the services that the older child with cerebral palsy may need are: attendant care, continuing therapy, special education, counseling, vocational training, and recreation training. The services required will vary from person to person depending on the nature and severity of the handicap.

Important advances have taken place in the last decade which have a great affect on the long term well-being of children born with cerebral palsy. Advanced technology is being applied to the needs of severely disabled persons with cerebral palsy, including biofeedback, computers and engineering devices. Technological innovations made have been made in the areas of speech and communication, self-care, and adapting jobs. The future may bring even more significant applications.

Another other important development has been an increased ability of disabled persons, including those who are severely disabled, to live independently in the community. Independent living opportunities exist in the form of group, shared and supervised apartments, and of disabled individual living on their own in the community with appropriate support services. Independent Living Centers staffed and run by persons with disabilities have proven to be important resources for disabled persons. Treatment of cerebral palsy requires close cooperation among educational, medical and social services, the family and the individual. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within the limits of safety and health. Teachers and classmates should understand that, although children with cerebral palsy are physically handicapped, they are more like their classmates than different from them.

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Resources

Information on Cerebral Palsy

United Cerebral Palsy Associations
66 East 34th Street
New York, NY 10016
(212) 481-6300

National Easter Seal Society
2023 West Ogden Avenue
Chicago. IL 60612
(312) 243-8400

National Institute for Neurological and Communicative Disorders and Stroke
National Institute of Health, HHS
Building 31, Room 8A-06
Bethesda, MD 20205
(301) 496-5751

Information of Special Education

ERIC Clearinghouse on the Handicapped and Gifted
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(793) 620-3660

Information on Equipment for Children with Disabilities

ABELEDATA
c/o National Rehabilitation Information Center
4407 8th Street NE
Washington, DC 20017
(202) 635-6090

Accent on Information
P.O. Box 700
Gillum Road and High Drive
Bloomington, IL 61701
(309) 378-2961

Information on Design of Accessible Facilities

Adaptive Environments Center
Massachusetts College of Art
26 Overland Street
Boston, MA 02215
(617) 266-2666

Information on Communication Aids

Trace Center Research and Development Center
314 Waisman Center
1500 Highland Avenue
Madison, WI 53706
(608) 262-6966

Information on Rehabilitation and Independent Living

National Rehabilitation Information Center
4407 8th Street, N.E.
Washington, DC 20007
(202) 635-5822

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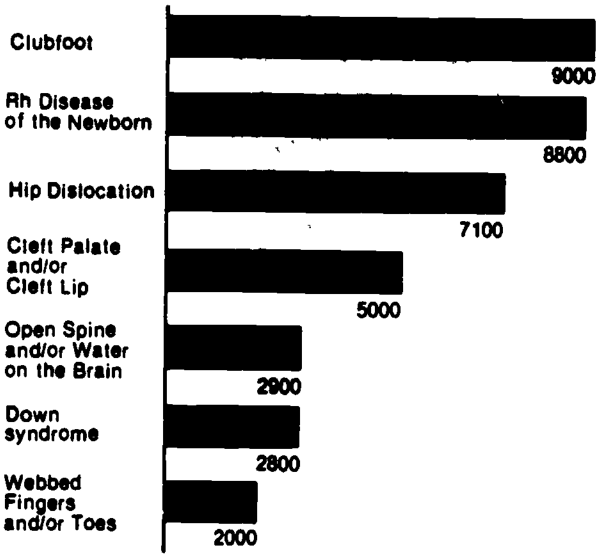
1275 MAMARONECK AVE., WHITE PLAINS, NY 10605
Community Services Department

Public Health Education Information Sheet

CLEFT LIP AND PALATE

Some 5,000 children (one out of every 700 births) are born with cleft lip or palate in the United States each year. "Cleft" describes a split where parts of the upper lip or palate (roof of the mouth) fail to grow together. Some have only cleft lip, while more have only cleft palate. About 40 percent have both cleft lip and palate. The defect appears more often among Orientals and certain tribes of American Indians than among white Americans. It occurs less frequently among black Americans.

ESTIMATED AVERAGE ANNUAL NUMBER OF LIVE BIRTHS WITH SPECIFIED BIRTH DEFECTS, UNITED STATES, 1970 - 1979



Source: Centers for Disease Control

(These estimates are based on hospital discharge notices covering about one-third of the births in the United States. Only those structural defects evident at birth are shown.)

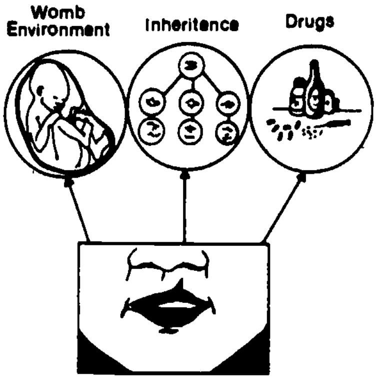
What Causes Cleft Lip and Palate?

There is no one cause for all clefts. Scientists believe that any number of factors such as drugs, disease, heredity, malnutrition, and adverse environment may act on each other to disturb normal growth. Many infants with cleft palate are premature and have other defects.

Heredity appears to play a role in about 25 percent of cases. In the other 75 percent, there is no family history of the defect, even among distant relatives. It is known that if both parents are normal and have a child with a cleft, the chances that subsequent babies will have a cleft increase after each affected child. If either parent was born with a cleft, there is about a four percent risk that their first child will have a cleft, and the chances become greater after each affected birth.

How Do Clefts Affect a Baby's Face?

Cleft lip may involve one or both sides of the upper lip. The split may be only in the upper lip, or may extend up into the nostril. Usually the split goes through the outer skin, muscles, and inside of the lip. Cleft palate may involve only the soft part of the palate toward the back of the throat, or it may extent forward through the hard palate.



Scientists believe that various factors act together to cause cleft palate or cleft lip.

How are Cleft Lip and Palate Treated?

Treatment usually combines surgery, speech therapy, dental corrections, and psychological help. Depending on the type of cleft and infant's general condition, corrective surgery can be started within the first few months. It may be a simple stitching together of the separated edges of the lip; or with a cleft palate, several operations may be necessary. Sometimes tissue grafts are needed. Temporary dental splints or plates are used to keep the upper jaws in proper alignment before and between operations. Braces may be needed later because teeth usually grow in crooked and some may remain impacted in the jaw.

What are the Special Problems Related to Cleft Lip and Palate?

Feeding is the first problem to be overcome. Since a split in the roof of the mouth makes it difficult for a baby to suck, food backs up through its nose and may cause choking. Parents are taught to feed the baby in an upright position, in small amounts, using a nipple with a large hole or syringe. A specially fitted device called and obturator, worn in the mouth, helps in some cases.

Defective speech is one of the most serious results of cleft palate and, to a lesser extent, cleft lip. Psychological problems may result from speech difficulties and the child's unusual appearance before clefts are repaired, and require a professional counselor's help. Clefts have no relation to mental ability or retardation.

Ear infections are common. Difficulty in swallowing affects air pressure around the inner ear through the canal which connects the two. Frequent or severe ear infections may lead to hearing loss.

Can Cleft Lip and Palate be Prevented?

If there is any history of cleft palate or lip in the family, or a history of any other condition of which the cleft is a part, a genetic counselor can assess the chances for passing on the defect.

Non-genetic factors that have been linked to increased risk of clefts include maternal alcohol abuse, diabetes, and treatment with certain anti-cancer drugs or anticonvulsants. Preventive measures therefore include avoidance of alcohol, and medically supervised changes in drug treatment in selected cases. Tighter medical control of diabetes throughout early pregnancy may reduce risk, although this has not been proved. Early and regular prenatal care and good health habits are important for prevention of many birth defects, but cannot guarantee that all babies will be normal.

What Research is Being Done?

Studies have shown that mouth clefts are established before the tenth week of pregnancy. By then, upper jaw and nose tissues have finished growing toward a midline where they fuse to form the palate and upper lip. Because there are so many factors or combinations of factors that may affect this complicated process, research takes many paths.

Scientists are studying the effects on facial development of drugs used to treat epilepsy. Children of epileptic mothers taking anticonvulsant drugs have increased risk of cleft lip and palate. Investigators are also studying genetic differences in body chemistry that may put some individuals at special risk.

Some investigators believe that certain facial characteristics among patients and relatives may help predict the defect. Others continue to explore ways of improving corrective measures and psychological adjustment in children already affected.

For additional copies contact your local March of Dimes chapter.

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This information sheet is made possible through contributions to the March of Dimes

DEVELOPMENTALLY DELAYED

"Developmentally delayed" is a term often used to describe a child who does not seem to be growing and changing according to expected steps. A child can be delayed in one or several, often overlapping, areas. These areas are body movements, speech and hearing, self-care, response to other people, ability to behave, and ability to follow directions. Often both the cause and the extent of delay are difficult to diagnose.

There are many stages in a child's growth. These stages are predictable and happen at about the same age in most children. When these actions and skills do not seem to happen at the expected age, parents will want to start asking questions.

There may be nothing wrong or there may be a reason to be concerned and to get help in infancy or early childhood.

Programs which stimulate a child to develop new skills and abilities are offered by the Florida public school system. These programs rely on people in schools, health centers, and at home to encourage and support a child's growth and progress.

The term "developmental delay" most often simply alerts parents to watch closely as a child grows. Since parents usually know their child best, they are often the first to recognize a potential problem and get help. Fortunately, in today's world, the child with a developmental delay need not be handicapped or held back in any way.

In fact, a child with a physical or mental disability is not, at birth, handicapped, but instead is simply disabled. Doctors, parents, teachers, therapists, relatives and friends will be the ones who may convince a child with a developmental disability that he or she is handicapped.

For all who work with these children, it may be hard to avoid doing this, for our own fears, misunderstandings, and prejudices will come out in many different ways. Often, a person may not even be aware that this is happening.

It is especially important that you, as a parent who cares for a child with a developmental disability, treat your child as if he or she will succeed. There may be unusally difficult obstacles in the way, but your child can still reach some level of success if he or she is supported, encouraged, loved and allowed to succeed as well as fail.

Source: First Steps: A Guide for Parents of Children With Developmental Disabilities. Published by The Florida Developmental Disabilities Planning Council

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NATIONAL INFORMATION CENTER FOR HANDICAPPED CHILDREN AND YOUTH
P O BOX 1492 WASHINGTON, D C 20013

Down Syndrome

Definition

Down syndrome is the most common and readily identifiable genetic condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason and typically due to no one's fault, accident in cell development results in 47 instead of the usual 46 chromosomes. This extra genetic material changes the orderly development of body and brain.

Incidence

Approximately 4,000 children with Down syndrome are born in the U.S. each year, about 1 per 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for children born to women and men over 35. Most common forms of the syndrome do not usually occur more than once in a family.

Characteristics

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- poor muscle tone
- slanting eyes with folds of skin at the inner corners (called epicanthic folds)
- white ("Brushfield") spots in the iris of the eye
- transverse crease on the palm (Simian crease)
- flat bridge of the nose
- short neck
- small head
- small mouth
- heart disorders in approximately ⅓ of people with Down syndrome
- a tendency to respiratory infections

Educational Implications

Shortly after a diagnosis of Down syndrome is confirmed, parents are encouraged to enroll their child in an infant stimulation/early childhood education program. These programs offer special instruction in the acquisition of language and teach specific exercises for gross and fine motor development while also working on cognitive, self-help, and social skills. Research has shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, family involvement, and a stimulating home environment have also been found to have a positive effect on the child's overall development.

Children with Down syndrome develop in different ways and at different paces. Their level of retardation may range from mild to severe with the majority functioning in the mild range. Due to these individual differences it is impossible to predict their future school achievement.

The same general principles of instruction for any child with retarded development apply to a child with Down syndrome. Emphasis is placed on concrete rather than abstract concepts. Tasks and activities are taught in a step by step manner and prompt consistant feedback is continually reinforced. Children with Down syndrome must be helped to learn everyday tasks that non-handicapped children learn incidentally. It is important that all members of the school team and the parents understand the child's capabilities and limitations. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within the limits of safety and health. Teachers and classmates should also understand that children with Down syndrome are more like their classmates than they are different from them.

Medical/Health Implications

There is a wide variation in mental abilities, behavior and developmental progress in individuals with Down syndrome just as in the "normal" regime.

Individuals with Down syndrome are usually smaller than their "normal" peers and their physical as well as intellectual development is slower. Approximately one-third of babies born with Down syndrome have heart defects, most of which are now successfully correctable by surgery. Some individuals with Down syndrome are born with gastro-intestinal tract problems that can be surgically corrected.

A lowered resistance to infection makes children with Down syndrome more prone to respiratory problems.

Eye problems such as crossing and far or near sightedness are higher in the population with Down syndrome while hearing problems may result in mild to moderate hearing loss and speech difficulty.

Some individuals with Down syndrome suffer from a condition known as Atlantoaxial Dislocation. A misalignment of the top two vertebrae of the neck, this condition makes these individuals more prone to injury if they participate in activities which over extend or flex the neck. Parents are urged to have their child examined by a physician in order to determine whether or not their child should be restricted from sports and exercise activities which place stress on the neck. Although this misalignment is a potential serious condition, if properly diagnosed these individuals can be protected from serious injury.

Children with Down syndrome may have a tendency to become obese as they grow older. This weight gain has negative implications for the individuals' later health and longevity. A supervised diet and exercise program may help reduce this problem.

Older individuals with Down syndrome have been found to age prematurely. This aging process has become more apparent since the recent increase in the life span of individuals with the syndrome. There may be a connection between Down syndrome and the eventual appearances of Alzeheimer's disease, although further research needs to be done.

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Resources

Association for Retarded Citizens, United States
2501 Avenue J
Arlington, TX 76011
(817) 640-0204

Caring
P.O. Box 196
Milton, WA 98354
(206) 922-8194

National Down Syndrome Congress
1640 W. Roosevelt Road
Chicago, IL 60608
(312) 226-0416
Toll Free (800) 446-3835
~~National Down Syndrome Society~~
~~146 East 57th Street~~
~~New York, NY 10022~~
~~Hotline: (800) 221-4602~~
~~NY only: (212) 764-3070~~

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70 West 40th Street
New York, New York 10018

Hotline: (800) 221-4602
NY only: (212) 764-3070

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P.O. BOX 1492 WASHINGTON, D.C. 20013

Emotional Disturbance

Definition

Many terms are used to denote severe behavior problems (emotional handicaps or disturbances, behavior disorders, psychological disorder, social maladjustment, delinquency, schizophrenia, mental illness, and psychosis). However, most people would agree that each of these terms indicate behavior that is significantly different from what is expected of someone at a particular age.

Public Law 94-142, The Education for All Handicapped Children Act, defines serious emotional disturbance as "a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

- An inability to learn which cannot be explained by intellectual, sensory, or health factors;
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- A general pervasive mood of unhappiness or depression; or
- A tendency to develop physical symptoms or fears associated with personal or school problems" (*U.S. Federal Register* 42, August 23, 1977, pp. 42478-424-79).

The *Federal Register* definition includes children who are schizophrenic. The law excludes socially maladjusted children (except those determined to be seriously emotionally disturbed) and autistic children (who are included in the "other health impaired" category).

Incidence

For the school year of 1983-84, 362,073 children and youth with emotional disturbance were provided services in the public schools (Seventh Annual Report to Congress, U.S. Department of Education, 1985).

Characteristics

The causes of emotional disturbance have not been adequately determined. Although various factors such as heredity, brain disorder, diet, stress, and family functioning have been suggested as possible causes, research has not shown any of these factors to be the direct cause of behavior problems. Some of the characteristics and behaviors seen in disturbed children include:

- Hyperactivity (short attention span, impulsivity);
- Aggression/self-injurious behavior (acting out, fighting);
- Withdrawal (failure to initiate interaction with others, retreat from exchanges of social interaction, excessive fear or anxiety;
- Immaturity (inappropriate crying, temper tantrums, poor coping skills);
- Social maladjustment (truancy, delinquency); and
- Learning problems (deficits in academic achievement.

The profoundly disturbed child is typically identified as psychotic or schizophrenic. His or her behavior tends to show distorted thinking, excessive anxiety, bizarre motor acts, and frequent mood changes.

Many children who are not emotionally disturbed may display these same behaviors at various times during their development. However, when a child is emotionally disturbed, these behaviors continue over long periods of time. The child's behavior thus signals that the child is not coping with the environment or peers and, in fact, may be bringing harm to himself or herself, and/or to others.

Education

Educational instruction for children with emotional disturbances may be similar to the programming provided to other handicapped children. Major objectives include developing social skills and increasing self-control. Other goals in addition to teaching basic self-care may include teaching basic self-care skills. Career education (vocational programs) is rapidly becoming a major part of secondary education for those children, and is recommended as part of every adolescent's individualized education program (IEP).

Behavior modification is one of the most widely used approaches to teaching children with emotional/behavioral disorders. This approach increases appropriate behaviors and decreases inappropriate behaviors by using the principles of reinforcement and shaping. Art, music, play, and drama therapies have been helpful to some children. Most professionals consider a well structured program to be vitally important when working with disturbed children, regardless of the particular approach chosen. It is important that teachers and parents react as consistently as possible.

The approaches described above together with extra support for teachers have allowed more children with emotional disturbances to be educated in the public schools in the past. Programs are moving towards intensive, short-term intervention rather than specialized placements. The focus of intervention is early detection and prevention.

Other Considerations

Families of children with emotional disturbance may need help in understanding their child's condition and in learning how to work effectively with him or her. Help is available from psychiatrists or psychologists in public or private mental health settings. Sometimes it is necessary to remove the child from the home and to obtain residential care. Each child should be provided services based on his or her individual needs and all persons who are involved with the child should be aware of the care he or she is receiving, that is, it is important to coordinate all services with communication between home, school, and the therapeutic community.

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Resources

American Association of Psychiatric Services for Children
1522 K Street, N.W.
Suite 1112
Washington, DC 20005

(Provides information on meetings and professional journals)

Council for Children with Behavior Disorders
c/o Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

(Distributes a fact sheet on emotional disturbance)

Mental Health Association
1800 North Kent Street
Arlington, VA 22209

(Offers referral services to parents Some affiliates provide parent support services)

National Alliance for the Mentally Ill
1200 15th St., N.W.
Washington, DC 20005

(Distributes literature on emotional and behavioral problems. State affiliates provide support services)

National Clearinghouse for Mental Health Information
National Institute of Mental Health
15C-17 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857

(Distributes literature on schizophrenia and depression as well as child development)

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Epilepsy

Definition

According to the Epilepsy Foundation of America, epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working properly, a persons consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

Some people can experience a seizure and not have epilepsy. For example, many children have convulsions from fevers. These febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure does not mean the person has epilepsy.

Incidence

About 2.5 million Americans have epilepsy. Of the 100,000 new cases that develop each year, three quarters of them are in children and adolescents.

Characteristics

Although the symptoms listed below are not necessarily indicators of epilepsy, it is wise to consult a doctor if you or a member of your family experiences one or more of them:

- "Blackouts" or periods of confused memory;
- Episodes of staring or unexplained periods of unresponsiveness;
- Involuntary movements of arms and legs;
- "Fainting spells" with incontinence or followed by excessive fatigue;
- Odd sounds, distorted perceptions, episodic feelings of fear that cannot be explained.

Seizures can be generalized, meaning that all brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are partial if the brain cells not working properly are limited to one part of the brain. Partial seizures may produce periods of automatic behaviour and altered consciousness.

Educational Implications

Epilepsy is defined as one of the potentially handicapping conditions in P.L. 94–142, The Education for All Handicapped Children Act. A student with epilepsy doesn't necessarily require a special education placement unless he or she also has some other special need such as a learning disability or mental retardation. In these instances, the epilepsy or related conditions may then interfere with the child's ability to learn.

If a child's physical or intellectural skills seem markedly altered since the seizures began, tell your doctor. There may be an associated hearing or perception problem caused by the brain changes. In addition, if a child has the type of seizure characterized by a brief period of fixed staring at school, he/she may be missing parts of what the teacher is saying. Ask your child's teacher to observe and document these episodes.

It's important that teachers understand about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. Most parents find that a friendly conversation with the teacher(s) at the beginning of the school year is the best way to handle the situation. Even if a child has seizures that are largely controlled by medication, it is still best to notify the school staff about the condition.

Children and youth with epilepsy must deal with the psychological and social aspects of the condition; this includes its lifelong nature, uncertain occurrence, loss of self control, and negative attitudes towards the condition.

School personnel and parents should work together to monitor the effectiveness of medication as well as any side effects. Their written observations will be helpful to the neurologist.

Individual decisions must be made regarding a child's participation in physical activities. It is important that both parents and teachers avoid overprotection. Teachers and classmates should also understand that, although children with epilepsy may have special needs, they are more like their classmates than different from them.

There are many materials available for parents and teachers, so that they can understand how to work most effectively together. The student will benefit the most when both teachers and parents are working together.

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Resources

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700

Epilepsy Information Line
University of Washington-Seattle
Toll Free Information Line.
(800) 426-0660

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Learning Disabilities

Definition

The regulations for Public Law 94-142 (The Education for Alll Handicapped Children Act) define a learning disability as "disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations."

The Federal definition further states that learning disabilities include "such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." According to the law, learning disabilities do not include learning problems that are primarily the result of visual, hearing, or motor handicaps; mental retardation; or environmental, cultural, or economic disadvantage. Definitions of learning disabilities also vary among states.

Having a single term to describe this category of children with handicaps reduces some of the confusion, but there are many conflicting theories about what causes learning disabilities, how many children with learning disabilities there are, and so on. The label "Learning Disabilities" is all-embracing; it describes a syndrome, not a specific child with specific problems. The definition is comprehensive; it assists in classifying children, not teaching them. Parents and teachers need to concentrate on the individual child. They need to observe both how and how well the child performs, to assess strengths and weaknesses, and to provide and invent ways to help each child learn. It is important to remember that there is a high degree of interrelationship and overlapping among the areas of learning. Therefore, children with learning disabilities may exhibit a combination of characteristics. These problems may mildly, moderately, or severly impair the learning process.

Prevalence

Many different estimates of the number of learning disabled children have appeared in the literature (ranging from 1% to 30% of the general population). Differences in estimates perhaps reflect variations in the definition. The most widely cited estimate is that 2% to 3% of school-aged children and youth are learning disabled.

Characteristics

Students who have learning disabilities may exhibit a wide range of traits, including problems with reading comprehension, spoken language, writing, or reasoning ability. Hyperactivity, inattention, and perceptual coordination problems may also be associated with learning disabilities, but are not examples of it. Other traits that may be present include a variety of symptoms of brain dysfunction, such as uneven and unpredictable test performance, perceptual impairments, motor disorders, and such emotional characteristics as impulsiveness, low tolerance for frustration and problems in handling day to day situations.

One of the most apparent characteristics of learning disabilities is a significant difference in the child's achievement in some areas, as compared to his or her overall intelligence.

The major learning disabilities occur in four categories:

1. Spoken language: Delays, disorders, and deviations in listening and speaking.
2. Written language: Difficulties with reading, writing, and spelling.
3. Arithmetic: Difficulty in performing arithmetic functions or in comprehending basic concepts.
4. Reasoning: Difficulty in organizing and integrating thoughts.

Educational Implications

Because learning disabilities are manifested in a variety of behaviour patterns, the Individual Education Program (IEP) must be designed carefully. A team approach is important for educating the child with a learning disability, beginning with the IEP process and continuing with close collaboration among special class teachers, parents, resource room teachers, regular class teachers, and others.

Some teachers report that the following strategies have been effective with some students who have learning disabilities:

- High structure and clear expectations
- The use of short sentences and a simple vocabulary
- Opportunities for success in a supportive atmosphere
- Flexibility in classroom procedures (e.g., allowing the use of tape recorders for note-taking and test-taking when students have trouble with written language)

- Use of self-correcting materials that provide for immediate feedback without embarrassment.

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Resources

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515 or 8077

Closer Look
LD TEENLINE
800-522-3458 (Mon. thru Fri. 10 am to 4 pm)
A toll-free information and referral service for parents of learning disabled teens, educators and teens themselves.

Division of Learning Disabilities
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Foundation for Children With Learning Disabilities (FCLD)
P.O. Box 2929
Grand Central Station
New York, NY 10016
(212) 687-7211

National Network of Learning Disabled Adults (NNLDA)
808 North 82 Street #F2
Scottsdale, AZ 85257

Orton Dyslexia Society
742 York Road
Baltimore, MD 21204
(301) 296-0232

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March of Dimes
BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, New York 10605

Public Health Education Information Sheet

LOW BIRTHWEIGHT

Until recent years, many doctors restricted a woman's diet during pregnancy. They believed that little weight gain and a small baby were best for safe, easy delivery. Others felt that this was not best for healthy births. Indeed a recent study showed that a 24- to 30-pound weight gain for mother and a 7-pound, 4-ounce birthweight for baby were far healthier and safer for both.

Low birthweight now is considered the most common problem at birth, affecting one in every 12 babies born each year in the United States. It helps account for some 70 percent of our infant deaths.

WHAT IS LOW BIRTHWEIGHT?

Babies weighing 2,500 grams (5 pounds, 8 ounces) or less at birth are considered "low birthweight." If they weigh 1,500 grams (3 pounds, 5 ounces) or less, they are designated "very low birthweight."

Low birthweight can be separated into two categories:

- **Preterm births** are babies born before 37 full weeks of pregnancy. These babies usually weigh less than 2,500 grams, and they account for most cases of low birthweight. The earlier a baby is born, the less it is likely to weigh, and that puts the baby at risk for many complications.
- **Small-for-date** babies (also called "small for gestational age" or "growth-retarded") may be full-term but are too small. Their low birthweight results from a slow-down or temporary halt during the baby's growth in the womb, and puts them at risks similar to those of a preterm baby.

WHAT CAUSES LOW BIRTHWEIGHT?

There are several known reasons why babies may be born too small, too soon, or both. Some are as yet unknown; others are suspected.

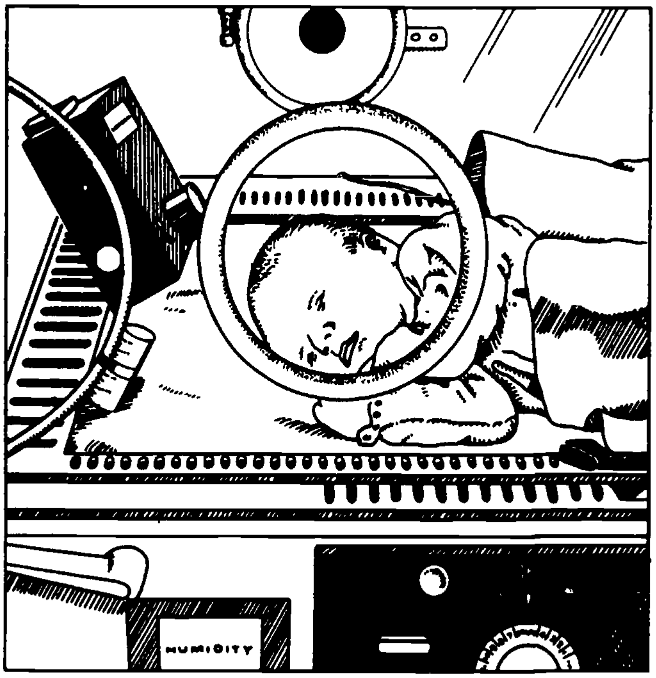
Earlier pregnancies that ended in miscarriage or a low-birthweight baby may be the result of conditions that could lead again to a low-birthweight baby. There may be an inherited disease in her family that can cause fetal defects. Defects in an unborn baby, inherited or caused by an environmental factor, may keep it from growing to its normal birthweight.

Medical background of a mother influences birthweight, especially if she has high blood pressure, diabetes, heart, kidney, or breathing problems, hepatitis, viral or bacterial infections. Toxemia of pregnancy also may cause prematurity.

A mother's habits during pregnancy may affect birthweight. Among these are:

- Poor nutrition. An unborn baby is nourished by what its mother eats.
- Lack of early and regular prenatal care.
- Smoking, alcohol and drugs. Smokers tend to have smaller babies. Drug or alcohol use may stunt an unborn baby's growth.

Social factors, such as low income or little schooling, may place mothers at risk of having a low-birthweight baby. These mothers may be unable to afford good food and health care, or have never learned how to take care of themselves. Teenagers, especially, may not know or care about improving their health habits. Teenagers under 17 are among the mothers at greatest risk of having low-birthweight babies.



HOW ARE LOW BIRTHWEIGHT PROBLEMS TREATED?

Special lifesaving equipment in intensive care nurseries helps to sustain small babies who otherwise might not survive. If a baby has trouble breathing, special cribs (isolettes), oxygen, and medication are right at hand. If the baby has low blood sugar, glucose can be fed through its veins.

If the infant is jaundiced, it may be treated with special lights in the nursery (phototherapy). If anemic, it may be treated with dietary iron supplements. In severe cases, it is given a blood transfusion.

Bleeding in the brain can't be corrected except in rare cases where vitamin K may help. Doctors watch for and treat the secondary effects of brain bleeding to help prevent possible brain damage. They examine normal spaces in the brain (ventricles) with such devices as ultrasound or CAT scanners. The spaces may begin to fill with fluid, which could be damaging. Doctors may put a tube inside to help drain the fluid off (shunting). In other cases, a hollow needle is put into the lower spine to drain off fluid. This is done every few days or so, until, as often happens, the excess fluid build up stops.

HOW DOES LOW BIRTHWEIGHT AFFECT A BABY?

Any of the complications that can happen to a newborn are more likely to happen to a low-birthweight baby than one of normal size.

The baby may have trouble breathing. Its lungs may not get enough oxygen to supply its blood system and body tissues. Some low-birthweight babies have low blood sugar (hypoglycemia), which may cause tremors, eye-rolling, poor appetite or brain damage. Jaundice (yellowish skin) may show that the baby's liver is slow to start working on its own. (During pregnancy, the mother's liver works for both of them.)

A premature baby may be anemic (have fewer red blood cells). Normally, the unborn baby stores iron during the later months of pregnancy and uses it in early infancy to make red blood cells. Born too soon, the infant may not have enough time to build up iron stores.

Low-birthweight babies may not have enough fat under their skins to help keep a healthy body temperature. This can cause blood chemistry changes and slow growth.

One of the most severe results of low birthweight is bleeding in the brain. It happens to 40 to 45 percent of infants weighing less than 1,500 grams and may result in brain damage or death.

Later in childhood, nervous system and behavior problems may occur, as a result of the low birthweight.

CAN LOW BIRTHWEIGHT BE PREVENTED?

Through public and professional health education, parents and health care workers can learn how to avoid or treat many factors that may contribute to low birthweight.

The first step is **early and regular prenatal care.** Health care professionals often can tell in advance which pregnant women or unborn babies may be at risk. Threatening medical conditions often can be safely treated and good health habits outlined. Weight gain can be carefully watched for unusual changes that might affect birthweight.

Among programs sponsored by the March of Dimes, a recent San Francisco study showed that preterm delivery (birth before 37 weeks) could be prevented in a large number of cases when the start of preterm labor was noted early enough for drug treatment to be effective.

Through public health education and community programs, **good nutrition** can be taught and made available where needed, mothers can be motivated to take care of their health, and to avoid cigarette smoking, alcohol use, and taking unprescribed drugs.

WHAT RESEARCH IS BEING DONE ON LOW BIRTHWEIGHT?

The March of Dimes supports many areas of research related to the cause, prevention and treatment of low birthweight. Investigators are studying fetal cells and the role of hormones in promoting fetal growth. They also are studying hormone influence on newborn blood sugar put out by the liver, to help prevent damaging low blood sugar levels.

Scientists are looking for the causes of bleeding in the premature baby's brain, to learn why some have it and others not.

Researchers are seeking a better understanding of how labor starts, to help find ways of preventing preterm labor. They are looking for better ways of treating breathing difficulties, to prevent side effect damage to the lungs and eyes. Temperature regulation in newborns is under research, and so are environmental factors in the nursery (light, noise, etc.) that might disturb growth.

Other grants support study of home care of low-birthweight babies for ways to prevent possible later mental and behavior problems.

For additional copies contact your local March of Dimes chapter

March of Dimes
BIRTH DEFECTS FOUNDATION

This information sheet is made possible through contributions to the March of Dimes.

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Mental Retardation

Definition

Persons with mental retardation are those who mature at a below average rate and experience unusual difficulty in learning and social adjustment. The American Association on Mental Deficiency (AAMD) provides the following technical definition, which is widely accepted.

"Mental Retardation refers to significantly subaverage general intellectual functioning in or associated with impairments in adaptive behavior and manifested during the development period."

Intellectual functioning is defined by a score on an IQ test. Persons with mental retardation usually score below 70, or in specific cases, based on new definition, below 75. Adaptive behavior refers to the person's adjustment to everyday life. Difficulties may occur in learning communication, social, academic and vocational skills. The amount of difficulty experienced will depend upon the person's age or development stage. The developmental period is from birth to age 22.

The AAMD definition does not mention prognosis or cause of mental retardation. Although there are more than 250 specific identified causes, in most cases the exact reasons for retardation are unknown.

Mental retardation is not a disease, nor should it be confused with mental illness. Mentally retarded children grow into mentally retarded adults; they do not remain "eternal children." The big difference is that they learn more slowly and with much greater difficulty.

Incidence

Depending upon the definition and measurement approach used, estimates of mentally retarded persons in the general population range from 1% (when relying on the adaptive behavior measurement) to 3% (when the IQ score is emphasized).

According to data reported to the U.S. Department of Education by the states, in the 1983-84 school year, 750,534 students with mental retardation were provided services by the public schools. This number represents 1.86% of the school enrollment.

About 89% persons with mental retardation are mildly retarded; about 6% are moderately retarded; and about 5% are severely or profoundly retarded.

Many authorities agree that individuals with mental retardation develop in the same way that nonretarded persons do, but at a slower rate, and reach a lower overall level of functioning. Others suggest that persons with retardation have difficulties in particular cognitive areas, such as attention, perception or memory. Depending on the extent of the retardation—mild, moderate, severe, or profound—individuals will develop differently in academics, social, and vocational skills.

Mildly retarded persons are in many respects quite similar to their nonretarded peers. While still young their retardation is not readily apparent. Moderately retarded persons are more obviously handicapped, and their retardation is usually apparent before school age. Severely or profoundly retarded persons have obvious intellectual impairments and frequently have other handicaps such as cerebral palsy, epilepsy, blindness, or deafness.

Appropriate educational opportunities beginning in infancy and continuing throughout the development period will allow retarded children to develop to their fullest potential. They can enter the competitive labor market and the mainstream of daily life. Persons with retardation can learn to care for their basic needs and can perform useful work with supervision.

Educational Implications

Persons with mental retardation have the capacity to learn, to develop, to grow. The great majority of retarded persons can become productive and full participants in society. As with all education, individualization is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

In teaching persons with retardation, it is important to:

- Use concrete materials,
- Proceed in small sequential steps and to review each step frequently,
- Provide prompt and consistent feedback, and
- Stress the child's success.

Simple everyday tasks that nonretarded persons learn without instruction need to be structured and specifically taught to persons with retardation. Similarly, tasks should be presented so that the students are able to apply what they have learned to other situations. Special care should be taken to obtain and hold the students' attention.

Children and adults with retardation need the same basic services that other human beings need for normal development. These include education, vocational preparation, health services, recreational opportunities, and many more. In addition, many persons with retardation need specialized services to meet extraordinary needs. Such services include diagnostic and evaluation centers, special early education opportunities beginning with infant stimulation and continuing through preschool, additional day training after completing school with an emphasis on independent living and vocational skills, sheltered employment, assistance in obtaining full employment, and community living opportunities.

