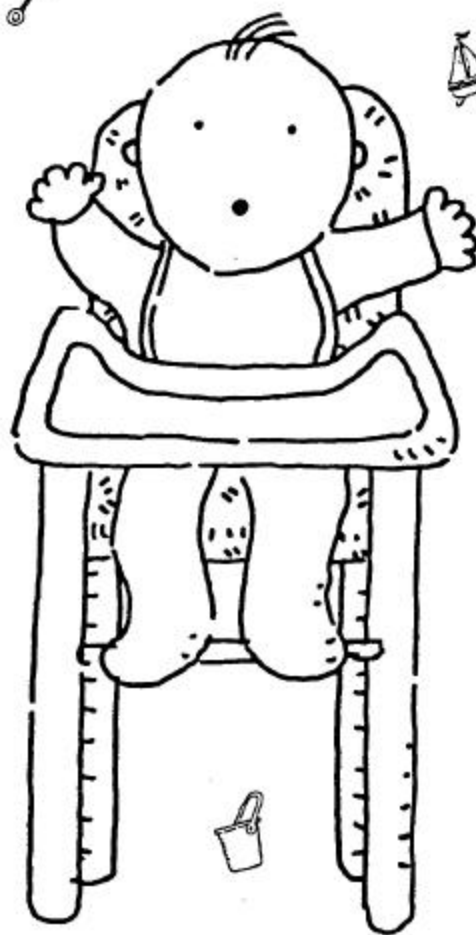




BEGINNING WITH FAMILIES

A PARENTS' GUIDE TO EARLY INTERVENTION



W E L C O M E

Virginia cares about children and their families. Parents and professionals who are committed to the interests of children wrote this book. All of us hold onto a dream for our children. It is our hope that this book will help your dreams become a reality.

- I. Do you have a question or a concern about the way your child is growing or developing? (such as learning how to sit up, or crawl, or learning to talk?)

Call "FIRST STEPS" Virginia's free information line:
1-800-234-1448

- II. Would you like to talk with another parent or caregiver concerned about children with special needs?

Call the Parent Educational Advocacy Training Center (PEATC):
1-800-869-6782 or 703-923-0010 or 703-569-6200 (en español)

www.peatc.org

Call Virginia's Parent-to-Parent and Early Intervention Family Representatives:
1-888-604-2877 or 804-222-1945

PTPofVA@aol.com

- III. Do you want to find out about programs in your community that are experienced in helping children? Check the listing on the next page for your county or city and the telephone number to call.

- IV. Sometimes even the best plans can run into some difficulty. If you have any problems in getting help for your child contact:

Department for Rights of Virginians with Disabilities:
1-800-552-3962, www.cns.state.va.us/drwd

Or you can write or call:

Office of Early Intervention
Department of Mental Health, Mental Retardation and Substance Abuse Services
P.O. Box 1797

Richmond, VA 23214

1-804-786-3710

alucas@dmhmrsas.state.va.us

www.dmhmrsas.state.va.us/vababiescantwait/

Helping your child is the most important thing you can do. This book offers some sound advice and insight gathered from those parents and children who have walked down the same road you are on now. Share this book with your child's doctor, with other family members, and professionals you meet. And don't wait to contact the organizations we have listed above. Take the first step in helping your child toward a healthier and happier life. We will be waiting to hear from you.

Family Support & Advocacy and Public Awareness Committees
Virginia Interagency Coordinating Council

The members of the VICC gratefully acknowledge the generosity of PEATC for sharing their work and their wisdom.

