Intended for parents of handicapped infants and young children, the booklet provides guidelines for child rearing and suggests additional resources. The booklet stresses that the handicapped child needs what every child needs, that home is where a baby starts learning, the importance of getting a thorough evaluation if the parent suspects something is wrong, and the value of keeping activities with the child fun. Twenty-three books are recommended. Getting diagnostic and programmatic help from professionals is discussed as are sources of additional information about available programs. A final section stresses the value of parent groups. Forty-eight organizations that can help parents are listed according to specific disability. (DB)
one step at a time
by Barbara Scheiber

Closer Look
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Closer Look extends sincere thanks to the following people who generously shared experience and knowledge in the preparation of this booklet.

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ONE STEP AT A TIME

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YOUR CHILD NEEDS WHAT
EVERY CHILD NEEDS

You may only recently have learned that your baby has a handicap. Or you may be worried, because you think something is wrong. Perhaps something did go wrong during the first few months or years of your child's life - and you are trying to find out what you can do about it.

This booklet was written for you. We want you to know that there are a great many things that you, and others who love your child, can do. We're not going to say that raising a handicapped child is a bed of roses, but then no child is easy. Life is full of bumps, a handicap is a far harder one than most. But - no matter how handicapped a child is - there's a lot of help you can give.

From the very beginning, the most important thing you can do is to let your child know that he's a loved and wanted part of the family. The more he knows you're there, responding to his needs and caring about him, the more he'll be able to grow. The many different ways that you find to reach out to your child will form the basis of his own sense of self-worth — and that sense is the best start he can get.

What are some of the ways that you can help your handicapped child while he's still very young? Well, basically - if you always remember that a child with a disability is a child, you'll do a great deal quite spontaneously. A handicapped child's needs are really not different from every child's needs. But because of his or her disability there may be more things to do. You may have to do them more often, or in somewhat different ways. Whatever these things are, just about every parent can learn them. So can other members of the family. And all of this can become an important and rewarding part of family life.

That's what this booklet is about. It's about you, your child, what you can do together — and how you can find other people to help you and your child grow.
A NEW DAY HAS DAWNED

Once, there was a feeling that nothing could be done about very young handicapped children. Parents were advised to wait until their babies were older, because it was believed that children didn't learn very much during the first three years or so of life. Often, parents were told flatly that there was no hope.

What happened, as a result, was that many handicapped babies were left alone in a silent, empty world. They failed to get the smiles and sounds, the attention and human warmth that nourish all babies. That kind of deprivation made many children far more handicapped than they ever had to be. They fell further and further behind.

Without any advice on how to deal with their child's problems, most parents felt at a complete loss. Some struggled through many long hours of trial and error and made discoveries on their own. They found that their children could make progress. They formed organizations to push for services, started their own preschool programs and wrote books about their experiences. These pioneer parents, together with professionals who have done remarkable research into the ways that children learn, have helped to bring about the dawn of a new day.

Now, we know that every child can learn—at his own pace and in his own way. Most important are these simple facts: learning begins the day a baby is born, and learning is a natural part of living.

Home is where a baby starts learning.

Attitudes toward learning are very different from the traditional ones most of us grew up with. They include these ideas:

- The attention and stimulation you give to your child during his early weeks, months, and years are related to learning.

- Touching, holding, talking, singing, smiling, comforting—all the things you do when you care for and play with your baby—contribute to his development. They are the building blocks of education.
Every child needs a wide range of stimulating activities. Handicapped children even more so. Without them, a handicapped child may miss too many experiences that are a part of other children's everyday life. They may not have any way to discover what their environment is all about. For infants with a physical, visual, or hearing disability, it is hard or sometimes impossible to learn about the world the way that other infants do. New pathways must be found to reach and teach them.

Once you gain confidence, you'll find yourself getting very creative in thinking of ways to put your child in touch with the world. Trying out ideas of your own can be a happy part of family life.

Progress may be very slow, and there may be setbacks. Not all your efforts will be successful. But it is important to keep trying because even the most severely disabled child can make progress. And experience has proven that for many children early help can and does make a marked and dramatic increase in ability to grow and participate in the everyday world.

Education for infants:

Not only is education for all handicapped children now acknowledged as a right, but special education programs are becoming available to far younger children than ever before. In some states, the law says that programs for children with disabilities must start at birth. Others have programs for handicapped children starting at two or three years old.

"Infant education" is a term most of us never heard of until very recently. Now, it is an expanding and exciting field. But lessons for babies are not the kind we associate with formal schooling. Many of the activities are ones that come naturally, though adults haven't always realized how important it is to do these things with little children whose growth is blocked or delayed for one reason or another. New education programs that are springing up are based on ways of planning play activities so that a child's physical, intellectual, and emotional development is encouraged to the maximum possible extent.

Professionalism is changing:

Along with new ideas about education of your children there is a healthy change in relationships between parents and professionals. An outdated view endowed professionals with super powers, as if one could bring a child to an expert's office to get all "fixed up." Many parents can recount tense and frustrating experiences, sitting in waiting rooms for hours at a time while their child was seen, examined, and treated behind a closed office door. Diagnosis,
when given was usually in terminology that parents could not understand. All too often parents left these encounters dazed and distraught with no idea whatsoever of what they themselves could do to help their child.

One of the brightest hours now on the horizon is the view of parents and professionals as genuine partners in the job of helping children. Psychologists, neurologists, audiologists, teachers, language therapists, psychiatrists, pediatricians, physical therapists, early childhood specialists, and others too— all have a great deal of exciting and important knowledge that can make a big difference in how well the child learns and develops. But mothers and fathers live with their child every day. They are eager for knowledge that they can put to use. And only they can see the countless happenings, the momentary changes that tilt by , the difficulties that keep cropping up. The chance for continuing feedback between parents and professionals offers great promise.

So we are seeing a new respect for parents’ strength and resourcefulness for their deep wish to learn what to do and to do it! More and more parents are not only being planned for but with. More and more parents and professionals are communicating as equals. Where a lucky break for the children?

"You’ll learn and grow, too!"