Other Considerations

Recent scientific development conclude that preventive measures are effective in reducing the incidence of retardation. Some specific approaches to prevention include:

- Being sure that women are vaccinated for rubella at least three months before they become pregnant,
- Providing proper prenatal care for the mother-to-be, including attention to diet and providing the infant with an adequate diet,
- Checking for Rh factor incompatibility between mother and infant and preventing harm when it occurs by exchanging the baby's blood at the time of birth and providing special immunization for the mother, and
- Preventing children from eating paint containing lead and providing quick treatment if lead poisoning does occur.

Mental retardation has been defined traditionally as an irreversible condition. However, recent advance in technology have been such that there are strong indications that it may be possible within the foreseeable future to significantly enhance intellectual functioning and to reverse certain deteriorative processes. With the application of the current development of new knowledge, the scientific community is working to seek cures for disorders and conditions that cause mental retardation.

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Resources

American Association on Mental Deficiency
5101 Wisconsin Avenue, N.W., Suite 405
Washington, DC 20016

Council for Exceptional Children
Division on Mental Retardation
1920 Association Drive
Reston, VA 22091

International League of Societies for the Mentally Handicapped
12 Rue Forestiere
Brussels 5, Belgium

National Association for Retarded Citizens/US
P. O. Box 6109
2501 Avenue J
Arlington, TX 76011

National Head Injury Foundation
18A Vernon Street
Framingham, MA 01701

People First International
(Self Advocacy Group)
P. O. Box 12642
Salem, OR 97304

President's Committee on Mental Retardation
U.S. Department of Health & Human Services
Office of Human Development Services
Washington, D.C. 20006

Special Olympics, Inc.
1701 K Street, N.W., Suite 203
Washington, DC 20006

The Association for Persons with Severe Handicaps
7010 Roosevelt Way, N.E.
Seattle, WA 98115

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Speech and Language Impairments

Definitions

Speech and language impairments refer to problems in communication. Examples include fluency problems (called dysfluency or commonly, "stuttering"), articulation problems, voice disorders, and aphasia (a difficulty using words, usually as a result of brain injury).

The development of speech and/or language may be delayed due to many factors, including environment or hearing loss. Sometimes speech or language impairments may result from other conditions, such as learning disabilities, mental retardation, and cerebral palsy.

Prevalence

Five percent of school aged children are estimated to have speech and language disorders. The number of students identified with delayed speech decreases steadily as children mature.

Characteristics

A child with delayed communication is noticeably behind his or her agemates. Frequently a child will have greater receptive (understanding) than expressive (speaking) language skills. In that case, children may be able to follow directions but have problems producing comprehensible speech or correct syntax and articulation. (Syntax refers to the order of words in a sentence, articulation refers to how sounds are formed. Articulation disorders are characterized by substituting one sound for another such as "wabbit" for "rabbit," by omitting sounds such as saying "han" for "hand," or by distortions such as saying "thay" for "say".)

Students whose primary language is different from standard English may have difficulty communicating in the majority language.

Stuttering, a disorder of speech flow, most often appears between ages 3 and 4 and may progress from a periodic to a chronic problem. Although many children who stutter recover by puberty or early adolescence, speech and language therapy should be considered.

Physical problems, such as cleft lip or palate, may result in difficulties with certain sounds or with control of the voice quality. Articulation problems, a very common form of speech disorder, result in omissions, substitutions, or distortions of sounds.

Typical voice disorders include hoarseness, breathiness, or sudden breaks in loudness or pitch. Frequently, voice disorders are combined with other speech problems to form a complex communication disorder.

Educational Implications

Language experiences are central to a young child's development. Because they introduce and interpret the world to their children via language, parents play a crucial role in stimulating interest and skills with words.

Speech and language therapists function in a support role for teachers of children with communication handicaps. Sometimes therapists remove a child from the class for individual speech therapy, although many therapists now consult with teachers about the best ways to help the child in the regular class setting. The same kinds of helpful techniques may be shared with the parents, so the improvement approach is consistent at home and at school.

Many speech and language "problems" are part of a child's normal development in learning to talk. They become problems when the child is seriously behind his or her same age friends. If you are concerned about a child's speech or language, consult a speech and language therapist. In all cases, it is important to remember that children with speech and language impairment are more like their classmates than different from them.

Technology can help children whose physical conditions make communication difficult. The use of electronic communication devices allows even severely physically disabled people to engage in the give and take of shared thought.

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Resources

American Cleft Palate Educational Foundation
Parent Liaison Committee
Louisiana State University Medical Center
Department of Audiology and Speech Pathology
3735 Blair
Shreveport, LA 71103

American Speech Language and Hearing Association
10801 Rockville Pike
Rockville, MD 20852

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234

Division for Children with Communication Disorders
c/o The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Institute of Nerological and Communicative Disorders and Stroke
National Institutes of Health, HHS
Building 31, Room 8A—06
Bethesda, MD 20205

Prescription Parents (Cleft Lip/Palate)
P. O. Box 426
Quincy, MA 02269

Trade Research and Development Center for the Severely Communicatively Handicapped
314 Waisman Center
1500 Highland Avenue
Madison, WI 53706

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SPINA BIFIDA

Definitions

Spina bifida means cleft spine, which is an incomplete closure in the spinal column. The three types of spina bifida (from mild to severe) are:

1. SPINA BIFIDA OCCULTA: There is an opening in one or more of the vertebrae (bones) of the spinal column without damage to spinal cord.

2. MENINGOCELE: The meninges, or protective covering around the spinal cord, have pushed out through the opening in the vertebrae in a sac called the "meningocele". However, the spinal cord remains intact. This form can be repaired with little or no damage to the nerve pathways.

3. MYELOMENINGOCELE: Not only are there openings in vertebrae, but the spinal cord itself does not close. It usually protrudes from the back.

Prevalence

Approximately 40% of all Americans have spina bifida occulta, but very few of them ever even know it. The two other forms, collectively referred to as "spina bifida manifesta", occur in approximately one out of every thousand births. Of these, 4% have the meningocele form and 96% have myelomeningocele.

Characteristics

The effects of myelomeningocele, the most serious form of spina bifida, may include muscle weakness or paralysis below the cleft, loss of sensation below the cleft, and loss of bowel and bladder control. In addition, since the spinal cord is the system by which fluid is normally drained from the brain, the fluid may build up and cause hydrocephalus or accumulation of fluid on the brain. 70-90% of the children born with Spina Bifida have hydrocephalus. Hydrocephalus is controlled by a surgical procedure called "shunting" which relieves the fluid buildup in the brain area. Hydrocephalus may occur without Spina Bifida, but the two defects often occur together. If a drain (shunt) is not implanted, the pressure buildup can impair the functioning of the brain.

Educational Implications

Although spina bifida is relatively common, until recently most children born with a myelomeningocele died shortly after birth. Now that surgery to close the spine can be performed in the first 48 hours of life, children with spina bifida are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. School programs should be planned with this consideration in mind.

Many children with myelomeningocele need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of fluids. Catheterization in the schools has been an issue in the courts of some states. Where this issue has been litigated, the courts have held that clean, intermittent catheterization is a related service when it is necessary to help the child benefit from and have access to special education and related services.

Often children with spina bifida who also have a history of hydrocephalus experience learning problems. They may have difficulty with paying attention, expressive and receptive language, reading and math. Early intervention with children who experience learning problems can make it possible to be integrated with their non-disabled peers when they begin school.

Successful integration of a child with spina bifida into a school attended by non-disabled young people sometimes requires changes in school equipment or curriculum. In the same way as a student placement should be the least restrictive one appropriate for him or her, the day-to-day school pattern also should be as "normal" as possible. In adapting the school setting for the child with spina bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving Federal funds make their programs accessible. This could mean structural changes (for example, adding elevators or ramps) or schedule or location changes (for example, offering a course on the ground floor). Recent legislation provides up to $40 million in Federal funds throughout the nation for renovation of school buildings to make them accessible.

Children with spina bifida need to learn mobility skills, often with the aid of crutches, braces, or wheelchairs. It is important that all members of the school team and the parents understand the child's physical capabilities and limitations. Physical disabilities like spina bifida can have profound affects on children's emotional and social development. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within the limits of safety and health. Teachers and classmates should also understand that, although children with spina bifida are physically handicapped, they are more like their classmates than different from them.

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Resources

Information on Spina Bifida

Spina Bifida Association of America
343 South Dearborn Avenue, Suite 317
Chicago, IL 60604
(312) 663-1562
(800) 621-3141 (except Illinois)

March of Dimes Birth Defects Foundation
Post Office Box 2000
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
(312) 243-8400

National Center for Education in Child and Maternal Health
3520 Prospect Street, N.W.
Washington, DC 20007

Information on Special Education

ERIC Clearinghouse on the Handicapped and Gifted
1920 Association Drive
Reston, VA 22091
(703) 620-3600

Information on Equipment for Children With Disabilities

ABELDATA
National Rehabilitation Information Center
4407 Eighth Street, N.E.
Washington, DC 20017
(202) 635-6090

Accent on Information
Post Office Box 700
Gillum Road and High Drive
Bloomington, IL 61701

Information of Design of Accessible Facilities

National Center for a Barrier Free Environment
1015 - 15th Street, N.W.
Washington, DC 20036
(202) 466-6896

Adaptive Environment Center
Massachusetts College of Arts
26 Overland Street
Boston, MA 02215
(617) 266-2666

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Visual Impairments

Definitions

The terms "legally blind", "partially sighted", and "low vision" may mean different things in legal and educational contexts. The educational definitions of the terms are given below:

- Visual handicap indicates that some type of visual problem has resulted in a need for special education.
- Blindness refers to a condition with no vision or only minimal vision (light perception). Blind students learn via Braille or other non-visual media.
- Low vision refers to limited distance vision. People with low vision are able to see items close to them. They use a combination of vision and other senses to learn, although they may require adaptations in the lighting or size of print.

Visual impairments can include myopia, hyperopia, and astigmatism; problems in the visual field; and muscular problems that result in visual disturbances.

Incidence

The rate at which visual impairments occur in the general population increases considerably with age, especially after 65. For individuals under 45, the estimated incidence is 7 per 1,000; for individuals over 65, it is 44.5 per 1,000.

Characteristics

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appeared, and overall functioning level of the child. The child may be delayed in motor, cognitive, and/or social development.

A young child with visual handicaps has little reason to explore interesting objects in the environment, and thus may miss opportunities to have experiences and to learn. This lack of exploration may continue until hearing becomes motivating or until intervention begins.

Because the child cannot see parents or peers, he or she may be unable to imitate social behavior or understand nonverbal cues. Visual handicaps can create obstacles to a growing child's independence.

Educational Implications

The student with visual impairments should be tested early in order to assess remaining vision. Mainstreaming has been a successful way of serving the academically oriented student with visual handicaps. These students may need additional help with special equipment and modifications in the regular curriculum to emphasize listening skills, communication, orientation and mobility, vocation/

career, and daily living skills. Students with low or limited vision may need help in using their residual vision more efficiently and in working with special aids and materials. Students who have visual handicaps combined with other types of handicaps may have greater need for an interdisciplinary approach and may require greater emphasis on self care and daily living skills. It is important that all members of the school team and parents understand the child's physical capabilities and limitations. To promote growth, parents and teachers should avoid overprotection and encourage children to take risks within the limits of safety and health. Teachers and classmates should also understand that, although children with visual impairments and children who are blind are handicapped, they are more like their classmates than different from them.

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Resources

American Association of Workers for the Blind
206 North Washington Street
Alexandria, VA 22314

American Council for the Blind
1211 Connecticut Avenue, N.W.
Washington, DC 20036
(800) 424-8666 toll free
(202) 833-1251

American Foundation of the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000

American Printing House for the Blind
1800 Frankfort Avenue
Louisville, KY 40206
(502) 895-2405

Association for Education of the Visually Handicapped, Inc.
206 N. Washington Street
Alexandria, VA 22314
(703) 836-6060

Division for the Visually Handicapped
c/o The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

International Institute for Visually Impaired, 0–7, Inc.
1975 Rutgers Circle
East Lansing, MI 48823
(517) 351-6300
or
14 Gay Street
Newtonville, MA 02160
(617) 527-0476

National Association for Parents of the Visually Impaired, Inc.
2011 Hardy Circle
Austin, TX 78757

National Association for the Visually Handicapped
305 East 24th Street, 17-C
New York, NY 10010
(212) 889-3141

National Eye Institute
National Institutes of Health
Building 31, Room 6A32
Bethesda, MD 20205
(301) 496-5248

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(301) 659-9314

National Library Service
Division for the Blind and
Physically Handicapped
Library of Congress
1291 Taylor Street, N.W.
Washington, DC 20542
(202) 287-5100

National Retinitis Pigmentosa
Foundation
8331 Mindale Circle
Baltimore, MD 21207
(301) 655-1011
(301) 655-1190 (TTD)
(800) 638-2300

National Society to Prevent
Blindness
89 Madison Avenue
New York, NY 10016
(212) 684-3505

Recording for the Blind, Inc.
20 Roszel Road
Princeton, NJ 08540
(609) 452-0606

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DEAFNESS: A FACT SHEET

FROM THE NATIONAL INFORMATION CENTER ON DEAFNESS AND THE NATIONAL ASSOCIATION OF THE DEAF

Introduction

An estimated 16 million Americans have some degree of hearing impairment. Hearing impairments affect individuals of all ages, and may occur at any time from infancy through old age. The degree of loss may range from mild to severe. This variability in age at onset and degree of loss plus the fact that each individual adjusts differently to a loss of hearing makes it impossible to define uniformly the consequences of a loss.

Of the 16 million Americans who are hearing impaired, over two million are considered deaf. These individuals have hearing losses so severe that they cannot hear or understand either speech or most of the sounds in our everyday environment, even with the help of a hearing aid. The other 14 million hearing impaired Americans have less severe losses and often can be helped to understand speech through the use of a hearing aid.

Audiological/Medical Information

There are four types of hearing loss, each of which can result in different problems and different possibilities for medical and non-medical remediation.

Conductive hearing losses are caused by diseases or obstructions in the outer or middle ear (the conduction pathways for sound to reach the inner ear). Conductive hearing losses usually affect evenly all frequencies of hearing and do not result in severe losses. A person with a conductive hearing loss usually is able to use a hearing aid well, or can be helped medically or surgically.

Sensorineural hearing losses result from damage to the delicate sensory hair cells of the inner ear or the nerves which supply it. These hearing losses can range from mild to profound. They often affect certain frequencies more than others. Thus, even with amplification to increase the sound level, the hearing-impaired person perceives distorted sounds. This distortion accompanying some forms of sensorineural hearing loss is so severe that successful use of a hearing aid is impossible.

Mixed hearing losses are those in which the problem occurs both in the outer or middle and the inner ear.

A **central** hearing loss results from damage or impairment to the nerves or nuclei of the central nervous system, either in the pathways to the brain or in the brain itself.

Among the causes of deafness are heredity, accident, and illness. An unborn child can inherit hearing loss from the parents. In about 50% of all cases of deafness, genetic factors are a probable cause of deafness. Environmental factors (accident, illness, ototoxic drugs, etc.) are responsible for deafness in the remaining cases. Rubella or other viral infections contracted by the pregnant mother may deafen an unborn child. Hazards associated with the birth process (for example, a cut-off in the oxygen supply) may affect hearing. Illness or infection may cause deafness in young children. Constant high noise levels can cause progressive and eventually severe sensorineural hearing loss as can tumors, exposure to explosive sounds, heavy medication, and/or injury to the skull or ear.

Central hearing loss may result from congenital brain abnormalities, tumors, or lesions of the central nervous system, strokes, or some medications that specifically harm the ear.

The detection and diagnosis of hearing impairment have come a long way in the last few years. It is now possible to detect the presence of hearing loss and evaluate its severity in a newborn child. While medical and surgical techniques of correcting conductive hearing losses have also improved, medical correction for sensorineural hearing loss has been more elusive. Current research on a cochlear implant which provides electrical stimulation to the inner ear may lead to important improvements in the ability to medically correct profound sensorineural hearing loss.

Educational Implications

Deafness itself does not affect a person's intellectual capacity or ability to learn. Yet, deaf children generally require some form of special schooling in order to gain an adequate education.

Deaf children have unique communication needs: unable to hear the continuous, repeated flow of language interchange around them, deaf children are not automatically exposed to the enormous amounts of language stimulation experienced by hearing children during their early years. For deaf children, early, consistent, and conscious use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay. Without such assistance from infancy, problems in the use of English typically persist throughout the deaf child's school years. With such assistance, the language learning task is easier but by no means easy.

This problem of English language acquisition affects content areas as well. While the academic lag may be small during the primary grades, it tends to be cumulative. A deaf adolescent may be a number of grade levels behind hearing peers. However, the extent to which hearing impairment affects school achievement depends on many factors—the degree and type of hearing loss, the age at which it occurred, the presence of additional handicaps, the quality of the child's schooling, and the support available both at home and at school.

Many deaf children now begin their education between ages one to three in a clinical program with heavy parent involvement. Since the great majority of deaf children—over 90%—are born to hearing parents, these programs provide instruction for parents on implications of deafness within the family. By age four or five, most deaf children are enrolled in school on a full-day basis. Approximately one-third of school-age deaf children attend private or public residential schools. Some attend as day students and the rest usually travel home on weekends. Two-thirds attend day programs in schools for the deaf or special day classes located in regular schools, or are mainstreamed into regular school programs. Some mainstreamed deaf children do most or all of their schoolwork in regular classes, occasionally with the help of an interpreter, while others are mainstreamed only for special activities or for one or two classes.

In addition to regular school subjects, most programs do special work on communication and language development. Class size is often limited to approximately eight children to give more attention to the children's language and communication needs.

At the secondary school level, students may work toward a vocational objective or follow a more academic course of study aimed at postsecondary education at a regular college, a special college program for deaf students (such as Gallaudet College or the National Technical Institute for the Deaf), or one of the 100 or more community colleges and technical schools that have special provisions for deaf students.

Communication: Some Choices

Communication is an important component of everyone's life. The possible choices for communication involve a variety of symbol systems. For example, you may communicate in English through speaking and writing. Despite your skills, you probably cannot communicate with someone whose only language is Chinese, even though that person also speaks, reads, and writes quite fluently.

In the United States, deaf persons also use a variety of communication systems. They may choose among speaking, speechreading, writing, and manual communication. Manual communication is a generic term referring to the use of manual signs and fingerspelling.

American Sign Language

American Sign Language (ASL) is a language whose medium is visible rather than aural. Like any other language, ASL has its own vocabulary, idioms, grammar and syntax—*different from English.* The elements of this language (the individual signs) consist of the handshape, position, movement, and orientation of the hands to the body and each other. ASL also uses space, direction and speed of movements, and facial expression to help convey meaning.

Fingerspelling

When you spell with your fingers, you are in effect "writing in the air." Instead of using an alphabet written on paper, you are using a manual alphabet, that is, one with handshapes and positions corresponding to each of the letters of the written alphabet.

Conversations can be entirely fingerspelled. Among deaf people, however, fingerspelling is more typically used to augment American Sign Language. Proper names and terms for which there are no signs are usually fingerspelled. In the educational setting, the use of fingerspelling as the primary mode of communication in combination with spoken English is known as the Rochester method.

Manual English

When the vocabulary of the American Sign Language and fingerspelled words are presented in English word order, a 'pidgin' results. Pidgin Sign English (PSE) is neither strictly English nor ASL, but combines elements of both.

A number of systems have recently been devised to assist deaf children in learning English. These systems supplement some ASL signs with invented signs that correspond to elements of English words (plurals, prefixes, and suffixes, for example). There is usually a set of rules for word (sign) formation within the particular

Educational Institutions

Schools for deaf students have traditionally played an important role in advancing the welfare of deaf people through education of deaf students and public information efforts about the capabilities and accomplishments of deaf people. Two national institutions each have enrollments of over 1,000 deaf students.

Gallaudet College
800 Florida Avenue, NE
Washington, DC 20002

National Technical Institute for the Deaf
Rochester Institute of Technology
1 Lomb Memorial Drive
Rochester, NY 14623

For descriptions of the more than 100 postsecondary programs for deaf students at community colleges and technical schools around the country, order a copy of **College and Career Programs for Deaf Students** for $3.50 from:

College and Career Guide
c/o Gallaudet Research Institute
Center for Assessment and Demographic Studies
800 Florida Avenue, NE
Washington, DC 20002

Special Devices for Deaf People

Technology and inventiveness have lead to a number of devices which aid deaf persons and increase convenience in their daily lives. Many of these devices are commercially available under different trade names.

Telecommunications Devices for Deaf People (TDDs) are mechanical/electronic devices which enable people to type phone messages over the telephone network. The term TDD is generic and replaces the earlier term TTY which refers specifically to teletypewriter machines. Telecaption adapters, sometimes called decoders, are devices which are either added to existing television sets or built into certain new sets to enable viewers to read dialogue and narrative as captions (subtitles) on the TV screen. These captions are not visible without such adapters.

Signalling Devices which add a flashing and/or vibrating signal to the existing auditory signal are popular with hearing impaired users. Among devices using flashing light signals are door "bells", telephone ring signallers, baby-cry signals (which alert the parent that the baby is crying), smoke alarm systems. Alarm clocks may feature either the flasning light or vibrating signal.

Some Special Services

Numerous social service agencies extend their program services to deaf clients. In addition, various agencies and organizations—either related to deafness or to disability in general—provide specific services to deaf people. Among these special services are the following:

Captioned Films for the Deaf
A loan service of theatrical and educational films captioned for deaf viewers, Captioned Films for the Deaf is one of the projects funded by the Captioning and Adaptations Branch of the U.S. Department of Education to promote the education and welfare of deaf people through the use of media. This branch also provides funds for closed-captioned television programs, including the live-captioned ABC-TV news.

Registry of Interpreters for the Deaf, Inc.
A professional organization, RID maintains a national listing of individuals skilled in the use of American Sign Language and other sign systems and provides information on interpreting and evaluation and certification of interpreters for deaf people.

State Departments of Vocational Rehabilitation
Each state has specific provisions for the type and extent of vocational rehabilitation service, but all provide vocational evaluation, financial assistance for education and training, and job placement help.

Telecommunications for the Deaf, Inc.
TDI publishes an international telephone directory of individuals and organizations who own and maintain TDDs (telecommunications devices for deaf people) for personal or business use.

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Directory of Services

The April issue of the **American Annals of the Deaf** is a directory of the various programs and services for deaf persons in the United States. Copies of this reference may be purchased from:

American Annals of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910

Additional Information

If you have specific questions that were not answered by this fact sheet, please contact either the National Information Center on Deafness, Gallaudet College, Washington, DC 20002, or the National Association of the Deaf, 814 Thayer Avenue, Silver Spring, MD 20910.

The National Information Center on Deafness (NICD) is a centralized source of information on all aspects of deafness, including education, vocational training, sign language programs, law, technology, and barrier-free design.

NICHCY
NATIONAL INFORMATION CENTER FOR HANDICAPPED CHILDREN AND YOUTH
P O BOX 1492 WASHINGTON, D.C 20013

General Information About Handicaps and People with Handicaps

Definition

The regulations for Public Law 94–142 (The Education for All Handicapped Children Act) list 11 types of handicaps:

1. DEAF
   A hearing impairment so severe that the child is impaired in receiving linguistic information through hearing, with or without amplification.
2. DEAF-BLIND
   Simultaneous hearing and visual impairments, whose combination causes such severe communication and other developmental and educational problems that the child cannot be accommodated in special education programs designed soley for deaf children or blind children.
3. HARD OF HEARING
   A hearing impairment, whether permanent or fluctuating, which is less severe than the definition of "deaf" in this section.
4. MENTALLY RETARDED
   Below average general intellectual functioning existing along with deficits in adaptive behavior and manifested during the developmental period.
5. MULTIHANDICAPPED
   Several simultaneous impairments (such as mental retardation and blindness; mental retardation and orthopedic impairments; and so forth), the combination of which causes such severe educational problems that the child cannot be accommodated in special education programs designed solely for one of the impairments. (This definition does not include a deaf-blind child.)
6. ORTHOPEDICALLY IMPAIRED
   A severe orthopedic impairment, including an impairment caused by a birth defect (e.g., clubfoot, absence of an extremity), an impairment caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairment from any other cause (e.g., cerebral palsy, amputations, and fractures or burns which cause contractures).
7. OTHER HEALTH IMPAIRED
   An autistic condition manifested by severe communication and other developmental and educational problems; or limited strength, vitality, or alertness, due to chronic or acute health problems such as heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes.
8. SERIOUSLY EMOTIONALLY DISTURBED
   A condition in which the individual exhibits one or more of the following characteristics over a long period of time and to a marked degree: An inability to learn which cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems. (This definition includes children who are schizophrenic.)
9. SPECIFIC LEARNING DISABILITY
   A disorder of one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicap, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include a learning problem which is primarily the result of a visual, hearing, or motor handicap, of mental retardation, or of environmental, cultural, or economic disadvantage.
10. SPEECH IMPAIRED
    A communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment.
11. VISUALLY HANDICAPPED
    A visual impairment, with or without correction. The definition includes both partially sighted children and blind children.

Prevalance

In the school year 1981–82, over 4.2 million children received special education and related services in public schools.

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Resources

Alexander Graham Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 20007

American Coalition of Citizens with Disabilities
1200 15th Street, N.W.
Washington, DC 20036

American Council for the Blind
1211 Connecticut Avenue, N.W.
Suite 506
Washington, DC 20036

American Federation for the Blind
15 West 16th Street
New York, NY 10011

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburgh, PA 15234

Association for Persons with Severe Handicaps
7010 Roosevelt Way, N.E.
Seattle, WA 98115

Association for Retarded Citizens/U.S.
National Headquarters
P.O. Box 6109
2501 Avenue J
Arlington, TX 76011

Association for the Care of Children's Health
3615 Wisconsin Avenue
Washington, DC 20016

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

Down's Syndrome Congress
1640 West Roosevelt Road
Chicago, IL 60608

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785

Goodwill Industries of America
9200 Wisconsin Avenue, N.W.
Bethesda, MD 20814

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605

Mental Health Association
1800 North Kent Street
Arlington, VA 22209

National Association of the Deaf
814 Thayer Avenue
Silver Springs, MD 20910

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, DC 20005

National Spinal Cord Injury Association
369 Elliot Street
Newton Upper Falls, MA 02164

Spina Bifida Association of America
343 South Dearborn Street
Suite 319
Chicago, IL 60604

United Cerebral Palsy Association
666 East 34th Street
New York, NY 10016

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Severe and/or Multiple Handicaps

Definition

The term severe handicap indicates an intense degree of a condition such as mental retardation, deafness, blindness, physical disability or emotional disturbance. It may also refer to more than one, or a "multiple" handicap, such as mental retardation and cerebral palsy or blindness and physical disability.

An individual with severe handicaps need not be multihandicapped. Severity describes the degree of involvement in a specific disability.

Incidence

For the 1983–84 school year, the states reported to the U.S. Department of Education that they were providing services to 65,537 children with multiple handicaps. This number represents .17% of the total school enrollment. Severe handicaps are not one of the categories reported.

Characteristics

Children and youth with severe or multihandicaps may exhibit a wide range of characteristics, depending upon the combination of handicaps, the child's age, and the severity of the disabilities. There are, however, some traits that these children may share, including:

- Limited speech or communication;
- Difficulty in basic physical mobility;
- Inability to care for themselves;
- Failure to relate to or attend to others; and
- Tendency toward self-injury or abuse

Medical Implications

Many different medical problems may accompany severe handicaps. A few examples include seizures, hydrocephalus, and scoliosis. These conditions should be taken into consideration when establishing services for the child. A multidisciplinary team consisting of the child's parents, educational specialists, and medical specialists in the areas in which the child demonstrates problems should work together to plan and coordinate the child's services.

Educational Implications

In the past, children with severe and/or multiple handicaps were regularly excluded from the public schools. Since the implementation of P.L. 94–142, the Education for All Handicapped Children Act, public schools are now serving large numbers of severely and/or multiply handicapped students. Some of these children and youths have returned from institutions, others may be entering structured programs for the first time, and still others are graduates of high quality intervention programs.

Educational programs for children with severe and/or multiple handicaps need to incorporate a variety of components to meet the children's tremendous needs. Thus instruction should cover the following areas:

- Academics;
- Communication;
- Sensory stimulation; and
- Self-Sufficiency

Related services are of great importance, and the multidisciplinary approach is crucial. Appropriate persons such as speech and language therapists, physical and occupational therapists, and medical specialists need to work closely with the classroom teacher and parents.

Frequently, classroom arrangements must take into consideration students' needs for medication, special diet, or special equipment. Special aids and adaptive equipment enable the children to increase their range of functioning. In recent years, for example, computers have become effective communication devices. Other aids which may be seen in classrooms include: wheelchairs, typewriters, headsticks (headgear), clamps, modified handles on cups and silverware, and communication boards.

Vocational and leisure skills are a critical consideration for children and youth with severe handicaps. Programming for maximum independence should begin as early as elementary school. To help in post-school adjustment and prepare the student for the greatest degree of independence and self-sufficiency, the program should draw on community services, including group homes, vocational programs, and recreational programs.

Integration with nonhandicapped students is another concern. For many of these students, placement in a special class of a local school allows for interaction during the normal school day.

Editor's Note:

This fact sheet provides information of a general nature. The references and resources provide numerous opportunities to seek more specific information about severe and/or multiple handicaps.

References

Help for Families

Baker, B. L., and others. *Toward Independent Living: Steps to Independence. A Skills Training Series for Children With Special Needs*. 1980. (Research Press, Box 3177, Champaign, IL 61820)
Intended to help parents teach independent living skills to their moderately or severely retarded adolescents, the book focuses on self care, home care, information skills.

Cunningham, C., and Sloper, P. *Helping Your Exceptional Baby: A Practical and Honest Approach to Raising a Mentally Handicapped Child*. 1980. (Pantheon Books, 201 East 50th Street, New York, NY 10022)
The book describes exercises and games to stimulate development of young children with Down Syndrome and other types of retardation.

Doyle, P. B., and others. *Helping the Severely Handicapped Child. A Guide for Parents and Teachers*. 1979. homas Y. Crowell Publishers, 10 East 53rd Street, w York, NY 10022)
is book presents practical suggestions for helping the everely handicapped child at school and at home. There s also a section on special equipment.

atherstone, H. *A Difference in the Family: Life with a Disabled Child*. 1980. (Basic Books, Inc. 10 East 53rd Street, New York, NY 10022)
The author, educator and parent of a severely handicapped child, writes about parents' and siblings' feelings, marital stress, and both sides of the parent-professional partnership.

Finnie, N. R. *Handling the Young Cerebral Palsied Child at Home*. 1975. (E. P. Dutton, 2 Park Avenue, New York, NY 10016)
The book presents a practical approach (with illustrations) to feeding, dressing, and caring for the young child with cerebral palsy.

Freeman, R. D. and others. *Can't Your Child Hear? A Guide for Those Who Care About Deaf Children 1981*. (University Park Press, Baltimore, MD 21202)
Intended primarily for parents, the guide focuses on total communication as a way of life for deaf children.

Holland, E. *Let's Try to Help: A Guide for Parents of Young Multihandicapped Children*. 1976. (Oak Hill School, Connecticut Institute for the Blind, 120 Holcomb Street, Hartford, CT 06112)
Practical teaching methods and activities for parents of blind children with one or more additional handicaps.

Murray, J. B., and Murray, E. *And Say What He Is: The Life of a Special Child*. 1975. (MIT Press, 28 Carleton Street, Cambridge, MA 02142)
Parents of a severely handicapped child describe their encounters with the medical profession, educators, relatives, and friends.

Scott, E. P. and others. *Can't Your Child See?* 1977. (University Park Press, Baltimore, MD 21202)
Written for parents of visually handicapped children, the book includes a section on the needs of multiple handicapped blind children.

Education:

Jegard, S., and others. *A Comprehensive Program for Multihandicapped Children: An Illustrated Approach*. 1980. National Institute on Mental Retardation, Kinsmen NIMR Building, York University, 4700 Keele Street, Downsview, Ontario, M3J 1P3.
The book is designed for parents, teachers and childcare workers involved with multihandicapped and mentally retarded children. The text presents suggestions for developmental activities.

Sailor, W., Wilcox, B., and Brown, L. (Eds.) *Methods of Instruction with Severely Handicapped Students*. 1980. (Paul H. Brookes Publishers, P.O. Box 10624, Baltimore, MD 21204)
This book offers guidelines for the education of students with severe disabilities.

Van Etten, G., Arkell, C., and Etten, C. *The Severely and Profoundly Handicapped. Program, Methods, and Materials*. 1980. (C.V. Mosby Company, 11830 Westline Industrial Drive, St. Louis, MO 63141)
Sections on diagnosis, curriculum, materials and equipment are included in this text on education considerations.

Walsh, S. R., and Holzberg, R., (Eds.) *Understanding and Educating the Deaf/Blind Severely and Profound Handicapped*. 1979. (Charles C. Thomas Publishers, 2600 S. First Street, Springfield, IL 62717)

Fifteen authors contributed papers that focus on evaluation, programming and international education of deaf-blind severely and profoundly handicapped students

Other:

Blacher, J. *Severely Handicapped Young Children and Their Families Research in Review*. 1984. (Academic Press, Inc., Orlando, Florida 32887)
This book incorporates research conducted with families and educators reflecting the progress of the last decades to improve all aspects of teaching severely handicapped children.

Recources

Cerebral Palsy

United Cerebral Palsy Associations
66 East 34th Street
New York, NY 10016

With its affiliates 1) funds research; 2) advocates for the civil rights of disabled people; 3) provides education programs which emphasize prevention; and 4) provides direct services including medical services, special education, recreation, counseling and adapted housing.

Cornelia de Lange Syndrome

Cornelia De Lange Syndrome Foundation
60 Dyer Avenue
Collinsville, CT 06022

The organization is dedicated to parent/family support, education and research relating to individuals affected with CdLS. Publishes a newsletter Reaching Out and a CdLS Directory.

Deaf-Blind

National Association of Deaf-Blind
2703 Forest Oak Circle
Norman, OK 73071

Founded by parents to further educational, rehabilitation, and employment opportunities for deaf-blind people. Provides information and publishes a newsletter.

Deafness

Alexander Graham Bell Association
for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007

Devoted to providing hearing impaired people with the opportunity to develop and use speech. Provides information and publishes a newsletter.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910

NAD recommends and promotes legislation on behalf of deaf people in areas of education, rehabilitation, legal rights for the provision of interpreters, hearing aid regulations, and captioned television.

Down Syndrome

Down Syndrome Congress
1640 West Roosevelt Road
Chicago, IL 60608

With more than 500 affiliates they provide: family support, factual information, bibliographies of materials relating to the disability, local referrals, identification of local resource, and 2 newsletters.

National Down Syndrome Society
146 E. 57th Street
New York, NY 10022

Promotes better understanding of Down Syndrome, the potential of persons with Down Syndrome, and research on the disability. New parent packets of information are available. Toll-free hotline 800-221-4602 NY only 212-764-3070.

Epilepsy

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785

With over 100 affiliated Chapters and 60 local information and referral services, EFA is involved in advocacy and a wide variety of services and programs for the person with Epilepsy. Publishes a newsletter and other helpful information.

Hydrocephalus

Guardians of Hydrocephalus Research Foundation
2618 Avenue J
Brooklyn, NY 11235

Distributes literature on hydrocephalus. Operates a clinic in New York and runs five chapters in others parts of New York state.

Know Problems of Hydrocephalus
Route 1, Box 210A
River Road
Joliet, IL 60436

Is a parent group for families with children who have hydrocephalus.