Local Planning Groups For Early Intervention In Virginia

Area Served	Telephone	Area Served	Telephone	Area Served	Telephone
Abingdon	(276) 645-4736	Frederick County	(540) 636-4592	Pittsylvania Co.	(434) 799-5190
Accomack County	(757) 442-7599	Fredericksburg	(540) 899-4347	Poquoson	(757) 566-3300
Albemarle County	(434) 924-5694	Galax	(276) 223-3270	Portsmouth	(757) 393-8791
Alexandria	(703) 838-6400	Giles County	(540) 831-7529	Powhatan Co.	(804) 598-2200
Allegheny County	(540) 863-1620	Gloucester Co.	(804) 758-5250	Prince Edward Co.	(434) 392-8502
Amelia County	(434) 392-8502	Goochland Co.	(804) 598-2200	Prince George Co.	(804) 862-8049
Amherst County	(434) 948-4831	Grayson County	(276) 223-3270	Prince William	(703) 792-7772
Appomattox	(434) 948-4831	Greene County	(434) 924-5694	Pulaski Co.	(540) 831-7529
Arlington County	(703) 228-1640	Greensville Co.	(804) 862-8049	Quantico	(703) 792-7772
Augusta County	(540) 887-8060	Halifax County	(434) 575-7916	Radford	(540) 831-7529
Bath County	(540) 464-8560	Hampton	(757) 726-4012	Rappahannock Co.	(540) 937-2155
Bedford	(434) 948-4831	Hanover County	(804) 365-4649	Richmond	(804) 828-2742
Bland County	(276) 223-3270	Harrisonburg	(540) 434-6093	Richmond Co.	(804) 758-5250
Botetourt County	(540) 777-4747	Henrico County	(804) 261-8531	Roanoke	(540) 777-4747
Bristol	(276) 645-4736	Henry County	(276) 632-7128	Roanoke County	(540) 777-4747
Brunswick Co.	(434) 575-7916	Highland County	(540) 887-8060	Rockbridge Co.	(540) 464-8560
Buchanan County	(276) 964-6702	Hopewell	(804) 862-8049	Rockingham Co.	(540) 434-6093
Buckingham Co.	(434) 392-8502	Isle of Wight Co.	(757) 562-6806	Russell County	(540) 964-6702
Buena Vista	(540) 464-8560	James City	(757) 566-3300	Salem	(540) 777-4747
Campbell	(434) 948-4831	King & Queen Co.	(804) 758-5250	Scott County	(276) 523-8360
Caroline County	(540) 899-4347	King George Co.	(540) 899-4347	Shenandoah Co.	(540) 636-4592
Carroll County	(276) 223-3270	King William Co.	(804) 758-5250	Smyth County	(276) 223-3270
Charles City	(804) 261-8531	Lancaster County	(804) 758-5250	South Boston	(434) 575-7916
Charlotte County	(434) 392-8502	Lee County	(276) 523-8360	South Hill	(434) 575-7916
Charlottesville	(434) 924-5694	Lexington	(540) 464-8560	Southampton Co.	(757) 562-6806
Chesapeake	(757) 547-8929	Loudoun County	(703) 777-0561	Spotsylvania Co.	(540) 899-4347
Chesterfield Co.	(804) 768-7205	Louisa County	(434) 924-5694	Springfield	(703) 246-7191
Clark County	(540) 636-4592	Lunenburg Co.	(434) 392-8502	Stafford County	(540) 899-4347
Clifton Forge	(540) 863-1620	Lynchburg	(434) 948-4831	Staunton	(540) 887-8060
Colonial Beach	(804) 758-5250	Madison County	(540) 937-2155	Suffolk	(757) 562-6806
Colonial Heights	(804) 862-8049	Manassas	(703) 792-7772	Surry County	(804) 862-8049
Covington	(540) 863-1620	Manassas Park	(703) 792-7772	Sussex County	(804) 862-8049
Craig County	(540) 777-4747	Marion	(276) 223-3270	Tazewell County	(540) 964-6702
Culpepper Co.	(540) 937-2155	Martinsville	(276) 632-7128	Virginia Beach	(757) 437-6068
Cumberland	(434) 392-8502	Mathews County	(804) 758-5250	Warren County	(540) 636-4592
Danville	(434) 799-5190	Mecklenburg Co.	(434) 575-7916	Washington Co.	(276) 645-4736
Dickenson Co.	(276) 926-8543	Middlesex Co.	(804) 758-5250	Waynesboro	(540) 887-8060
Dinwiddie Co.	(804) 862-8049	Montgomery Co.	(540) 831-7529	West Point	(804) 758-5250
Emporia	(804) 862-8049	Nelson County	(434) 924-5694	Westmoreland	(804) 758-5250
Essex County	(804) 758-5250	New Kent	(804) 261-8531	Williamsburg	(757) 566-3300
Fairfax	(703) 246-7191	Newport News	(757) 726-4012	Winchester	(540) 636-4592
Fairfax County	(703) 246-7191	Norfolk	(757) 683-8759	Wise County	(276) 523-8360
Falls Church	(703) 246-7191	Northampton Co.	(757) 442-7599	Wythe County	(276) 223-3270
Falls Mills	(276) 964-6702	Northumberland	(804) 758-5250	York County	(757) 566-3300
Fauquier County	(540) 937-2155	Norton	(276) 523-8360		
Fishersville	(540) 887-8060	Nottoway Co.	(434) 392-8502		
Floyd County	(540) 831-7529	Orange County	(540) 937-2155		
Fluvanna County	(434) 924-5694	Page County	(540) 636-4592		
Franklin City	(757) 562-6806	Patrick County	(276) 632-7128		
Franklin County	(276) 632-7128	Petersburg	(804) 862-8049		