The new awareness of the role of parents will not only make a difference to your child, it will matter a great deal to you. You’ll have the satisfaction of knowing that you’re doing what’s needed to help your child to feel good about himself, to trust the world, to want to take his own steps toward into life. The writers of a new book for parents entitled Home Stimulation put it this way:

Your disabled child grows in the same pattern as all children. His growth may be slow in some areas as his needs may be greater in others, but the goals are the same:

to help him attain as much independence as possible

to give him a sense of worth

to help him achieve his full potential

These are great and wonderful goals. We hope that as you work hard to reach them, you’ll find happy surprises and joys ahead. Knowing that you are your child’s first—and most important—teacher.
Children grow at different rates and in different styles. Some are easy going and placid from day one. Others are tigers, restless and on the go. These things are part of the uniqueness of each human being.

But — no matter how swift or how slow the tempo of growth may be, each child goes through similar stages as he or she develops. There is still disagreement about many aspects of child development, but a helpful body of knowledge has charted the sequences through which children pass during their early years.

Some children do skip a phase or two (we all knew kids who walked without ever having crawled) — but basically, growth is like a ladder with its rungs coded within each child’s being. And it’s encouraging to realize that all children can be boosted up that ladder — by fostering their own individual abilities — even though for some, the changes may be like films running in slow-motion. What one child can do in a few months may take another years to accomplish.

Generally speaking, growth can be watched in these areas:

- **Growth in body control and coordination** (gross motor) — development of skills like head control, rolling, sitting, crawling, standing, walking.

- **Growth in movements of small parts of the body** (fine motor) — reaching for and grasping objects, using and gaining control of tongue, lips, wrists, fingers, toes.

- **Growth in language** — from cooing and babbling to communicating meaningfully.

- **Growth in self-concept and social skills** — from smiling when familiar people come near to expressing feelings, making friends.

- **Growth in capacity for self-care** — drinking from a cup, getting dressed, making choices, becoming independent.
• **Growth in ability to think** to reason, to make sense out of what is seen, heard, felt and experienced — to solve problems (cognitive) — stacking blocks, painting pictures in a book — naming colors, counting.

Within each area of growth there are predictable steps. For instance, between the time a baby is born and the time he or she begins to walk alone, a child must:

- hold his head up
- be able to sit without support
- be able to roll from his back or stomach to a sitting position
- move from a sitting to a crawling position and back again
- be able to creep, crawl, scoot or roll across the floor
- pull to a standing position
- stand alone without help
- "cruise" — walk around holding on to furniture or a play pen.

One step at a time

Similar "milestones" can be pinpointed in all areas as a child goes from one stage in development to the next. Each step along the way can be broken down to the smallest possible tasks or skills that can be attempted by a child, using his own individual set of "can-do's."

Your own sensitivity to your child will help you know where he is at on the ladder of development, what he is able to do now and when he is ready to start something new.

**Practice, praise and watching.**

In *Learning Can Be Child's Play* June Mather gives a good idea of how you can catch clues about your child's readiness to move ahead. She points out that each child needs plenty of practice with each new skill and lots of praise. She writes:

"It is that very first step that is the important one to watch out for — the very first time your baby holds his head up. For instance, take note of the event, how you know that he is able to do this. After he has held his head up for the first time for a moment or two you can then provide him with opportunities to repeat this action. Do this by putting him in a position where he can hold his head up — in other words, lay him on his tummy rather than his back. Sometimes stroking his back or placing a small, firm pillow under his arms and beneath his chest will encourage him to hold his head up. An interesting sound to listen to or a bright object to look at will give him a reason to want to
hold his head up. Be on the lookout for “first times” so you can provide opportunities for the second time, then for the next one and the one that follows that.

The goal your child is ready for next may be to hold a spoon, or to make eye contact with another person, or to sit still long enough to hear a story. What matters is not the label of this or that handicapping condition that a child has been given — but how we can help him try out and eventually master these new and (for him) often very tough assignments.

When your child does reach a new level of achievement, you’ll feel like celebrating. You should! For a disabled child, each step up is a big success story.
WHAT IF YOU SUSPECT SOMETHING MAY BE WRONG?

Some children may have disabilities that don’t show up at birth. As the days go by, their parents may feel increasingly uneasy. This or that troubling sign keeps turning up—something seems to be wrong—but what?

As we said earlier, the normal rate of development varies a great deal from child to child. We hope you won’t worry unduly because some children take their first steps or say their first words sooner than your own.

But—since it is so true that children can be helped a great deal by getting an early start, you are right to check further if you really think your child’s growth is lagging too far behind. It helps to have some idea of the signals you may be getting that your child may be having unusual difficulty in some areas. A professional diagnosis and evaluation can put your doubts to rest—or can help you find out what you can do.

If, for example, your child really does seem to have trouble seeing, hearing, or moving his body around—please don’t bottle up your concern. You can get expert advice, and you should. We all tend to be somewhat timid about voicing our worries for fear of being put down as “over anxious” parents. But trust your instincts and observations. There are some things you can check out if you think something is wrong.

Professional baby-watchers have not only been able to describe the “milestones” of child development, they also have learned approximately when we can expect a child to reach them. These timetables are not absolutes—just clues that a child may be in need of professional attention and some extra, well-planned stimulus. And—by acting now—it’s possible to give him a boost that will help all the rest of his life. The point of all this is not to categorize kids as “too slow” or “too” anything—but to help them to do the best they can.

What are some of the “average” milestones to be aware of?

• Babies can usually reach for an object like a dangling ring, by the time they are six months old, and hold an object between thumb and forefinger in a “pincer grasp” between six and twelve months.
• Generally, babies are able to roll over by themselves by about six months and sit without support by eight months. Usually, you can expect a child to pull himself up to a standing position and to walk holding on to furniture or a playpen sometime between seven and thirteen months.

• Sometime between ten and fourteen months, babies begin to use some meaningful words, like “Mama” or “Dada,” and to imitate familiar sounds — like animal noises and “tick-tock.” Before that, probably by around six months, a baby begins to babble, turn to the sound of a speaking voice, laugh aloud. And, by two-and-a-half or three, children are usually able to put a few words together into short sentences.

• Children usually can wave bye-bye between eight and thirteen months, and play peek-a-boo and pat-a-cake.

There are other milestones, too, of course. Pointing to the eyes, nose, head, building a small tower of blocks, self-feeding, drinking from a cup: these are all some of the many things children learn to do — usually during the second year of life. We won’t attempt anything like a full timetable of a child’s development from birth to five years. The only point of listing any of them here is to encourage you to find out, when the “usual” things don’t happen, what can be done about it.