Mental Retardation

Association for Retarded Citizens/US
Post Office Box 6109
2501 Avenue J
Arlington, TX 76011

With its state and local chapters, promotes better education, training, job opportunities, and housing for mentally retarded children and adults. Also publishes a newsletter.

Muscular Dystrophy

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019

Provides a full range of services for persons with various types of dystrophy.

Neurofibromatosis

National Neurofibromatosis Foundation
70 West 40th Street, 4th Floor
New York, NY 10018

Promotes public awareness, provides professional workshops, produces publications, and offers referral services.

Prader Willi Syndrome

Prader Wili Syndrome
5515 Malibu Drive
Edina, MN 55436

The association shares knowledge and experience about the syndrome and how to manage it. Publishes a newsletter and other helpful information.

Scoliosis

National Scoliosis Foundation
48 Stone Road
Belmont, MA 02178

Provides educational information including audio-visual materials available for grades 5 through 9.

Scoliosis Association, Inc.
1 Penn Plaza
Suite 3300
New York, NY 10119

Provides education of the general public, sponsors screening programs in schools, and publishes a screening manual for school health personnel.

Spina Bifida

Spina Bifida Association of America
343 South Dearborn Street
Suite 319
Chicago, IL 60604

Emphasizes local parent support groups, of which there are approximately 100 in the U.S. and Canada. Publishes manuals and booklets for parents and teachers.

Tourette Syndrome

Tourette Syndrome Association
Bell Plaza Building
41-02 Bell Boulevard
Bayside, NY 11361

Maintains a clearinghouse of information on Tourette Syndrome. Publishes newsletter and other helpful information.

Tuberous Sclerosis

National Tuberous Sclerosis Association, Inc.
Post Office Box 159
Laguna Beach, CA 92652

Brochures, pamphlets for parents, reprints of articles, fact sheets and genetics of Tuberous Sclerosis are available. Publishes a newsletter and maintains a speakers bureau.

Other Helpful Organizations:

ABLEDATA
National Rehabilitation Information Center
4407 Eighth Street, N.E.
The Catholic University America
Washington, DC 20017-2299

Provides information on adaptive equipment and other rehabilitation aids.

Council for Exceptional Children
1920 Association Drive
Reston, VA 2209

Is a membership organization dedicated to advancing the education of exceptional children and youth. Produces publications on special education topics and also conducts computer searches of the literature.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605

Supports medical research, sponsors medical services and community services, and act as an information clearinghouse.

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

In addition to producing a large number of publications on disabilities, sponsors clinics, research, and workshops.

SKIP (Sick Kids [Need] Involved People)
216 Newport Drive
Severna Park, MD 21146

Serves as a support, resource and educational group to help families to plan a smooth transition from hospital to home for children with various levels of physical instability.

The Association for the Severely Handicapped (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115

Is a membership organization including educators, therapists, researchers, doctors, parents, and others concerned with severely handicapped children and adults. Publishes newsletter, journals, and books.

Trace Research and Development Center for the Severely Communicatively Handicapped
University of Wisconsin-Madison
314 Waisman Center
1500 Highland Avenue
Madison, WI 53706

Has list of publications concerning computers and other communication devices.

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TRAINING SESSION III

PEER COUNSELING SKILLS

LISTEN

When I ask you to listen to me
and you start giving advice
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why I shouldn't feel that way,
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something to solve my problem,
you have failed me, strange as that may seem.

Listen! All I asked, was that you listen.
not talk or do--just hear me.
Advice is cheap: 20 cents will get you both Dear Abby and Billy
Graham in the same newspaper.
And I can do for myself: I'm not helpless.
Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do
for myself, you contribute to my fear and weakness.

But, when you accept as a simple fact that I do feel what I feel,
no matter how irrational, then I can quit trying to convince
you and can get about the business of understanding what's
behind this irrational feeling.
And when that's clear, the answers are obvious and I
don't need advice.
Irrational feelings make sense when we understand what's
behind them.

Perhaps that's why prayer works, sometimes, for some people
because God is mute, and He doesn't give advice or
try to fix things. "They" just listen and let you
work it out for yourself.

So, please listen and just hear me. And, if you want to
talk, wait a minute for your turn; and, I'll listen to you.

Anonymous

TRAINING SESSION III

PEER COUNSELING SKILLS

OBJECTIVES

1. To familiarize supporting parents with peer counseling techniques.
2. To provide an opportunity for supporting parents to practice listening and attending skills in a role-play situation.
3. To emphasize the importance of confidentiality, non-judgmental interaction and a trusting relationship.

SAMPLE AGENDA FOR TRAINING SESSION III

I. ANNOUNCEMENTS

II. REVIEW

Review briefly last week's session and ask if there are any questions/comments.

III. INTRODUCTION GAME

When the group is assembled, each parent is given someone else's name tag. Each individual locates that person and shares with the group two or three things he remembers about the person.

IV. DISCUSSION: LISTENING AND ATTENDING SKILLS

Facilitators for this session should be trained in communication and listening skills. They will discuss developing communication skills with an emphasis on good listening and attending skills and telephone counseling. It is important to talk about nonverbal behavior and how it can influence how another person hears us.

As Egan says in The Skilled Helper, "Attending is a manner of being present to another; listening is what one does while attending."

Physical attending involves facing the other person squarely, maintaining good eye contact, and leaning toward the person in a relaxed manner. Attentive listening involves paying attention to what another is saying to you, being sensitive to their frame of reference and checking back occasionally with the person to be sure you are hearing correctly.

Review the finding that in the beginning of most helping situations helping people have a tendency to talk too much. In an overeagerness to help it is easy to jump in too quickly in a conversation. After responding to a person it is important to listen to their feedback to confirm that you were heard accurately. (See Handout on Listening Techniques and Developing a Relationship--Attachments V III A & B). It may be helpful to practice some of these examples as a group before breaking for role plays.

In addition to Egan's book there are a number of books dealing with communication skills and nonverbal behavior that will offer additional material and suggestions for discussion. A local public library or college bookstore would be a fine resource for such material.

It is important to talk about telphone techniques as the first contact with a referred parent will be by telephone. The support parent needs to set aside a time for the call when distractions and interruptions are at a minimum. This initial contact is often lengthy. He or she needs to be prepared to be a good listener. Being a good listener means being sensitive to questions and comments, and being accepting and non-judgmental. Stress being attentive to the conversation and not letting your mind wander! During the telephone call, set a mutually agreed-upon time to make a home visit. (See Handout on Phone Call Tips--Attachment V III-C.) You may want to practice some initial phone contacts from the examples on this sheet.)

Discuss the positive aspects of a parent-to-parent visit. Remind participants that they may be the first person the referred parent has talked with who has been through the same experience.

Parents can be reassured that no attempt is being made to have parent-to-parent interaction stylized. Acknowledge that each of us has our own style of interaction with others and that practice allows an opportunity to become more effective in the outreach to others.

V. REFRESHMENT BREAK

VI. ROLE PLAYS

Participants will be asked to form into groups of three. Each group will be given one or two role plays to discuss. Each group should designate one person to talk, another to listen, and a third to be the observor. The observor is to see that the listener uses attending behavior and provide feedback on the interaction based on what was learned in the discussion. The facilitator may want to demonstrate a role play with two parents initially. See handout on Sample Role Plays (Attachment V III-D).

A time limit should be established for this part of the session. The observor is responsible for noting if the listener came into the conversation too soon or tended to stop the flow of communication.

If there is time, each member of the trio should have a turn at being a listener, observor and a talker.

The entire group can join together to talk over any problems they may have experienced during this exercise. For instance, they may have found it difficult to stay focused on the other parents concerns rather than their own, or to refrain from giving advice.

VII. CLOSING

Preview training session IV and distribute handout on "Topics for Discussion - Parent to Parent Contacts" (Attachment V IIIE) and review tips for supporting parents (handed out during Training Session I).

This training session was adapted from Project COPE.

LISTENING

A. Listening is a skill where a person voluntarily and consciously gives his/her attention to another so he/she can hear what is being said.

B. It is not a natural art, but something that is learned and, hence, can be improved.

C. Few people listen objectively and well to others. Often people will get caught up in one aspect of the message and begin to think of an answer before the speaker is finished, or answers to problems that have not been asked for.

D. Common barriers to hearing:

1. His views are different from yours.
2. The attire or appearance of the speaker is extreme in any way.
3. You have heard the discourse before.
4. The thoughts of feelings being expressed shock you or cause you to feel anxious.
5. The person is telling you something that you don't want to hear.
6. The environment is noisy or frequent interruptions occur.
7. You are experiencing stress or discomfort to any degree.
8. The needs of another will demand a commitment or involvement by you.
9. You are self-centered and hear only your own voice.
10. You realize that an apology from you should be forthcoming.

E. Besides being able to hear what is being said, there is another aspect of listening, and that is hearing what is not being said.

LISTENING TECHNIQUES

A. 42% of the time spent communicating is done in listening.
   1. Speaking is done 32% of total communicating time.
   2. Reading - 15%
   3. Writing - 11%
   4. With a telephone conversation, the amount of time spent in listening is increased, but the amount heard is decreased because of lack of eye contact.

B. Listening tips:
   1. Avoid close-ended (yes/no) questions.
      a. Example: "I'll bet you're having some strong feelings."
      b. Better: "Can you tell me about some of your feelings?"

   2. Center around concerns of parent, not your own.
      a. Example: "I felt so guilty after the birth of my retarded child."
      b. Better: "What are you feeling right now?"

   3. Watch for "doors" (openings in conversation, pauses)
      1. Why might a parent be pausing?

   4. Be alert for your own negative feelings.
      1. Remain objective

   5. Avoid premature conclusions and interpretations.

   6. Keep the relationship open.

   7. Center constructive thoughts around your feelings.
      a. Don't ever give parent the impression that you think he or she is wrong.

C. Active Listening
   1. Above all, stop talking.

   2. Want to hear what is said.

   3. Want to be helpful.

   4. Show that you want to listen.

   5. Put the talker at ease.

   6. Ask appropriate questions.

   7. Listen for more than facts.
      a. What is this mother saying? "I'm doing just fine. I was just surprised to see all that hospital equipment. And my baby is so tiny. He doesn't even look like a baby. But he'll be fine - once he gets off the respirator and gets over the heart problem. I'm not even sure what it is. I forget to ask questions. I just keep looking at that equipment."

8. Empathize with the talker. Put yourself in his or her shoes.

9. Recognize that the speaker is someone who is separate from you. Don't get emotionally involved.

10. Accept the speaker's feelings -- as his or hers, not yours.
    a. Feel confident in suspending your feelings and all judgments in order to be totally open to what the parent is communicating. Be flexible.
    b. Example: A parent says: "I don't care what the doctor says, I'm going to give my newborn baby solid foods to make hime sleep."

11. Hold your temper.

12. Go easy on arguments and criticism.

13. Know that feelings are transitory. Feelings change.
    a. This doesn't mean that you expect a parent to change to your way of thinking!

14. Trust in the parent's capacity to handle their feelings, to work through them, and to find solutions to their problems.
    a. You are there to help support them in this process, if they choose

15. Be patient. Allow plenty of time. Don't interrupt. Don't be in a hurry to give answers, or everything you know.

16. Don't be preparing your answer while the parent is talking.
    a. Withhold evaluation until he/she is finished. Know what he/she is asking.

17. Take notes as the parent is talking (mental notes).

D. Methods of indicating that you are listening:

1. Repeat parent's last words, either as a statement ("David is jaundiced"), or a question ("So David is jaundiced?")

2. Paraphrase
    a. Take the important parts from a person's speech.
    b. This helps in making certain that you are understanding what another is saying, as well as that they know what you heard.
    c. Paraphrase this speech: "My husband and I went to the hospital last night - in the rain, wouldn't you know? My hair looked a wreck. Anyway, the baby was on a higher respirator setting and they had given her some new medicines. I can't imagine how they get the needles in her tiny arms! I'm not even sure what it was for - we never get to see the doctor."
    What is this parent feeling?

3. Listen for emotional meaning.
    a. Example: parent says, "The respirator is so huge and complicated. I'm sure I'll set it off if I touch Brian."
    b. You might say:

4. "Tracking" - following the person's monologue.
    a. Neutral noise - uh-huh, nod, etc.
    b. Injections - yes, of course, etc.
    c. Practical questions

5. Offering a chance to elaborate
    a. <u>Example</u>: "How did you feel about that?" "What happened then?"

    b. <u>More examples</u>: "Can you give me a specific example?"

6. Listen for contradictions
    a. Respond to feelings rather than intellectual content.
    b. <u>Example</u>: A parent asks, "This is probably too early to think about, since my daughter is only a month old, but can you tell me about schools for the mentally retarded? Do you know of any that can increase a child's I.Q.? Or should I even send her to school -- do you think it's worth it?"
    You might say:

E. Using one or more of these methods, as well as following a parent's speech patterns and vocabulary senses (See Developing a Relationship) will enable you to develop profound rapport.

1. Parent may feel comfortable with even a brand-new relationship, and relieved to find someone with similar experiences, and may be able to freely express thoughts and feelings, thus helping him or herself.

2. This comes with experience and practice.
    a. Don't force it - it may sound affected or ungenuine.
    b. Practice in daily family and neighborhood situations.
    c. Listen for speech patterns, etc., even if you don't attempt to match them at first.
    d. These skills will come naturally as you do counseling. Be yourself.
    e. This is not an overnight happening. It requires constant growing and improving. Practice on your spouse and friends.

F. Roadblocks to Effective Communication

1. Ordering
    a. Example of ordering: "Get a second opinion."
    b. Better: "A second opinion often helps to clarify a problem."

2. Threatening
    a. Example of threatening: "If you don't give your baby that medicine, you'll be sorry!"
    b. Better: "What was the doctor's reason for prescribing that medication?"

3. Moralizing
    a. Example: "You shouldn't feel depressed. Your baby died a full ten months ago."
    b. Better: "Each person reacts to death differently and takes his own amount of time to mourn and adjust."

4. Giving solutions, taking responsibility
    a. Example: "Your child needs to be evaluated by the March of Dimes. I'm going to call and make her an appointment."
    b. Better: "An evaluation may help to diagnose Laura's weaknesses. If you're interested, there are several places you might try..."

5. Lecturing, being completely rational.
    a. Example: "Life can be hard. You have to get hold of yourself."
    b. Better: "Life often gives us challenges for which our coping mechanisms are not prepared."

6. Judging, criticizing
    a. Example: "You really handled your meeting with the cardiologist poorly."
    b. Better: "Many parents have a difficult time communicating with members of the medical profession."

7. False praising
    a. Example: "You're a terrific mother!"
    b. Better: "A lot of parents have a hard time relating to their hospitalized newborns. Many are unable to touch and hold them, as you've been doing."

8. Labeling
    a. Example: "You're angry."
    b. Better: "It sounds to me as if you're angry. Tell me about it."

9. Denying reality
    a. Example: "Everything will be all right."
    b. Better: "We can never know what the future will bring. But what improvements have you seen since yesterday?

10. Invading privacy
    a. Example: "Was your marriage in trouble before Melissa was born?"
    b. Better: "What are some ways in which you can handle your present situation?"

11. Distracting
    a. Example: "So Tony has to have open heart surgery? Oh. Have you gotten his room ready at home?"
    b. Better: "What are you feeling about Tony's surgery?"

12. Diagnosing
    a. Example: "I can tell from your description that David has a tracheal-esophageal fistula."
    b. Better: "What has the doctor said about David's problem?"

Attachment V III-B

DEVELOPING A RELATIONSHIP

A. Developing rapport

1. Attempt to subtly match parent's:
    a. Tone (note of voice).
    b. Rate of speech (may be arhythmic).
    c. Intonation.
    d. Doing all three of these will enable you to have almost immediate rapport and allow parent to feel free to express him/herself.

2. Listen to how parent is experiencing the world, as evident through his/her "vocabulary sense".

a.	Visual	I see what you mean... It looks dark... I see red...
b.	Feeling	get a handle on the situation... things are rough... feel pinched in... churned up inside...
c.	Auditory	I hear what you say... harmonious situation... loud outfit...

    d. Respond in his/her "sense".

B. Qualities of a Relationship

1. Some people need to be dependent.

    a. Encourage them to do things for themselves--starting with little things.
    b. Example: How might you encourage this?

    c. These people may need more support, or contact for a greater amount of time.

    d. Find a balance between support and independence.

2. Counterdependent (afraid to be dependent)

    a. These people may be more anxious to know what they can do for themselves.
    b. Be careful not to get too "situation oriented" and ignore parent's feelings--they still have them!
    c. Sharing experiences and feelings may enable such a parent to open up.

- d. Enabling her to help herself may free her to express herself and trust you more.
- e. Don't be pushy. Allow her to have her own feelings and personality. Example: How might you attempt to get such a parent started talking?
- f. Don't take it personally.

3. Quiet

   - a. This may be a personality, or a relatively long-term response to a situation, or an isolated incident. The next call you make to him/her may be different.
   - b. Don't be afraid of periods of silence.
   - c. Let a parent know that you are not a social worker, just another parent. What difference might this make?
   - d. Let a parent know you would like to share his/her feelings, but don't be pushy.
   - e. Try to accept him/her feelings and accept him/her as is.
   - f. Don't take it personally.

4. Talkative

   - a. This parent may have less trouble in expressing and releasing emotions, or may just like to talk.
     1. Control conversation by returning to issues relating directly to the situation. What might you say to tactfully return to the situation at hand?

     2. Remember to try not to let parent take advantage of you. Cut the person off when necessary (politely, of course - "My baby awoke from her nap", "I must pick my husband up at the train", etc.)

5. Parents with Special Needs

   - a. Handicaps

     1. Blindness - This parent cannot read our reprints, library materials, etc. Find out whether he/she has someone at home who can read them aloud. If not, material can be taped and mailed to parent. If you cannot do it yourself, request someone who can.

        - a. Find out what special needs such a parent may have, from nursing to transportation. This parent may have more problems to solve than just facing his/her feelings.

     2. Deafness - This can be especially difficult since such a parent cannot normally be contacted by telephone. Discover if you can meet with the parent in person (with or without an interpreter), or whether you can speak to another person who can communicate with the parent.

        a. Reprints and library materials can be especially important for passing information to this parent.

    3. Physical Handicaps

        a. A parent in a wheelchair, etc., may have an especially difficult time getting to see his/her hospitalized baby. Discover what the particular parent's problems are.

b. Low Reading Level Parent

    1. A parent who cannot read well cannot get the full benefit from our written materials. You may decide to:

        a. Discuss the materials with the parent.
        b. Hand write shorter reprints in easier terms.
        c. Encourage parent to talk with medical staff even more than other parents - repitition may be helpful.

    2. This parent may also have trouble with materials handed out by the hospital, insurance company, etc.

        a. If possible, meet with the parent to help explain important papers.
        b. Parent may request that hospital, insurance company, etc., send a representative or meet with the parent to fully explain forms.

    3. Such a parent may be embarrassed at his/her low reading level.

        a. Emphasize importance of knowing what is happening (not withdrawing from the situation) - more important than knowing every word.

c. Parent with a Language Barrier

    1. Even if parent speaks some English, find an interpreter who can explain your thoughts to the parent, and his/her questions to you. Otherwise, parent may be too embarrassed or unable to express her thoughts, and questions and feelings may never be discussed.

Attachment V III-C

PHONE CALL TIPS

FIRST PHONE CALL

1. When to call
    a. Call at your earliest convenience after receiving the referral (always within 24 hours).
    b. If the parent is difficult to reach, try calling at several times of day.
    c. If you cannot reach him/her after several days:
        1. Send a Parent to Parent brochure with a note, including your name and phone number. Ask parent to call you, but keep calling.
        2. Or, leave a message if possible.
2. What to say
    a. Introduce yourself by name, as a Parent to Parent supporting parent.
        1. You may mention the name of the referral person, particularly if the parent has spoken to him/her.
    b. Ask if this is a good time to call.
        1. If not, ask when you can call back.
        2. Leave your name and phone number.
    c. Ask if parent is familiar with Parent to Parent. Even if they indicate a familiarity, give a brief overview, emphasizing:
        1. Parent (non-professional, non-medical) counseling.
        2. Counselors are just parents who have already been through similar situation.
        3. A list of our resources (reprints, library, resource list, parent meetings, etc.,).
        4. Describe Parent to Parent briefly.
    d. Mention your own experience, briefly, noting those aspects that may parallel parents'.
        1. Example: "My son, Frank, also has Down Syndrome and attends a special education class.
        2. Don't ever compare children-stress individuality.

    3. Be open and positive

    4. The purpose of sharing is to let a parent feel less alone, not to belittle his/her situation.

  e. Ask parents questions about their experience, beginning with their feelings.

    1. Show your interest through active listening (See Attachment V III-A) Listening Techniques).

    2. Avoid long responses.

    3. Don't be afraid of silences.

    4. Some examples of question topics include:

      a. How mother is feeling (physically, emotionally, etc.)

        1. Reassure parent that all feelings and emotions are normal and (probably) common.

      b. How baby (use name) is doing.

      c. How father is doing--what his reactions are.

  f. Offer support.

    1. "Can I help you?" gives permission to become involved.

    2. "What can I do for you?" helps to define a problem.

    3. Offer specific reprints.

    4. Ask if the parent has any questions.

    5. Go over courses of action discussed.

  g. Finally, give parent your name again and phone number.

    1. Make sure he/she knows to feel free to call you at any time (off-hours calls are rare), and that you will call back.

3. This call does not have to be more than five or ten minutes, but play it by ear. Don't feel you have to go over every topic mentioned.

4. Some parents will not respond to counselor's remarks freely.

  a. Don't take it personally.

  b. Let parents know you would like to share their feelings, but don't be pushy.

   c. Let parent know that you are not a social worker, just another parent.

   d. Parent may be more open next time. Try to understand their feelings and accept them as they are.

5. Call parent as needed.

   a. Every day or two in severe situations, or when a parent demonstrates strong emotional needs.

SAMPLE ROLE PLAY SITUATIONS

The following are common situations we often encounter in talking with "new" parents of special needs children. Discuss various ways of handling these situations and suggest some specific things you might say to enable the parent to work through the difficulty. You may wish to role play some of the situations to see how creative you can be "on the firing line".

Situation One

Mrs. A has been home two weeks with her Down Syndrome child and is anxious to find out about programs and services to help her child as soon as possible. However, her husband has not accepted the child and refuses to discuss anything to do with keeping the child at home. The mother is anxious to help her child while keeping the marriage together. OR The father has accepted the child and wants to look to the future, but the mother will do no more than care for the child's physical needs.

Situation Two

Mrs. B has her child with Cerebral Palsy at home and is smothering him with attention to the exclusion of her other responsibilities. She feels totally responsible for the child's condition and blames herself since she is sure she caused the disability by taking large doses of medication during the early months of pregnancy before she was aware she was pregnant. She now feels she must devote herself totally to this child to make up for the misery she has caused.

Situation Three

Mr. and Mrs. C have just been given a rather vague diagnosis of retardation from their physician. He presented them with some technical terminology and a rather negative prognosis for the child's development. The couple has two problems: they are unaware of other diagnostic or developmental services in the community and they have come to bitterly distrust all professionals as a result of the physician's manner of dealing with the situation.

Situation Four

Mr. and Mrs. D have accepted their Spina Bifida infant and are getting involved in service programs to benefit him.

However,

--the grandparents refuse to acknowledge the child's condition and are quick to criticize their daughter-in-law/son-in-law for having this child and for keeping him in the family. Difficulties arise in loyalty to parents or to spouse.

OR

--Former friends have stopped coming by and calling. They seem to be uneasy around the couple, especially when the child is present.

OR

--Older children in the family begin to have behavior problems, seeming to resent the increased attention and special care given to the new child. Mr. and Mrs. D admit that former activities have been curtailed but feel this necessary to give their special needs child the attention he needs.

Situation Five

Mr. and Mrs. E have recently had their first child, born with severe birth defects. One or the other refuses to consider having more children and has inquired into a tubal ligation/vasectomy. Their spouse wants to wait and try to get more facts hopefully to have more children. This has put a great strain on their relationship and the situation is rather tense at the time of your visit.

Situation Six

Mr. and Mrs. F. seem to accept their hearing impaired child, but have not yet sought out services for the child. During your visit they continually ask questions about your child, her developments and accomplishments, and whenever you turn the topic back to their child they again seek information on your experiences.

Situation Seven

The scene is a hospital visit. Supporting parents are visiting both the mother and father of the baby at a special evening visiting hour. The disabled baby is a two-day-old child with Down Syndrome. Heart surgery is anticipated. There is a sibling at home (a boy) who is six years old. The parents doubt whether they should tell their son about the baby being developmentally disabled. They ask your advice.

Situation Eight

The scene is a home visit. The parents are new to your state and community. They have a two-year-old child who has been diagnosed as having severe developmental lags. Their new pediatrician suggested that they talk with a support parent in order to learn more about community resources. The parents have no family here and seem to be very lonely. You see from the address that a nearby neighbor is someone with whom you recently talked on a similar referral visit.

Situation Nine

The scene is a visit to a family whose two-month-old baby has been diagnosed as having hydrocephalus with a high probability of being developmentally disabled. Shunt surgery performed when the baby was three days old has so far been successful.

The maternal grandparents are not accepting the diagnosis and keep telling the parents they should find another physician. They have remarked several times that it must be the father's fault, as their side of the family never has had any such problems.

You are asked by the father if they should find another physician. The mother asks you how much trouble the baby will have in learning. She mentions that the doctor has told them to be alert for seizures, and that scares her a lot. The parents are worried about the possibility of shunt failure and ask you how they will know if the shunt stops working.

TOPICS FOR DISCUSSION - PARENT TO PARENT CONTACTS

On Home Visit:

1. How to handle major interruption (child screaming upstairs).
2. How to handle one quiet and one talkative spouse, one interested and one disinterested spouse.
3. How to handle crying, anger.
4. How to handle siblings, other family members who may be in household.
5. How do you relate to their child?
6. How do you handle refreshments, food, dirnk -- if you want or don't want some.
7. What if you want more contact and they don't.
8. If new parents apologize about their home, furnishings, food, how do you respond?
9. What do you say if new parents come out with "wild" reasons for the disability of their child, with total denial of the disability?
10. How do you deal with the new parents' rejection of the child?
11. How do you know if new parents need professional help? Do you suggest this? How?
12. How do you know when it's time to go?

On Telephone Contact:

1. What do you say when new parent asks, "Tell me more about the P-to-P Program."
2. How much do you tell new family about you and your family, and your own experiences? Your experience in being a supportive parent?
3. How do you limit initial phone contact?
4. How do you deal with it if there is initial hesitancy to invite you to their home, and you believe that the reasons may be inhibitions about their housecleaning, their economic circumstances, etc.?
5. How do you set up details for the first meeting? Time when both parents can be present, what to say about siblings, relatives and friends who may want to be present?
6. How do you respond to "unanswerable" questions, such as "How far will my child go in school?"
7. How will you feel if the referred parent decides not to participate in the Parent to Parent Program?

In future personal contacts (or perhaps on first visit):

1. How will you deal with music or television blaring loudly?
2. What do you do if parents are not home when you go?
3. How do you know when this contact is too much for you to handle? When it brings back very painful memories for you? What do you do?
4. How do you handle effusive, immediate praise, affection, appreciation?
5. What do you do if the referred family becomes too dependent on you? What could you say to set your own limits during the first visit?
6. What to do if you don't want to enter into a social relationship with family, but want to limit your involvement to the supporting parent role?
7. What do you say if the referred family want advice on everything in the world -- finances, housing, marital conflicts, etc.?
8. What do you do if you witness or strongly suspect child abuse/child neglect by these referred parents?
9. If the referred family obviously strapped for money, food, toys, transportation, what do you do about giving/obtaining these things for them?
10. What do you do if referred family start talking about institutionalization or giving up child for adoption or foster care?
11. How much do you share about your special child? (If asked by referred family). Do you talk about, show pictures of, introduce to, etc.?
12. What do you do if parents disagree re: childrearing, etc., in your presence? If grandparent and parent disagree on what to do for child?
13. How do you respond if referred family imply or state that "their" child is more difficult, etc., than "your" child? ("You just don't know what it's like..." statements)
14. How do you handle information/opinions of a very derogatory nature about health care providers?
15. How do you distinguish between referred family obtaining appropriate medical/psychological consultations about their child and simply desperately "doctor-hopping"? How do you respond to the latter?
16. How do you judge readiness of referred parents to hear emotionally-laden terms like "retarded", "handicapped", "delayed", etc.?

Parent to Parent of Georgia

TRAINING SESSION IV

PARENT TO PARENT SUPPORT

"The first cry from my heart, when I knew she would never be anything but a child, was the age old cry that we all make before inevitable sorrow: 'Why must this happen to me?' To this there could be no answer and there was none."

Pearl S. Buck in The Child Who Never Grew

TRAINING SESSION IV

PARENT TO PARENT SUPPORT

OBJECTIVES

1. To explore the concerns of supporting parents about the responsibility of contacting new parents and offering support.
2. To discuss the grieving process, it's impact on families and the issue of acceptance.

SAMPLE AGENDA FOR TRAINING SESSION IV

I. ANNOUNCEMENTS

II. REVIEW

Review briefly last week's session and ask if there are any comments/ suggestions.

III. PARENT TO PARENT CONTACT

The facilitator for this session should be skilled in group dynamics. If a guest counselor has been invited, be sure the person has been informed of the goals and aims of parent-to-parent support. Counselors are often available through local mental health agencies or local college counseling centers.

The major portion of this session should be allocated to do problem-solving about the most effective way to handle various situations in parent to parent contacts.

By now parents will have detailed questions and concerns about the responsibility of visiting a new parent and offering support. Parents need to be reassured that an agency staff person will serve as a resource and back-up person for any visit. The discussion may be opened up with parents questions concerning last week's handout on Topics for Discussion and Tips for Supporting Parents.

For instance, parents often express concern about another parent crying during the visit. At these times, reassurance is needed. The presence of someone seen as empathetic and understanding may allow the new parent the emotional release of crying. When the crying stops, important and meaningful communication can take place between people who have shared the same human experience.

It is necessary to discuss the importance of being non-judgmental about any feelings or thoughts expressed by the parent. For instance, one may say out-of-home placement seems necessary. The visiting parent may have a strong bias against placing the infant/child out of the home. At this time, it is important to support the parent in such considerations and provide information about available resources which can help the parent make a thoughtful, informed decision. Handout on Crisis Intervention (Attachment V IVA) may be helpful.

Adequate time needs to be allotted for discussion about the similarities as well as the differences fathers and mothers have in dealing with the diagnosis of disability in their child. This portion of the discussion can be insightful for each parent and often stimulates significant exchange between husband and wife about how each perceived the other's response.

IV. REFRESHMENT BREAK

V. DISCUSSION: THE GRIEVING PROCESS

A discussion on the grieving process and stages was briefly introduced in Training Session I (See Perske's Bewildering Times). We will now discuss how this relates to parents and families and how we all handle it differently. An overview of the general literature dealing with grief can lay the groundwork for the discussion with a focus on how it relates to parents of a child with handicaps. The Seven Stages by Mary Leydorf, M.D., has excellent material on accepting a child with handicaps (See Attachment V IV-B).

It is important to acknowledge that not all parents will feel they have been through any of the stages. For some parents it will be the first time they realize or understand that their reaction to hearing their child has a handicap is identified as grieving. An excellent discussion can center around the issue of acceptance of an infant or child with a handicap, as well as adjusting or integrating the situation into daily living. Predictable Issues (Attachment V IV-C) illustrates that acceptance may be an ongoing issue. This is an excellent discussion point.

VI. CLOSING

Preview Training Session V.

VII. ADDITIONAL SUGGESTIONS

Use handout "Accepting Your Child (Attachment V IV-D) as a resource for new parents. This is an excerpt from First Steps a resource book published by the Florida Developmental Disabilities Planning Council. We highly recommend this excellent resource for all parents. It may be ordered by contacting:

Florida Developmental Disabilities Planning Council
1317 Winewood Blvd.
Building 1, Room 309
Tallahassee, FL 32301
(904) 488-4180

This training session adapted from Project COPE.

CRISIS INTERVENTION

A. Diminishing Anxiety

1. Stress may isolate parents from their baby or child.

    a. More acute with newborn; parents have had less time to develop attachments.

2. Coping mechanisms.

    a. Everyone has his/her own coping mechanisms, and they will function again.

        1. Everyone makes his own magic happen.

    b. Share ideas of what worked for you.

    c. How did the parent handle other crisis situations?

    d. How can this situation be improved?

    e. Ways of coping -

        1. Releasing emotions;
            a. Crying
            b. Screaming
            c. Getting angry
            d. Being afraid
            e. Walking and other physical activities can help to work off anger and other emotions.

        2. Relieving feelings and thoughts:
            a. Talking to others - family, friends, support group, religious leader, professional counselor
            b. Writing
                1. to self
                2. to baby
            c. Involvement
                1. Becoming actively involved
                2. Removing self from tension (temporarily effective Allows a parent time to "regroup")
                3. Denial (Not a healthy means of coping)

    f. Reopening social world

B. Helping a Hysterical Parent

1. Parent is crying incessantly, can't talk

    a. Find some pretext to get off the phone ("My son is flushing the cat down the toilet."). Tell parent you will call back in five minutes.

    b. Call back - very important! Time may allow parent to collect herself to speak more clearly.

c. On second call, if parent is still crying, try asking questions ("Are you upset about Carol? (the baby), "Is there something specific that has you so overwrought?")

    1. If parent is still crying, ask if she would like you to stay on the phone, to call back, to visit (your option), etc.

d. Keep in close contact (at least daily) until problem is resolved, or parent is more in control.

e. Those who experience frequent crying spells over an extended period of time, or those who have them often when all is apparently well, or those who refuse to answer their phones, may benefit from talking to a professional counselor.

C. Helping an Angry Parent

1. Parent may shout, be accusatory, etc.

2. Allow parent to express feelings

    a. Help them to define source and aim of their anger - they may be different.

        1. Don't focus on blame.

        2. Allow them to get specific, but point out that there may be (and often are) more than one reason for outpouring of emotion.

    b. Let them know that their feelings are common to most parents who have a hospitalized and/or handicapped infant, or are under any such stressful situation.

3. If they are willing, aid them in coming to solutions to the problem(s), or prevention in the future.

4. They may prefer to stay angry rather than getting logical.

    a. That's all right, but don't allow them to continue beating your ear for a length of time if they are unwilling to calm down.

    b. Tell them you will call back, and do.

5. Be objective.

    a. Don't take the anger personally, even if it is aimed at you.

        1. Don't take on their anger, or return it.

        2. You may be the lightning rod of their anger--release it.

    b. Be aware that you are hearing only one side of the story.

        1. Parents may not have heard or understood correctly.

2. You may wish to call the baby's nurse or social worker to get a clearer idea of what happened, or to alert them to the parent's feelings.

    a. Don't call behind parent's back. Let them know you would like to talk to the nurse; ask her permission to do so.

    b. You may be the only one the parent feels confident in telling. Don't break that confidence, but get help (for you or the parent) as needed.

Attachment V IV-B

THE SEVEN STAGES

Mary Leydorf, M.D., F.A.A.P.
Leydorf Medical Clinic
Rosemead, California

A parent of a mentally or physically handicapped child may experience seven emotions in a fairly predictable order. The amount of time spent at each stage varies widely from a few seconds to many years.