Rev. 2002

BEGINNING WITH FAMILIES

A PARENTS' GUIDE TO EARLY INTERVENTION

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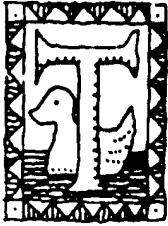
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P R E F A C E



This guide was written by the Parent Educational Advocacy Training Center (PEATC) as part of their responsibility as the Parent Training and Information Center for the state of Virginia. The contract to support this project was through the Office of Special Education Programs in the U.S. Department of Education.

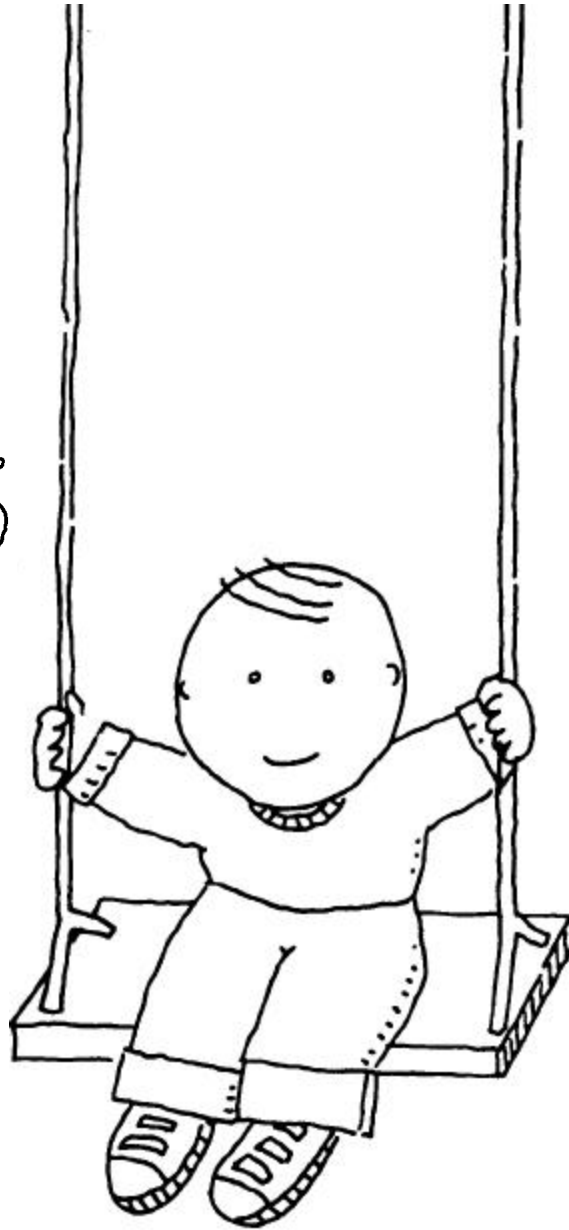


Founded in 1978, PEATC was one of the original seven Parent Training and Information Centers and has gained national recognition for its training programs that build collaboration between parents and professionals.

PEATC believes that children reach their greatest potential when families and service providers enjoy an equal, respectful partnership. PEATC builds upon parents' expertise to make effective educational choices with and for their children. The Center strives to motivate educational systems to be responsive to the dignity, dreams, and integrity of individuals with disabilities and their families.

Services provided by PEATC include:

- training courses for families and educators to enhance knowledge and build skills to advocate for each child's appropriate education;
- information and assistance to individuals in problem solving and identification of services needed;
- consultation to help organizations develop programs and policies;
- community collaboration to advocate for the inclusion of families' perspectives and responsive community resources;



- product development to reach a wide audience through newsletters, textbooks and training materials.