Some disabilities may not be apparent until around two, when we expect children to be using language. A lack of speech development at that age can be a clue that some professional attention is called for. Don’t put it off. It’s quite possible that no serious problem exists. Play, stimulation, planned activities at home or in a preschool program may be what’s needed. Whatever the answer, if you ask questions of appropriate professionals when you are worried, the better for everyone.

Many problems fall into a general grouping simply called “developmental delay or lag.” With early and appropriate help, a child’s slow, delayed or unusual developmental pattern may eventually not be a handicap to him at all.
All this talk about developmental sequences may sound as if you and your baby have to stick to a very strict schedule.

Just the opposite is true. Almost every kind of activity that will help your child grow can be woven into the fabric of daily life — things you do when you’re feeding or bathing or playing with your youngster.

Play is the key word. Play is what a young child’s day is made of. The aspect of play that hasn’t always been so obvious to everyone is that play is a way of learning. Play is child’s work.

One problem that affects many handicapped children is that their disabilities may prevent them from being able to play naturally. This can mean that they don’t make the subtle steady gains that come from the bumps, bruises, tugs and tumbles of ordinary play. And — they don’t have the pleasure of play, which is, after all, one of the good things of life.

In all the things you do, you’re showing your young child what an interesting world he lives in — and tempting him to touch it, feel it, smell it, taste it (within reason), to know it as well as he can. Our hope is that he will be able to take part, and enjoy it as fully as possible.

Some tips to remember

Even fun and games can be exhausting — so try not to overdo it. Your mood — and your child’s mood — change from day to day. You’ll get signals from your child about how much and how long to carry on. Be flexible, and don’t think you have to give everything else up for the sake of your child. Pleasure — yours and your child’s — is basically what will keep things moving along. Try to find a few times each day when you can easily fit in play-routines without feeling pressured. How often and how long you do ‘things depend on your child’s needs and all the other demands on your time.

We’re talking about very simple fun, to start with. Things like: hanging wind chimes where the breeze will stir some casual music... tying bright objects or
colorful fabric to the side of the crib. Cradling, rocking, singing, moving a baby from room to room, placing him in different positions. In other words, making his world as interesting as possible.

Keep it up! — Even when babies can’t show they like it

Babies and their parents, in the natural course of things, are constantly interacting with each other, what one writer called “wooing” each other. A child who doesn’t respond, because his disability has kept him from reacting in expected ways, may discourage a parent and just be left alone. But even when you aren’t getting much reward for your efforts, it is important to keep trying to arouse a handicapped baby’s interest.

Keep the vibes coming — even if you think hardly anything is being communicated. One mother writes that for a long time she didn’t smile while she took care of her baby; suddenly, she realized that it made a big difference in the way she did things when she smiled — and that her baby could feel the difference. It’s a good tip.

As a child gets older, the activities you’ll use to stimulate and teach will change, of course. Some new methods for teaching basic self-care skills and encouraging appropriate behavior may need to become part of your bag of tricks.

There are a great many learning activities that draw on the everyday events that go on around the house, from washing dishes to playing hide and seek or planting a garden. We’ve listed some books with easy-to-follow suggestions for teaching self-care skills, for helping a child take part in normal daily activities and express his feelings and ideas.

Remember: Your child needs to do things for himself!

Please remember, always, that one of the basic goals you’re reaching for is independence. Self-awareness and self-esteem are the launching pads for independence.

The important thing is for a child to learn to do things for himself not for you to do it for him. You help an infant turn over, so that he, eventually, will be able to do it. You do special exercises with him to strengthen his muscles and teach him to creep — by himself.

We do realize that a severe physical disability may prevent some children
from doing many things without assistance. But independence is their birthright too, and should be encouraged in every possible way. A book filled with practical wisdom, Handling The Young Cerebral Palsied Child at Home by Nancy R. Finnie, stresses this point. The author writes

"... no cerebral palsied child will ever become independent unless he is given an opportunity to try. Even if a child cannot use his hands or speak, he is sure to have some way of indicating what he wants and in this way he can cooperate. For example, if you are building a house with blocks, have a book with different pictures, and get him to act as a 'foreman' and direct proceedings."

Finding another way

If a child doesn't have one or more of his important senses, it may, at first, seem like a staggering assignment for a parent to help him learn. But — every other sense that's available can be stimulated, and the child can go from feeling secure and loved to learning about his environment, and joining the action

- A blind child never needs to be allowed to have "blind hands." From his earliest infancy, he can respond to sound, to engage in what a famous author, Dr. Selma Fraiberg, calls "a touch-dialogue," to being picked up and carried around the house. Give him toys to feel, objects that make pleasant sounds to listen to and to reach for when he's ready. With your encouragement, he can be just as self-reliant as any other child, just as eager and able to play happily and feel proud of what he does.

- Please don't forget to talk to your young child. Child development specialists stress the importance of early language stimulation. One writer, Ira Gordon, in Baby Learning Through Baby Play, calls this "surrounding a child with a language envelope." Even though an infant doesn't understand the words, he will react to the sound, rhythm and pattern of your voice, the beginning of language learning.

- For a child with a hearing loss, talking — about all the daily happenings that go on around him and the people and objects he sees and feels — is even more crucial. There are many excellent materials to help mothers and fathers stimulate language development of children with hearing loss. At this point, we want simply to remind parents to talk, naturally, as they do things for and with all their young children. These first associations with love and language create a strong foundation for later communication.

- Children with a severe lack of muscle control tend to lose out on learning-
by-exploring. Experienced baby-teachers advise parents to take a young child who can’t move by herself on trips around the house, giving her the chance to feel the shapes, textures, sizes, motions of as many different kinds of objects as possible. A child who can’t sit up can be held so he can get an upright view of the world. A child who can’t splash in a tub can be carefully wedged so that he won’t slip or fall and will get the feel of water. In other words, try to help your child do as many ordinary everyday, normal things as possible, to stimulate his interest and desire to perform.

- Some special activities can help to strengthen physically disabled young children, relax stiffened muscles, increase control and confidence — and these are best worked out with the help of a physical therapist and other early childhood specialists.

- Play, laughter and fun with your little child is the beginning of his social life, his sense of joy in living. Everyone in and near the family is part of his social set — grandparents, sisters, brothers, aunts, uncles, neighbors and mailmen, storekeepers and policemen, too. The old tendency to keep a handicapped child wrapped in cotton and away from places where he might get hurt, or stared at, is changing — and it’s a good thing too!