	STAGE	DESCRIPTION	TREATMENT
1.	Confusion	A reality before diagnosis is made--often professionals are unsure, and require a planned time interval for study of the child. Parents are uncertain, bewildered.	Establishment of a firm diagnosis with confirmation, as quickly as possible. If this is impossible, a full explanation as to why a waiting period is necessary.
2.	Denial	When presented with the diagnosis, the parents do not accept it. "He'll outgrow it." "How could that doctor know, he only spent 5 minutes with the child." "Uncle Herman's third child had the same thing and he's O.K." Attention is often focused on one small item and the total picture is ignored: i.e. "He can spell 'cat'; therefore, he is not retarded."	A thorough, full examination and supportive laboratory studies. Consultation with a specialist. Presentation of a diagnosis to both parents at the same time, and answering all questions honestly.
3.	Anger-Guilt	An aggressive, outgoing parent will turn his dismay outward, often against the doctor who first made the diagnosis of abnormality. Also common is to turn against the spouse. Occasionally the obstetrician is accused, etc. The passive parent will turn his disappointment inward: "What did I do wrong?" "Did I really want this child?"	Point out the realities. The parent did NOT do something wrong. (If this is true--exception is child-beating.) The obstetrician gave good care--get birth records, etc.

The Seven Stages
Mary Leydorf, M.D., F.A.A.P.

	STAGE	DESCRIPTION	TREATMENT
4.	Hope	There may be excessive hope for a miracle. Frantic searching for a "cure". "Shopping" from doctor to doctor, medical centers, without allowing consistent treatment.	Parents are open to quackery and should be protected. They should know that if treatment is available through future research their child will receive it. They should be specifically informed of "con" programs now known to exist.
5.	Depression	A resigned attitude but an unhealthy one. May range from "blue", "listless", to real withdrawal and attempt to hide the child. Indicates diagnosis of child's abnormality is accepted.	Commence a program--include the parent totally. Use other parents of children with handicaps. Suggest membership in parent groups.
6.	Acceptance	This stage suggests the beginning of a good parent-child relationship. On this firm basis help may be given to the child. The parent accepts the child "for what he is." The parent realizes both the normal areas and abnormal areas. "He is a child first--and handicapped second." Relaxed attitude predominates.	Fast progress is made if a correct program which cares for the total child is offered. Programs can include: medical care, educational therapy, physical therapy, speech therapy and psychological management, and should work together smoothly in a team effort. The parent will be an important "working" member of the team.
7.	Understanding	The parent not only understands his own child, but is enriched by having to strengthen his own ability to cope with life. He can now help others. This is the final stage. Fulfillment is reached and a new dimension is now added to this parent's personality.	None. We should listen to these parents, for they can tell us much.

Attachment V IV C

PREDICTABLE ISSUES FOR FAMILIES WITH HANDICAPPED CHILDREN

These are issues that are unique to families with handicapped children and often result in family conflict. However, families may adjust very well to these issues without professional help.

1) Confrontation with the initial diagnosis.

This often creates a family crisis. Parents' reactions are highly individualistic. Factors influencing these reactions are: individual personality, nature of the marital relationship, parental aspirations for the child, feelings about deviancy, etc.

Common reactions include:

denial
guilt
ambivalence
frustration
anger
shame
sorrow

Hopefully, there is an acceptance which allows the family to have respect for the handicapped child, themselves as individuals, and the family unit.

2) Confrontation with the social stigma of "deviant."

This may be more of a problem for one member of the family than another. It may be a problem for members of the extended family or for friends and social acquaintances. This may result in increased isolation of the immediate family from their family network and general social contacts.

3) Acquiring special services for the handicapped child.

Parents may develop feelings of incompetence and helplessness when the child's developmental needs go beyond what family members can do. Parents may question their parental abilities and feel the need to acquire professional skills. Some parents feel overwhelmed and intimidated when facing professional and social service agencies. The family may also encounter frustration and disappointment when trying to find appropriate services for their child.

4) Meeting the special demands of physical care and financial expenditures for the handicapped child.

Physical care and financial burdens of having a handicapped child may tax family resources to their limit. Such problems as marital conflict, over-burdening of one family member, or neglect of sibling may result. Help from outside sources and appropriate allocation of these demands may be needed to avoid emotional stress.

5) Developing realistic expectations for the handicapped child's cognitive and emotional growth.

Unlike normal children, there is often no clear patterns of developmental expectations - expectations must remain flexible and continually be altered at each developmental stage the child enters. That is the transition periods of:

1. Infancy
2. Pre-school years
3. School age
4. Adolescent Period
5. Late adolescent - Early adulthood

Re-evaluation of parental expectations at all points of developmental milestones may be difficult. For some parents it may again bring about disappointment and the need for reacceptance.

Many parents have written about the anguish they felt when they first learned that their child had a developmental disability They talk of the unsteady path that their feelings followed for days, weeks, even months after they knew their much-loved child would live his or her life with a handicapping condition

In the beginning many parents are shocked. They can hardly believe that such a thing could happen to them and their child. Many parents refuse at first even to believe that the information could be true. Gradually, as they accept the information and go beyond their shock and dismay, parents frequently become depressed and angry. But these feelings pass, and parents usually are able to accept their child — with his or her special limitations. They recognize that each of us is handicapped or limited in some way. In fact, no one is really perfect.

Somewhere, somehow, most parents manage to get over the questions that focus on the past and the pain — "Why did this happen to me?" — and turn instead to the question that will open the door to the future: "Now that this has happened, what will I do about it?" (Kushner, 1983) Once this important transition is made, the parents of a child with a developmental disability can tackle the important business of life, planning for a future that may well be as bright as that of any child's.

Your Child's Needs

In fact, once you can accept your special child and his or her limitations, you will quickly realize that your child's needs are more *like* other children's needs than *not like* them Your child will go through the same social experiences, the same developmental processes, the same psychological learning as other children The disability may cause problems which may interfere with your child's growth or experiences, causing some delay in developing certain skills But, if your child is allowed to be a child — experience, learn, feel and think as a child — and if he or she is treated with all the love and attention all children deserve, he or she will continue on to more mature growth and development.

Perhaps this can be better understood if you can see that your child is first of all a child, and only secondly a child with a disability It really is up to you to determine how much of his or her potential your child can reach, given the particular disabling condition

Your child's needs include the need for:

- physical and emotional care
- stimulation of body and senses
- education
- recreation, sports and play
- medical care
- social opportunities
- legal resources and protection
- independence and self-sufficiency
- and especially, love, affection and acceptance as a real person

Your Child's Rights

Once you understand that your child has the same needs as any child (in addition to whatever special needs he or she may have because of the particular disability) you may also be interested to discover that your child's rights are the same as the rights of all people.

Your child has the right to live his or her life in the most comfortable, creative and fulfilling manner possible, in freedom, with joy and with the opportunity for continuing growth Your child has the right to a job matched to his or her abilities and limitations He or she needs equal treatment and equal opportunity and the certainty of living with dignity

Your child, like all children, has many other rights as well Some of these include

- The right to be part of a family
- The right to religious freedom and practice

- The right to speak openly without fear of punishment.
- The right to protection against abuse or demeaning treatment.
- The right to privacy.
- The right to suitable social and recreational activity.
- The right to appropriate and humane medical care.
- The right to education and training services.
- The right to live in the least restrictive environment possible
- The right to a responsible, impartial guardian or advocate to protect and ensure the exercise of these rights.

In Florida, these rights are protected by Florida Statute, Chapter 393.

Your Child's Disability

If you have just learned of your child's disability, you are probably at a loss about what you need to do first. You may be near panic, or close to despair, or very angry Many parents report these as well as other intense feelings. All are hard to deal with, but they can and do change. Parents need to remind themselves that their child's disability is not their fault. And, once these painful and negative feelings are recognized, you can take deliberate steps to handle your feelings. Only then will you be able to deal with your child in a truly positive way

Discovery

In the meantime, while you are still struggling to come to terms with your child's disability, there is much you can do.

1. *If you have just learned of your child's disabling condition, no matter what your child's age and level of handicap, now is not the time to make a decision to send your child to an institution or other situation where others would provide the care.* Later on, that may be a choice you will make, but it requires clear thinking and careful consideration of all your options You need to know much more about your child, his or her special disability, potential and limitations. You even may be counseled now — by doctors, grandparents or well-meaning friends — that sending your child "away" will be best for your entire family. Resist these pressures, at least for now, until you can get the information you need.

Right now, all your child really needs is to be loved and treated like every other child You will want to explore all possibilities at this stage, not settle on a quick solution Your child's life deserves this careful thought.

2. *Begin talking with other parents.* One of the best ways to get information about your child's disability is to ask the parents of a child with the same condition. Talking with someone who has "been there" will give you a great deal of information on what you can expect as your child grows. Other parents also can offer the understanding, support and encouragement that comes from actual experience. In this difficult time, other parents can do much to help and often are delighted to do so

If you do not know how to find these other parents, you can start by contacting the organizations working with the major disabilities listed in Section 6 of this guide. Remember that it is important for both you and your child to ask for help and information.

3. *Find out where your child is today, and start there.* Nothing you read or hear about your child is final or exact Each child is different, and the degree or severity of the disability may differ in many ways. Also, if your child is very young, detailed testing may be impossible. Some developmental disabilities, like autism, are very difficult to diagnose Others, like Down Syndrome, although easy to identify, can vary greatly from child to child Finally, with constant changes in research, service and legislation, there is much more that can be done today, regardless of the disability. These changes may help your child's future.

4. *Take that first step.* It is important to get started, to take the first step, no matter how much you, your doctor or other professionals know about the disability. Even if your child is only a tiny baby, he or she can begin immediately in an infant stimulation program. If your child is older, it is even more important to start immediately on a program that will help the child and reduce the negative effects of his or her disabling condition.

Many parents also have found that to begin a program of positive action brings relief to them as well as to the child. It gives a sense of moving forward, of helping their child and themselves. Even if an exact diagnosis is not complete, children who are delayed in their development need not wait to get help. Starting treatment early has the added benefit of reducing later problems.

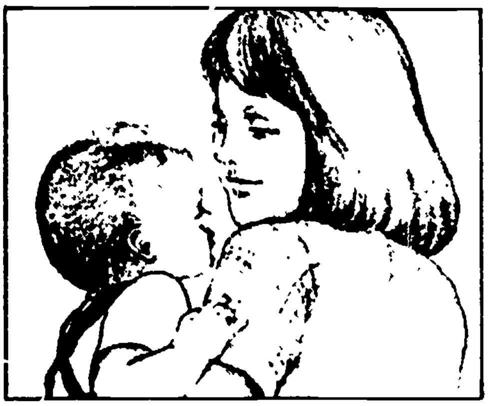
5. *Get as much information as you can about your child's disability.* The more you know about your child's problem, the better. This guide includes brief descriptions of some disabilities, but there is much more to know. Much of the information you will find may not agree Neither will the opinions offered by people you and your child meet. You will more than likely read and hear different points of view and will need to make up your own mind

When you are gathering information, be aware that much has changed in the past ten years in the field of helping children with disabilities. Try to get recent information. Even then, it may be that no one knows exactly what your child's problem is. Luckily, you can still get information on how to treat your child, no matter what the diagnosis.

Early Intervention

The reasons for seeking immediate help for a child with a developmental disability are many Perhaps most important, by providing training and care for your child at an early age, you actually may reduce the limitations your child may face in later life. An effective educational program can give your child every opportunity to develop to the fullest the capacities and potential he or she may have.

The chart which follows shows some steps in a child's normal development. It shows at *about* what age children *do* certain things. Some children do these things earlier or later, but most follow the steps in order.



What is a *developmental disability*? A developmental disability is a mental, physical or emotional condition which affects the normal development of an individual. A person with a developmental disability is someone who is limited physically and / or mentally in his or her ability to perform the activities of daily living (taking care of personal needs, graduating from high school, getting a job, raising children, etc.). A person who has a developmental disability has a need for a combination of special care and treatment. He or she may require extended or lifelong services that are individually planned to meet special needs

Federal legislation* defining developmental disabilities states that the person's ability to carry out certain major life activities must be affected. These life activities are defined as

- self care
- learning
- mobility

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*Public Law 95-602, the "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978" which was passed November 6, 1978

- self-direction
- economic sufficiency
- use of receptive and expressive language
- capacity for independent living.

In order to be considered developmentally disabled under the federal definition, a person must be affected in three of the areas listed.

Florida legislation defines "developmental disability" as a disorder or syndrome which may be the result of retardation, cerebral palsy, autism, or epilepsy and which constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

In the "Retardation Prevention and Community Services Act" passed by the Florida legislature in 1977, state treatment programs for the developmentally disabled were directed to emphasize those programs that have the potential to prevent or reduce the severity of retardation and other developmental disabilities.

The legislature also insisted that first priority be given to developing and using those services and programs which will allow persons with developmental disabilities to "achieve their greatest potential for independence and productive living, which will enable them to live in their own homes or in facilities located in their own communities . . ."

TRAINING SESSION V

RESOURCES

"The encouraging thing is that every time you meet a situation, though you may think at the time it is an impossibility and you go through the tortures of the damned, once you have met it you find that forever after you are freer than you were before. If you can live through that you can live through anything. You gain strength, courage and confidence by every experience in which you really stop to look fear in the face."

Eleanor Roosevelt in You Learn By Living

TRAINING SESSION V
RESOURCES

OBJECTIVES

1. To increase supporting parents awareness of community resources.
2. To provide supporting parents with accurate information on state and national resources available to families with special needs.

SAMPLE AGENDA FOR TRAINING SESSION V

I. ANNOUNCEMENTS

II. REVIEW

Review Session IV briefly and ask if there are any questions/ comments.

III. DISCUSSION: COMMUNITY RESOURCES

To be effective, supporting parents must be aware of the services provided in the community. This session is devoted to those in the community who provide services for special needs children. Directing new parents to the services is a major function of the Program. Representatives of the local agencies discuss their services, who is eligible to receive their services, and how to obtain them. Many of the presenters may have films or slide presentations describing their programs, and should have, as well, pamphlets and written materials to enable supporting parents to understand the special services offered by each agency. The following agencies are a sample of available resources:

A. Local Association for Retarded Citizens
B. Local United Cerebral Palsy
C. Public school programs for the developmentally disabled
D. Respite care agencies
E. March of Dimes
F. Regional Center or similar agency dealing with the coordination of services for families of and persons with disabilities.
G. State or County social services

A panel consisting of several of these spokespersons would be excellent.

The presentation should end with a question and answer period. Given the number of service providers participating in this session you will need to decide when would be an appropriate time to have a refreshment break.

IV. STATE AND NATIONAL RESOURCES

Attachment V V-A to this training session lists Florida services available to families with special needs. The last chapter of this training manual contains a complete list of state and national resources. It is important that each supporting parent have a copy of this information for their reference.

V. CLOSING

Review Training Session VI.

VI. ADDITIONAL SUGGESTIONS

Attachment V V-B is a sample letter to thank local resource providers for agreeing to participate in this training session.

Attachment V V-A

SECTION [illegible] FLORIDA SERVICES

In Florida the Department of Health and Rehabilitative Services (HRS) is the state agency primarily responsible for the evaluation and treatment of persons with developmental disabilities HRS meets this responsibility by providing services locally through its regional offices Because of the size of our state and the number of services needed, HRS divides the state into 11 districts Each district may serve one or more counties A directory of these districts and the counties included in each can be found on page 29 of this section

HRS provides services grouped into specific program areas These areas are

- Aging and Adult Services
- Alcohol Drug Abuse and Mental Health
- Children's Medical Services
- Children, Youth and Family Services
- Developmental Services
- Economic Services
- Health
- Health Planning and Development
- Medicaid
- Vocational Rehabilitation

A complete list of specific services offered within each program is included for your information in Section 8, page 34, of this guide It is not necessary for you to contact a specific program office or to know exactly what services your child may need Simply call or write the District Administrator of the district office nearest you and you will be referred to the appropriate program office Or you may call the Developmental Disabilities Planning Council at (904) 488-4180 to ask for assistance

Other services and treatment programs are provided by not-for-profit agencies, county public health units, voluntary agencies, associations, local school districts, and other state agencies The names and addresses of some of these are included in the next few pages

Medical / Health Related Services

The associations and corporations listed below offer a wide variety of programs and services, from advocacy assistance to treatment programs Some are related to a specific disability, others are more general Most offer information and referral services as part of their programs and can direct you to other agencies in your immediate location

American Diabetes Association
Florida Affiliate Inc
3101 Maguire Boulevard, Suite 288
Post Office Box 19745
(305) 894-6664

American Heart Association, Inc
Florida Affiliate Office
810 63rd Avenue North
Post Office Box 42150
St Petersburg, Florida 33742
(813) 522-9477

American Red Cross
National Headquarters
17th and D Street, N W
Washington, D C 20006
(202) 737-8300

(Also you may want to check your local phone directory under American Red Cross)

Arthritis Foundation
Florida Chapter
3205 Manatee Avenue West
Bradenton Florida 33505
(800) 282-9487

Association for Retarded Citizens Florida
106 North Bronough, Suite M1-7
Tallahassee, Florida 32301
(904) 681-1931

Florida Association of Rehabilitation Facilities
124 West Jefferson Street
Tallahassee, Florida 32301
(904) 224-3660

Florida Easter Seal Society
1010 Executive Center Drive
Suite 10[illegible]
Orlando, Florida 32803
(305) 896-7881

Florida Epilepsy Foundation
Post Office Box 6059C
Orlando, Florida 32853
(305) 422-1439

Florida Society for Autistic Citizens
1523 Julie Tonia Drive
West Palm Beach, Florida 33406
(305) 965-0409

Leukemia Society of America, Inc
National Headquarters
800 2nd Avenue
New York, New York 10017
(212) 573-8484

March of Dimes Birth Defects Foundation
Regional Office
12550 Biscayne Boulevard
North Miami, Florida 33181
(305) 895-2856

Mental Health Association of Florida
Post Office Box 11068
Tallahassee, Florida 32302-3068
(904) 877-4707

Muscular Dystrophy Association
1301 Seminole Boulevard Suite 105
Largo, Florida 33540
(813) 585-5446

National Kidney Foundation of Florida, Inc

Davis Boulevard Suite 304
Tampa Florida [illegible]3606
(813) 251-3[illegible]27
National Multiple Sclerosis Society
Area Office
1524 Roswell Road Suite C
Marietta Georgia 30062
(404) 977-1002
Spina Bifida Coalition of Florida
996 Florida Town Road
Pace, Florida 32570
(904) 994 4001
United Cerebral Palsy of Florida Inc
Post Office Box 6476
Tallahassee, Florida [illegible]301
(904) [illegible] 2141
Upjohn Healthcare Services
Florida Region Administration
Post Office Box 260[illegible]
Winter Park, Florida [illegible]
(305) 629-0636

Education and Related Services

Many children with disabilities will spend their educational lives in special programs or classes These programs fall into five basic types

1 **State schools for the disabled** for those children who are blind deaf, have cerebral palsy or other severe disabilities
2 **Segregated schools** in which children with all types of physical and mental disabilities within a given area in a community are bused to and educated in a single segregated facility
3 **Segregated classrooms** are located within a regular elementary or secondary school and made up of children who have the same or similar defects For example, all children with mental retardation will be taught together in a regular school but in a "special" class with a specialist teacher for the full school day
4 **Integrated classrooms** usually offer a special class for a particular problem in a regular school The children are in this class for only part of the school day joining other students for some school subjects For example a child who has mental retardation may have an academic class in a special classroom but join students without disabilities for art physical education, shop subjects or music
5 **Itinerant programs** will serve a child who has acquired special skills which allow him or her to handle a regular school program For example, a child who is blind will need to read, write and type in Braille before being placed in a regular class at the appropriate grade level An itinerant teacher, trained in Braille, will visit the child regularly to locate books in Braille to transcribe special materials or to help with any problems between the child and the regular teacher Otherwise, the child functions in the same way as other students Children with specific learning disabilities and who have no other obvious physical impairments are often placed in programs of this type

All of these programs are offered at different levels, depending on the ability of the individual student Placement and follow-up services (which "follow" a child to be sure a placement is right for that child) are offered through the public school system in Florida For information on education and related services you may wish to contact

The Bureau of Education for Exceptional Students
Florida Department of Education
Knott Building
Tallahassee, Florida 32301
(904) 488-1570
Florida Instructional Materials Center for the Visually Handicapped (FIMC)
5002 North Lois Avenue
Tampa, Florida 33614
(800) 282-9193
Captioned Videotape Project for the Hearing Impaired
Florida School for the Deaf and Blind
Post Office Box 1209
St Augustine, Florida 32084
(904) 824 1654
FSDB Outreach Project
Child Study Center
Florida School for the Deaf and Blind
Post Office Box 1209
St Augustine, Florida 32084
(904) 824-1654
Division of Blind Services
Florida Department of Education
Knott Building
Tallahassee, Florida [illegible]301
(800) 342 1828
Division of Blind Services Library for the Blind and Physically Handicapped
Post Office Box 2299
Daytona Beach Florida 32015
(800) 342-5627
Manderfield Industrial Training Laboratory
401 Platt Street
Daytona Beach, Florida 32014
(904) 252-4722

Family Support

Many of the agencies already listed in the guide offer support services to families with children who have disabilities You also can find out about other programs and services by contacting the agencies and organizations below

Florida Council of Handicapped Organizations
Post Office Box 2027
Satellite Beach, Florida 32937
(305) 777-2964
Head Start
Humanics Associates
Florida Office
255 Whooping Loop, Suite 255
Altamonte Springs Florida 32701
(305) 834-6538
Parents Anonymous of North Florida
Mt Vernon Square, Suite M
1106 Thomasville Road
Tallahassee, Florida 32303
(904) 224-8481
or

Parents Anonymous of Gulf Coast
Post Office Box 1006
Bradenton Florida 34282
(813) 746-1904
National Hotline - (800) 421-0353

Also, check the list of HRS services in Section 8 to see if a specific HRS program area may be helpful

ECONOMICS

Earlier in this guide you found a number of possible sources of financial assistance to help with meeting your child's medical treatment expenses. Often the financial burden of a child with disabilities creates a drain on other areas of your budget as well. If you need help in meeting your everyday expenses the Department of Health and Rehabilitative Services (HRS) may be able to help

Some of the economic services administered by the HRS District Office which serves your county include

Aid to Families with Dependent Children
Food Stamps
Refugee Assistance Program
Low-Income Energy Assistance Program and
Work Incentive Program

If you need assistance, contact your HRS District Office (see page 29)

Community Assistance

For several years now both state and federal efforts at serving persons with disabilities and their families have been directed at helping the disabled to remain in the community. To do this, both the federal and state governments have developed and continue to support a number of community-oriented services. These services help to make it possible for a person with disabilities to live work and play in a community setting

TRANSPORTATION

Getting places is a problem often brought up by parents and individuals with disabilities. Sometimes even when services are available in a particular area, they are of no use to a person with disabilities because he or she is unable to get to them

In many communities, both public and private organizations provide transportation to schools, workshops, recreation and medical facilities. Sometimes agencies arrange for buses or car pools using specially designed vans. If public transportation can be used, some agencies may provide the fare. There may even be a business in your area that will provide transportation for your child for a fee

All public school systems must provide free transportation, to and from school, to children with disabilities which limit free physical movement. Some Florida counties have special transportation services. For information call your local school system transportation department or your county social services unit

RECREATION

Recreation includes many different activities that will greatly benefit your child: physical exercise, socializing, playing, and generally having fun. Your child is entitled to recreation programs and the use of public recreational facilities just as other children are. Remember that these programs and facilities are paid for by your taxes or organizations that are bound by nondiscrimination laws and practices. You may have to insist that your child be included, but to do so is certainly your right and is in the best interest of your child

Many groups already have special programs to meet the needs of children with disabilities. Others have programs which group children with similar disabilities together. For example your local YMCA may sponsor a summer day camp for children who are deaf. Or your area may have a Scout troop for those children who are confined to wheelchairs. Check with your local groups or clubs to see what is being done. If no programs are underway, ask the group to start one

You may also want to contact your county recreation department for information about any special programs they may sponsor. Phone numbers may be found in the telephone book under your local government listing

Some programs are just for those children who have disabilities. The Florida Special Olympics is one of these programs. Held throughout the year, the Special Olympics gives children who are mentally retarded a chance to compete for awards in physical events such as swimming, basketball, volleyball, track and field events in county, district and state games

For information, contact the physical education teachers in local special education schools or write to

State Special Olympics Headquarters
2639 N Monroe Street Suite 151-A
Tallahassee, FL 32303
(904) 385-8178

Summer camp programs, both day and overnight, are designed for children with disabilities and give children a chance to explore a new environment — and to get along without a parent. They also allow the parent(s) a chance to have a vacation

Persons with disabilities may form their own group or club for the purpose of socializing eating out dancing going on trips etc Some private companies specialize in arranging trips for people with disabilities

All of these possibilities may require some extra effort on your part But playing and being with friends is an important part of being a child Other parents may be a good place to start your search to find recreational activities suitable for your child Some of the sources already listed may be helpful, too

RELIGIOUS TRAINING

Both children and adults with disabilities will benefit from religious education and participation in religious services People with disabilities have the same feelings values and spiritual needs as anyone else Growing spiritually is a vital part of every person's development and is no different in a person with a disability

Hopefully, your minister, priest or rabbi is already familiar with meeting the spiritual needs of people with disabilities If not, perhaps he or she will be willing to learn more about disabling conditions to be better able to serve your child

Some Associations for Retarded Citizens have sponsored special programs to involve both clergy and congregation with people with disabilities Your local association may be able to provide information, guidelines and materials for training members of your church to provide religious education and services to your child

Employment Options

Today, more than ever before, your child can look forward to several options for both finding and keeping a job Depending on your child's specific disability, these options range from sheltered workshops to modified or adapted work stations in a regular employment situation In fact, your child may well be able to assume financial responsibility for part or all of his or her care Your child will have the opportunity to lead a productive full and satisfying life — including having a paying job — if special care and training begin at an early age and are continued as long as necessary

Job specific training is available through your public school system and through vocational rehabilitation programs offered by the state or private agencies

Goodwill Industries of America is an example of an agency that may both train and employ people with disabilities For information on the agency nearest you call or write

Goodwill Industries of America
9200 Wisconsin Avenue
Washington, D C 20014
(301) 530-6500

For assistance in exploring employment options for your child contact your local school system or the HRS District Office serving your area

Alternative Living Arrangements

Keeping your child at home or in a home-like environment while he or she is very young is thought by many parents and professionals to be best for the child During this period when your child is growing and learning so much, you and your family can provide for most of your child's needs Many agencies also provide services in the community to help in your effort to keep your child at home These community services include day care, respite care, infant stimulation and school programs

Yet even with these services, some parents cannot manage at home You may need some other alternative You might consider placing your child in foster care or in an adoptive home

Or you may consider placing your child in a community-based residential program or group home for children or adults who are physically or mentally handicapped Here young people can be with friends their own age, maintain a normal daily routine and still get the supervision and care they need

Voluntary agencies may be able to provide assistance in finding a [illegible] home So will your HRS District Office

Finally an institutional residential program may be necessary You may want to consider both private and public facilities In general, very young children are accepted into public facilities only if they have very serious medical or behavioral problems Private facilities may be able to accept your child, but they are usually very expensive The current trend in Florida and other states is away from large institutions In fact two of Florida's six institutions already have been closed and residents moved to smaller community facilities

For information on state residential facilities contact the HRS District Office serving your area

Legal Aid

Sometimes, even with the number of state and federal laws, people with disabilities and their families need to defend their rights to receive needed services

If you feel that your child is not being treated equally, there are many steps you can take These steps may include complaints to appropriate boards, appeals and grievance procedures If you still are not satisfied with your child's treatment program you may require legal assistance

In Florida if you need legal help, you can contact the Statewide Human Rights Advocacy Committee (address and phone number below) for help, or you can call or write one of the statewide legal services listed below

Statewide Legal Assistance or Referral Services

Statewide Human Rights Advocacy Committee
1317 Winewood Boulevard
Building 1, Room 310
Tallahassee, Florida 32301
(904) 488-4180

Florida Bar Lawyer Referral Service

The Florida Bar
Tallahassee, Florida 32301-8226
(800) 342-8012

Florida Commission on Human Relations
325 John Knox Road, Suite F-240
Tallahassee, Florida 32303
(800) 342-8170

Florida Justice Institute, Inc
1401 Amerifirst
One S E 3rd Avenue
Miami, Florida 33131
(305) 358-2081

Florida Legal Services, Inc
[illegible] West Pensacola, Room 216-218
Tallahassee Florida 32301
(904) 222-2151

Governor's Commission on Advocacy for Persons with Developmental Disabilities
Office of the Governor
The Capitol
Tallahassee, Florida 32301
(800) 342-0823

Southern Legal Counsel, Inc
115 N E 7th Avenue
Gainesville, Florida 32601
(904) 377-8288

You may also want to get a copy of *The Pro Bono Directory* from The Florida Bar The directory is a complete listing of low cost and free legal assistance Send your request to:

Legal Assistance Project
Department of Public Interest Programs
The Pro Bono Directory
The Florida Bar
Tallahassee, Florida 32301
(904) 222-5286

HRS District Offices

HRS District One (includes [illegible] Okaloosa Santa Rosa Walton)
P O Box 12836
160 Governmental Center
Pensacola Florida 32576
(904) 436-8700

HRS District Two (includes Bay, Calhoun, Franklin, Gadsden, Gulf Holmes Jackson Jefferson Leon Liberty Madison, Taylor Wakulla, Washington)
2639 N Monroe, Suite 200-A
Tallahassee, Florida 32303
(904) 488-0567

HRS District Three (includes Alachua Bradford Citru Columbia, Dixie Gilchrist Hamilton Hernando, Lafayette Lake Levy, Marion Putnam Sumter Suwannee Union)
1000 N E 16th Avenue, Building C
Gainesville Florida 32601
(904) 395-1005

HRS District Four (includes Baker Clay Duval, Flagler, Nassau St Johns Volusia)
5920 Arlington Expressway
P O Box 2417F
Jacksonville, Florida 32231
(904) 723-2050

HRS District Five (includes Pasco, Pinellas)
2255 East Bay Drive
Clearwater, Florida 33516
(813) 536-5911

HRS District Six (includes [illegible] Hillsborough Manatee [illegible] Polk)
4000 W Buffalo Avenue
Tampa Florida 33614
(813) 272-2540

HRS District Seven (includes Brevard Orange Osceola Seminole)
400 W Robinson Suite 801
Orlando Florida 32801
(305) 423-4208

HRS District Eight (includes Charlotte Collier DeSoto Glades Hendry Lee Sarasota)
12381 Cleveland Avenue
Ft Myers Florida [illegible]
(813) 936-2211

HRS District Nine (includes Indian River Martin Okeechobee, Palm Beach St Lucie)
111 Georgia Avenue
West Palm Beach, Florida 33401
(305) 837-5078

HRS District Ten (includes Broward)
201 W Broward Boulevard
Ft Lauderdale Florida 33301
(305) 467-4298

HRS District Eleven (includes Dade Monroe)
401 N W 2nd Avenue
Miami Florida 33128
(305) 377-5058

Source #1

PARENT TO PARENT
SAMPLE LETTER

TO: Service Providers
FROM: Group Leader
RE: Training Session
DATE:

Thank you for agreeing to present a brief presentation (ten minutes or so) on the services you provide to children who are handicapped or to their parents. The session will be held on (date, time) at (place) .

Your presentation should include the following information:

1. What services are available
2. Who is eligible to receive the services
3. How services are obtained

So that parents will have printed information about these services, will you also have 20 brochures or copies of a summary of your presentation available for each parent.

The Parent to Parent of Florida program is part of a statewide program sponsored by the Florida Developmental Disabilities Planning Council. Parent to Parent is a support network of parents with handicapped children who make themselves available to parents whose children have recently been diagnosed handicapped or have other special needs in order to provide support and information during this crisis.

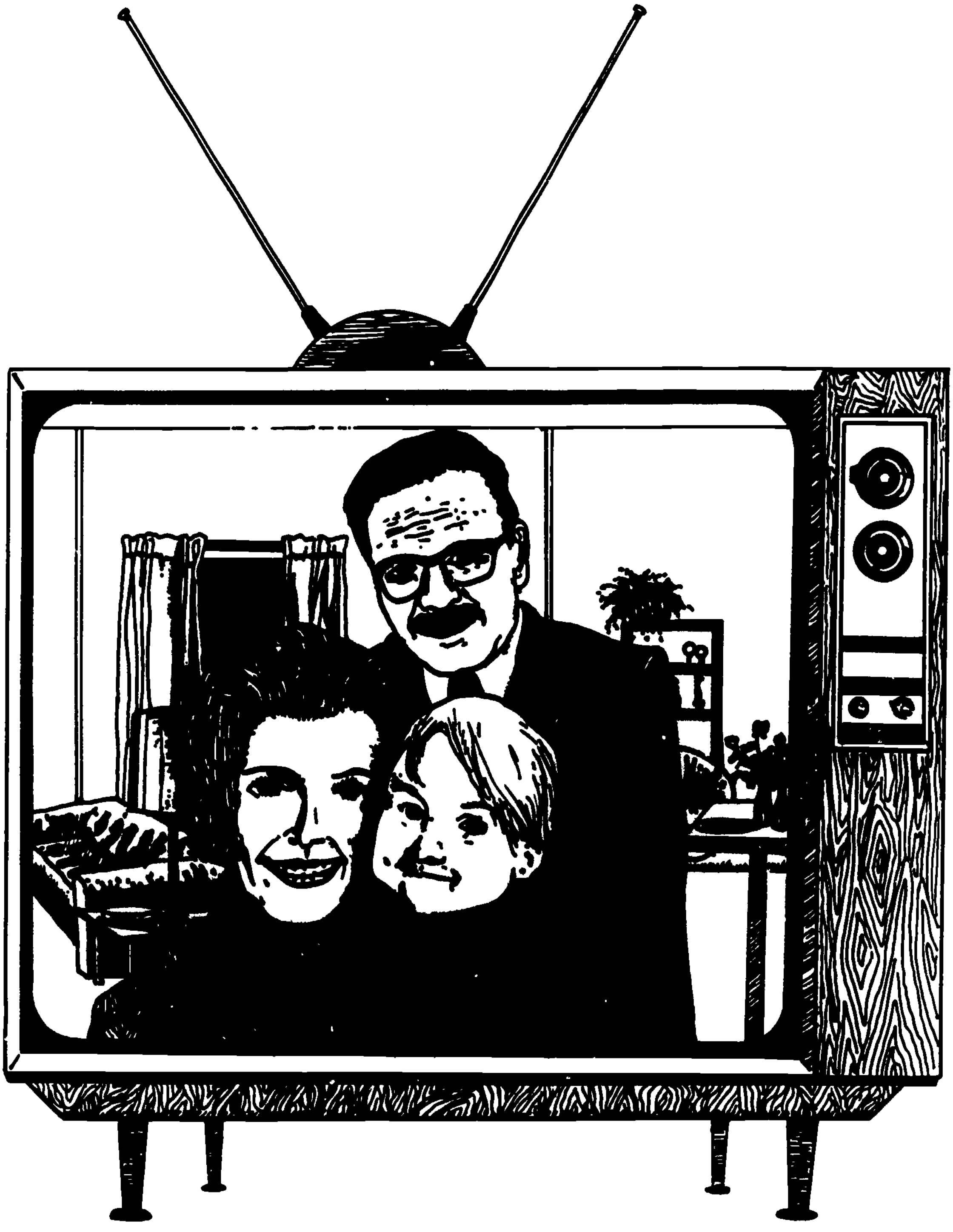
The group of parents who are volunteering to become supporting parents are attending a series of six training sessions to familiarize themselves with peer help skills and various developmental disabilities and to become better informed about the services available to parents and handicapped children in our community.

We appreciate your interest and help in this endeavor. If you have any questions, please call me at ____________.