The primary writers for this guide were Winifred Anderson and Cherie Takemoto:

- Winifred Anderson has a long-standing commitment to children with disabilities and their families. She was the co-founder and executive director of the Parent Educational Advocacy Training Center (PEATC) for 13 years.

Prior to founding PEATC, Anderson served for eight years as the director of

Resurrection Children's Center. During those years, she was instrumental in establishing the preschool as a model demonstration and outreach program to promote the inclusion of children with disabilities in a neighborhood school.

With Stephen Chitwood and Deidre Hayden, Anderson co-authored *Negotiating the Special Education Maze: A Guide for Parents and Teachers*, published by Woodbine House in 1990; the third edition was published in 1997.

- Cherie Takemoto is now the Executive Director of PEATC. When she co-wrote *Beginning with Families*, she was an early childhood specialist for PEATC and mother to two budding advocates. Margaret, who was six at the time, and great at communicating, with tact and sensitivity, exactly what she thought. Peter, who was four, never had a problem communicating (verbally or nonverbally) just how upset he was when he was not doing exactly what he wanted to do - despite his developmental delays.

Takemoto negotiated the early intervention maze as she accessed services for Peter. She has been involved in early intervention as co-chair of her local Early Intervention Interagency Coordinating Council and state Family Support and Advocacy Subcommittee. Later she served as a parent representative, and chair, on the Virginia Interagency Coordinating Committee.

PEATC also received thoughtful and exceptional assistance from a group of parents with experience in early intervention. We wish to acknowledge the following people. These biographies reflect who they were when they contributed to this publication:

- Lidia Carvallo was a human resources aide for the Arlington County Parent Infant Education Program. Her warmth, knowledge and sensitivity have made many Hispanic families feel welcome at her program. Lidia served as a parent board member of the PEATC board.
- Kathy Maggio is a mother of six children, including Maria. At the time this was first written, Maria liked to unplug her oxygen tank in order to keep up with her brothers. Maria, who was five at the time, liked to train puppies and has multiple disabilities. Kathy is a former member of the Virginia Interagency Coordinating Council and is now kept busy working for a local college, pursuing a master's degree, tutoring local children, and being an advocate on two disability boards.
- Don Smith is a father of two girls. The youngest, Kimberly, was in an early intervention program when Don contributed to this publication. Don's hope for Kimberly is that she be able to experience life, liberty and happiness like other children her age. Don was also the chair of the Prince William Interagency Coordinating Council in Virginia.





baby's life begins in a family. The family is the first place that a baby learns about life and love. You, as a parent,* are your baby's first and most important teacher.

Brothers, sisters and other members of a family also stimulate a baby, providing new possibilities in a rich world. Families help us face life when things are hard and celebrate when things go well.

Families come in all sizes. While some consist of a mother, father and children, others may be as small as one child and a mother. A family can also include lots of brothers and sisters, parents, grandparents, aunts, uncles and cousins. Closely-knit neighbors or friends can come together as a family.

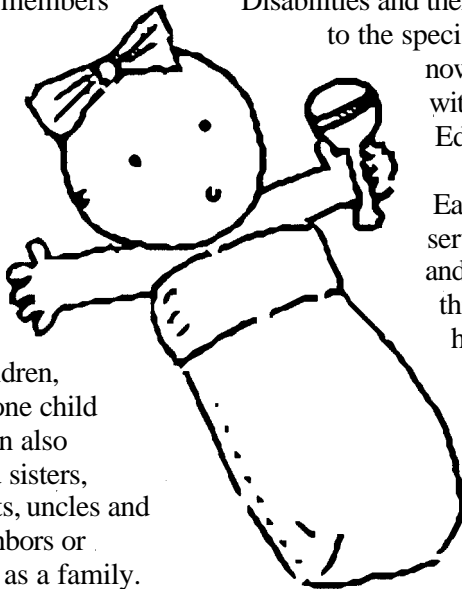
Children of divorced or separated parents may be a part of two different families. We all need families.



When a baby has a disability, life for the whole family is changed. Getting necessary treatment and services often requires a lot of determination, as well as good organizational and management skills. Learning how to take care of your baby and finding information on particular disabilities or conditions can be difficult. In the rush of caring for your child's special needs, it becomes difficult to do some of the important family things previously taken for granted.