- Children need other children. Some mothers have started their own infant stimulation and play groups, or persuaded existing preschool programs to accept handicapped children, because they’ve known how much it matters to have companionship and fun.

- Helping a young child explain his disability to his playmates is something that needs to be handled in the most realistic and straightforward way possible. One little boy who was asked why he had no arms, replied to his friend, “I just came that way.” That was that, all the other four-year-olds in his preschool accepted his explanation.

Your own attitude has a great deal to do with keeping things fun. Often parents, mothers, especially, feel that everything they do or don’t do — every day, or even every hour — will affect their child for the rest of his life. It sometimes seems easier to be grimly determined than relaxed and easy-going about playing with your child.

On the day when nothing is fun for you, try to enlist the aid of friends and relatives, and do something that’s good for you. Over the years, one of the best things you can give your child is a feeling that life is enjoyable.
BOOKS ABOUT LEARNING

Here are some books on how all young children learn. Most of them weren't written especially for parents of handicapped children — but you can easily adapt their delightful ideas to stimulate your child's growth through play no matter what stage of development he may have reached.

BABY LEARNING THROUGH BABY PLAY: A PARENT'S GUIDE FOR THE FIRST TWO YEARS
By Ira Gordon, St. Martin's Press, New York, Distributed by Gryphon House, 3706 Otis Street, Mt. Rainier, Maryland 20822 1970

CHILD LEARNING THROUGH CHILD PLAY
By Ira Gordon, St. Martin's Press, New York, Distributed by Gryphon House, 3706 Otis Street, Mt. Rainier, Maryland 20822 1972

CHILDREN AND ADULTS: ACTIVITIES FOR GROWING TOGETHER

CHILD'S WORK: A LEARNING GUIDE TO JOYFUL PLAY
By Paul S. Shakesby, Running Press, 125 S. 22nd St., Philadelphia, Pennsylvania 19103 1974

I SAW A PURPLE COW AND 100 OTHER RECIPES FOR LEARNING FOR PARENTS AND TEACHERS
By Ann Cole, Carolyn Haas, Faith Bushnell, Betty Weinberger. Distributed by Gryphon House, 3706 Otis Street, Mt. Rainier, Maryland 20822 1972

LEARNING CAN BE CHILD'S PLAY: How Parents Can Help Slower-Than-Average Preschool Children Learn and Develop Through Play Experiences
By June Mathier, illustrated by Martha Perske, Abingdon Press, 201 Eighth Avenue South, Nashville, Tennessee 37202 1976

THE MAGIC YEARS
By Selma Fraiberg, Charles Scribner's Sons Publishers, 597 5th Avenue, New York, New York 10017 1959

Toys

It's hardly possible to think of play without toys. But toys don't have to be
fancy or expensive. Imagination and a sense of what you are trying to teach your child to do can help you collect many different, interesting, colorful and useful things you already have in the house, like sponges to squeeze, clothespins to snap, boxes to stack, plastic containers to nest in one another, mirrors to smile at, large buttons to pick up and put into a plastic bottle—bright magazine pictures to cut and paste. For lots of ideas about using materials in playing with your child, we recommend...

EXPLORING MATERIALS WITH YOUR YOUNG CHILD WITH SPECIAL NEEDS:

Commonwealth Mental Health Foundation, 4 Marlboro Rd., Lexington, Massachusetts 02173 1975

Also, you should know about toy lending libraries. Their main purpose is to make it possible for parents to share stimulating toys that fit into their children's needs. Toys are checked out the same way books are borrowed from a library. Other materials may also be available on loan—such as a special chair for a child whose muscle tone is very poor or standing tables or strengthen legs. You may also be able to get instructions on how to make them yourself.

A toy lending library can be a fine project for a group of parents to set up. It is basically a center for teaching parents how to help their handicapped children, since no equipment or playthings is loaned without explanation and demonstrating how to use it most effectively. For clear guidelines for getting one started, read...

THE PARENT-CHILD TOY-LENDING LIBRARY:

A GUIDE TO SECURING AND INSTALLING


Books with special ideas:

The following books were written to help children with specific handicapping conditions or markedly delayed development. Since parents may be looking for more than one type of activity to help a child, we have attempted to divide these books according to handicaps. These are all unusually helpful publications, based on experience and understanding, and we hope they will help to give you and your child a good start. You might also share some of them with teachers who want to include handicapped children in their preschool programs.
A CUP OF KINDNESS A BOOK FOR PARENTS OF RETARDED CHILDREN
By Louise Whitbeck Fraser, Special Child Publications, 4535 Union Bay Place NE, Seattle, Washington 98105 1973

CHATS WITH JOHNNY'S PARENTS

EDUCATIONAL GAMES FOR PHYSICALLY HANDICAPPED CHILDREN
Cratty & Breen, Love Publishing Co., 1777 S. Belair, Denver, Colorado 80222 1975

ELIZABETH
A mother's account of the development of her blind baby girl By Sharon Ulrich, University of Michigan Press, 615 East University, Ann Arbor, Michigan 48106 1972

GET A WIGGLE ON A GUIDE FOR HELPING VISUALLY IMPAIRED CHILDREN GROW
By Sherry Raynor, Richard Drouillard, Ingham Intermediate School District, 2630 West Howell Road, Mason, Michigan 48845 1975

HANDLING THE YOUNG CEREBRAL PALSYED CHILD AT HOME

HEARING-IMPAIRED PRESCHOOL CHILD A BOOK FOR PARENTS
By Jean E. Semple, M.A., Charles C. Thomas, Publisher 301-327 E Lawrence Ave., Springfield, Illinois 62717 1970

HOME STIMULATION FOR THE YOUNG DEVELOPMENTALLY DISABLED CHILD
Commonwealth Mental Health Foundation, 4 Marlboro Road, Lexington, Massachusetts 02173 1973

INFANT STIMULATION
A pamphlet for parents of multiply-handicapped children By Sandra Hottman, copies available from the author Children's Rehabilitation Center, University of Kansas Medical Center, Rainbow Boulevard and 39th, Kansas City, Kansas 66103 1973

JOHN TRACY CLINIC CORRESPONDENCE COURSE
For parents of preschool deaf or deaf-blind children John Tracy Clinic Correspondence School, 806 West Adams Boulevard, Los Angeles, California 90007
LANGUAGE-RELATED ACTIVITIES: A MANUAL FOR PARENTS OF LANGUAGE-LEARNING DISABLED PRESCHOOLERS
Montgomery County Easter Seal Treatment Center, 1000 Twinbrook Pkwy, Rockville, Maryland 20851

THE SPECIAL CHILD HANDBOOK
Practical information on finding schools, programs, support and financial assistance. Also has a directory of state agencies and organizations to contact for additional help.