Parent to Parent of Georgia

TRAINING SESSION VI

REFERRAL PROCESS AND COMMUNITY OUTREACH



TRAINING SESSION VI
REFERRAL PROCESS AND COMMUNITY OUTREACH

OBJECTIVES

1. To insure that supporting parents understand the referral process.
2. To familiarize supporting parents with referral forms.
3. To assign an individual to be the referral coordinator (agency staff person, volunteer parent, etc.)
4. To outline the community outreach process and responsibilities.

SAMPLE AGENDA FOR TRAINING SESSION VI

I. ANNOUNCEMENTS

II. REVIEW

Review Session V briefly and ask if there are any comments/ questions.

III. DISCUSSION: REFERRAL PROCESS

Distribute the following handouts to participants:

A. Steps in Referral Process (Attachment V VI-A)

B. Intake Information Form (Attachment V VI-B)

C. Referred Family Information Form (Attachment V VI-C)

D. Referral Response Card and Letter Format (Attachments V VI D & E)

Discuss this procedure and answer any questions.

Note: The referral process may be changed to adapt to your group's situation. For example, an additional step may be added if you are using an answering service.

IV. REFRESHMENT BREAK

V. DISCUSSION: COMMUNITY OUTREACH

An energetic, ongoing publicity campaign is vital to the development and growth of the program. The general public, parents of handicapped persons, professionals, and service providers must be made aware of the existence of the program. It is essential that the supporting parents participate in this area.

Brochures describing the program are an excellent means of publicizing the program. Doctors' and dentists' offices, churches, and hospital lounges are excellent places to have them on hand. (See attachments V VI F&G--samples of parent to parent brochures.) Posters and pamphlets displayed in public buildings, hospitals, medical offices, and businesses are another way of alerting the public to the program. The "Social Services" section of the Yellow Pages will provide the names of any agencies and groups who will post Parent to Parent materials for their clientele. One should not forget to alert the local "Welcome Wagon" to the program's existence, and supply them with materials. Make sure, too, that the Parent to Parent program is listed in the Yellow Pages.

Letters describing the Program and packets explaining developmental disabilities should be sent to local physicians and pastors (Attachment V VI-H). The same letters and packets may be sent or taken by supporting parents to the Obstetric and Pediatric Departments of local hospitals. (See Attachment V VI-I) When supporting parents speak to the staff and members of the local developmental disabilities offices, brochures and a letter of introduction to the program may be circulated. The local school administration and PTAs should be included on the mailing list.

Television and radio stations are required to devote a portion of their programming day to Public Service Announcements. They are usually quite receptive to Public Service Announcements which reflect local groups and their concerns, and hence can be very helpful in publicizing the Parent to Parent Program, particularly if the supporting parents themselves participate in making the contacts with the station personnel. Local radio and television talk shows are another possibility which can easily be overlooked, but which are accessible to a Parent to Parent Program. (See Attacnments V VI-J & K.) When appearing on television talk shows, do take your child with you, if appropriate. People are really interested in seeing your child; you should check with television personnel about the feasibility of doing so.

Developing a slide film presentation describing the program in pictures and sound is an excellent method of explaining the program fully and dramatically to various public audiences.

The following attachments are included for your use:

A. Sample News Release (V VI-L)
B. Public Relations Overview (V VI-M)
C. Publicity to Professionals (V VI-N)
D. Publicity to Media (V VI-O)

Again, these are just suggestions and guides. Your group is unique and may not use all of these materials.

An effective outreach procedure to keep your program going and growing should include:

A. Printed material to explain the program.
B. Selective contacts to all relevant sources of referrals.
C. Identification of all media outlets in the community, including information on who to contact, news format they prefer to use, deadlines, etc.
D. Utilization of personal affiliations and associations of staff and volunteers to expand referral networks.

E. Personal contacts; availability to answer requests for additional information or presentations to groups.

F. Persistence; follow-up; provision of information again and again to assure visibility to those who need you, when and where they need you.

VI. EVALUATION

See form entitled "Evaluation of Volunteer Training (Attachment V VI-P).

VII. CLOSING

VIII. GRADUATION

On completion of the training sessions, a graduation party may be held to honor the new supporting parents. Certificates should be awarded at this time.

The party offers an excellent opportunity for the participants to deepen their acquaintance with others present for the training. Much of the satisfaction of membership in Parent to Parent is the bond that develops between parents, which is maintained through the many social events. The graduation party is indeed one of those events, and care should be taken that the atmosphere is appropriately festive.

PARENT TO PARENT OF FLORIDA
REFERRAL PROCESS

1. The referral is taken by the designated person (Referral Coordinator) answering the referral phone number. This person takes information and records it on the Intake Information Form.

    A. Ascertain whether the caller is referring a parent or is the parent him/herself.

    B. Explain that if the caller will give some general information, you will contact a parent who will get back to the referred parent as soon as possible, usually on the same day.

    C. The Referral Coordinator may need to call the referred family to obtain enough information to select an appropriate supporting parent. She/he will explain the reason for calling to the referred parent.

    D. If the Referral Coordinator is a trained supporting parent and the parent is making a self-referral, the Referral Coordinator may be able to handle the call. If not, a match will be made.

2. The Referral Coordinator selects an appropriate supporting parent by considering some or all of the following factors: age of parents, marital status, economic status, racial, religious, or cultural factors, age of child, diagnosis or degree of child's disability, make-up of family group, geographic location of family residence, etc.

3. The supporting parent will be contacted and given all information obtained. The supporting parent should tell the Referral Coordinator if it is not a convenient time for them to accept a referral. This will permit the selection of another supporting parent who will contact the family immediately.

4. The supporting parent makes contact with the referred parent as soon as possible, preferably within 24 hours. Do not be afraid to ask for a change in supporting parent if, after contacting the family, you feel you cannot relate to them.

5. Once an initial contact has been made, the supporting parent must notify the Referral Coordinator.

6. The supporting parent will record information as it is obtained and any progress notes on the Referred Family Information form. This form will be returned to the Referral Coordinator upon termination of the contact.

7. If problems occur, notify the Referral Coordinator who can assist with finding a suitable solution or contact the agency resource person if different from the Referral Coordinator.

8. The Referral Coordinator will respond to the referral source, if not the referred parents themselves, by letter or card.

Attachment V VI-B

PARENT TO PARENT
INTAKE INFORMATION FORM

DATE	REFERRAL COORDINATOR	PARENT'S NAMES	CHILD'S NAME	D.O.B.	HOME ADDRESS PHONE	REASON REFERRED (DISABILITY)	REFERRED TO DATE/TIME	DATE/TIME CONTACT MADE	DATE CONTACT TERMINATED

apted From Source #3

PARENT TO PARENT PROGRAM
REFERRED FAMILY FORM

CHILD

Name of child____________________________________

Child's D.O.B.____________________________________

Type of disability____________________________________

When diagnosed__________________Where__________________

Special concerns (if any)____________________________________

FAMILY

Parents' Names____________________________________

Parents' Ages (if known)____________________________________

Address____________________________________

Phone____________________________________

Number and Ages
of other children____________________________________

REFERRAL

Referral source and
date of referral____________________________________

Phone__________________Agency Worker__________________

CONTACTS

Name of supporting parent(s)____________________________________

Phone____________________________________

Number and type (home visit or phone) of contacts__________________

Progress of case____

Terminated? ____________________yes ____________________no

Other Agencies Involved____

Additional Information____

Attachment V VI-D

DRAFT - LETTER FORMAT

PARENT TO PARENT PROGRAM

Dear ____________________

Thank you for referring ______________________________ to Parent to Parent. Contact has been made by a supporting parent and will continue as needed.

Our goal is to meet the needs of the referred parents and to do this your feedback is important to us. We welcome your comments about our program.

Sincerely,

____________________ ____________________
Name Phone Number

Parent to Parent of Georgia

DRAFT - POSTCARD FORMAT

PARENT TO PARENT PROGRAM

Dear ______________________________

Thank you for your recent referral to Parent to Parent. Contact has been made by a supporting parent and will continue as long as it is needed.

Our goal is to meet the needs of the referred parents. We welcome your comments about our program; your feedback is important to us.

We look forward to offering continued assistance and support to your patients or clients.

Sincerely,

______________________________ ______________________________
Name Phone Number

*Note: on postcard referred family name would not be mentioned.

Parent to Parent of Georgia

PILOT PARENTS believe that offering emotional support and factual information about a child's handicap enables parents to view, in a positive manner, their child's ability to grow, learn, and develop to his fullest potential.

PILOT PARENTS offer . . .

- ..emotional support and understanding.
- factual information about developmental disabilities.
- .factual information about medical services, educational programs, and supportive agencies
- . introduction to helpful persons and groups that share their interests and concern

The PILOT PARENT PROGRAM serves parents of all children with developmental disabilities

PILOT PARENT PROGRAM
3212 Dodge Street
Omaha, Nebraska 68131
(402) 348-9220

A Program sponsored by the
Greater Omaha Association for Retarded Citizens

PILOT PARENTS PROGRAM

Parents of Handicapped Children

HELPING

Parents of Handicapped Children

SAMPLE BROCHURE

Attachment V VI-F

The **PILOT PARENT PROGRAM** is a program in which parents of handicapped children help parents who have recently learned that their child has mental retardation, cerebral palsy, epilepsy, or autism.

PILOT PARENTS PROGRAM

PILOT PARENTS have had the experience of learning their child is handicapped. They have asked many of the same questions that "new parents" ask.

PILOT PARENTS have learned, through their personal experiences that raising a handicapped child can be rewarding.

PILOT PARENTS have taken training to enable them to assist and guide "new parents" of handicapped children.

If you have a handicapped child and would like to talk to another parent, please call. A **PILOT PARENT** with similiar experience and background will contact you.

Parents of Handicapped Children
HELPING
Parents of Handicapped Children

If you know of someone who could benefit from talking to a parent, please call. **PILOT PARENTS** are available to assist "new parents" in person or by telephone. They are also available to visit with other family members.

"The Pilot Parent Program has filled a tremendous void in our lives. Our son had every professional available to meet his needs. We as parents had nothing. Pilot Parents provided us with an opportunity to meet and talk with other parents who knew and understood all our feelings both good and bad, and could relate to our hopes for him".

Janie Grimm Pilot Parent

"After we learned our child was handicapped we felt alone and isolated. The most important thing our Pilot Parents did for us was to share their experience and allow us to express our feelings with people who could understand what we were going through".

Mary Jo Simpson – New Parent

"From my exposure to the Pilot Parent Program, I have consistently found it to be a most innovative and effective aid to parents of handicapped children".

Frank J. Menolascino, M.D.
Past President of the National
Association for Retarded Citizens

"As a father of a multi-handicapped son, I see a definite need for a husband's active involvement in Pilot Parents. It is often the husband who is withdrawn and does not associate with his child or, aid in obtaining services for him. Another father can offer the "new father" the emotional support and assistance he needs in this time of crisis".

Larry Heeren - Pilot Parent

"Pilot Parents gives us the continuing opportunity to share our experience with others, and help make the thought of raising a handicapped child less threatening"

Jane Upton - Pilot Parent

"The Pilot Parent Program is by far one of the best run and most effective operations of its kind in the Nation".

Robert Perske
President's Committee
on Mental Retardation

Included in these presentations are a 13-minute color/sound filmstrip titled "We Can Help . . . We've Been There" and an award-winning 28 minute documentary filmed in part in Loma Linda Medical Center titled "What Was I Supposed To Do?" Of course, these are also available to parents and parent groups.

PROJECT COPE was developed through a grant from the California State Department of Health and has provided assistance to parents since 1977. Now COPE is expanding its services to include assistance to the professional working with patients—who are developmentally disabled—and their parents.

COPE is a team of professionals and supervised, trained parent volunteers who can provide the short term intervention necessary to share feelings and information on an immediate and confidential level.

Medical advice is not given and confidentiality is observed. Families having medical concerns are referred back to their physicians.

Contact **PROJECT COPE** for further information about professional presentations, referrals, or personal assistance.

To receive the **COPE NEWSLETTER**, write

PROJECT COPE
9160 Monte Vista Avenue
Montclair, California 91763
or phone [714] 621-3884

Brochure donated by San Bernardino Uptown Lions Club

COPE
A PROJECT OF OPARC

A PARENT TO PARENT SUPPORT GROUP

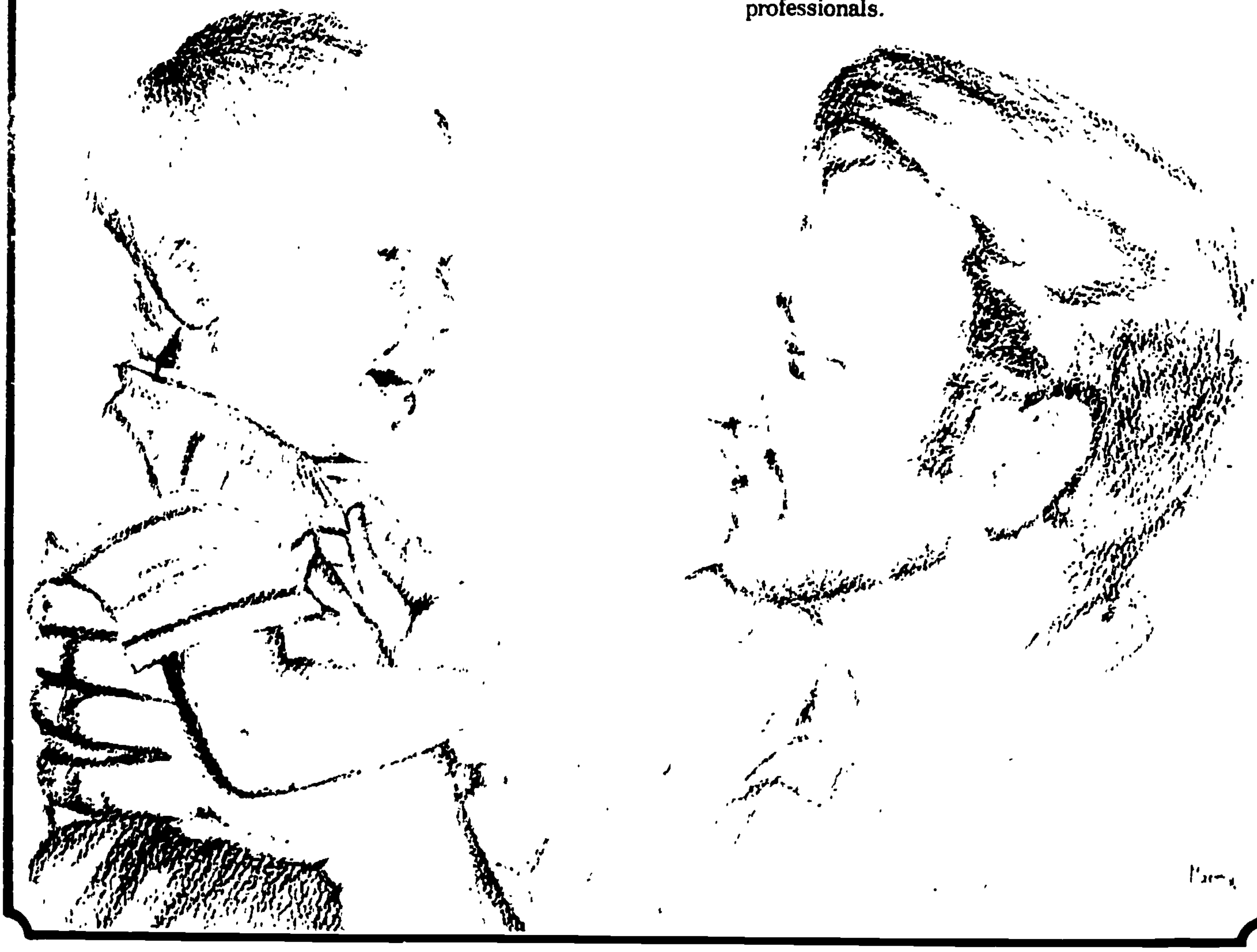
Attachment V VI-G

Parents who have recently received a diagnosis that their child has a developmental disability have many very important needs. They need to know:

- *That there is a way to gain more **information, understanding and knowledge** about their child's specific problems.
- *That there may be special **educational programs** available to their child.
- *That they—and the entire family—can find emotional, psychological and social support within parent groups.

PROJECT COPE is here to help the **professional** meet these needs.

- *With knowledge of available **community resources** and how to best use them.
- *With trained **para-professionals** who can spend time with families during crisis events.
- *With **literature, media, and materials** on all aspects of developmental disability, issues of family life, and parent advocacy.
- *With **in-service training programs** for physicians, nurses, social workers, public health personnel, and other helping professionals.



SAMPLE POSTER

photograph by [illegible]

If your child is handicapped, he needs all the help he can get.

You, the parent, can help him the most by

- Having positive attitudes about him and his abilities;
- Knowing what services he may need, and where to obtain them;
- Knowing how to help him learn at every opportunity.

The handicapped child can overcome, if you teach him how.

For more information call **Pilot Parent Program**

Greater Omaha Association for Retarded Citizens
3[illegible]2 Dodge Street
Omaha, Nebraska 6813[illegible]
348-9220

Initial Introductory Letter to Physicians

Dear Physician:

Allow us to introduce ourselves. We are the Parent to Parent Program of ________________. This means we are parents of special needs children who have had some measure of success in handling this problem in our own families. Because of our experience with this problem we have some understanding of what parents go through when they first learn that their child is handicapped. For this reason we want to be available to parents who struggle with this same problem.

We have undergone a period of training. However, we are not therapists nor counselors and are not interested in formal referrals. We only ask that you pass out the attached brochures to parents who may be interested in friendly visits with another parent of a disabled child. Feel free to place these brochures in your reception area.

If you would like further information or more brochures, please call

________________________________.

We nave learned how valuable it is to talk with other parents of the handicapped who have befriended us. We want to be helpful friends to any of your parents in similar circumstances who would seek us out.

Sincerely,

Source: Pilot Parents

Postcard included in
Hospital Packet for Parents

If you would like to talk to another parent of a child who has a similar handicap to that of your child, call Parent to Parent at ______________, or fill in this card, drop it in the mail and Parent to Parent will contact you.

NAME:________________________________

ADDRESS:________________________________

CITY, STATE:________________________________

PHONE:________________________________

Postcard Request for More
Parent to Parent Materials

HOSPITAL PERSONNEL

If you would like more Hospital Packets made available to you, please call the Parent to Parent Coordinator at ______________ or drop this card in the mail and these additional packets will be sent to you as soon as possible.

NAME:________________________________

ADDRESS:________________________________

CITY, STATE:________________________________

PHONE:________________________________

Source: Pilot Parents

RADIO PUBLIC SERVICE ANNOUNCEMENT

If you have just been told your child is handicapped and are plagued with feelings of isolation, guilt, and despair, Parent to Parent can help. Supporting parents are parents helping parents of handicapped children. They've been there. They've asked all the same questions -- "why me?" They are trained to direct you to services and give you factual information which can help you help your loved one. Supporting parents listen and understand. They're your friends.

Supporting parents have learned through this Program to cope with their problems and are eager to lessen the burden on you. They are not just limited to help those with mental retardation but with epilepsy, cerebral palsy, multiple handicaps, autism, and other special needs.

The Parent to Parent Program is a program of the____________________. There is no charge for the trained parent volunteer.

If you are a parent who knows of someone who has a handicapped child, call the Parent to Parent program at ________________and they will get in touch with a trained parent volunteer who is willing to help you and be your friend.

Source: Pilot Parents

SAMPLE PUBLIC SERVICE ANNOUNCEMENT

PARENT TO PARENT PROGRAM

If you are a parent with a recently disabled child and are feeling lonely and frustrated, trained parent volunteers in the Parent to Parent program can help you.

They can provide emotional support, understanding and information to help you and your child.

If you have a disabled child, call Parent to Parent in ________________
at ________________.

You will be contacted by a parent whose experience will closely match your own and who can offer you informal and personal assistance.

A P.S.A. is usually 30 seconds long, approximately 70 - 80 words.

Source: Pilot Parents

Attachment V VI-L

SAMPLE NEWS RELEASE

"GRIFFIN DAILY NEWS"

FOR RELEASE: MARCH 6, 1981

SUBMITTED BY: BETH WHITEHURST
228-7848

SUBJECT: VOLUNTEERS COMPLETE TRAINING FOR "PARENT TO PARENT PROGRAM" SERVING PARENTS OF CHILDREN WITH DISABILITIES.

Twelve Griffin residents have just completed 14 hours of training to prepare themselves as supporting parents in a Parent to Parent Program in Griffin. Mrs. Greg Whitehurst is the organizer.

The Parent to Parent Program is an opportunity for parents who have a child with a disability to make themselves available to parents who have just learned that their child also has special needs. This can be a time of crisis for a family. Feelings can range from anger to denial or guilt, to depression and sometimes to rejection or isolation.

A parent who has been helped by Parent to Parent explains the program this way: "Every parent can learn from other parents. Raising a child with a handicap intimidated me, but when I could see and know parents who were doing this and doing it well, it gave me courage to do what I wanted to do: raise my child the best way possible, to simply love and enjoy him and treat him as a growing and learning person regardless of his handicap. It even gave me the courage to admit that my child has a handicap."

Parent to Parent is a peer support program that is being developed throughout the United States. In Griffin the sponsoring agency is the Griffin Association for Retarded Citizens. The telephone number is 228-9919. Inquiries will be welcomed.

Parents who have participated in the training are:________________

__________, ________________, ____________

Source: Parent to Parent of Georgia

Note: it would be very good to have a picture of PtP group for the paper... Must be black and white, or newspaper could be asked to send their photographer.

Attachment V VI-M

PUBLIC RELATIONS - OVERVIEW

VISIBILITY - our public sees and hears who we are.

CREDIBILITY - our public believes we know who we are!!!

DEPENDABILITY - our public can depend on us to do what we promise to do.

WHO - are you (your organization)

WHAT - do you do

WHERE - what area do you cover

WHEN - when do you go into action

WHY - information sharing, sharing personal knowledge of crisis, isolation

HOW - the Referral System

JUDGMENT - know how much your group can do....timetable to do.... know your audience....know protocol for getting to your audience....know type of presentation you are scheduled to make (10 min. to physicians? 30 mins to nurses? personal conversation with social worker?)

CREATIVITY - Take risks....try something that seems interesting to you, yet is appropriate to group
If you make a mistake....pick up from that point and go on. (everyone makes mistakes --- just take the mistakes made by people who run for public office)

EDUCATION OR PREPARE - Know your subject (brochure, Fact sheet)
Choose your MAIN POINT
Find out something about your audience
Organize your information
" " handouts
Prepare yourself for some anxiety...how will you handle it: deep breathing...relaxation exercises.
Repeat your MAIN POINT if necessary

RELAX - Relax and be yourself
Positive body language

SPEAKERS SHOULD BE: ARTICULATE, ELOQUENT, ACCURATE
or
Be bright, be brief and be gone.

Source: Parent to Parent of Georgia

PUBLICITY - TO PROFESSIONALS:

1. Decide how much your group can realistically undertake.
2. Divide the professionals you wish to reach into different categories, eg. Chaplains, Nurses, Pediatricians, Public Health Nurses, School Counselors.
3. Invite parents and professionals on the Core Group to take responsibility for reaching the professional groups of their choice (see the Clayton Planning Worksheet - this section).
4. Some tips for reaching:
   A. Physicians:
      a) Best method is parent to own or to child's physician.
      b) Call Medical Secretary of Hospital and ask for best method to follow to be invited to present to physicians..... you will probably have to speak to the Chief of the section you are interested in talking to.
      Note: You will probably only have an opportunity to make a 5 to 10 minute presentation, for example an OB/GYN or Pediatric Section Meeting.
      Be prepared for a rather awkward hour such as 7:30 a.m. or 5:30 p.m.
      Your material and hand-outs need to be very well-prepared to take advantage of this short space of time.
      Distribute the hand-outs after you have spoken (less distraction).
   B. Nurses:
      a) Call the Director of Continuing Education and ask to do an In-Service for Nurses (usually 30 minutes). In many hospitals the physicians have to have o.k.'d the program first.
      b) If you can borrow or rent the film "Sharing the Experience With Gavin" it is excellent for nurses.

   C. Chaplains and Social Workers:
   This usually can be by appointment and in a one-to-one office situation at a convenient time.

   D. Inter-Agency Committee:
   Find out if your area has an Inter-agency Committee since you can make one presentation and reach representatives from Public Health, Dept. of Family and Children Service, Mental Retardation, Mental Health, Ministerial Association, Dept. of Education, etc. Otherwise request an appointment with Director of each agency and explain Parent to Parent then ask if there is an opportunity to present at an agency staff meeting.

   NOTE:
   1. Always have Posters, Brochures, and an information folder for each individual's file cabinet. Ask in advance how many packages of material you will need.
   2. A short announcement prepared for use in a hospital newsletter or a church bulletin would be good to have available.

5. If you are in a large city with a number of hospitals, keep a 3-ring binder with each hospital indexed. Keep a record of who was contacted and the dates and a note as to when contact should be made again, eg. in 9 to 12 months.

IF YOU CANNOT DO IT ALL.....DO WHAT YOU CAN.......WELL!

Source: Parent to Parent of Georgia

PUBLICITY - MEDIA:

1. **CELEBRITY?**
   Media personnel are often associated with celebrity-status and glamour but in reality the staff of newspapers, radio and television are men and women doing a job just like everyone else.

2. **NEWS IS THEIR JOB:**
   so, if you have a story that is of interest to their public they will use it.

3. **APPROPRIATE CONTACT:**
   Do not try to contact everybody's favorite Anchorman(woman) to do your story on T.V. Approach the appropriate person.

4. **CONTACT PEOPLE ARE USUALLY:**

Television:	Public Service Director/ Assignment Editor
Radio:	General Manager
Newspaper:	Editor

5. **NAMES:**
   Find out the name of the person you need to talk to from the receptionist and address the person by name.

6. **DEADLINES:**
   Ask receptionist when the deadlines are and then ask for an appointment either way in advance of or after the deadline.

7. **5 - W's OF JOURNALISM:**
   Have facts on the Who, What, When, Where and Why of a story before approaching your editor.

8. **HUMAN INTEREST:**
   A good story about somebody (in the community) is usually popular.

9. **AUTHORIZATION:** Always get written authorization to use a name or picture or recognizable story from the person(s) involved.

10. **IDENTIFY:**
    Identify the person submitting the material with name and telephone number, so that further information or clarification can be obtained.

11. **REPORTER'S CALL:**
    If a reporter does call for further information and has to leave word, call back as soon as possible.....he (she) may be working on a deadline.

12. **DOUBLE SPACE:**
    Double-space typed material you submit for a newspaper article or for a radio p.s.a. (public service announcement).

Source: Parent to Parent of Georgia

Attachment V Vi-P

PARENT TO PARENT PROGRAM

EVALUATION OF VOLUNTEER TRAINING

The purpose of this evaluation is to learn whether you have found the training sessions to be helpful. Your evaluations will help us plan future training. Your cooperation and assistance are greatly appreciated. It is not necessary for you to put your name on the evaluation.

Please mark the answer which comes closest to your true feelings about the statement.

For example: If you are undecided about a statement, mark the answer as follows:

		X		
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

1. I found all six sessions helpful.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

2. The sessions answered most of my questions about Parent to Parent.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

3. Factual material was presented in a clear and understandable way.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

4. The sessions provided the right amount of factual information.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

5. Material could have been presented in less than six meetings.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

6. There should have been more sessions held.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

7. I found the pamphlets and handouts to be well correlated with the discussions.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

8. Role playing of sample encounters helped me understand what to expect as a volunteer.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

9. Discussion of facts and feelings are equally important in the sessions.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

10. I feel prepared to visit new families after the sessions.

Strongly Disagree	Disgree	Undecided	Agree	Strongly Agree

11. I would recommend scheduling ongoing training for parent volunteers.

Strongly Disgree	Disagree	Undecided	Agree	Strongly Agree

12. Comments and/or suggestions for future training sessions:

____

____

____

____

____

____

CHAPTER VI

OTHER MATERIAL

"If I could never really be like other people then at least I would be like myself and make the best of it."

Christy Brown in My Left Foot

RAP SESSIONS -- MONTHLY MEETINGS

Rap sessions should be set up on a monthly basis with a summer break and should follow closely after the final weekly training session so that group solidarity can be maintained. The cohesiveness of the group will be sacrificed if too much time elapses between meetings.

Content of the sessions should be established on the basis of needs and interests of parents. Once a parent support program has been established, a committee of parent volunteers can set a six-month to one-year rap session calendar to cover topics felt to increase their knowledge and effectiveness. Staff can then make the arrangements for the speakers.

Allocate time at each session for parents to share with one another. Parents who have been on referral visits may want to share and talk about the experience with the group, respecting confidentiality at all times.

Staff and parents can share any in-service training they may have done within the community or at conferences. Parents have a real interest in where presentations about the project are made.

Some ideas for rap sessions:

1. A fathers only/mothers only time
2. A pediatrician talking about developmental disabilities
3. A dentist discussing dental care for children
4. A discussion on behavior management of children with disabilities
5. A sibling panel
6. A counselor talking about dealing with stress
7. A panel on speech and language development: include a speech pathologist, a speech therapist, and an audiologist
8. A counselor to discuss particular aspects of single parenting
9. A lawyer addressing conservatorships, wills, and trusts

As parents make referral visits, they may wish to extend an invitation to referred parents to attend rap sessions. A policy can be established by the group.

Occasional get-togethers for entire families, such as picnics and pot lucks, are successful and fun for everyone.

Source: Project COPE

PARENT TO PARENT

BELOW ARE LISTED SEVERAL IDEAS FOR FUTURE MEETINGS. PLEASE INDICATE YOUR INTEREST IN EACH IDEA BY WRITING A 1 IF YOU ARE VERY INTERESTED, A 2 IF YOUR INTEREST IS MODERATE, OR A 3 IF THE IDEA LEAVES YOU COLD.

____ HANDLING STRESS IN EVERYDAY LIFE.
____ DEVELOPMENTAL DISABILITIES.
____ GENETICS
____ I.E.P.
____ CHILDREN'S DEVELOPMENTAL REACTIONS TO HOSPITALIZATION.
____ FAMILY REACTIONS TO A "SPECIAL CHILD".
____ THERAPEUTIC REACTION (PHYSICAL EDUCATION).
____ ADULT SPEAKERS WHO HAVE HANDLED A HANDICAP SUCCESSFULLY.

OTHER SUGGESTIONS APPRECIATED ... ______________________________

Source: Special Parents

CHAPTER VII

BIBLIOGRAPHY AND FILMS

"The real meaning of life is to give oneself to a cause that will outlast it."

William James

FILMS

THE HANDICAPPED CHILD: INFANCY THROUGH PRESCHOOL (Filmstrip)
Concept Media
P. O. Boz 19542
Irvine, CA 92714

Includes eight programs: (1) The Family Crisis, (2) Risk Factors, (3) Initial Assessment and Intervention, (4) Intervention: Sensory/Motor, (5) Intervention: Cognitive/Language Development, (6) Intervention: Social/Emotional, (7) Intervention: Adaptive Behavior, (8) Intervention: Self Help Skills.

This program is sometimes available through local HRS offices.

A NEW SET OF FEARS, A NEW SET OF HOPES (Video)
Department of Media
Meyer Children's Rehabilitation Institute
444 South 44th Street
Omaha, Nebraska 68131
Contact: Rita Jim
(402) 559-7467

Illustrates the adjustment of a family consisting of a young couple and their four children when one of the children is born with Down Syndrome.

THEIR BEST TEACHER: PROFESSORS LEARN FROM A MENTALLY RETARDED BOY (Video and 16mm film)
Lawren Publications
P. O. Box 666
Mendocino, CA 95460
(707) 937-0536

The film presents the family life experiences of a family with a 15 year old young man with moderate to severe mental retardation. The film serves as a model of family life and adaptation to a family member with a disability.

COLIN AND RICKY (Video and 16mm film)
Lawren Productions
Box 666
Mendocino, CA 95460
(707) 937-0536

Portrays the adjustment of a sibling to the birth of his brother with Down Syndrome.

GIFT OF LOVE

Available in 1/2" an d 3/4" VHS videocassette
Thought-provoking interviews with four families
Free loan from the National Down Syndrome Society
70 West 40th Street
New York, NY 10018
(800) 221-4602

YOU DON'T OUTGROW DOWN SYNDROME

Available in 33 mm slide/tape and 1/2" and 3/4" VHS videocassette
Alerts physicians and hospital personnel to the need for information and support for parents of a newborn with Down Syndrome. Parents and physicians voice difficulties and problems encountered. Strongly advocates parent support groups.

For rent and purchase price write:
National Association for Down Syndrome
Box 63
Oak Park, IL 60303
(312) 543-6060

CAN WE HELP? WE'VE BEEN THERE (filmstrip)

A fine overview of Project COPE. Use at first meeting. Available through OPARC, 9160 Monte Vista Avenue, Montclair, CA 91763. (714) 621-3884.

WHAT WAS I SUPPOSED TO DO? (16mm, documentary)

James Stanfield Film Associates
P. O. Boz 1983
Santa Monica, CA 90406

Parents share their experiences in parenting a child with disabilities with the helping profession. The film has great impact and is not recommended as a film for new parents.

THE PERSON WITH EPILEPSY (16mm)

Excellent portrayal of a person with epilepsy
Free loan for a period of three days
Abbott Laboratories
Audio-Visual Services
Attn: Ruth Price
Dept. 383
Abbott Park, IL 60064

DOWN SYNDROME: NEW EXPECTATIONS

For rental and purchase price: National Association for Down Syndrome, Box 63, Oak Park, IL 60303, (312) 543-6060.
Highlights four persons with Down Syndrome at various life stages.

PREMATURELY YOURS
Slide/tape and videocassette
Polymorph Films
118 South Street
Boston, MA 02111
(617) 542-2004

Focuses on the strengths and skills of premature infants and effectively encourages both parents and hospital staff to respond do, and interact with, premies.

TO HAVE AND NOT TO HOLD (slide/tape and videocassette)
Polymorph Films
(see above)

The parents of premature infants require care as specialized as that given their babies. This film contains a series of interview with parents speaking candidly about the events surrounding their baby's early birth. Gives a great deal of valuable information to parents which helps them understand and accept the experience of the NICU.

PARENT TO PARENT OF FLORIDA
BOOK LIST

GENERAL

Coping With Tragedy Successfully - Facing the Problems of A Seriously Ill Child By: Jerome Schulman

Helping Your Exceptional Baby By: Cliff Cunningham and Patricia Sloper (Pantheon Books, 1980)

Is My Baby All Right? By: Virginia Apgar, M.D. (Simon and Schuster, Inc., 1972)

Parent Papers, Sticks and Stones by Elizabeth Piepers, Human Policy Press, Box 127 University Station, Syracuse, NY 13210

Physically Handicapped Children: A Medical Atlas for Teachers, E. E. Bleck and D.A. Nagel (Grune and Stratton, NY, NY 10003)

Special Children, Special Parents by Albert Murphey

Special People by Shirley Cohen (Prentice-Hall, 1977)

We Have Been There by Terrell Dougan, Lynn Isbell and Pat Vyas (Abingdon Press, 1983)

Fight Back by Jean Edwards, Ednick Communications, P. O. Box 3612, Portland, Oregon 97208

Parents Speak Out: Then and Now by Ann Turnbull and H. Rutherford, Chas. Merrill Co.

Selecting a Preschool: A Guide for Parents of Handicapped Children Ann Turnbull, University Port Press, Baltimore, M.D. Contact: Pro-Ed of Austin, TX.

New Life In the Neighborhood: How Persons With Retardation and Other Disabilities Can Help Make a Good Community Better. Robert Preske, Abingdon Press.