* The term "parent" in this book means anyone who is in charge of the care and well-being of a child. Included are single parents, parents by birth or adoption, guardians, grandparents, foster parents, or surrogate parents.

In 1986, some help for your family and others came when the U.S. Congress passed legislation to encourage states to set up programs for infants and toddlers with disabilities and their families. This program, now referred to as Part C - Early Intervention for Infants and Toddlers with Disabilities and their Families, was added to the special education law that is now called the Individuals with Disabilities Education Act (IDEA).



Early intervention services can begin at birth and last until a child turns three. They are set up to help each child make developmental progress and to help the family in meeting the child's unique needs.

Early intervention services can include:

- help to families that will encourage their babies to learn and grow;
- assistance in getting services that will help children to develop, as well as other benefits like Supplemental Security Income (SSI), social services, or medical assistance;
- family counseling and home visits;
- occupational, physical and speech therapy;
- planning and assistance as children prepare to leave one program and move on to new programs or services.

A complete list of services included in the legislation is in the Glossary under "Early Intervention Services."

At the federal level, Part C – Early Intervention for Infants and Toddlers with Disabilities and their Families is run by

the U.S. Department of Education. At the state level, there is a designated agency that is responsible for a comprehensive early intervention system; information about that agency is in the “welcome” page of this guide. A list of phone numbers for local agencies is included in back of the “welcome” page at the beginning of this guide.

When the Part C program was enacted, Congress found that early intervention services must focus on the whole family in order to work. It was also recognized that services must go beyond those which meet a baby's developmental needs. Many families are concerned with the basics such as help with money, food or housing. Others are not likely to get help for their children unless they are treated with respect and believe that the services will truly benefit their children. Rules and requirements can become barriers between the different programs and can also keep families from being able to use their services. For these reasons, the Part C Early Intervention Program must be comprehensive and coordinated.

Because we, at the Parent Educational Advocacy Training Center (PEATC) also believe that early intervention must work around the needs of families rather than the needs of programs, this parents' guide to early intervention is called *Beginning with Families*. As you begin your journey with your child – into this system of early intervention and possibly other programs and services down the road – it is our hope that you will always begin with your family.

Since passage of the original legislation by Congress, a number of parents and

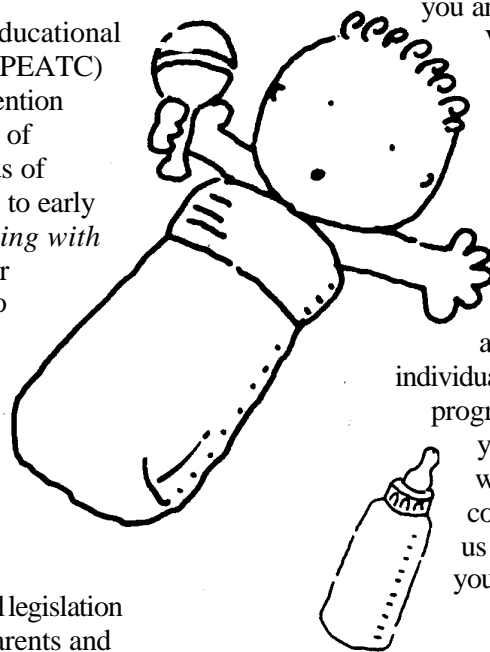
professionals have been working together to put the ideas into practice. This has led to a number of rules and regulations, and other prescriptive requirements to define a system or program for early intervention. Rather than describe all the technical terms and requirements of the law, this guide begins with you and your family.

To make the whole system of early intervention work for you, we hope that you can begin at home.

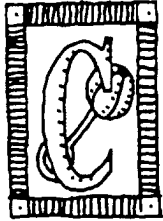
- Think about how you feel and what is important to you, as a family.
- Help others understand you and your family as people with many of the same dreams and needs as other families, as well as with unique needs of your own.
- Learn how to organize your feelings, thoughts, and information to make the early intervention system work for you and your family.

First and most important, your child needs you and your family.

With some help from friends and professionals, you and your family will help your child to grow, learn and love life. As your child grows older and moves on from individual doctors, programs or services, you and your family will be what are constant. And so, let us begin with you ... your child's family.