STEPS TO INDEPENDENCE: A SKILLS TRAINING SERIES FOR CHILDREN WITH SPECIAL NEEDS
By Bruce L. Baker, Alan I. Bachtel, Louis I. Heitets, and Diane M. Murphy, Research Press, 2612 North Mattis Avenue, Champaign, Illinois 61820
- Training Guide 1976
  - Early Selt Help Skills 1976
  - Intermediate Selt Help Skills 1976
  - Advanced Self Help Skills 1976
  - Behavior Problems 1976
  - Toilet Training 1977
  - Speech and Language Level I 1978
  - Speech and Language Level II 1978

SPEECH AND LANGUAGE DELAY: A HOME TRAINING PROGRAM

OUR WORLD, OUR WORDS: 1976
A series designed for language development of young children, including
ADVENTURES, HOMEWORK. For more information about these and other materials, write to
Language Development Programs
Bill Wilkerson Hearing and Speech Center
1114 19th Ave S
Nashville, Tennessee 37212

THE EXCEPTIONAL PARENT
A magazine offering helpful advice for parents of handicapped children of all ages; 296 Boylston Street, Third floor, Boston, Massachusetts 02116
GETTING HELP FROM PROFESSIONALS: DIAGNOSIS

The first stop for a parent seeking help for a handicapped child is usually at the doctor's office. If you are going there because you have a strong suspicion that something may be wrong, please remember that you know your child better than anybody else, and have had twenty-four hours a day to notice things that a doctor may not see during an office visit. So be sure to bring up the things that concern you. This isn't always easy, an office is so different from home and you may feel uneasy in this more impersonal setting.

Keep records.

It's a good idea to make a list of your questions ahead of time, even to keep a diary noting the things that trouble you. Documentation help both you and the doctor and can save possible misunderstanding. Your notes may tell clearly whether the problem is improving, or whether it's becoming chronic.

Your family doctor, pediatrician, or the physician you see at a clinic should give your child a thorough physical check-up, and should be able to recommend a specialist (or several specialists) who can do more detailed examinations, if necessary.

If you are going to consult with a number of specialists, it's helpful to rely on one of these professionals as the "team coordinator." It probably will be your family doctor - but perhaps one of the specialists you see will be a good choice. You do need a professional to help you put it all together, to talk over next steps to take, to ask questions when you're confused and puzzled, to go back to for a new look at the situation. It's important to have someone you are comfortable with, who is easy to talk to about your feelings and concerns.

Sometimes - it's important to worry.

What if your doctor says "Don't worry, he'll outgrow it." Well, that may very well be true. Reassurance is important, if there's no reason to worry, you won't help yourself or anybody else by looking for signs of trouble. But if you are convinced from your own observations over a period of time that something
is wrong, take action. You can calmly insist on a referral to a specialist for testing and evaluation, or arrange for evaluation on your own.

Pediatric neurologists, ophthalmologists, psychologists, psychiatrists, speech and language pathologists, audiologists and other specialists are available for private consultation, at hospital clinics, diagnostic centers, or other places we'll mention later. Each of these experts may be needed to help figure out what's wrong, and how to help.

Unusual delay in speaking, as we pointed out earlier, may be an important clue that a child needs special help. There are many different causes of speech or language difficulties—a qualified speech or language pathologist will check out various problems that may exist. This professional is in a position to steer you to other specialists to find out what kinds of care, treatment and educational programs are appropriate. Don't ignore language problems even if you are told to "wait and see."

Extra points to keep in mind:

Whether you receive the painful report that your child has a handicap soon after birth, or find out later, after a period of questioning and consultation, we'd like to emphasize these points about diagnosis:

- It's hard to absorb shocking or distressing news. It's difficult to understand it all at once. But you will want—and need—to know the facts so that you can deal with them. Let your doctor or other professional helper know that you would like to call or come back when you've had a chance to collect your feelings and thoughts. You should feel free to ask for more information when you're ready.

- Be sure that diagnostic reports are explained to you in simple, clear language. They should not be loaded up with professional jargon. It may take courage on the doctor's part (just as it does for you) to come face to face with the truth. But you have the right to know it, and to ask for additional consultation in order to learn more.

- Be absolutely certain that your child gets a complete examination. Hearing and vision, for instance, must be checked out to see if problems in these areas are interfering with normal development. One of the reasons for having one doctor act as coordinator is that there will be less likelihood that some important piece of the diagnostic puzzle will be overlooked.

- Diagnosis of a handicapping condition is not the final word about a child. It
certainly does not predict what he will be able to do with his life, or what potential can be nurtured through stimulation and education.

- Ask about programs that are available in your community for infants and young children with disabilities of various kinds. Your professional consultants may be aware of new programs that are now under way that can help your child's development and can refer you to those that are appropriate.

- Even if there are no special infant or preschool programs to join, your doctor may tell you what you can do at home. For instance, he may show you some simple exercises, ways of positioning your child when you hold him, things to do to strengthen his muscles and his coordination. This can become part of your regular routine when you visit the doctor's office to check on your child's progress. Ask if he or she can tell you about other parents of handicapped children you can talk to about the problems you're facing.
Parents looking for educational services for infants and young children with disabilities can become frustrated, because there is still a shortage of good programs. But new things are happening. During this past decade, increased knowledge about how young handicapped children can be helped has led to a growth in special preschool programs.

A new kind of prescription

Ideally, the diagnostic reports you receive as a result of your visits to professionals should give you an idea about your child’s level of functioning in key areas of development. What can he do? What kinds of things should he be encouraged to try to do next? Where is he at — in areas of motor development, coordination, communication, social and emotional development?

The answers to these questions are part of a new type of prescription — individual educational prescription. Rx of this kind is based on scales of development, with simple activities carefully mapped out, using toys, exercises, games and other play to help a child achieve new goals — one step at a time.