Families, Professionals, and Exceptionality: A Special Partnership. Ann Turnbull and H. Rutherford, Chas. Merrill Publishers.

Tapping the Wellsprings: A Problem Solving Guide for Families with Disabled and Chronically Ill Members, Ann Turnbull, Paul H. Brookes Publishing.

The Helping Interview (2nd Edition, Alfred Benjamin, Houghton Mifflin.

Career Education for Handicapped Children and Youth, D. Brolin, Chas. E. Merrill.

The Disabled and Their Parents: A Counseling Challenge, Leo Buscaglia, Charles B. Slack, Inc.

Without Spanking or Spoiling: A Practical Approach to Toddler and Preschool Guidance, Elizabeth Crary, Parenting Press.

Time to Begin, Valentine Dmitriev, Caring, Inc. Learning program for preschool age children with handicaps.

Infant Learning: A Cognitive Linguistic Intervention Stragety, C. Dunst, DLM Resources.

A Difference in the Family: Living with Disabled Child, Helen Featherstone, Penguin Books.

Families of Handicapped Children: Needs and Supports Across the Life Span. R. Fewell and P. Vadasy, Pro-Ed Publications.

Learning Through Play, R. Fewell and P. Vadasy. DLM Resources. Excellen activities for infants and toddlers.

Early Childhood Interagency Transition Model, Jill Gallaher, Mary Maddox, Eugene Edgar. Edmark.

Developmental Disability: A Family Challenge, Mary Theodore, Sr. Paulist Press.

Ready, Set Go, Talk to Me: Individualized Programs for Use in Therapy, Home and Classroom, D. Horstmeier and J. McDonald, Merrill Pub.

The Adult Transition Model, Bonnie Horton, Mary Maddox, Eugene Edgar. Edmark.

Working with Parents of Handicapped Children, W. H. Howard, J. C. Dardig and A. Rossett. Merrill Pub.

Home Care for the Chronically Ill or Disabled Child: A manual and resource book for parents and professionals. Monica Loose Jones, Harper and Row.

Creative Games for Learning, Merrill B. Karnes, Council for Exceptional Children, Arlington, VA

Parents are People Too, Laura Knox, Intersect, Publisher.

On Children and Death, Elizabeth Kubler-Ross, MacMillian.

The Exceptional Child: A guidebook for churches and community agencies, James L. Paul, Syracuse University Press. How people in a community can be helpful to the family of a handicapped person.

Beatitudes for Special People, Martha Perske. Special Pastoral Services, 8716 S.E. Ellis, Archdiocese of Portland, OR 97266. Pack of pictures suitable for posting on walls. Fosters positive attitudes toward the handicapped.

Our Special Child: A guide to successful parenting of handicapped children, Bette M. Ross, Revell Co.

The Family With A Handicapped Child: Understanding and Treatment, Milton Seligman, ed., Grune and Stratton

AUTISM

Autism - A Practical Guide for Parents and Professionals, Maria J. Paluszny, M.D.

Autistic Children: A Guide for Parents by Laura Wing, M.D.

Early Childhood Autism, Laura Wing, M.D.

Autism publications available from The National Society for Autism, 1234 Massachusetts Avenue, N.W., Washington, DC 20005, (202) 783-0125

CEREBRAL PALSY

Cerebral Palsy: It's Individual and Community Problems by William M. Cruckshank

Down All The Days, Christy Brown, Fawcett World, 1971

Handling the Young Cerebral Palsied Child At Home, Nancie Finne, Dutton Publishing House, 1975.

CYSTIC FIBROSIS

Coping with Prolonged Health Impairment in Your Child, A. McCollum, Little Brown & Co., 1975.

DOWN'S SYNDROME

Show Me No Mercy: A compelling story of remarkable courage about a boy with Down's Syndrome who overcomes almost impossible obstacles to be reunited with his father, Robert Perske, Abingdon Press.

The Gift of Martha, Claire Canning, Developmental Evaluation Clinic, Children's Hospital Center, 300 Longwood Ave, Boston, MA 02115

Teaching Your DS Infant, M. Hanson, Pro-Ed Pub. (Well illustrated)

To Give An Edge: A Guide for New Parents of DS Children, M. Horrobin and J. Rynders, Calwell Press.

The Child with Down's Syndrome, David W. Smith and Ann C. Wildson, W. B. Saunders Co.

Down's Anomoly, G. Smith and J . M. Berg, Churchill Press. Medical aspects of DS.

Antenatal Diagnosis in Down's Syndrome (Health and Human Services publication #77-538)

Down's Syndrome: Growing and Learning, S.M. Pueschel, editor. Andrews and McNeal, Inc.

Hope for the Families: New Directions for Parents of Persons with Retardation of Other Disabilities, Robert Perske, Abingdon Press.

Make the Most of Your Baby, June Mather

Your Down's Syndrome Child by David Pitt, M.D., Available from: Association for Retarded Citizens National, 2501 Avenue J, Arlington, TX 76011, (817) 640-0204

EPILEPSY

A Handful of Stars, Barbara Girion

Living With Epilepsy, Margaret Walker Sullivan, Irvington Pub.

Epilepsy Publications available from: Epilepsy Foundation of America, 57 Forsyth Street, Suite 1005, Atlanta, GA 30301, (404) 523-4197

HEARING IMPAIRED

If You Have A Deaf Child, S. Tracy, et al, University of Illinois Press

Your Deaf Child: A Guide for Parents, Helmer R. Myklebust

LEARNING DISABILITIES

A Parent's Guide to Hyperactivity, Quebec Association for Children's Disabilities.

A Parent's Guide to Learning Disabilities, Quebec Association for Children's Disabilities.

Listen To Your Heart, Elise Wentworth, Houghton Mifflin

Something Is Wrong With My Child, Richardson, Brutten and Mangelo, Harcourt, Brace, Jovanovich, 1973)

The Learning Disabled Child: Ways That Parents Can Help, Suzanne H. Stevens, John F. Blair, Pub.

LOW BIRTHWEIGHT

A Time to Be Born, David Bell, William Morrow, 1974)

Beginnings: A Young Mother's Personal Account of Two Premature Births, Ellen Galinsky, Houghton Mifflin, 1976)

The Premature Infant: A Handbook for Parents, Available from: The Hospital for Sick Children, Room 1218, 555 University Avenue, Toronto, Ontario, Canada M5G-1X5

PERSONAL EXPERIENCES

Annies' Coming Out, Rosemary Crossley and Anne McDonald, Penguin Books of Great Britain. Autobiographical account of a mentally normal child with cerebral palsy put in an institution for the retarded.

Mary Fran and Mo: The Story of Two Special Sisters, Maureen Lynch, St. Martin's Press.

May's Boy: An Incredible Story of Love, Shirlee Monty, Thos. Nelson, pub. Severely disabled at birth, Leslie Lemke confounds audiences with his musical ability.

Chris...Our Brother, Pamela Pueschel, Linda Crepau, Child Development Center, Rhode Island Hospital, Providence, RI 02902; $2.00 per copy or $15.00 for 10. Checks to S.M. Pueschel.

The Furies and the Flame, Ingrid Rimland, Arena Press. A gripping true story of the guild, heartbreak, and ignorance of raising and fully rehabilitating a brain damaged child.

SIBLINGS/CHILDREN

Like It Is, Barbara Adams, Walker & Co. A first person narrative of several young people who speak out on the nature of their disabilities. Grade 5 and up.

A Little Time, Anne Norris Baldwin, Viking. Story of a girl whose younger brother has Down Syndrome. Grade 4 and up.

Love is Like Peanuts, Betty Bates, Holiday House. A 14 year old girl accepts a summer babysitting job with a small girl with brain damage and her 4 year old brother. Junior teen level.

Someone Special, Just Like You, Tricia Brown, Holt, Rinehart and Winston. Simple text with mostly pictures.

Me Too, Vera Cleaver and Bill Lippincott. Harper and Row. Story of a 12 year old girl whose sister is developmentally disabled. Grade 7 and up.

What If You Couldn't, Janet Kamien, Scribner. A book about disabilitie that asks the reader to imagine that he or she is the person with the disability.

Don't Forget Tom, Hanne Larse, John Day Book. Order through Harper and Row. Everyday life of a mentally retarded child described in colorful book for preschool and early elementary age children.

Show Me No Mercy, Robert Perske, Abingdon Press. Listen as 1984's outstanding book for adolescents in World Book Encyclopedia yearbook.

Dark Dreams, C. L. Rinaldo, Harper and Row. Story of a friendship with a brain damaged boy. Grade 7 and up.

The Alfred Summer, Jan Slepian, Macmillan. Story about two disabled boys who befriend each other. Junior teen level.

Kelly's Creek, Doris Buchanan Smith, Thos. Crowell, Pub. Order through Harper and Row. Grades 4-6.

A Special Kind of Sister, Lucia B. Smith, Holt. Story about 7½ year old Sarah who has a five year old brother who is mentally retarded. Preschool - 3rd grade.

Friends After All: Accepting Handicapped Differences through Short Stories, Suzan Wapnbick and Eric Kimmel, Ednick. Set of 5 books, 28 pages each.

My Brother is Special, Maureen Crane Wartski, Westminster Press. Effective illustration of how one family members disability affects other family members, especially siblings. Ages 8-14.

Janet at School, Paul White, John Day Book, order through Harper and Row. Janet, age 5, has spina bifida. Ages K-4th grade.

Don't Feel Sorry for Paul, Bernard Wold, Lippincott, order through Harper and Row. Grades 4-6.

My Sister is Different, Betty Ren Wright, Raintree Children's Books. Carlo struggles with his positive and negative feelings about his mentally disabled sister. Grade 5 and up.

About Handicaps: An Open Family Book for Parents & Children Together, Sara Bonnett Stein, Walker & Company.

Attitude toward disability, A bibliography of children's books. Pediatric Projects Inc. P. O. Box 2175 Santa Monica, CA 90406.

Brothers and Sisters - A Special Part of Exceptional Families by Thomas H. Powell and Peggy Ahrenhold Ogle.

Giant Steps for Stephan, Carol Bennett. Available from: After School Exchange, 1111 Belrose Road, Mayfield Heights, Ohio 44124

SICKLE CELL ANEMIA

Sickle Cell - A Complete Guide to Prevention and Treatment, Shirley Linde. Available from: Sickle Cell Foundation, 2391 Benjamin E. Mays Drive, Atlanta, GA 30311.

SPINA BIFIDA

Living With Surgery, Paul Melluzzo and Elizabeth Neallon

My Children, My Children, Robert Reed, Harcourt, Brace, Jovanich, 1977

The Child With Spina Bifida, Elizabeth Anderson and Bernie Spain, Publisher: Methuen and Company, Ltmd. 11 New Satter Lane, London, England EC4P-4EE

SOCIAL/SEXUAL

Being Me: A Social/Sexual Guide for Those Who Work with the Developmentally Disabled, Jean Edwards and Suzan Wapnick, Ednick Communications

Feeling Free: A social/sexual training guide for those who work with the hearing and visually impaired, Jean Edwards, Suzan Wapnick, Penny Mock, Larry Whitson, Ednick Communications.

Sara and Allen: The Right to Choose, Jean Edwards, Suzan Wapnick, Ednick Communications.

VISUALLY IMPAIRED

Get A Wiggle-on (for the infant stage)
Move It (for the toddler stage
Richard Drouillard and Sherri Raynor
Order from: Atlanta Area Services for the Blind, Inc. 763 Peachtree Street, N.E., Atlanta, GA 30308

Raising the Young Blind Child, Battia Scharf, Isabelle Spaulding and Shulamith Kastein

PERIODICALS

Programs for the Handicapped (Free bimonthly publication)
Clearinghouse on the Handicapped
Office of Information and Resources for the Handicapped
Room 3119, Switzer Building
Washington, DC 20202

Word from Washington (free legislative newsletter)
Chester Arthur Building
425 1st Street N.W.
Suite 141
Washington, DC 20001

Computer-Disability News (free quarterly newsletter)
The National Easter Seal Society
2023 W. Ogden Avenue
Chicago, IL 60612

PARENTELE
5538 N. Pennsylvania Street
Indianapolis, IN 46220
(317) 259-1654
Annual subscription: $15

Disabled USA
President's Committee on Employment of the Handicapped
Washington, DC 20210
Published Monthly--Reports progress in opportunities for people with disabilities and developments in rehabilitation and employment.

The Independent
Center for Independent Living
2539 Telegraph Avenue
Berkeley, CA 94704
Published Quarterly--Articles about disabilities and up-to-date information on independent living.

Report
The National Center for a Barrier Free Environment
1015 15th Street, N.W., Suite 700
Washington, DC 20005
Published Bimonthly--News about legislation related to accessibility, news briefs and summaries of articles and books mainly concerned with barriers.

The Exceptional Parent
296 Boylston Street, 3rd Floor
Boston, MA 02116
Published 8 times yearly --Emphasis on education, diagnosis, attitudes, care; covering all handicaps, it is directed toward parents.

The Green Source Book (formerly Green Pages)
Source Book Publications
P. O. Box 1586
Winter Park, FL 32789
Published annually--National directory of products and services for the disabled. Subscription includes an occasional newsletter, "Green Papers", with legislative information and stories about people with handicaps.

Upfront
Mafex Associates, Inc.
90 Cherry Street, Box 519
Johnstown, PA 15907
(Published 11 times a year)
A newspaper for and about physically and mentally disabled people.

Sibling Information Network Newsletter
Department of Educational Psychology
Box U-64
University of Connecticut
Storrs, CT 06268
Research and literature reviews, meetings, family relationship information of interest to siblings of youth with handicaps.

Perinatal Press
c/o The Perinatal Center
Sutter Memorial Hospital
52nd and F Streets
Sacramento, CA 95819

Especially Grandparents
King Co. ARC
2230 Eighth Avenue
Seattle, WA 92121

OTHER PUBLICATIONS

Directory of National Information Sources on Handicapping
Conditions and Related Services (#E-82-22007)
Superintendent of Documents
U. S. Government Printing Office
Washington, DC 20402

National Information Center for Handicapped Children and Youth
P. O. Box 1492
Washington, DC 20013
Information on all disabilities. Cost: Free

Contact disabilities organizations for pamphlets (i.e., local ARC, March of Dimes, UCP, etc.)

"Introduction to Your Child" Booklets
(About thirty booklets available on various disabilities - $.90 each)
Educational Materials Center
Light for the Way - Booklet Series
School of Health, Loma Linda University
Loma Linda, CA 92350

Talk to Me and Talk to Me, II
Addresses language acquisition of blind children - Cost: Free
The Blind Children's Center
P.O. Box 29159
Los Angeles, CA 90029

Parent's Guide to the Development of Preschool Handicapped Children: Resources and Services. Cost: Free
Printed by the Library of Congress. Call your Talking Book Services.

Choosing good toys for young children
National Association for Education of Young Children
1834 Connecticut Ave., NW
Washington, DC 20009
(send stamped, self-addressed envelope)

A Different Way of Seeing
(single copy free - for elementary school children answering questions about vision and blindness)
American Foundation for the Blind
M.C. Migel Memorial Library
15 W. 16th Street
New York, NY 10011

A Reader's Guide for Parents of Children with Mental, Physical or Emotional Disabilities
(free - send mailing label)
National Maternal and Child Health Clearinghouse
3520 Prospect, N.W.
Ground Floor
Washington, DC 20057

People First
(free - written for general public on relating to persons with disabilities)
N.C. Council on Developmental Disabilities
Dept. of Human Resources
616 Albemarle Building
325 N. Salisbury Street
Raleigh, NC 27611

Social and Psychological Aspects of Genetic Disorders
(free bibliography)
National Center for Education
Maternal and Child Health
3520 Prospect Street, N.W.
Washington, DC 20007

Developing a Sense of Competence in Young Children
Cost: Free
National Institute of Mental Health
Division of Scientific and Public Information
5600 Fishers Lane
Rockville, MD 20857

Responding to Disability: A Question of Attitude
Minnesota Council for Handicapped
208 Metro Square
St. Paul, MN 55101
Cost: Free

Epilepsy Can Be Expensive, A Guide on how to save money on medicine
Epilepsy Association of North Carolina
2155 McClintock Road
Charlotte, NC 28205
Cost: Free

CHAPTER VIII

RESOURCES

"Hope is the beginning of plans....."

Norman Cousins

STATE OF FLORIDA
ORGANIZATIONS

Alcohol, Drug Abuse & Mental Health Program--Children's Section
Department of Health & Rehabilitative Services
1317 Winewood Blvd.
Tallahassee, FL 32301
(904) 487-2415

American Diabetes Association
Florida Affiliate, Inc.
3101 Maguire Blvd., Suite 288
P. O. Box 19745
Orlando, FL 32814
(305) 894-6664

American Heart Association, Inc.
Florida Affiliate Office
810 63rd Avenue North
P. O. Box 42150
St. Petersburg, FL 33742
(813) 522-9477

Arthritis Foundation
Florida Chapter
3205 Manatee Avenue West
Bradenton, FL 33505
(800) 282-9487

Association for Retarded Citizens/Florida
106 North Bronough, Suite M1-7
Tallahassee, FL 32301
(904) 681-1931

Bureau of Education for Exceptional Students
Department of Education
Knott Building
Tallahassee, FL 32301
(904) 488-1570

Captioned Videotape Project for the Hearing Impaired
Florida School for the Deaf and Blind
P. O. Box 1209
St. Augustine, FL 32084
(904) 824-1654

Children's Medical Services Program
Department of HRS
1323 Winewood Blvd.
Building 5, Room 127
Tallahassee, FL 32301
(904) 487-2690

Developmental Services Program
Department of HRS
1311 Winewood Blvd.
Building 5, Room 215
Tallahassee, FL 32301
(904) 488-4257

Division of Blind Services
Florida Department of Education
2540 Executive Center Circle West
Tallahasseee, FL 32301
(800) 342-1828
(904) 488-1330

Division of Blind Services Library for the Blind & Physically Handicapped
P. O. Box 2299
Daytona Beach, FL 32015

Florida Developmental Disabilities Planning Council
1317 Winewood Blvd.
Building 1, Suite 309
Tallahassee, FL 32301
(904) 488-4180

Florida Association of Rehabilitation Facilities
1605 E. Plaza Drive, Suite 8
Tallahassee, FL 32308-5311
(904) 877-4816

Florida Bar Lawyer Referral Service
The Florida Bar
Tallahassee, FL 32301-8226
(800) 242-8012

Florida Commission on Human Relations
325 John Knox Road, Suite F-240
Tallahassee, FL 32303
(800) 342-8170

Florida Council of Handicapped Organizations
P. O. Box 2027
Satellite Beach, FL 32937
(305) 777-2964

Florida Association for Children with Learning Disabilities
5683 Deefield Road
Orlando, FL 32808
(305) 295-8203

Florida Easter Seal Society
1010 Executive Center Drive, Suite 101
Orlando, FL 32803
(305) 896-7881

Florida School for the Deaf and the Blind Child Study Center
207 North San Marco Avenue
St. Augustine, FL 32084
(904) 824-1654

Florida Society for Children and Adults with Autism
1523 Julie Tonia Drive
West Palm Beach, FL 33415
(305) 965-0409

Florida Epilepsy Foundation
P. O. Box 6059 C
Orlando, FL 32853
(305) 422-1439

Florida Instructional Materials Center for the Visually Handicapped
5002 North Lois Avenue
Tampa, FL 33614
(800) 282-9193

Florida Justice Institute, Inc.
1401 Amerifirst Building
One S.E. 3rd Avenue
Miami, FL 33131
(305) 358-2081

Florida Legal Services, Inc.
226 West Pensacola, Room 216-218
Tallahassee, FL 32301
(904) 222-2151

Governor's Commission on Advocacy for Persons with Developmental Disabilities
Office of the Governor
The Capital
Tallahassee, FL 32301-8047
(800) 342-0823
(904) 488-9071

Handicapped & Workstudy Program
Division of Vocational Education
Department of Education
Knott Building
Tallahassee, FL 32301
(904) 488-5965

Head Start
Humanics Associates
Florida Office
255 Whooping Loop, Suite 255
Altamonte Springs, FL 32701
(305) 834-6538

March of Dimes Birth Defects Foun
Regional Office
12550 Biscayne Boulevard
North Miami, FL 33181
(305) 895-2856

Mental Health Agency
Department of HRS
1317 Winewood Blvd.
Tallahassee, FL 32301
(904) 488-8304

Mental Health Association of Flori
345 S. Magnolia Drive, Suite A13
Tallahassee, FL 32301
(904) 877-4707

Muscular Dystrophy Association
1301 Seminole Boulevard, Suite 105
Largo, FL 33540
(813) 585-5446

National Kidney Foundation of Flor
Inc.
One Davis Boulevard, Suite 304
Tampa, FL 33606
(813) 251-3627

Office of Vocational Rehabilitatio
Department of HRS
1309 Winewood Boulevard
Tallahassee, FL 32301

Parents Anonymous
1106 Thomasville Road
Tallahassee, FL 32303
(800) FLA-LOVE
(904) 224-8481

The Pro Bono Directory
Legal Assistance Project
Dept. of Public Interest Programs
The Pro Bono Directory
The Florida Bar
Tallahassee, FL 32301
(904) 222-5286

Southern Legal Counsel, Inc.
115 N.E. 7th Avenue
Gainesville, FL 32601
(904) 377-8288

Spina Bifida Coalition of Florida
996 Florida Town Road
Pace, FL 32570
(904) 994-4001

State Special Olympics Headquarters
2639 N. Monroe Street, Suite 151-A
Tallahassee, FL 32303
(904) 385-8178

Statewide Human Rights Advocacy
Committee
1317 Winewood Boulevard
Building 1, Room 310
Tallahassee, FL 32301
(904) 488-4180

University of Miami Child Development
Center Multi-disciplinary Training
Facility
P. O. Box 016820
Miami, FL 33101
(305) 547-6624

Upjohn Healthcare Services
Florida Region Administration
P. O. Box 2607
Winter Park, FL 32790

Note: If you would like information on Parent to Parent support groups in the State of Florida, please contact the Parent to Parent of Florida office at (904) 769-6606.

NATIONAL ORGANIZATIONS

Aid to Adoption of Special Kids
3530 Grand Avenue
Oakland, CA 94610
(415) 451-2275

Alexander Graham Bell Association
for the Deaf
3417 Volta Place, N.W.
Washington, DC 30007
(202) 337-5220

American Brittle Bone Society
1256 Merrill Drive
Marshallton
West Chester, PA 19380
(215) 692-6248

American Alliance for Health,
Physical Education, Recreation &
Dance
Information and Research
Utilization Center
1900 Association Drive
Reston, VA 22091
(703) 476-3400

American Association for the
Advancement of Science Project
on the Handicapped in Science
Office of Opportunities in Science
1776 Massachusetts Avenue, N.W.
Washington, DC 20036
(202) 467-4400

American Association of University
Affiliated Programs for the
Developmentally Disabled
1234 Massachusetts Avenue, N.W.
Washington, DC 20005

American Association on Mental
Deficiency
5101 Wisconsin Avenue, N.W.
Washington, DC 20016
(202) 686-5400

American Cleft Palate Education
Association
331 Salk Hall
University of Pittsburgh
Pittsburgh, PA 15261

American Civil Liberties Union
132 West 43rd Street
New York, NY 10036

American Coalition of Citizens with
Disabilities (ACCD)
1200 15th Street, N.W., #201
Washington, DC 20005
(202) 785-4265

American Council for the Blind
1211 Connecticut Avenue, N.W. Suite 5
Washington, DC 20036
(202) 833-1251

American Foundation of the Blind (AFB)
15 West 16th Street
New York, NY 10011
(212) 620-2000

American Genetics Association
818 18th Street N.W.
Washington, DC 20036

American Kidney Fund
7315 Wisconsin Avenue
Bethesday, Maryland 20814-3266
800-638-8299

American Occupational Therapy Assoc.
1383 Piccard Drive, Suite 300
Rockville, MD 20850
(301) 948-9626

American Physical Therapy Association
1111 N. Fairfax Street, Suite 200
Alexandria, VA 22314
(703) 684-2782

American Printing House for the Blind
P. O. Box 6085
1839 Frankfort Avenue
Louisville, KY 40206
(502) 895-2405

American Red Cross
National Headquarters
17th and D Streets, N.W.
Washington, DC 20006
(202) 737-8300

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400

Arthrogryposis Association, Inc.
5430 E. Harbor Heights Drive
Port Orchard, WA 93866
(206) 871-5057

Association for Persons with Severe
Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115
(206) 523-8446

AAWE/Alleviates Alliance
206 N. Washington Street, Suite 320
Alexandria, VA 22314
(703) 836-6060

Association of Birth Defect Children
3201 East Crystal Lake Avenue
Orlando, FL 32806
(305) 898-5342

Association for Children & Adults
with Learning Disabilities (ACLD)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515

Association for Retarded Citizens
National
2501 Avenue J
Arlington, TX 76011
(817) 640-0204

Asthma & Allergy Foundation of
America
1302 18th Street, N.W., Suite 303
Washington, DC 20036
(202) 293-2950

Boy Scouts of America
Scouting for the Handicapped Division
1325 Walnut Hill Lane
Erving, TX 75062
(214) 659-2000

Cancer Research Institute
Memorial Donations
133 East 58 Street
New York, NY 10022
(212) 688-7515
(800) 223-7874

The Candlelighters Foundation
2025 "I" Street, N.W. Suite 1011
Washington, DC 20006
(202) 659-5136

Center on Human Policy
4 East Huntington Hall
Syracuse University
Syracuse, NY 13210
(315) 423-3951

Clearinghouse on the Handicapped
Office of Special Education and
Rehabilitative Service
Room 3106 Switzer Building
Washington, DC 20202
(202) 732-1245

Compassionate Friends, Inc.
P. O. Box 1347
Oak Brook, IL 60521
(312) 323-5015

Cooley's Anemia Foundation
105 East 22nd Street, Suite 911
New York, NY 10010
(212) 598-0911

Cornelia de Lange Syndrome Foun
60 Dyer Avenue
Collinsville, CT 06022
(202) 693-0159

Center for Law and Education, Inc.
Gutman Library, 3rd Floor
6 Appian Way
Cambridge, MA 02138
(617) 495-4666

Children's Brain Research Clinic
2525 Belmont Road, N.W.
Washington, DC 20008

Children's Defense Fund
122 C Street, N.W.
Washington, DC 20001
(202) 628-8787

Closer Look
Parents Campaign for Handicapped
Children and Youth
1201 16th Street, N.W.
Washington, DC 20036
(202) 822-7900

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Cystic Fibrosis Foundation
6000 Executive Boulevard, Suite 309
Rockville, MD 20852
(301) 881-9130

Dental Guidance Council for Cerebral
Palsy
122 East 23rd Street
New York, NY 10010
(212) 677-7400

Developmental Disabilities Office
U.S. Department of Health and
Human Services
200 Independence Avenue, S.W.
Room 338E
Washington, DC 20201

Disability Rights
Education Defense Fund, Inc.
2032 San Pablo Avenue
Berkeley, CA 94702
(415) 644-2555

Dysautonomia Foundation
120 E. 41st
New York, NY 10017
(212) 889-0300

Dystrophic Epidermolysis Bullosa
Research Association of America
2936 Avenue W
Brooklyn, NY 11229
(212) 774-8700

Ephphatha Services for the Deaf
and Blind
P. O. Box 15167
Mineapolis, MN 55415

Epilepsy Foundation of American
4351 Garden City Drive, Suite 406
Landover, MD 20785
(305) 459-3700

Foundation for Children with
Learning Disabilities
P. O. Box 2929
Grand Central Station
New York, NY 10163
(212) 687-7211

Friedreich's Ataxia Group in America
P. O. Box 11116
Oakland, CA 94611

Girl Scouts of the U.S.A.
Scouting for Handicapped Girls
830 Third Avenue
New York, NY 10022
(212) 940-7500

Human Resources Center
I.U. Willets Road
Albertson, NY 11507

Human Growth Foundation
4607 Davidson Drive
Chevy Chase, MD 20815
(301) 656-7540

Hydrocephalus Parent Support Group
9430 Reagan Road
San Diego, CA 92126

Institute for the Achievement of
Human Potential
8801 Stenton Avenue
Philadelphia, PA 19118

International Association of Parents
of the Deaf
814 Thayer Avenue
Silver Springs, MD 20910
(301) 585-5400

International Institute for Visually
Impaired, 0-7, Inc.
1975 Rutgers Circle
East Lansing, MI 48823

John Tracy Clinic (Deafness, hearing
impairments, deaf/blind)
806 West Adams Blvd.
Los Angeles, CA 90007
(213) 748-5481

Joseph P. Kennedy Jr. Foundation
1350 New York Avenue, N.W., Suite 500
Washington, DC 20005
(202) 393-1250

Juvenile Diabetes Foundation, Int'l.
3 E. 26th Street
New York, NY 10010
(212) 889-7575

Know Problems of Hydrocephalus
Route 1, River Road, Box 210A
Joliet, IL 60436

LaLeche League International
9616 Minneapolis
Franklin Park, IL 60131
(312) 455-7730

Library of Congress
Division for Blind and Physically
Handicapped
1291 Taylor Street, N.W.
Washington, DC 20542

Little People of America
Box 633
San Bruno, CA 94066
(415) 589-0695

Leukemia Society of America, Inc.
National Headquarters
800 2nd Avenue
New York, NY 10017
(212) 573-8484

MPS Society
552 Central Avenue
Bethpage, NY 11714
(516) 433-4419

March of Dimes National Foundation
1275 Maroneck Avenue
White Plains, NY 10605

Mental Disability Legal Resource
Center
Commission on the Mentally Disabled
American Bar Association
1800 M Street, N.W.
Washington, DC 20036
(202) 331-2240

Mental Retardation Association of
America
211 East 300 South, Suite 212
Salt Lake City, UT 84111
(801) 328-1575

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019
(212) 586-0808

Myoclonus Families United
c/o NORD
2153 East 22nd Street
Brooklyn, NY 11220

National Amputation Foundation
1245 150th Street
Whitestone, NY 11356
(212) 767-0596

National Association for Deaf/Blind
2703 Forrest Oak Circle
Norman, OK 73071
(405) 733-7311

National Association for Disabled
Citizens
P. O. Drawer 8075
Maitland, FL 32751
(305) 628-8850

National Association for Down's
Syndrome
Box 63
Oak Park, IL 60303
(312) 543-6060

National Association for Parents o
the Visually Impaired, Inc.
2011 Hardy Circle
Austin, TX 78757

National Association for the Deaf
Legal Defense Fund
Florida Avenue & 7th Street, N.E.
Suite 311
Washington, DC 20002

National Association for Sickle-Cel
Disease (NASCD)
3460 Wilshire Blvd., Suite 1012
Los Angeles, CA 90010

National Association for Visually
Handicapped
305 East 24th Street, 17-C
New York, NY 10010
(212) 889-3141

National Association of Private
Residential Facilities for the
Mentally Retarded
6269 Leesburg Pike
Falls Church, VA 22044
(703) 536-3311

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788

National Ataxia Foundation
6681 Country Club Drive
Minneapolis, MN 55427
(612) 546-6220

National Hearing Association
1010 Jorie Blvd., Suite 308
Oak Brook, IL 60521
(312) 323-7200

National Association of the
Physically Handicapped
70 Elm Street
London, OH 43140
(614) 852-1664

National Center for a Barrier-Free
Environment
1015 15th Street, NW, Suite 700
Washington, DC 20005
(202) 466-6896

The National Clearing House for
Human Genetic Diseases
3520 Prospect Street, N.W.
Ground Floor, Suite 1
Washington, DC 20057
(202) 842-7617

National Down Syndrome Congress
1640 W. Roosevelt Road
Chicago, IL 60608
(312) 226-0416

National Down Syndrome Society
70 West 40th Street
New York, NY 10018
(212) 764-3070
(800) 221-4620

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
(312) 243-8400
(312) 243-8800 (TDD)

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(301) 659-9314

National Foundation for Ileitis
and Colitis
295 Madison Avenue
New York, NY 10017
(212) 685-3440

National Genetics Foundation
555 West 57th Street
New York, NY 10019
(212) 586-5800

National Head Injury Foundation
280 Singletary Lane
Framingham, MA 01701
(617) 879-7473

National Hearing Aid Society
20361 Middlebelt Road
Livona, MI 48152
(313) 478-2610

National Hemophilia Foundation
19 W. 34th Street, Room 1204
New York, NY 10001
(212) 563-0211

National Ichthyosis Foundation
151 Toyon Drive
Vallejo, CA 94589

National Information Center for
Handicapped Children and Youth
(NICHCY)
P. O. Box 1492
Washington, DC 20013

National Institute for Rehabilitation
Engineering
97 Decker Road
Butler, NJ 07405
(201) 838-2500

National Juvenile Law Center
St. Louis University School of Law
3701 Lindell Blvd.
St. Louis, MO 63108

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314

National Neurofibromatosis Foundation
70 West 40th Street, 4th Floor
New York, NY 10018
(212) 869-9034

National Organization on Disability
2100 Pennsylvania Avenue, N.W.
Suite 234
Washington, DC 20037
(202) 293-5960

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314

National Retinitis Pigmentosa
Foundation
Rolling Park Building
8331 Mindale Circle
Baltimore, MD 21207
(301) 655-1011

National Reye's Syndrome
Foundation
P. O. Box RS
Benzonia, MI 49616

National Society for Children
and Adults with Autism
1234 Massachusetts Avenue, M.W.
Suite 1017
Washington, DC 20005
(202) 783-0125

National Spinal Cord Injury
Association
149 California Street
Newton, MA 02158
(617)964-0521

National Tay-Sachs and Allied
Diseases Association
92 Washington Avenue
Cedarhurst, NY 11516
(516) 569-4300

National Tuberous Sclerosis Assoc.
P. O. Box 612
Winfield, IL 60190
(312) 668-0787

Office for Handicapped Individuals
U.S. Department of Health and Human
Services
200 Independence Avenue, S.W.
Washington, DC 20201

Osteogenesis Imperfecta Foundation
632 Center Street
Van Wert, OH 45891

Orton Dyslexia Society
724 York Road
Baltimore, MD 21204
(301) 296-0232

Parent Care
University of Utah Medical Center
50 North Medical Drive, Room 2A210
Salt Lake City, Utah 84132
(801) 581-5323

Parent Network
1301 E. 38th Street
Indianapolis, IN 46205

People First International
P. O. Box 12642
Salem, OR 97309
(503) 378-5143

Polio Information Center
510 Main Street
Roosevelt Island, NY 10044

Prader-Willi Association
5515 Malibu Drive
Edina, MN 55436
(612) 933-0115

President's Committee on Employmen
of the Handicapped
Washington, DC 20010

President's Committee on Mental
Retardation
Washington, DC 20201

Scoliosis Research Society
444 N. Michigan Avenue, Suite 1500
Chicago, IL 60611
(312) 822-0970

Scoliosis Association
1428 183 Main Street, East
Rochester, NY 14604
(716) 546-1814

Sharing Our Caring
P. O. Box 400
Milton, WA 98354
(Down Syndrome)

Sibling Information Network
Department of Educational Psycholog
Box U-64, The Univ. of Connecticut
Storrs, CT 06268
(203) 486-4034

Siblings for Significant Change
Room 808
823 United Nations Plaza
New York, NY 10017

Support Organization for Trisomy
(SOFT)
7326 S. 145 Street, East
Midville, Utah 84947
(801) 566-0674

Special Education Programs
U. S. Dept. of Education
Switzer Building
330 "C" Street, S.W.
Washington, DC 20202

Spina Bifida Association of
America
343 South Dearborn Street, Room 317
Chicago, IL 60604
(312) 663-1562

United Cerebral Palsy Assocations
66 East 34th Street
New York, NY 10016
(212) 481-6300