YOUR CHILD'S FIRST AND BEST ADVOCATE



Children with special needs, like all children, depend on their parents for security, warmth and nurturing. In turn, a child will show a parent a part of him* that others might not know. It

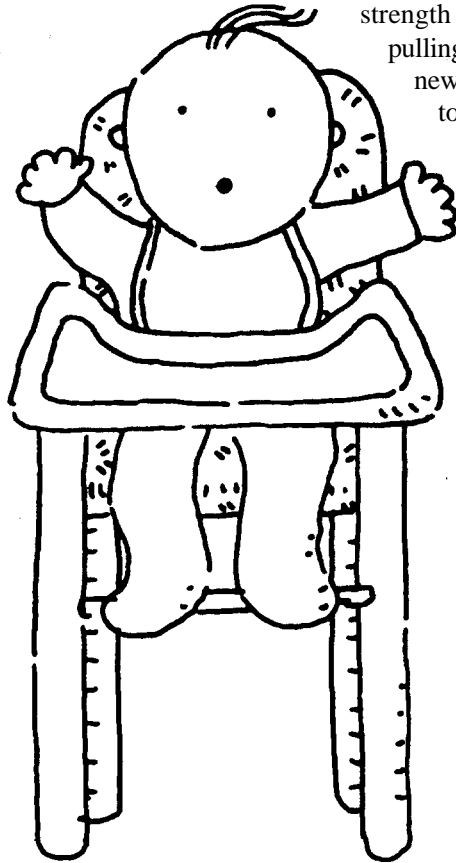
may be something as simple as the way your baby grasps your finger that says that you are his anchor in this scary world. You are your child's first and best advocate. You have the passion, the dreams, and the commitment to guide your family through a complicated maze of decisions and special services.

Beginning now and in the coming years, you will observe what interests your child. You will see what makes him thrive and what he would rather avoid. You will gather information from all of the evaluations, consultations, and histories that professionals will have written or said about your child. You will find out how to help your child by trial and error. You will also learn how children with similar needs have been helped.

Raising a child with special needs is not easy. Schedules and special care may be

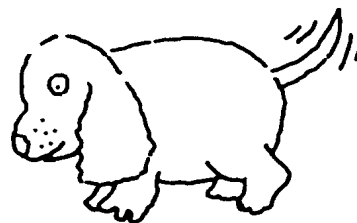
complicated. You may find that you have little time to devote to yourself and the rest of your family. With all of your worries and stress, sometimes your spouse, other children, or special people in your life may feel left out.

The Chinese symbol for crisis is "danger" and "opportunity." Having a child with special needs is a challenge that can threaten family stability. Previously held notions that "this is the type of thing that happens to other families" or "my child is going to grow up just like me" suddenly do not apply. A family who finds the strength to respond to the crisis by pulling together will find many new opportunities for learning to love and grow as a family.



UNDERSTANDING YOUR CHILD'S DISABILITY

"When the doctor told us that Melissa had cerebral palsy, we were in shock. I remember seeing the doctor's mouth moving, but the words that came out did not fit Melissa at all. Sure she had some problems at birth, but she was such a beautiful baby. How could she have the terrible problem he was talking about? After the initial shock, my wife and I



* To avoid sexist use of pronouns, the masculine gender (he, his, him) is used in Chapters I, III, and V. The feminine gender (she, hers, her) is used in Chapters II, and IV.

found out everything we could about cerebral palsy. We learned that children with this disability are no longer institutionalized. Soon, we met other families with children having CP. When we understood CP, we were better able to revise our dreams, to cope and to help Melissa.”

Just as with Melissa's dad, when you learn more about your child's special needs you can better understand and care for those needs. For instance, your child may be sensitive to touch and you may need to find different ways to soothe him. Another child may be unable to breast feed. Understanding the patterns of development associated with particular diagnoses and disabilities may be helpful. Where there is no diagnosis, finding out how symptoms can be treated may also be useful.

For many families, the doctor is their first source of information. Parents have found that they are able to obtain accurate information by writing down questions, taking notes or bringing a friend or support person to help ask questions and listen.

Make sure that you understand the words your physician is using. If you do not understand, ask for an explanation. If the doctor is too busy, arrange a time when you can meet again to discuss your child and his care (or change doctors!)