Early childhood teachers team up with various specialists, such as speech pathologists, psychologists, physical therapists and others to assess a child’s needs as accurately as possible, and to plan a constructive program and help to put it into action . . . with parents.

One of the important things to remember about prescriptions of this kind is that they must be looked over regularly, re-evaluated to make sure that the plans fit the child and his changing self.

Home teaching

"Home-based" programs are designed to introduce parents to ways of teaching their babies and young children while they care for and play with them. In these programs, teachers visit a child’s home about once a week, bringing along a batch of appealing toys and other play materials. The teacher’s work with parents and children is based on the kind of assessment and prescription we’ve just described.
By noting which skills a child needs help in learning, an individual program is worked out — setting long and short-term goals in various areas of development. Then, for about an hour or so, lessons are discussed, and parents are usually shown, too, how to keep records of progress.

Home visitors should be able to listen to and talk over many different kinds of problems that come up from week to week — from sleeping problems to temper tantrums, and to offer practical counsel, or to help parents find ways of getting additional advice.

Programs like these are a boon to families in rural areas, or to mothers with problems getting transportation — or in finding sitters for other children in the family. Your State Department of Special Education or Public Health Department may be able to tell you if there are trained home visitors in your area.

Parent-infant centers

Parents in various parts of the country now have the opportunity to bring their babies (sometimes, when they are just a few weeks old) to centers where concerned and skilled staff members are on hand for evaluation and treatment.

A mother and father of a tiny, month-old girl, just diagnosed as having Down's syndrome, watch — nervously at first — as an experienced physical therapist shows them how strong their baby is, how much she already is doing, how to begin to entice her into more activity.

A mother listens intently as a speech pathologist explains how important it is to encourage normal movements of her child’s tongue, jaw and lips. She is given some exercises to do to help her child suck and swallow easily. (Most of us may not be aware of the connection between eating and speech. The organs involved in both activities are practically the same.)

Discouraged and ready to be rejected, a young couple brings their 16-month old son to an Infant Center. He had meningitis shortly after birth and is blind. They were told “nothing can be done.” All he can do is startle to sound. The Center does accept him, believing that a way will be found to help him grow. Right now, no one even tries to predict how far he will be able to go. What’s important is to make a start.

These are a few examples of what Infant Centers are doing. We encourage you to see if you can find a program of this kind. Or maybe you can start one with other parents, with the help of professionals at a local hospital, health center or university.
An extra plus of parent-infant programs is that they give parents a chance to meet together, to talk about whatever problems are uppermost in their minds, and to help one another get through some of the hard adjustments of these first few years. Time after time, mothers and fathers have talked about the support and encouragement they've gained from this sharing and the amount they've learned about practical management of day-to-day problems.

Preschools

There are many different kinds of public and private preschool programs for handicapped children. Some start with the kind of parent-infant program described above, and graduate children into programs for toddlers, for two, three and four-year-olds and kindergarteners. Age grouping is not as important as developmental level in working with disabled young children, and many programs include children who are older than the usual preschool age.

Programs vary. Some include only children with specific handicapping conditions, such as cerebral palsy, Down's syndrome, deafness. Some concentrate on the complex needs of children with a combination of several disabling conditions. Others use no categorical labels, but open their doors to children with any physical, sensory, behavior or developmental problem or delay, mild or severe.

A growing number of people are convinced of the value of mixing young handicapped children in classrooms with non-handicapped children. Individual goals — for example, in areas of speech, physical coordination, social and emotional development — are worked out for each of the children with special needs, and many of them get extra help from specialists. But they have the chance to learn by watching, listening to and playing with non-handicapped peers.

One mother put it this way: "Handicapped kids don’t make the same demands on each other. In a regular preschool, a kid has to learn more about how to get along." Another mother, whose son is now in a special first grade, said, "When he was in the regular preschool, he felt like he was right in the gang. He got a kind of ease — and he still has it. I can see the difference. He feels okay about himself. It was a great start."

Not every kid can — or should be — in totally integrated classrooms. You'll make your decision about where your child belongs. Visiting programs in advance is a must. Talk with other parents and teachers. A lot depends, of course, on what's available, and what opportunities you can open up for your own child.
Good preschool programs have had remarkable success. Dramatic stories tell of almost unbelievable progress made by children who start out seeming "hopeless." Some, at two, can’t sit up or say words. Others may have uncontrollable outbursts, constantly scream, or pull toys apart, or crouch tearfully in corners. It is exciting to see the same children begin to make their needs known, to learn to concentrate quietly on puzzles or finger painting, or to be able to swing triumphantly on climbing bars. A little girl who once was labelled "severely disturbed" wears a long purple dress, a huge hat, puts on a dab of lipstick and bows to the mirror. "I’m lovely," she seems to say.

Some make it to regular classrooms when they reach elementary school age. Others can’t go that far. But for them, too, and for their parents, early childhood programs offer fresh promise. Even when the best decision is, eventually, for some children to live away from home in a residential setting, the growth that has been stimulated through early play activities can make their later life easier, more productive and more independent.
HOW CAN YOU FIND PROGRAMS?

First, check with your local school system. People in the Superintendent's office, or the Department of Special Education, will be able to tell you about preschool programs run by the public schools — and will also have information about some programs operated by other public agencies and private groups.

Recent state and federal policies have improved the outlook for young children with disabilities, some states require that services for handicapped children be extended at birth. Be sure to find out what's going on in your own area. And please don't fail to let the school system know that you have a handicapped child who needs services — even if no special program now exists.

Some states have Early Childhood Coordinators working on preschool programs for handicapped children. This is a good person to talk to for an overview of preschool activities. If the position doesn’t happen to be filled, write or call the State Director of Special Education to find out more about early childhood educational services in your state.

Where else can you look?

Preschool services for handicapped children are sponsored by a number of different agencies, both public and private. Here is a suggested checklist of places to contact in order to locate a program geared to the individual needs of a young child with a disability.

Crippled Children's Services. There is a Crippled Children’s agency in every state, set up to locate and diagnose children with handicapping conditions and to find medical and other health-related services for them. The term “crippled” may be misleading, since agencies serve a variety of handicapping conditions and illnesses. You can find out which groups of children are served in your state and where local clinics are held by calling the State Crippled Children’s Service or local Health Department. The agency helps parents with financial planning and may pay for all or part of cost of care, depending on child's condition and family's resources.
**Day care programs.** More and more day care programs are open to some children with special needs. These programs vary, and it's a good idea to make a visit, talk things over with the director and teachers, and see if the program is appropriate and if your child is eligible. Day care must be licensed by the state, and is given in schools, community centers, private houses, churches, and specially constructed facilities. To find out about day care in your area, call the local and state Department of Human Resources, and/or Department of Social Service.