United Ostomy Association
2001 West Beverly Bldg.
Los Angeles, CA 90057
(212) 413-5510

The United States Association
for Blind Athletes
55 West California Avenue
Beach Haven, NJ 08008

The Voice
2939 Hollandale
Dallas, TX 75234
(214) 349-3271 (V/TDD)
(Hearing Impaired)

Youth Law Center
693 Mission Street
Second Floor
San Francisco, CA 94105
(415) 543-3379

TOLL FREE TELEPHONE SERVICES

AMC Cancer Information Center	800-525-3777
American Council of the Blind	800-424-8666
American Kidney Fund	800-638-8299
Better Hearing Institute Hearing Helpline	800-424-8576
Cancer Information Service National Line	800-4-CANCER
Captioned Films for the Deaf	800-237-6213
Center for Special Education Technology Information Exchange	800-345-8324
Child Abuse Registry	800-342-9152
Children's Defense Fund	800-424-9602
Closer Look LD Teen Line	800-522-3458
Epilepsy Information Line	800-542-7054
ERIC Clearinghouse on Adult Career and Vocational Education	800-848-4815
Foundation Center	800-424-9836
Heartlife	800-241-6993
HEATH Resource Center	800-54-HEATH
International Shriners Headquarters	800-237-5055
Job Accommodation Network	800-526-7234
Job Opportunities for the Blind	800-638-7518
National Alliance of Blind Students	800-424-8666
National Center for Stuttering	800-221-2483
National Committee for Citizens in Education	800-NETWORK
National Crisis Center for the Deaf (TDD Only)	800-446-9876
National Down Syndrome Congress	800-232-6372
National Down Syndrome Society	800-221-4602

National Easter Seal Society	800-221-6827
National Health Information Clearinghouse	800-336-4797
National Hearing Aid Society	800-521-5247
National Information Center for Educational Media	800-421-8711
National Rehabilitation Information Center (Voice/TDD)	800-32-NARIC
National Special Needs Center	800-233-1222 800-833-3232 (TDD)
National Spinal Cord Injury Hotline	800-526-3456
Orton Dyslexia Society	800-222-3123
Poison Information	800-542-6319
Resource Center for the Handicapped	800-22-SHARE
RP Foundation Fighting Blindness	800-638-2300
Special Education Software Center	800-327-5892
Spina Bifida Hotline	800-621-3141
Tripod Service for Hearing Impaired	800-352-8888
Washington PAVE	800-5-PARENT

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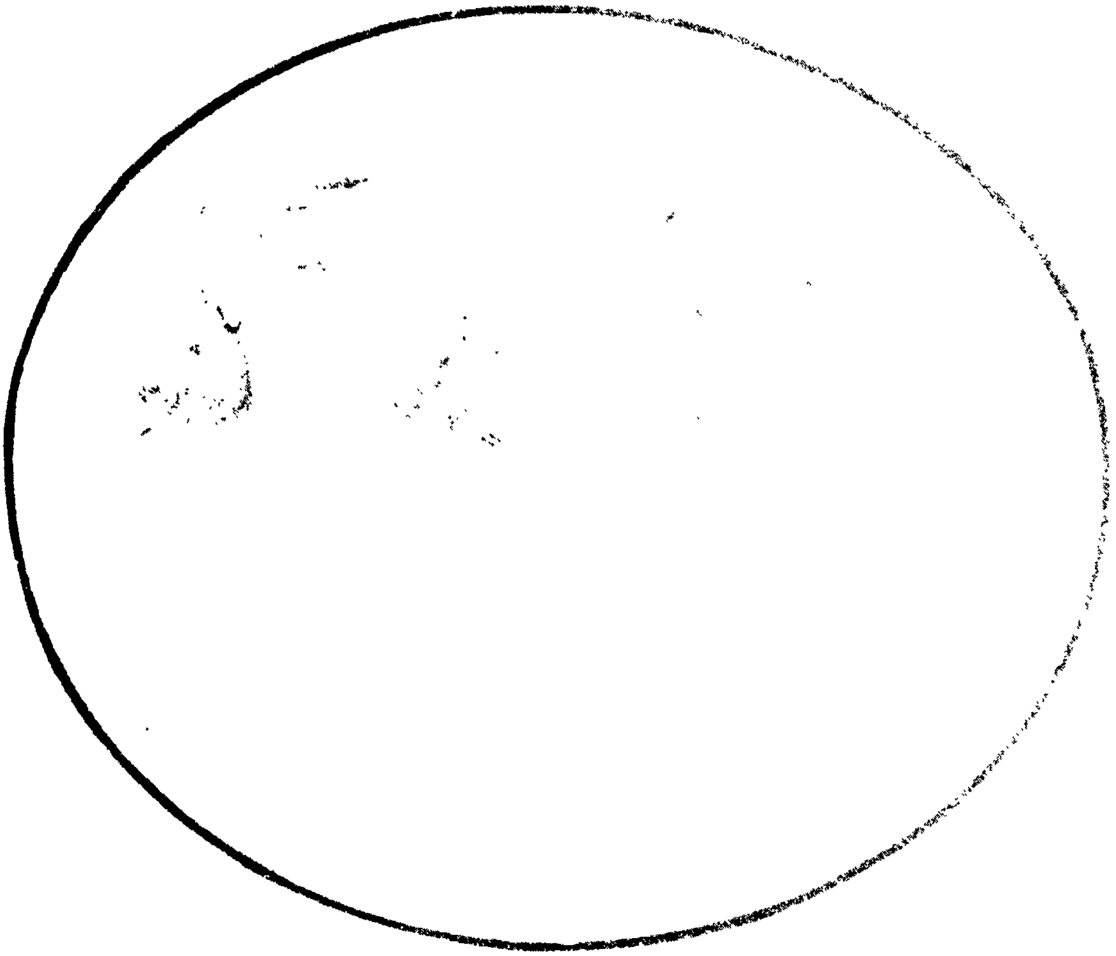
Parent to Parent
OF FLORIDA



Materials For Parent Training

Parent to Parent of Florida
621 Kraft Avenue
Panama City, Florida 32401
(904) 769-6606

This project is funded in part by the Department of Health and Human Services, Administration on Developmental Disabilities and the Florida Developmental Disabilities Planning Council.

Parent to Parent
OF FLORIDA
621 KRAFT AVENUE
PANAMA CITY, FLORIDA 32401
(904) 769-6606

PARENT TO PARENT OF FLORIDA PHILOSOPHY

Parents of special needs children who have come to accept and understand their child's disability are one of the best sources of information and emotional support for other parents of children with special needs who may be experiencing difficulties. By virtue of having "been there" a unique bonding occurs between parents establishing an almost immediate rapport and sharing of common feelings and experiences.

A supporting parent's skills are enhanced through their participation in parent to parent support training; however, it is their willingness and ability to share their experience that qualifies them to positively interact with other parents. Supporting parents are not trained to be professional counselors or therapists but are parents who have successfully met the challenges of parenting a special needs child and, hence, are viewed by parents as capable helpers. Parent to Parent of Florida defines special needs as any sensory, physical, or learning disorder, developmental disabilities such as cerebral palsy, autism, epilepsy, mental retardation or spina bifida, children with emotional disturbances, and those children who are high risk or developmentally delayed due to prematurity, environment or some unknown cause.

As a result of parent to parent interaction, parents are better able to approach their child's ability to grow, learn and develop to his or her potential with an optimistic attitude and within a supportive environment. Early success in relating to this life experience will positively affect family relationships and future decisions made on behalf of the child.

We believe parent to parent support should be available not only at the time of the initial crisis but throughout the child's life. The areas of concern are endless and range from coping with the initial diagnosis to a myriad of specific issues such as sexuality and guardianship.

Parent to Parent of Florida believes that the benefits of parents helping other parents facilitates the developmental growth of families through heightened awareness, knowledge, and acceptance of their child's special needs. Parent to parent support should be easily accessible within the local community to all parents of special needs children.

FUNDED BY THE FLORIDA DEVELOPMENTAL DISABILITIES PLANNING COUNCIL
PARENT TO PARENT OF FLORIDA IS LOCATED AT UNITED CEREBRAL PALSY OF PANAMA CITY, FLORIDA

PARENT TO PARENT OF FLORIDA

FACTS ABOUT PARENT TO PARENT SUPPORT PROGRAMS

1. THE PURPOSE of parent to parent support programs is to match trained support parents with parents who are experiencing a time of crisis or seeking information.

2. SUPPORTING PARENTS is the term for trained volunteers who are personally well adjusted and who have successfully integrated a child with special needs into their family and are willing to share their feelings and experiences with other parents. Supporting parents are open-minded and non-judgmental.

3. SPECIAL NEEDS are defined as any sensory, physical or learning disorder, developmental disabilities such as cerebral palsy, autism, epilepsy, mental retardation or spina bifida, children with emotional disturbances, and those children who are high risk or developmentally delayed due to prematurity, environment or some unknown cause.

4. SUPPORTING PARENTS are trained to be peer support parents by successfully completing a series of workshops on communication skills, developmental disabilities, local, state and national resources, community outreach and the referral process.

5. REFERRED PARENTS is the term for parents who are experiencing a time of crisis related to their child's disability or seeking information. These situations may include the time of the initial diagnosis, hopsitalization, the educational process, sexuality, group home exploration or guardianship issues.

6. INITIAL CONTACT by a supporting parent is made within 24 hours of a request being received, or as soon as possible thereafter. Contact is made either by phone or in person. The amount and kind of continued contact depends on the needs and desires of the referred parents.

7. PARENT TO PARENT makes contact with referred families only when these families express an interest in talking with a supporting parent. Contact is never made without the referred parent's consent and confidentiality is maintained at all times.

8. SUPPORTING PARENTS do not provide formal counseling but do offer encouragement, emotional support and information on an informal and personal basis. Supporting parents model appropriate early accessing of resources.

9. SUPPORTING PARENTS do not give advice, particularly medical advice. They may give general suggestions or outline options, but they leave decisions to the referred parents.

10. SUPPORTING PARENTS serve to model the normalization principle for families experiencing the crisis of acceptance and make them aware of the important affect their attitude will have on their child's development.

11. PARENTS are matched as closely as possible according to several relevant criteria: diagnosis or degree of child's disability, age of child, marital status, racial, religious or cultural factors, geographic location of residence, etc.

12. PARENT TO PARENT support may help to reduce the incidence of child abuse and neglect by providing an emotional outlet and reducing family stress.

13. PARENT TO PARENT support programs strengthen the partnership between parents and professionals in a local community. Supporting parents are the nucleus for each local program and receive support and assistance from at least one professional person within the community.

NICHCY

NATIONAL INFORMATION CENTER FOR HANDICAPPED CHILDREN AND YOUTH
P.O. BOX 1492 WASHINGTON, D.C. 20013

March, 1984

You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap

By Patty McGill Smith

IF YOU HAVE RECENTLY LEARNED that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *denial*—"this cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by feelings of *grief* and inexplicable *loss* that one does not know how to explain, nor how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?". Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?".

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?". For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertantly let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", or "Why my child?", many parents are also saying, "Why has God done this to me?". How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?". One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to the National Information Center to get that local information.

Talk With Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request *accurate* information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is *your* child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are somethings that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. At the end of this paper, a person is listed who will help you get started in gaining the information and assistance you need. While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel *with* another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Patty McGill Smith has recently moved to Washington from Omaha, Nebraska with her two youngest daughters, Marianne, age 17 and Jane, age 13. Jane, who was diagnosed at 14 months of age, has a mental handicap and epilepsy. She has been the source of inspiration for her mother's writing and her second career.

Patty's first career was at home raising seven children. The five older children are currently in five other cities of the mid-west. They are involved in careers in law, mental retardation, biology and two are in their first year of college.

The second career for Patty began as the staff coordinator of the Pilot Parents Program of the Greater Omaha Association of Retarded Citizens. This eventually became a four state center for Pilot Parents and a national resource for information about parent to parent programs.

In 1979 Patty moved to the Meyers Children's Rehabilitation Institute at the University of Nebraska Medical Center where she coordinated statewide services for parents, siblings, advocates, and professionals working with parents.

On January 16, 1984, she became Deputy Director of the National Information Center for Handicapped Children and Youth. Patty views this as a "wonderful opportunity" for a parent to serve as the link and liaison to parent organizations and groups nationwide. One of her major responsibilities will be to facilitate the exchange of as much current information and support among parents as possible. She invites parents everywhere to send information about the programs and the good things that are happening in helping parents where they live. Parents in need of assistance may write to:

Patty Smith, *Deputy Project Director*
National Information Center for Handicapped Children and Youth
1555 Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

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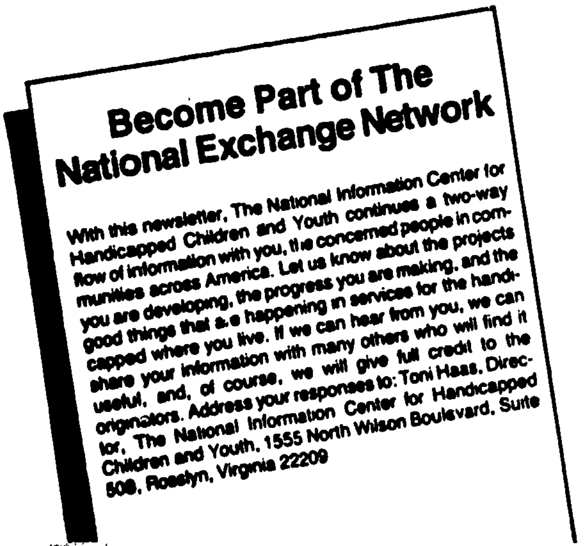

Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

LISTEN

When I ask you to listen to me
and you start giving advice
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why I shouldn't feel that way,
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something to solve my problem,
you have failed me, strange as that may seem.

Listen! All I asked, was that you listen.
not talk or do--just hear me.
Advice is cheap: 20 cents will get you both Dear Abby and Billy
Graham in the same newspaper.
And I can do for myself: I'm not helpless.
Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do
for myself, you contribute to my fear and weakness.

But, when you accept as a simple fact that I do feel what I feel,
no matter how irrational, then I can quit trying to convince
you and can get about the business of understanding what's
behind this irrational feeling.
And when that's clear, the answers are obvious and I
don't need advice.
Irrational feelings make sense when we understand what's
behind them.

Perhaps that's why prayer works, sometimes, for some people
because God is mute, and He doesn't give advice or
try to fix things. "They" just listen and let you
work it out for yourself.

So, please listen and just hear me. And, if you want to
talk, wait a minute for your turn; and, I'll listen to you.

Anonymous

PARENT TO PARENT OF FLORIDA

LISTENING TECHNIQUES

A. 42% of the time spent communicating is done in listening.
    1. Speaking is done 32% of total communicating time.
    2. Reading - 15%
    3. Writing - 11%
    4. With a telephone conversation, the amount of time spent in listening is increased, but the amount heard is decreased because of lack of eye contact.

B. Listening tips:
    1. Avoid close-ended (yes/no) questions.
        a. Example: "I'll bet you're having some strong feelings."
        b. Better: "Can you tell me about some of your feelings?"

    2. Center around concerns of parent, not your own.
        a. Example: "I felt so guilty after the birth of my retarded child."
        b. Better: "What are you feeling right now?"

    3. Watch for "doors" (openings in conversation, pauses)
        1. Why might a parent be pausing?

    4. Be alert for your own negative feelings.
        1. Remain objective

    5. Avoid premature conclusions and interpretations.

    6. Keep the relationship open.

    7. Center constructive thoughts around your feelings.
        a. Don't ever give parent the impression that you think he or she is wrong.

C. Active Listening
    1. Above all, stop talking.

    2. Want to hear what is said.

    3. Want to be helpful.

    4. Show that you want to listen.

    5. Put the talker at ease.

    6. Ask appropriate questions.

    7. Listen for more than facts.
        a. What is this mother saying? "I'm doing just fine. I was just surprised to see all that hospital equipment. And my baby is <u>so</u> tiny. He doesn't even look like a baby. But he'll be fine - once he gets off the respirator and gets over the heart problem. I'm not even sure what it is. I forget to ask questions. I just keep looking at that equipment."

8. Empathize with the talker. Put yourself in his or her shoes.

9. Recognize that the speaker is someone who is separate from you. Don't get emotionally involved.

10. Accept the speaker's feelings -- as his or hers, not yours.
    a. Feel confident in suspending your feelings and all judgments in order to be totally open to what the parent is communicating. Be flexible.
    b. <u>Example</u>: A parent says: "I don't care what the doctor says, I'm going to give my newborn baby solid foods to make hime sleep."

11. Hold your temper.

12. Go easy on arguments and criticism.

13. Know that feelings are transitory. Feelings change.
    a. This doesn't mean that you expect a parent to change to <u>your</u> way of thinking!

14. Trust in tne parent's capacity to handle their feelings, to work through them, and to find solutions to their problems.
    a. You are there to help support them in this process, if they choose

15. Be patient. Allow plenty of time. Don't interrupt. Don't be in a hurry to give answers, or everything you know.

16. Don't be preparing your answer while the parent is talking.
    a. Withhold evaluation until he/she is finished. Know what he/she is asking.

17. Take notes as the parent is talking (mental notes).

D. Methods of indicating that you are listening:

1. Repeat parent's last words, either as a statement ("David is jaundiced"), or a question ("So David is jaundiced?")

2. Paraphrase
    a. Take the important parts from a person's speech.
    b. This helps in making certain that you are understanding what anotner is saying, as well as that they know what you heard.
    c. Paraphrase this speech· "My husband and I went to the hospital last night - in the rain, wouldn't you know? My hair looked a wreck. Anyway, the baby was on a higher respirator setting and they had given her some new medicines. I can't imagine how they get the needles in her tiny arms! I'm not even sure what it was for - we never get to see the doctor."
    What is this parent feeling?

3. Listen for emotional meaning.
    a. Example: parent says, "The respirator is so huge and complicated. I'm sure I'll set it off if I touch Brian."
    b. You might say:

4. "Tracking" - following the person's monologue.
    a. Neutral noise - uh-huh, nod, etc.
    b. Injections - yes, of course, etc.
    c. Practical questions

5. Offering a chance to elaborate
    a. Example: "How did you feel about that?" "What happened then?"

    b. More examples: "Can you give me a specific example?"

6. Listen for contradictions
    a. Respond to feelings rather than intellectual content.
    b. Example: A parent asks, "This is probably too early to think about, since my daughter is only a month old, but can you tell me about school for the mentally retarded? Do you know of any that can increase a child's I.Q.? Or should I even send her to school -- do you think it's worth it?"
    You might say:

E. Using one or more of these methods, as well as following a parent's speech patterns and vocabulary senses (See Developing a Relationship) will enable you to develop profound rapport.

1. Parent may feel comfortable with even a brand-new relationship, and relieved to find someone with similar experiences, and may be able to freely express thoughts and feelings, thus helping him or herself.

2. This comes with experience and practice.
    a. Don't force it - it may sound affected or ungenuine.
    b. Practice in daily family and neighborhood situations.
    c. Listen for speech patterns, etc., even if you don't attempt to match them at first.
    d. These skills will come naturally as you do counseling. Be yourself.
    e. This is not an overnight happening. It requires constant growing and improving. Practice on your spouse and friends.

F. Roadblocks to Effective Communication

1. Ordering
    a. Example of ordering: "Get a second opinion."
    b. Better: "A second opinion often helps to clarify a problem."

2. Threatening
    a. Example of threatening: "If you don't give your baby that medicine, you'll be sorry!"
    b. Better: "What was the doctor's reason for prescribing that medication?"

3. Moralizing
    a. Example: "You shouldn't feel depressed. Your baby died a full ten months ago."
    b. Better: "Each person reacts to death differently and takes his own amount of time to mourn and adjust."

4. Giving solutions, taking responsibility
    a. Example: "Your child needs to be evaluated by the March of Dimes. I'm going to call and make her an appointment."
    b. Better: "An evaluation may help to diagnose Laura's weaknesses. If you're interested, there are several places you might try..."

5. Lecturing, being completely rational.
    a. Example: "Life can be hard. You have to get hold of yourself."
    b. Better: "Life often gives us challenges for which our coping mechanisms are not prepared."

6. Judging, criticizing
    a. Example: "You really handled your meeting with the cardiologist poorly."
    b. Better: "Many parents have a difficult time communicating with members of the medical profession."

7. False praising
    a. Example: "You're a terrific mother!"
    b. Better: "A lot of parents have a hard time relating to their hospitalized newborns. Many are unable to touch and hold them, as you've been doing."

8. Labeling
    a. Example: "You're angry."
    b. Better: "It sounds to me as if you're angry. Tell me about it."

9. Denying reality
    a. Example: "Everything will be all right."
    b. Better: "We can never know what the future will bring. But what improvements have you seen since yesterday?

10. Invading privacy
    a. Example: "Was your marriage in trouble before Melissa was born?"
    b. Better: "What are some ways in which you can handle your present situation?"

11. Distracting
    a. Example: "So Tony has to have open heart surgery? Oh. Have you gotten his room ready at home?"
    b. Better: "What are you feeling about Tony's surgery?"

12. Diagnosing
    a. Example: "I can tell from your description that David has a tracheal-esophageal fistula."
    b. Better: "What has the doctor said about David's problem?"

PARENT TO PARENT OF FLORIDA

DEVELOPING A RELATIONSHIP

A. Developing rapport

1. Attempt to subtly match parent's:
   - a. Tone (note of voice).
   - b. Rate of speech (may be arhythmic).
   - c. Intonation.
   - d. Doing all three of these will enable you to have almost immediate rapport and allow parent to feel free to express him/herself.

2. Listen to how parent is experiencing the world, as evident through his/her "vocabulary sense".

a. Visual	I see what you mean... It looks dark... I see red...
b. Feeling	get a handle on the situation... things are rough... feel pinched in... churned up inside...
c. Auditory	I hear what you say... harmonious situation... loud outfit...

   - d. Respond in his/her "sense".

B. Qualities of a Relationship

1. Some people need to be dependent.
   - a. Encourage them to do things for themselves--starting with little things.
   - b. Example: How might you encourage this?
   - c. These people may need more support, or contact for a greater amount of time.
   - d. Find a balance between support and independence.

2. Counterdependent (afraid to be dependent)
   - a. These people may be more anxious to know what they can do for themselves.
   - b. Be careful not to get too "situation oriented" and ignore parent's feelings--they still have them!
   - c. Sharing experiences and feelings may enable such a parent to open up.

d. Enabling her to help herself may free her to express herself and trust you more.
e. Don't be pushy. Allow her to have her own feelings and personality. Example: How might you attempt to get such a parent started talking?
f. Don't take it personally.

3. Quiet

   a. This may be a personality, or a relatively long-term response to a situation, or an isolated incident. The next call you make to him/her may be different.
   b. Don't be afraid of periods of silence.
   c. Let a parent know that you are not a social worker, just another parent. What difference might this make?
   d. Let a parent know you would like to share his/her feelings, but don't be pushy.
   e. Try to accept him/her feelings and accept him/her as is.
   f. Don't take it personally.

4. Talkative

   a. This parent may have less trouble in expressing and releasing emotions, or may just like to talk.
      1. Control conversation by returning to issues relating directly to the situation. What might you say to tactfully return to the situation at hand?

      2. Remember to try not to let parent take advantage of you. Cut the person off when necessary (politely, of course - "My baby awoke from her nap", "I must pick my husband up at the train", etc.)

5. Parents with Special Needs

   a. Handicaps

      1. Blindness - This parent cannot read our reprints, library materials, etc. Find out whether he/she has someone at home who can read them aloud. If not, material can be taped and mailed to parent. If you cannot do it yourself, request someone who can.

         a. Find out what special needs such a parent may have, from nursing to transportation. This parent may have more problems to solve than just facing his/her feelings.

      2. Deafness - This can be especially difficult since such a parent cannot normally be contacted by telephone. Discover if you can meet with the parent in person (with or without an interpreter), or whether you can speak to another person who can communicate with the parent.

        a. Reprints and library materials can be especially important for passing information to this parent.

    3. Physical Handicaps

        a. A parent in a wheelchair, etc., may have an especially difficult time getting to see his/her hospitalized baby. Discover what the particular parent's problems are.

b. Low Reading Level Parent

    1. A parent who cannot read well cannot get the full benefit from our written materials. You may decide to:

        a. Discuss the materials with the parent.
        b. Hand write shorter reprints in easier terms.
        c. Encourage parent to talk with medical staff even more than other parents - repitition may be helpful.

    2. This parent may also have trouble with materials handed out by the hospital, insurance company, etc.

        a. If possible, meet with the parent to help explain important papers.
        b. Parent may request that hospital, insurance company, etc., send a representative or meet with the parent to fully explain forms.

    3. Such a parent may be embarrassed at his/her low reading level.

        a. Emphasize importance of knowing what is happening (not withdrawing from the situation) - more important than knowing every word.

c. Parent with a Language Barrier

    1. Even if parent speaks some English, find an interpreter who can explain your thoughts to the parent, and his/her questions to you. Otherwise, parent may be too embarrassed or unable to express her thoughts, and questions and feelings may never be discussed.

PARENT TO PARENT OF FLORIDA

PHONE CALL TIPS

FIRST PHONE CALL

1. When to call
   a. Call at your earliest convenience after receiving the referral (always within 24 hours).
   b. If the parent is difficult to reach, try calling at several times of day.
   c. If you cannot reach him/her after several days:
      1. Send a Parent to Parent brochure with a note, including your name and phone number. Ask parent to call you, but keep calling.
      2. Or, leave a message if possible.
2. What to say
   a. Introduce yourself by name, as a Parent to Parent supporting parent.
      1. You may mention the name of the referral person, particularly if the parent has spoken to him/her.
   b. Ask if this is a good time to call.
      1. If not, ask when you can call back.
      2. Leave your name and phone number.
   c. Ask if parent is familiar with Parent to Parent. Even if they indicate a familiarity, give a brief overview, emphasizing:
      1. Parent (non-professional, non-medical) counseling.
      2. Counselors are just parents who have already been through similar situation.
      3. A list of our resources (reprints, library, resource list, parent meetings, etc.,).
      4. Describe Parent to Parent briefly.
   d. Mention your own experience, briefly, noting those aspects that may parallel parents'.
      1. Example: "My son, Frank, also has Down Syndrome and attends a special education class.
      2. Don't ever compare children-stress individuality.

        3. Be open and positive

        4. The purpose of sharing is to let a parent feel less alone, not to belittle his/her situation.

    e. Ask parents questions about their experience, beginning with their feelings.

        1. Show your interest through active listening (See Attachment V III-A) Listening Techniques).

        2. Avoid long responses.

        3. Don't be afraid of silences.

        4. Some examples of question topics include:

            a. How mother is feeling (physically, emotionally, etc.)

                1. Reassure parent that all feelings and emotions are normal and (probably) common.

            b. How baby (use name) is doing.

            c. How father is doing--what his reactions are.

    f. Offer support.

        1. "Can I help you?" gives permission to become involved.

        2. "What can I do for you?" helps to define a problem.

        3. Offer specific reprints.

        4. Ask if the parent has any questions.

        5. Go over courses of action discussed.

    g. Finally, give parent your name again and phone number.

        1. Make sure he/she knows to feel free to call you at any time (off-hours calls are rare), and that you will call back.

3. This call does not have to be more than five or ten minutes, but play it by ear. Don't feel you have to go over every topic mentioned.

4. Some parents will not respond to counselor's remarks freely.

    a. Don't take it personally.

    b. Let parents know you would like to share their feelings, but don't be pushy.

    c. Let parent know that you are not a social worker, just another parent.

    d. Parent may be more open next time. Try to understand their feelings and accept them as they are.

5. Call parent as needed.

    a. Every day or two in severe situations, or when a parent demonstrates strong emotional needs.

BEWILDERING ("WEIRD") TIMES

You will have them, all right. You may wonder if you are losing your mind. Probably not. But strange times will come, and getting through them takes energy and grit.

Some experts have described in detail the stages you are expected to face. The only trouble is that parents who are adjusting to children with handicaps do not follow a set course. Each parent reacts differently.

Here are a few oversimplified descriptions of stages you may—or may not—experience. And many parents could add to this list.

The Drags. It is as if your spring had run down. You feel so tired you can hardly drag yourself around. The sun may be shining, but to you the day seems cloudy. You may feel a lump in your throat or knots in your stomach. It is hard to breath, and every once in a while you may hear yourself sighing. You may even wonder if you have the flu. When these times come, you wish you could find a warm cozy hole, crawl into it, and close a lid after you.

This may be your mind's way of telling you that "out there," there is too much to take. So you slow down, withdraw, move within yourself, interact less with the world around you, and take some time out. This is OK, providing you do not stay out too long.

The Speeds. When this stage approaches, you feel as though somebody has wound your spring too tightly. You move around at a frenzied pace . . .

so much to think about
so much to do
so much ground to cover
so many places to go
so many people to see.

It is as if a combination of the Ten Commandments and St. Vitus Dance energizes your movements. Many new ideas and concepts which need to be acted upon come to your mind. It is your personality's way to "get at it," even if some motions are wasted.

The Blocks. Tough news came from the doctors. But somehow your ears refused to hear what they told you, and your eyes remained blind to the evidence they presented. The knowledge that your child possesses a handicap is hard to take. You may even talk to others as if your child has no handicap. That is OK for awhile. Parents' minds need time to change from believing their child's a superbaby to seeing that child as he or she really is. It is all right to make this shift slowly. But it is unhealthy if it is never made.

The Hurts. No professional can describe all the types of anguish and pain parents feel after learning their child has a handicap. Nevertheless, all of them hurt; they hurt badly!

Such pain can force you to become edgy and nervous; to walk floors or lie awake all night, tossing and turning; or to break down and cry—fathers included.

Bear in mind that when you do feel such pain, it may be your body and mind saying to you that you are strong enough to bear the hurt you must feel. It is my hunch that you will never suffer pain beyond what you can endure. There are many mechanisms within you to dull the senses when things become overwhelming. Some people can become stronger from enduring pain.

If you happen to be hurting while reading these sentences, you may feel anger toward the author of these words. That is OK, too. This book is not intended to bring you comfort. Its purpose is to help you grow and adjust so that you can accept, love, and act creatively on behalf of your child. You cannot do this without experiencing some hurts, enduring them, and working your way through them.

The Guilts. At times you may feel you have committed some horrible sin against God and man. You may even look deeply into your past, searching for that single horrid act that

From <u>Hope for the Families: New Directions for Parents of Persons with Retardation or Other Disabilities</u>. Perske and Perske. Abingdon Press, 1981. Reproduced with permission.

caused it all. But I am willing to wager that no matter how hard you search, you probably will never find such a cause.

Nevertheless, on some days you feel sure that you must be the worst human specimen on the face of the earth. Somewhere, somehow, you committed an unpardonable sin, and now you are paying for it.

Such guilt is phony. It is not the same kind of guilt you feel when you are caught with your hand in the cookie jar—or when you commit other real transgressions of greater magnitude. Therefore, you need not drag out all the black things in your life, examining them one by one. This exercise only gets in the way of adjusting to your child's handicap.

The Greats. While a few days earlier you may have felt that you were the world's worst mom or dad, now it may come to you that you are one of the greatest. You secretly may feel that God has chosen you to bear this extra burden because you are more special than other human beings.

Of course, it is more pleasant to fantasize yourself as being great. It is better than feeling you are the world's worst. So enjoy it while you can. But be careful. Sooner or later somebody will say or do something to send you crashing off your pedestal. When that happens, it is to be hoped you will not fall into the guilt trap again. Instead, you may achieve a fresh stability from knowing you are not a superparent. But you aren't a superdemon either. You have your weaknesses and strengths, like everyone else.

The Hates. After hurting for a time, you may search irrationally for chances to blame others and hurt them. Almost anybody you can think of may become a target:

your spouse
your neighbor
your doctor
your minister
your children
your parents
or in-laws.

So you watch and wait. Sooner or later, someone—being human—will say or do something to "justify" unleashing your anger at them.

Fortunately, your gracious friends and relatives often remain unruffled when you blow your stack at times like these.

It is all right to feel such anger and hatred, even though it is irrational. Acting on that anger, however, can be precarious It could make others hurt . . . then you hurt because you caused them pain . . . and the vicious circle starts over again.

The Escapes. Sometimes when you awaken at 2:00 A.M., you may wish you could close your eyes and never open them again. These wishes usually will remain secret because you will be ashamed of them. Nevertheless, many parents of children with handicaps openly confess to going through stages when they felt such an urge to escape. In spite of such in-the-wee-hours-of-the-morning urges, grit your teeth and hang on. By the time the sun rises, the situation often looks brighter.

Consider These Options

- If you feel like ending it all . . . wait. In time you will realize that such escapes are stupid. They create more problems than they solve.

- Do not divorce your mate this week. Better to wait, even though you harbor fears that your spouse has rotten genes . . . or that it is all his or her fault. (Your marriage partner may be harboring secretly the same fears about you.) It is better to contain such fears for the present and try to work together as a team.

- Shout epithets if you must. But let it come as no surprise that your curses lack the power to shake the foundations of God, nor do they wither the earth. It may be wiser, however, to utter them under your breath, in order to save wear and tear on your throat.

- Do not blame your doctor. The news that your child has a handicap will hurt no matter how he or she breaks the news to you. On the other hand, if your physician, in relating to you and your child, develops irrational blocks, guilts, and greats because of the handicap . . . get yourself another doctor.

- If you find yourself in the drags, enjoy the misery only for a limited time. Then grit your teeth and get going. Move those muscles! Work! Scrub that sink or mow that lawn. Do it even though you do not want to.

- When the speeds come on, stop. Sit down for a moment. Then talk slowly, walk slowly. Pick only one of the 241,000 things you feel you should do that day, and do it.

- Learn to admit to yourself that no matter how real these feelings may seem, they are strange and irrational. They will pass.

- Know that time is your best friend. In time, beautiful sanity can grow out of the terrible chaos.

- Look around and choose genuine support-persons—key professionals, advocates, relatives, friends—who are capable of entering your struggle in a helpful way. More are available than ever before, so do not try to "go it alone." In an international symposium on persons with handicaps, the participants asserted that although the initial pain in parents (upon learning their child is handicapped) remains high, their ability to move through those bewildering stages became easier because of the outside support they received.[1] Also, in a report to the President it was learned that child abuse in one program was nonexistent because of the many helpful family supports from the outside.[2]

- Try to keep the "unbearables" you experience from overflowing onto your child with the handicap. After all, the barriers he or she must overcome or live with are almost unbearable, too. It does not help to heap more burdens on these children when it is all they can do to carry their own.

So, there will be bewildering times in your lives. But as you hang on and move through each one, you will find precious opportunities to be strong and tender at the same time—with yourself, with your child, and with those around you.

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1. R. Perske, ed. *Improving the Quality of Life. A Symposium on Normalization and Integration A Symposium of the International League of Societies for the Mentally Handicapped* (Arlington, Tex.: Association for Retarded Citizens. National Headquarters, 1977).
2. R. Perske, "A Coordinated Effort to Take the Risk Out of 'At Risk,' " *The Report to the President, Mental Retardation The Leading Edge—Service Programs That Work* (Washington, D.C.: President's Committee on Mental Retardation, 1978)

NORMALIZATION

Normalization means...A normal rhythm of the day. You get out of bed in the morning, even if you are profoundly retarded and physically handicapped; you get dressed, and leave the house for school or work, you don't stay home, in the morning you anticipate envents, in the evening you think back on what you have accomplished; the day it not a monotonous 24 hours with every minute endless.

You eat at normal times of the day and in a normal fashion; not just with a spoon, unless you are an infant; not in bed, but at a table; not early in the afternoon for the convenience of the staff.