**Early and Periodic Screening, Diagnosis and Treatment (EPSDT).** This is a comprehensive health care program for children and youth up to age 21 who are eligible for Medicaid. Eligibility is related to income level, but various other factors may be taken into account. The program provides early prevention and screening for health problems, diagnosis, follow-up treatment, and periodic re-evaluation of health. Children may be checked and treated for vision, hearing, dental problems, anemia and sickle cell anemia, immunization, lead poisoning — and other health needs. For information on eligibility and where to go for the services — you can contact your local or state social service and/or public health office.

**Easter Seal Societies.** Services provided by Easter Seal vary in different communities. You may find that among services offered handicapped preschoolers in your community are evaluation, family counseling, information and referral, speech, physical and occupational therapy, and educational programs. It is worth your while to check.

**Family and child service agencies.** These agencies are staffed by social workers experienced in counseling, locating resources, working with schools and other agencies. They may be able to help you locate a program — or may even have one going. Fees are usually modest. You can locate the one nearest you from the phone book (listing may start with the word Catholic, Protestant, Jewish, or Community), or look under Social Services listed in yellow pages.

**Head Start.** A big effort is being made by Head Start to expand services for handicapped preschoolers. According to federal law passed in 1972, handicapped children must make up at least ten percent of the Head Start enrollment. Head Start is primarily for people who meet poverty-level financial requirements, but there are exceptions. Check to see if you are eligible. Head Start projects are helping many young children who previously were unserved. The program has a firm commitment, too, to helping families develop understanding and skill in caring for their youngsters. Handicapped children who are eligible for Head Start are defined by legislation as "mentally retarded."
hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, crippled or other health impaired children who by reason thereof require special education and related services.

To find out about Head Start for handicapped children in your own area, contact your local school system. For more information about the national program, write to: 'Head Start, P.O. Box 1183, Washington, D.C. 20013.'

**United Way or Health and Welfare Councils.** These are good sources of information about services in your community. They can help you find clinics, child guidance centers and other programs. To find these organizations, look in the yellow pages under “Social Service Organizations.”

**Hospitals with children's services.** Check out hospitals not only for diagnostic services but also for special preschool or therapeutic programs. The public may be largely unaware of small excellent programs run for young children with developmental problems, within hospital departments. Hospitals affiliated with universities are usually very good resources.

**Libraries.** There is a rich store of information about community resources in your local library. A phone call to the Library Administration Office or the Public Service Division may lead you to the information you are seeking. Check bulletin boards, look for announcements about new community projects and meetings, or just ask the librarian.

**Local or state departments of health, mental health and/or mental retardation.** These departments do sponsor programs which offer diagnostic and evaluation services and also, in some places, infant stimulation and preschool programs. Very likely, if the departments are large, they will have central information offices which can answer your questions. Look for pediatric clinics, public health clinics, maternal and child health clinics, well baby clinics, or neighborhood health clinics in your community — and use their services.

**Mental health clinics and child guidance centers.** Find out if these resources exist near your home, and what they offer. They can provide diagnosis and evaluation of emotional and learning problems in early childhood, and therapeutic programs of various kinds.

**University departments of special education and/or early childhood development, psychology, social work.** These are good sources of information, often they keep track of preschools in order to place graduate students for field work. Related programs should be checked out, too — such as Rehabilitation, Nursing, Physical Therapy, Occupational Therapy, Speech and Hearing.
universities run fine model programs. Graduate students in appropriate programs might be able to make home visits and give ideas. Some universities offer special services such as diagnosis and evaluation, educational planning and referral to specialized educational and treatment centers. To find out, check with departments of child development or special education.

**Voluntary associations and parent organizations.** Developmental nursery school programs may be run by advocacy organizations such as local chapters of the Association for Retarded Citizens, United Cerebral Palsy Association, Society for Autistic Children, Association for Children and Adults with Learning Disabilities, Mental Health Associations. Parent organizations are usually gold mines of information on what's going on, and where. All of these groups are concerned about improving services, and will welcome your help in exerting pressure for high-quality programs.

Getting in touch with an organization concerned about your child's needs may turn out to be one of the most meaningful steps you take. There is a list of major national groups in the last section of this booklet. By joining with other parents and concerned professionals you can add to the ranks of people who are working hard to give all handicapped children the best possible start in life they can get.
BE GOOD TO YOURSELF

We've been talking about babies and children, and how to help them grow. We hope, if this is all new to you, it will be the beginning of good feelings and rewarding experiences. If you're already well aware of how much parents can do to help handicapped children enjoy life and take part in the real world, we hope you've found some new thoughts, or books to read, or more encouragement as you do this big job.

But we haven't really said much about parents, and how they feel. The main word we'd like to get across is "please . . . be good to yourself." We think it's worth repeating that you should take care not to exhaust yourself physically and emotionally by trying to do absolutely everything you can to help your child. Remember — you're a person, too — and your needs, wishes, pleasures, goals all matter very much. The lives of other members of your family matter, too. The idea of stimulating handicapped children to reach their potential is tantalizing. But it doesn't need to be done at the expense of other kinds of personal fulfillment, or other family relationships.

We hope that you'll talk with other parents of handicapped children. There is hardly any other person who can help you more than someone who has been through the same kind of experience.

You'll also profit from other parents' practical suggestions for action and information about available resources. We strongly urge you to find out about the nearest chapter of the parents' organization concerned about your own child's handicap. Many hundreds of parents have gained enormous strength from sharing their feelings, problems — and solutions.

Infant and nursery-age programs are giving parents the time and place to discuss problems they are having in adjusting to difficult situations. This new freedom to talk openly together is helpful and supportive. If you feel overwhelmed by problems, and feel that you need more help coping with your feelings and reactions, you can look into resources in your community for counseling — by religious leaders, psychologists or other mental health professionals.
But — back to having time off. An afternoon out or a weekend. Look for people who are willing and able to take care of your handicapped youngster for brief periods. Many children with disabilities don't really need special attention, a competent person can usually learn what to do for those who have complicated needs.