Normalization means...A normal rhythm of the week. You live in one place, go to work in another, and participate in leisure activities in yet another. You anticipate leisure activities on weekends, and look forward to getting back to school or work on Monday.

Normalization means...A normal rhythm of the year. A vacation to break the routines of the year. Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities. Just think...we thrive on these seasonal changes!

Normalization means...Normal developmental experiences of the new life cycles.

In childhood, children, but not adults, go to summer camps. In adolescence, one is interested in grooming, hairstyles, music, boyfriends, and girlfriends. In adulthood, life is filled with work and responsibilities. In old age, one has memories to look back on, and can enjoy the wisdom of experience.

Normalization means...Having a range of choices, wishes, and desires respected and considered. Adults have the freedom to decide where they would like to live, what kind of job they would like to have, and can best perform. Whether they would prefer to go bowling with a group, instead of staying home to watch television.

Normalization means...Living in a world make of two sexes. Children and adults both develop relationships with members of the opposite sex. Teenagers become interested in having boyfriends and girlfriends, and adults may fall in love, and decide to marry.

Normalization means...The right to normal economic standards. All of us have basic financial privileges, and responsibilities. Are able to take advantage of compensatory economic security means, such as child allowances, old age pensions and minimum wage regulations. We should have money to decide how to spend; on personal luxuries, or necessities.

Normalization means...Living in normal housing in a normal neighborhood. Not in a large facility with 20, 60 or 100 other people because you are retarded, and not isolated from the rest of the community. Normal locations and normal size homes will give residents better opportunities for successful integration with their communities.

Bengt Nirje

THE SEVEN STAGES

Mary Leydorf, M.D., F.A.A.P.
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A parent of a mentally or physically handicapped child may experience seven emotions in a fairly predictable order. The amount of time spent at each stage varies widely from a few seconds to many years.

STAGE	DESCRIPTION	TREATMENT
1. Confusion	A reality before diagnosis is made--often professionals are unsure, and require a planned time interval for study of the child. Parents are uncertain, bewildered.	Establishment of a firm diagnosis with confirmation, as quickly as possible. If this is impossible, a full explanation as to why a waiting period is necessary.
2. Denial	When presented with the diagnosis, the parents do not accept it. "He'll outgrow it." "How could that doctor know, he only spent 5 minutes with the child." "Uncle Herman's third child had the same thing and he's O.K." Attention is often focused on one small item and the total picture is ignored: i.e. "He can spell 'cat'; therefore, he is not retarded."	A thorough, full examination and supportive laboratory studies. Consultation with a specialist. Presentation of a diagnosis to both parents at the same time, and answering all questions honestly.
3. Anger-Guilt	An aggressive, outgoing parent will turn his dismay outward, often against the doctor who first made the diagnosis of abnormality. Also common is to turn against the spouse. Occasionally the obstetrician is accused, etc. The passive parent will turn his disappointment inward: "What did I do wrong?" "Did I really want this child?"	Point out the realities. The parent did NOT do something wrong. (If this is true--exception is child-beating.) The obstetrician gave good care--get birth records, etc.

The Seven Stages
Mary Leydorf, M.D., F.A.A.P.

STAGE		DESCRIPTION	TREATMENT
4.	Hope	There may be excessive hope for a miracle. Frantic searching for a "cure". "Shopping" from doctor to doctor, medical centers, without allowing consistent treatment.	Parents are open to quackery and should be protected. They should know that if treatment is available through future research their child will receive it. They should be specifically informed of "con" programs now known to exist.
5.	Depression	A resigned attitude but an unhealthy one. May range from "blue", "listless", to real withdrawal and attempt to hide the child. Indicates diagnosis of child's abnormality is accepted.	Commence a program--include the parent totally. Use other parents of children with handicaps. Suggest membership in parent groups.
6.	Acceptance	This stage suggests the beginning of a good parent-child relationship. On this firm basis help may be given to the child. The parent accepts the child "for what he is." The parent realizes both the normal areas and abnormal areas. "He is a child first--and handicapped second." Relaxed attitude predominates.	Fast progress is made if a correct program which cares for the total child is offered. Programs can include: medical care, educational therapy, physical therapy, speech therapy and psychological management, and should work together smoothly in a team effort. The parent will be an important "working" member of the team.
7.	Understanding	The parent not only understands his own child, but is enriched by having to strengthen his own ability to cope with life. He can now help others. This is the final stage. Fulfillment is reached and a new dimension is now added to this parent's personality.	None. We should listen to these parents, for they can tell us much.

PARENT TO PARENT OF FLORIDA

DOs AND DON'Ts FOR SUPPORTING PARENTS

DOs

1. Listen to what the referred parent has to say.

   Allow the referred parents to express their feelings and ask questions. Do not overwhelm them with your experiences, suggestions, and general information. Let the new parents vent their emotions.

2. Visit and take pictures with you.

   At some time during your contact with the referred parents, have a few pictures of your child from birth to the present with you. Referred parents are anxious to see how other children with the same handicap look when they are older.

3. Be sure to relate to baby or child when visiting a family.

   Hold and play with the child. If the child is obviously handicapped you may be the first to relate positively other than the family. Also acknowledge spouses and siblings.

4. Encourage parents to take pictures of their child.

   An opportunity once lost can never be regained. Regardless of what they think their child looks like, encourage parents to take pictures right from birth.

5. Take referred parents to the services if need be.

   A referred parent may need transportation to a service, or perhaps may need moral support to get there. If necessary, accompany them rather than have them miss an appointment.

6. Be a crutch for your referred family.

   A supporting parent can be a "crutch" for the referred family by offering the support needed until they are able to cope with the situation. However, care should be taken to not allow the family to become too dependent.

7. Supporting parents help new families to make new friends.

   Many times friends will stop associating with families with a child diagnosed handicapped. Through the supporting parents and the Parent to Parent program, new friendships can be developed.

8. Commit yourself to Parent to Parent for one year.

   Support parenting can be very time consuming; therefore, a commitment for only one year is asked. However, it is not compulsory to leave and you can remain with the program as long as you wish.

9. Supporting parents are expected to attend monthly or bi-monthly meetings.

   Monthly or bi-monthly meetings are held to continue education, keep abreast with community services, and share experiences. These meetings should be held on the same evening each month, perhaps the same evening as the training sessions.

10. Encourage parents to take time out for themselves.

11. Remember to do #10 yourself.

DON'Ts

1. Do not be critical or judgmental.

   Supporting parents should not be critical or make a judgment of a family's home, furniture, housekeeping, or personal appearance. The only thing to be concerned with is the family's adjustment to their child and the obtaining of services for their child.

2. Do not give advice, particularly medical advice or advice regarding medications.

   Supporting parents are not professionals. Do not give specific instructions; give several suggestions and leave final decisions to the parents.

3. Don't be too positive in your attitudes when a family has just learned that their child is handicapped.

   When talking to a referred family, be reassuring but do not be too enthusiastic about your child. It may be some time before they will be able to accept the thought that raising a handicapped child has its pleasures and rewards.

4. Don't be too positive about specific services. Try to keep an open mind about the services.

   If the supporting parent is too positive about a specific service the parent may be made to feel they have made a poor choice if theirs is not the same. There may be unknown reasons why they cannot select the same service as the supporting parent.

5. Don't use alot of "alphabet soup"; i.e., IEP, ARC, HAB, DD.

   Supporting parents help referred parents with new medical terms and vocabulary. Assure new parents they will learn the terms in time.

6. Don't overload with too much reading material.

   Overload is different for everyone. Offer the referred parents the materials but explain to them you do not expect them to read everything.

7. Do not allow the referred family to drain you.

   If they have emotional problems, a referred family can become too dependent and demand too much from you. Discuss this with your professional resource persons. It may be they need professional help.

8. Don't worry about delay in obtaining referrals.

   Supporting parents are matched with referred families. This occasionally results in some supporting parents receiving several referrals while other have yet to be assigned one. Be patient. Your time will come. Get involved in other aspects of the program; i.e., fundraising, newsletter, educational activities, etc.

PARENT TO PARENT OF FLORIDA
REFERRAL PROCESS

1. The referral is taken by the designated person (Referral Coordinator) answering the referral phone number. This person takes information and records it on the Intake Information Form.

    A. Ascertain whether the caller is referring a parent or is the parent him/herself.

    B. Explain that if the caller will give some general information, you will contact a parent who will get back to the referred parent as soon as possible, usually on the same day.

    C. The Referral Coordinator may need to call the referred family to obtain enough information to select an appropriate supporting parent. She/he will explain the reason for calling to the referred parent.

    D. If the Referral Coordinator is a trained supporting parent and the parent is making a self-referral, the Referral Coordinator may be able to handle the call. If not, a match will be made.

2. The Referral Coordinator selects an appropriate supporting parent by considering some or all of the following factors: age of parents, marital status, economic status, racial, religious, or cultural factors, age of child, diagnosis or degree of child's disability, make-up of family group, geographic location of family residence, etc.

3. The supporting parent will be contacted and given all information obtained. The supporting parent should tell the Referral Coordinator if it is not a convenient time for them to accept a referral. This will permit the selection of another supporting parent who will contact the family immediately.

4. The supporting parent makes contact with the referred parent as soon as possible, preferably within 24 hours. Do not be afraid to ask for a change in supporting parent if, after contacting the family, you feel you cannot relate to them.

5. Once an initial contact has been made, the supporting parent must notify the Referral Coordinator.

6. The supporting parent will record information as it is obtained and any progress notes on the Referred Family Information form. This form will be returned to the Referral Coordinator upon termination of the contact.

7. If problems occur, notify the Referral Coordinator who can assist with finding a suitable solution or contact the agency resource person if different from the Referral Coordinator.

8. The Referral Coordinator will respond to the referral source, if not the referred parents themselves, by letter or card.

PARENT TO PARENT OF FLORIDA
COMMUNITY OUTREACH

I. Organize a public relations committee and designate a Chairperson. Utilize specific skills of committee members with most appropriate task.

II. Identify potential sources of referrals.

Possible sources include but are not limited to the following: hospitals, clinics, physicians, clergy, social service agencies, school systems, early intervention programs, therapists and all disability related agencies (ARC, UCP, Easter Seals, Epilepsy Foundations, Spina Bifida Association, March of Dimes, etc.)

III. Types of Outreach

A. Printed Materials; i.e., introductory letter, brochures, posters, press releases, informational folders, newsletters.

B. Radio and Television--public service announcements, community talk shows.

--identify all media, contact person, format preference, deadlines, etc.

C. Speakers--civic groups, physician and nurse inservices, interagency committees, etc.

D. One-to-one contact with your child's providers, church, etc.

E. Follow-up to assure visibility.

IV. Questions to be addressed

A. Who -- are you (your organization)?

B. What -- do you do?

C. Where -- what area do you cover?

D. When -- can you be contacted?

E. Why -- is this important?

F. How -- can you be contacted?

V. Your community outreach efforts should be creative, well prepared, tasteful, and timely. If so, they will result in visibility, referrals, and a credible program.

STATE OF FLORIDA
ORGANIZATIONS

Alcohol, Drug Abuse & Mental Health Program--Children's Section
Department of Health & Rehabilitative Services
1317 Winewood Blvd.
Tallahassee, FL 32301
(904) 487-2415

American Diabetes Association
Florida Affiliate, Inc.
3101 Maguire Blvd., Suite 288
P. O. Box 19745
Orlando, FL 32814
(305) 894-6664

American Heart Association, Inc.
Florida Affiliate Office
810 63rd Avenue North
P. O. Box 42150
St. Petersburg, FL 33742
(813) 522-9477

Arthritis Foundation
Florida Chapter
3205 Manatee Avenue West
Bradenton, FL 33505
(800) 282-9487

Association for Retarded Citizens/Florida
106 North Bronough, Suite M1-7
Tallahassee, FL 32301
(904) 681-1931

Bureau of Education for Exceptional Students
Department of Education
Knott Building
Tallahassee, FL 32301
(904) 488-1570

Captioned Videotape Project for the Hearing Impaired
Florida School for the Deaf and Blind
P. O. Box 1209
St. Augustine, FL 32084
(904) 824-1654

Children's Medical Services Program
Department of HRS
1323 Winewood Blvd.
Building 5, Room 127
Tallahassee, FL 32301
(904) 487-2690

Developmental Services Program
Department of HRS
1311 Winewood Blvd.
Building 5, Room 215
Tallahassee, FL 32301
(904) 488-4257

Division of Blind Services
Florida Department of Education
2540 Executive Center Circle West
Tallahasseee, FL 32301
(800) 342-1828
(904) 488-1330

Division of Blind Services Library for the Blind & Physically Handicapped
P. O. Box 2299
Daytona Beach, FL 32015

Florida Developmental Disabilities Planning Council
1317 Winewood Blvd.
Building 1, Suite 309
Tallahassee, FL 32301
(904) 488-4180

Florida Association of Rehabilitation Facilities
1605 E. Plaza Drive, Suite 8
Tallahassee, FL 32308-5311
(904) 877-4816

Florida Bar Lawyer Referral Service
The Florida Bar
Tallahassee, FL 32301-8226
(800) 242-8012

Florida Commission on Human Relations
325 John Knox Road, Suite F-240
Tallahassee, FL 32303
(800) 342-8170

Florida Council of Handicapped Organizations
P. O. Box 2027
Satellite Beach, FL 32937
(305) 777-2964

Florida Association for Children with Learning Disabilities
5683 Deefield Road
Orlando, FL 32808
(305) 295-8203

Florida Easter Seal Society
1010 Executive Center Drive,
Suite 101
Orlando, FL 32803
(305) 896-7881

Florida School for the Deaf and the Blind Child Study Center
207 North San Marco Avenue
St. Augustine, FL 32084
(904) 824-1654

Florida Society for Children and Adults with Autism
1523 Julie Tonia Drive
West Palm Beach, FL 33415
(305) 965-0409

Florida Epilepsy Foundation
P. O. Box 6059 C
Orlando, FL 32853
(305) 422-1439

Florida Instructional Materials Center for the Visually Handicapped
5002 North Lois Avenue
Tampa, FL 33614
(800) 282-9193

Florida Justice Institute, Inc.
1401 Amerifirst Building
One S.E. 3rd Avenue
Miami, FL 33131
(305) 358-2081

Florida Legal Services, Inc.
226 West Pensacola, Room 216-218
Tallahassee, FL 32301
(904) 222-2151

Governor's Commission on Advocacy for Persons with Developmental Disabilities
Office of the Governor
The Capital
Tallahassee, FL 32301-8047
(800) 342-0823
(904) 488-9071

Handicapped & Workstudy Program
Division of Vocational Education
Department of Education
Knott Building
Tallahassee, FL 32301
(904) 488-5965

Head Start
Humanics Associates
Florida Office
255 Whooping Loop, Suite 255
Altamonte Springs, FL 32701
(305) 834-6538

March of Dimes Birth Defects Foundati
Regional Office
12550 Biscayne Boulevard
North Miami, FL 33181
(305) 895-2856

Mental Health Agency
Department of HRS
1317 Winewood Blvd.
Tallahassee, FL 32301
(904) 488-8304

Mental Health Association of Florida
345 S. Magnolia Drive, Suite A13
Tallahassee, FL 32301
(904) 877-4707

Muscular Dystrophy Association
1301 Seminole Boulevard, Suite 105
Largo, FL 33540
(813) 585-5446

National Kidney Foundation of Florida
Inc.
One Davis Boulevard, Suite 304
Tampa, FL 33606
(813) 251-3627

Office of Vocational Rehabilitation
Department of HRS
1309 Winewood Boulevard
Tallahassee, FL 32301

Parents Anonymous
1106 Thomasville Road
Tallahassee, FL 32303
(800) FLA-LOVE
(904) 224-8481

The Pro Bono Directory
Legal Assistance Project
Dept. of Public Interest Programs
The Pro Bono Directory
The Florida Bar
Tallahassee, FL 32301
(904) 222-5286

Southern Legal Counsel, Inc.
115 N.E. 7th Avenue
Gainesville, FL 32601
(904) 377-8288

Spina Bifida Coalition of Florida
996 Florida Town Road
Pace, FL 32570
(904) 994-4001

State Special Olympics Headquarters
2639 N. Monroe Street, Suite 151-A
Tallahassee, FL 32303
(904) 385-8178

Statewide Human Rights Advocacy
Committee
1317 Winewood Boulevard
Building 1, Room 310
Tallahassee, FL 32301
(904) 488-4180

University of Miami Child Development
Center Multi-disciplinary Training
Facility
P. O. Box 016820
Miami, FL 33101
(305) 547-6624

Upjohn Healthcare Services
Florida Region Administration
P. O. Box 2607
Winter Park, FL 32790

Note: If you would like information on Parent to Parent support groups in the State of Florida, please contact the Parent to Parent of Florida office at (904) 769-6606.

NATIONAL ORGANIZATIONS

Aid to Adoption of Special Kids
3530 Grand Avenue
Oakland, CA 94610
(415) 451-2275

Alexander Graham Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 30007
(202) 337-5220

American Brittle Bone Society
1256 Merrill Drive
Marshallton
West Chester, PA 19380
(215) 692-6248

American Alliance for Health, Physical Education, Recreation & Dance
Information and Research Utilization Center
1900 Association Drive
Reston, VA 22091
(703) 476-3400

American Association for the Advancement of Science Project on the Handicapped in Science
Office of Opportunities in Science
1776 Massachusetts Avenue, N.W.
Washington, DC 20036
(202) 467-4400

American Association of University Affiliated Programs for the Developmentally Disabled
1234 Massachusetts Avenue, N.W.
Washington, DC 20005

American Association on Mental Deficiency
5101 Wisconsin Avenue, N.W.
Washington, DC 20016
(202) 686-5400

American Cleft Palate Education Association
331 Salk Hall
University of Pittsburgh
Pittsburgh, PA 15261

American Civil Liberties Union
132 West 43rd Street
New York, NY 10036

American Coalition of Citizens with Disabilities (ACCD)
1200 15th Street, N.W., #201
Washington, DC 20005
(202) 785-4265

American Council for the Blind
1211 Connecticut Avenue, N.W. Suite 506
Washington, DC 20036
(202) 833-1251

American Foundation of the Blind (AFB)
15 West 16th Street
New York, NY 10011
(212) 620-2000

American Genetics Association
818 18th Street N.W.
Washington, DC 20036

American Kidney Fund
7315 Wisconsin Avenue
Bethesday, Maryland 20814-3266
800-638-8299

American Occupational Therapy Assoc.
1383 Piccard Drive, Suite 300
Rockville, MD 20850
(301) 948-9626

American Physical Therapy Association
1111 N. Fairfax Street, Suite 200
Alexandria, VA 22314
(703) 684-2782

American Printing House for the Blind
P. O. Box 6085
1839 Frankfort Avenue
Louisville, KY 40206
(502) 895-2405

American Red Cross
National Headquarters
17th and D Streets, N.W.
Washington, DC 20006
(202) 737-8300

American Society for Deaf Children
814 Thayer Avenue
Silver Spring, MD 20910
(301) 585-5400

Arthrogryposis Association, Inc.
5430 E. Harbor Heights Drive
Port Orchard, WA 93866
(206) 871-5057

Association for Persons with Severe Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115
(206) 523-8446

AAWE/Alleviates Alliance
206 N. Washington Street, Suite 320
Alexandria, VA 22314
(703) 836-6060

Association of Birth Defect Children
3201 East Crystal Lake Avenue
Orlando, FL 32806
(305) 898-5342

Association for Children & Adults with Learning Disabilities (ACLD)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515

Association for Retarded Citizens National
2501 Avenue J
Arlington, TX 76011
(817) 640-0204

Asthma & Allergy Foundation of America
1302 18th Street, N.W., Suite 303
Washington, DC 20036
(202) 293-2950

Boy Scouts of America
Scouting for the Handicapped Division
1325 Walnut Hill Lane
Erving, TX 75062
(214) 659-2000

Cancer Research Institute
Memorial Donations
133 East 58 Street
New York, NY 10022
(212) 688-7515
(800) 223-7874

The Candlelighters Foundation
2025 "I" Street, N.W. Suite 1011
Washington, DC 20006
(202) 659-5136

Center on Human Policy
4 East Huntington Hall
Syracuse University
Syracuse, NY 13210
(315) 423-3951

Clearinghouse on the Handicapped
Office of Special Education and Rehabilitative Service
Room 3106 Switzer Building
Washington, DC 20202
(202) 732-1245

Compassionate Friends, Inc.
P. O. Box 1347
Oak Brook, IL 60521
(312) 323-5015

Cooley's Anemia Foundation
105 East 22nd Street, Suite 911
New York, NY 10010
(212) 598-0911

Cornelia de Lange Syndrome Foundati
60 Dyer Avenue
Collinsville, CT 06022
(202) 693-0159

Center for Law and Education, Inc.
Gutman Library, 3rd Floor
6 Appian Way
Cambridge, MA 02138
(617) 495-4666

Children's Brain Research Clinic
2525 Belmont Road, N.W.
Washington, DC 20008

Children's Defense Fund
122 C Street, N.W.
Washington, DC 20001
(202) 628-8787

Closer Look
Parents Campaign for Handicapped Children and Youth
1201 16th Street, N.W.
Washington, DC 20036
(202) 822-7900

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Cystic Fibrosis Foundation
6000 Executive Boulevard, Suite 309
Rockville, MD 20852
(301) 881-9130

Dental Guidance Council for Cerebral
Palsy
122 East 23rd Street
New York, NY 10010
(212) 677-7400

Developmental Disabilities Office
U.S. Department of Health and
Human Services
200 Independence Avenue, S.W.
Room 338E
Washington, DC 20201

Disability Rights
Education Defense Fund, Inc.
2032 San Pablo Avenue
Berkeley, CA 94702
(415) 644-2555

Dysautonomia Foundation
120 E. 41st
New York, NY 10017
(212) 889-0300

Dystrophic Epidermolysis Bullosa
Research Association of America
2936 Avenue W
Brooklyn, NY 11229
(212) 774-8700

Ephphatha Services for the Deaf
and Blind
P. O. Box 15167
Mineapolis, MN 55415

Epilepsy Foundation of American
4351 Garden City Drive, Suite 406
Landover, MD 20785
(305) 459-3700

Foundation for Children with
Learning Disabilities
P. O. Box 2929
Grand Central Station
New York, NY 10163
(212) 687-7211

Friedreich's Ataxia Group in America
P. O. Box 11116
Oakland, CA 94611

Girl Scouts of the U.S.A.
Scouting for Handicapped Girls
830 Third Avenue
New York, NY 10022
(212) 940-7500

Human Resources Center
I.U. Willets Road
Albertson, NY 11507

Human Growth Foundation
4607 Davidson Drive
Chevy Chase, MD 20815
(301) 656-7540

Hydrocephalus Parent Support Group
9430 Reagan Road
San Diego, CA 92126

Institute for the Achievement of
Human Potential
8801 Stenton Avenue
Philadelphia, PA 19118

International Association of Parents
of the Deaf
814 Thayer Avenue
Silver Springs, MD 20910
(301) 585-5400

International Institute for Visually
Impaired, 0-7, Inc.
1975 Rutgers Circle
East Lansing, MI 48823

John Tracy Clinic (Deafness, hearing
impairments, deaf/blind)
806 West Adams Blvd.
Los Angeles, CA 90007
(213) 748-5481

Joseph P. Kennedy Jr. Foundation
1350 New York Avenue, N.W., Suite 500
Washington, DC 20005
(202) 393-1250

Juvenile Diabetes Foundation, Int'l.
23 E. 26th Street
New York, NY 10010
(212) 889-7575

Know Problems of Hydrocephalus
Route 1, River Road, Box 210A
Joliet, IL 60436

LaLeche League International
9616 Minneapolis
Franklin Park, IL 60131
(312) 455-7730

Library of Congress
Division for Blind and Physically
Handicapped
1291 Taylor Street, N.W.
Washington, DC 20542

Little People of America
Box 633
San Bruno, CA 94066
(415) 589-0695

Leukemia Society of America, Inc.
National Headquarters
800 2nd Avenue
New York, NY 10017
(212) 573-8484

MPS Society
552 Central Avenue
Bethpage, NY 11714
(516) 433-4419

March of Dimes National Foundation
1275 Maroneck Avenue
White Plains, NY 10605

Mental Disability Legal Resource
Center
Commission on the Mentally Disabled
American Bar Association
1800 M Street, N.W.
Washington, DC 20036
(202) 331-2240

Mental Retardation Association of
America
211 East 300 South, Suite 212
Salt Lake City, UT 84111
(801) 328-1575

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019
(212) 586-0808

Myoclonus Families United
c/o NORD
2153 East 22nd Street
Brooklyn, NY 11220

National Amputation Foundation
1245 150th Street
Whitestone, NY 11356
(212) 767-0596

National Association for Deaf/Blind
2703 Forrest Oak Circle
Norman, OK 73071
(405) 733-7311

National Association for Disabled
Citizens
P. O. Drawer 8075
Maitland, FL 32751
(305) 628-8850

National Association for Down's
Syndrome
Box 63
Oak Park, IL 60303
(312) 543-6060

National Association for Parents of
the Visually Impaired, Inc.
2011 Hardy Circle
Austin, TX 78757

National Association for the Deaf
Legal Defense Fund
Florida Avenue & 7th Street, N.E.
Suite 311
Washington, DC 20002

National Association for Sickle-Cell
Disease (NASCD)
3460 Wilshire Blvd., Suite 1012
Los Angeles, CA 90010

National Association for Visually
Handicapped
305 East 24th Street, 17-C
New York, NY 10010
(212) 889-3141

National Association of Private
Residential Facilities for the
Mentally Retarded
6269 Leesburg Pike
Falls Church, VA 22044
(703) 536-3311

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
(301) 587-1788

National Ataxia Foundation
6681 Country Club Drive
Minneapolis, MN 55427
(612) 546-6220

National Hearing Association
1010 Jorie Blvd., Suite 308
Oak Brook, IL 60521
(312) 323-7200

National Association of the
Physically Handicapped
70 Elm Street
London, OH 43140
(614) 852-1664

National Center for a Barrier-Free
Environment
1015 15th Street, NW, Suite 700
Washington, DC 20005
(202) 466-6896

The National Clearing House for
Human Genetic Diseases
3520 Prospect Street, N.W.
Ground Floor, Suite 1
Washington, DC 20057
(202) 842-7617

National Down Syndrome Congress
1640 W. Roosevelt Road
Chicago, IL 60608
(312) 226-0416

National Down Syndrome Society
70 West 40th Street
New York, NY 10018
(212) 764-3070
(800) 221-4620

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
(312) 243-8400
(312) 243-8800 (TDD)

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
(301) 659-9314

National Foundation for Ileitis
and Colitis
295 Madison Avenue
New York, NY 10017
(212) 685-3440

National Genetics Foundation
555 West 57th Street
New York, NY 10019
(212) 586-5800

National Head Injury Foundation
280 Singletary Lane
Framingham, MA 01701
(617) 879-7473

National Hearing Aid Society
20361 Middlebelt Road
Livona, MI 48152
(313) 478-2610

National Hemophilia Foundation
19 W. 34th Street, Room 1204
New York, NY 10001
(212) 563-0211

National Ichthyosis Foundation
151 Toyon Drive
Vallejo, CA 94589

National Information Center for
Handicapped Children and Youth
(NICHCY)
P. O. Box 1492
Washington, DC 20013

National Institute for Rehabilitation
Engineering
97 Decker Road
Butler, NJ 07405
(201) 838-2500

National Juvenile Law Center
St. Louis University School of Law
3701 Lindell Blvd.
St. Louis, MO 63108

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314

National Neurofibromatosis Foundation
70 West 40th Street, 4th Floor
New York, NY 10018
(212) 869-9034

National Organization on Disability
2100 Pennsylvania Avenue, N.W.
Suite 234
Washington, DC 20037
(202) 293-5960

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314

National Retinitis Pigmentosa Foundation
Rolling Park Building
8331 Mindale Circle
Baltimore, MD 21207
(301) 655-1011

National Reye's Syndrome Foundation
P. O. Box RS
Benzonia, MI 49616

National Society for Children and Adults with Autism
1234 Massachusetts Avenue, M.W.
Suite 1017
Washington, DC 20005
(202) 783-0125

National Spinal Cord Injury Association
149 California Street
Newton, MA 02158
(617)964-0521

National Tay-Sachs and Allied Diseases Association
92 Washington Avenue
Cedarhurst, NY 11516
(516) 569-4300

National Tuberous Sclerosis Assoc.
P. O. Box 612
Winfield, IL 60190
(312) 668-0787

Office for Handicapped Individuals
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Osteogenesis Imperfecta Foundation
632 Center Street
Van Wert, OH 45891

Orton Dyslexia Society
724 York Road
Baltimore, MD 21204
(301) 296-0232

Parent Care
University of Utah Medical Center
50 North Medical Drive, Room 2A210
Salt Lake City, Utah 84132
(801) 581-5323

Parent Network
1301 E. 38th Street
Indianapolis, IN 46205

People First International
P. O. Box 12642
Salem, OR 97309
(503) 378-5143

Polio Information Center
510 Main Street
Roosevelt Island, NY 10044

Prader-Willi Association
5515 Malibu Drive
Edina, MN 55436
(612) 933-0115

President's Committee on Employment of the Handicapped
Washington, DC 20010

President's Committee on Mental Retardation
Washington, DC 20201

Scoliosis Research Society
444 N. Michigan Avenue, Suite 1500
Chicago, IL 60611
(312) 822-0970

Scoliosis Association
1428 183 Main Street, East
Rochester, NY 14604
(716) 546-1814

Sharing Our Caring
P. O. Box 400
Milton, WA 98354
(Down Syndrome)

Sibling Information Network
Department of Educational Psychology
Box U-64, The Univ. of Connecticut
Storrs, CT 06268
(203) 486-4034

Siblings for Significant Change
Room 808
823 United Nations Plaza
New York, NY 10017

Support Organization for Trisomy (SOFT)
7326 S. 145 Street, East
Midville, Utah 84947
(801) 566-0674

Special Education Programs
U. S. Dept. of Education
Switzer Building
330 "C" Street, S.W.
Washington, DC 20202

Spina Bifida Association of
America
343 South Dearborn Street, Room 317
Chicago, IL 60604
(312) 663-1562

United Cerebral Palsy Assocations
66 East 34th Street
New York, NY 10016
(212) 481-6300

United Ostomy Association
2001 West Beverly Bldg.
Los Angeles, CA 90057
(212) 413-5510

The United States Association
for Blind Athletes
55 West California Avenue
Beach Haven, NJ 08008

The Voice
2939 Hollandale
Dallas, TX 75234
(214) 349-3271 (V/TDD)
(Hearing Impaired)

Youth Law Center
693 Mission Street
Second Floor
San Francisco, CA 94105
(415) 543-3379

TOLL FREE TELEPHONE SERVICES

AMC Cancer Information Center	800-525-3777
American Council of the Blind	800-424-8666
American Kidney Fund	800-638-8299
Better Hearing Institute Hearing Helpline	800-424-8576
Cancer Information Service National Line	800-4-CANCER
Captioned Films for the Deaf	800-237-6213
Center for Special Education Technology Information Exchange	800-345-8324
Child Abuse Registry	800-342-9152
Children's Defense Fund	800-424-9602
Closer Look LD Teen Line	800-522-3458
Epilepsy Information Line	800-542-7054
ERIC Clearinghouse on Adult Career and Vocational Education	800-848-4815
Foundation Center	800-424-9836
Heartlife	800-241-6993
HEATH Resource Center	800-54-HEATH
International Shriners Headquarters	800-237-5055
Job Accommodation Network	800-526-7234
Job Opportunities for the Blind	800-638-7518
National Alliance of Blind Students	800-424-8666
National Center for Stuttering	800-221-2483
National Committee for Citizens in Education	800-NETWORK
National Crisis Center for the Deaf (TDD Only)	800-446-9876
National Down Syndrome Congress	800-232-6372
National Down Syndrome Society	800-221-4602

National Easter Seal Society	800-221-6827
National Health Information Clearinghouse	800-336-4797
National Hearing Aid Society	800-521-5247
National Information Center for Educational Media	800-421-8711
National Rehabilitation Information Center (Voice/TDD)	800-32-NARIC
National Special Needs Center	800-233-1222 800-833-3232 (TDD)
National Spinal Cord Injury Hotline	800-526-3456
Orton Dyslexia Society	800-222-3123
Poison Information	800-542-6319
Resource Center for the Handicapped	800-22-SHARE
RP Foundation Fighting Blindness	800-638-2300
Special Education Software Center	800-327-5892
Spina Bifida Hotline	800-621-3141
Tripod Service for Hearing Impaired	800-352-8888
Washington PAVE	800-5-PARENT

PARENT TO PARENT PROGRAM

EVALUATION OF VOLUNTEER TRAINING

The purpose of this evaluation is to learn whether you have found the training sessions to be helpful. Your evaluations will help us plan future training. Your cooperation and assistance are greatly appreciated. It is not necessary for you to put your name on the evaluation.

Please mark the answer which comes closest to your true feelings about the statement.

For example: If you are undecided about a statement, mark the answer as follows:

		X		
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

1. I found all six sessions helpful.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

2. The sessions answered most of my questions about Parent to Parent.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

3. Factual material was presented in a clear and understandable way.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

4. The sessions provided the right amount of factual information.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

5. Material could have been presented in less than six meetings.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

6. There should have been more sessions held.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

7. I found the pamphlets and handouts to be well correlated with the discussions.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

8. Role playing of sample encounters helped me understand what to expect as a volunteer.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

9. Discussion of facts and feelings are equally important in the sessions.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

10. I feel prepared to visit new families after the sessions.

Strongly Disagree	Disgree	Undecided	Agree	Strongly Agree

11. I would recommend scheduling ongoing training for parent volunteers.

Strongly Disgree	Disagree	Undecided	Agree	Strongly Agree

12. Comments and/or suggestions for future training sessions:

____

____

____

____

____

____

Date ______________

PARENT TO PARENT OF FLORIDA

APPLICATION FOR SUPPORTING PARENTS

I. FAMILY INFORMATION

Name ______________________________________ Age __________

Address ____________________________________ Phone __________
City, State

Education ______________________ Occupation ______________

Place of Employment ______________________________________

Interests/Hobbies ____

Marital Status ___ Separated ___ Married ___ Divorced ___ Widowed ___ Single

Spouse's Name ______________________________ Age __________

Education ______________________ Occupation ______________

Place of Employment ______________________________________

Interest/Hobbies ____

How would you rate your family's income?

___ Low Income ___ Low Average ___ Average ___ High Average ___ High Income

Name of Each Child	Birthdate	Sex

II. INFORMATION REGARDING SPECIAL NEEDS CHILD

Name of your special needs child _________________________

Describe your child's special needs ______________________

____

____

____

____

Does your child have any other problems? ___ Yes ___ No

If yes, what are they?______________________________

Does this child live at home? ___ Yes ___ No

If not, where?______________________________

Please list the programs in which this child has participated (starting with most current program).

NAME OF PROGRAM	DATES OF PARTICIPATION

PARENT TO PARENT OF FLORIDA
REFERRED FAMILY FORM

CHILD

Name of child____

Child's D.O.B.____

Type of disability____

When diagnosed____________________ Where____________________

Special concerns (if any)____

____

FAMILY

Parents' Names____

Parents' Ages (if known)____

Address____

____

Phone____

Number and Ages
of other children____

____

REFERRAL

Referral source and
date of referral____

Phone____________________ Agency Worker____________________

CONTACTS

Name of supporting parent(s)____

Phone____

Number and type (home visit or phone) of contacts____________________

____

Progress of case____________________

Terminated? ________yes ________no

Otner Agencies Involved____________________

Additional Information____________________