There are groups of young people who are especially interested. Youth-ARC (Association for Retarded Citizens) is one example. Local chapters of the Council for Exceptional Children (CEC), which is made up of teachers and other professionals in the field of special education, may be able to meet your needs. CEC chapters include student members in training to work as teachers who may welcome the chance to spend time with and help a child with a handicap. Church groups, the Red Cross, Women's Clubs, and other civic organizations have taken a special interest in this community need. Public health nurses can help in some instances, too. Some communities have respite care programs set up by local organizations which either arrange to have sitters or companions come to your home while you're away, or have your child stay overnight in a place where he will get proper care and attention. Whatever you do, avoid getting isolated.

In many places, parents have formed their own groups to help each other out. They have gone to hospitals or homes to talk with mothers of babies born with handicaps, listened with empathy and shared experiences. This has been an enormous help to parents living through the first heartbreaking days, learning to cope with tough realities, and eventually finding humor and growth and new ability to roll with the punches.

One parent, Celia Wyman, helped start a group called Parents of Down's Syndrome Children. In a letter to new parents of handicapped children, she wrote:

"(the birth of your child) has already given a new direction to your life and may well give you a new set of values as you learn and grow. We . . parents are realists and certainly not Pollyannas. But we truly believe that our Down's syndrome children have added a new dimension to our lives for us, it has been a humbling experience, but one that has added to our strength and maturity, to the benefit of all our loved ones."
THE BIGGER PICTURE

For every handicapped child who gets early help, there are thousands who aren't being reached. We hope your child is one of the lucky ones; we know that too many who could grow, talk, laugh, run, play, learn --- are still shut out; denied the experiences that make life begin . and keep going.

We are at a point in history when we can really bring about change. True, we don't have all the answers. But we know enough to see a huge difference in what happens to children with disabilities when they get a good start.

As parents and teachers become increasingly sure of the remarkable progress that can be made, they are calling for programs to put new knowledge into practice. You can join this effort:

- Let your state and local departments of health and education know when you are aware of babies and young children in need of help who are not receiving services.

- Get together with members of parent organizations to inform administrators, legislators, and the general public of the great gains that can come from early education of handicapped children — starting at birth.

- Speak up! Make clear that it's worth the investment of funds to set up programs so that professionals and parents can work together to give each child a good beginning. Wasted lives are costly to everyone . and every child who gets a boost forward in his early years stands a better chance of being productive in adulthood.

At a conference on needs of handicapped young children, professionals, administrators and parents came together and discussed the strides that have been made in recent years. They talked of how babies and preschoolers can be helped by sensitive screening for possible problems, by planning with parents on "what-to-do" from the moment of diagnosis, by active collaboration between professionals and parents. They pointed to the big gap that still exists between what we know and what we do, and they concluded by asking "What are we waiting for?"

It's a good question!
Write to these organizations to find out about affiliated state or local chapters near your home. Ask them about their newsletters, and any information they can send you about caring for your child. This is not a complete list. There are many other organizations that help children with serious diseases and health problems. If you need more information, please write to CLOSER LOOK.

Autism
National Society for Autistic Children
1234 Massachusetts Avenue, N W
Suite 1017
Washington, D C 20005

Cerebral Palsy
United Cerebral Palsy Association
66 East 34th Street, 3rd Floor
New York, New York 10016

Deaf-Blind
National Association for the Deaf-Blind
2703 Forest Oak Circle
Norman, Oklahoma 73071

Centers and Services for Deaf-Blind Children
Room 3151, Donohoe Building
400 6th Street, S W
Washington, D C 20202

Emotionally Disturbed
Mental Health Association, National Headquarters
1800 North Kent Street
Arlington, Virginia 22209

Epilepsy
Epilepsy Foundation of America
4351 Garden City Drive
Landover, Maryland 20795

Health Impairments
American Cancer Society
777 Third Avenue
New York, New York 10017

American Cleft Palate Association
331 Salk Hall
Pittsburgh, Pennsylvania 15261

American Heart Association
7320 Greenville Avenue
Dallas, Texas 75231

American Lung Association
1740 Broadway
New York, New York 10019

Asthma and Allergy Foundation of America
19 West 44th Street, Suite 702
New York, New York 10036

The Candlelighters Foundation
2025 Eye Street, Suite 1011
Washington, D C 20006

Cystic Fibrosis Foundation
Suite 309
6000 Executive Boulevard
Rockville, Maryland 20852

Juvenile Diabetes Foundation
23 East 26th Street, 4th Floor
New York, New York 10010
The National Association of the Physically Handicapped, Inc
76 Elm Street
London, Ohio 43140

Osteogenesis Imperfecta Foundation
632 Center Street
Van Wert, Ohio 45891

Spina Bifida Association of America
343 South Dearborn Street
Room 319
Chicago, Illinois 60604

Speech Impairments
American Speech—Language—Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

Visual Impairments
American Council of the Blind
1211 Connecticut Avenue, N.W.
Suite 506
Washington, D.C. 20036

American Council of the Blind—Parents
Rt A Box 78
Franklin, Louisiana 70538

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

International Institute for Visually Impaired 0-7, Inc
1975 Rutgers Circle
East Lansing, Michigan 48823

National Association for Parents of Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

National Association for Visually Handicapped
305 East 24th Street
New York, New York 10010

National Federation of the Blind
1800 Johnson Street
Baltimore, Maryland 21230

General
The Association for the Severely Handicapped
7010 Roosevelt Way, N.E.
Seattle, Washington 98115

March of Dimes Birth Defect Foundation
1275 Mamaroneck Avenue
White Plains, New York 10605

National Easter Seal Society for Crippled Children and Adults
2023 W. Ogden Avenue
Chicago, Illinois 60612

National Genetic Foundation
555 West 57th Street
New York, New York 10019
**Closer Look**, the national information center for handicapped people, is set up to help parents of handicapped children and youth by giving practical advice on how to find educational programs and other kinds of services.

Parents and professionals seeking assistance in dealing with problems and needs of a mentally, physically or emotionally disabled child or young adult should write to **Closer Look, Box 1492, Washington, D.C. 20013**. Be as specific as possible, including facts about a person’s handicapping condition (known or suspected), age, and the kind of help being sought. The staff will respond with an appropriate packet that includes background pamphlets, suggestions on steps to take to locate services, and other useful information.

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