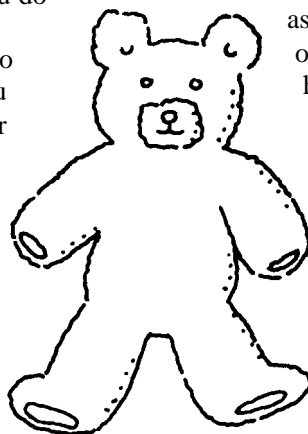
OTHER SOURCES OF INFORMATION

The local early intervention program is a good source of information about your child's special needs and can direct you to other support services. They may also be able to link you up with other parents on an informal basis or through a Parent to Parent program. Many school

districts also have Parent Resource Centers with information to help families even if a child is too young for special education. Many families have received assistance and support from local advocacy organizations such as the Arc (formerly the Association for Retarded Citizens), United Cerebral Palsy (UCP), or Parents of Down Syndrome (PODS).

National organizations may provide specific information that helps you understand and work with your child's special needs. For instance, the National Information Center for Children and Youth with Disabilities (NICHCY) is a clearinghouse that provides free information to assist parents, educators, caregivers, advocates and others in helping children and youth with special needs. They also can help you locate local, state or national groups organized around specific disabilities.

The National Organization for Rare Disorders (NORD), a clearinghouse for information about rare (and not so rare) disorders, has a network for families with similar disorders to provide mutual support. Another clearinghouse, National Information Center for Orphan Drugs and Rare Diseases (NICODARD), gives similar assistance and linkage to parents or to organizations that may be of further help. Each of these organizations has toll-free help numbers and websites listed in the appendix.



FEELINGS AND COPING

“When I found myself losing control, which happened often, I would gently lay my daughter in her crib or playpen and walk away for a few minutes. And then I would slowly walk back and pick her up. Getting away for a moment or two and then gradually returning to the situation helped me regain my control.”

Every parent experiences a range of emotions about their child. Feelings such as denial, guilt, sadness, anger, fear, and loneliness are normal reactions. Happiness, protectiveness, hope and pride also come into play. Recognizing your feelings can help you to cope with your own emotions, as well as your child's special needs.

DENIAL OR DISBELIEF: Some parents do not immediately accept a child's diagnosis. They may want to believe that their child will "grow out" of a particular condition. This reaction can help parents adapt at their own pace. It allows them time to dream and may help them to recognize the "normal" and even wonderful qualities in their children.

GUILT: Many parents feel at least a tinge of guilt about their children's special needs – even when there is no real reason. "If only I had (fill in the blank)" is a common reaction, even though the children's special needs were beyond their control. Parents who blame themselves can always find a tiny thread of truth to confirm their guilt.

Sometimes parents are lead by professionals to believe that guilt is a negative feeling that doesn't serve a useful purpose. Professionals with this view believe that even if a parent was in some part responsible for the problem, there is nothing that can be done about it.

On the other hand, some experts believe that by accepting guilt, parents feel less helpless in their situation. By being able to identify the cause (real or imagined) for the child's special needs, a parent can feel more in control and that it will not happen again and the family can move on in their lives.

In any case, when guilt, self-blame or other feelings keep a person from being able to think of anything else, or if a person is having trouble coping with feelings, professional counseling or therapy may be needed.

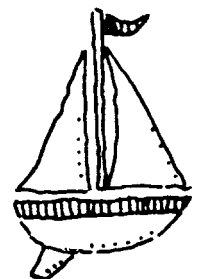
SADNESS: Sadness or depression is recognition that many of the hopes and dreams for a child may not be realized. The initial and ongoing reaction to having a child with special needs is viewed by many within the context of a grieving process similar to the feelings one has when someone dies. While this model fits for many parents, it does not work for everyone. As one parent stated:

"Sure I know and have experienced the emotions in the grieving process – denial, anger, guilt, depression, acceptance – many times. Yet I have not experienced a cycle or process. These feelings don't come in stages. And between all those emotions are impatience, joy, pride, reflection, love, defensiveness, protectiveness, and happiness – just to name a few. My son is very much alive and lets me know it every day, thank you."

Still, sometimes you may feel sad. It may be the first day of school... not being on the soccer team ... or watching how frustrated your child gets when he is trying to do something that he can't. Hopefully these feelings of sadness will be balanced with other feelings of pride, happiness and relief.

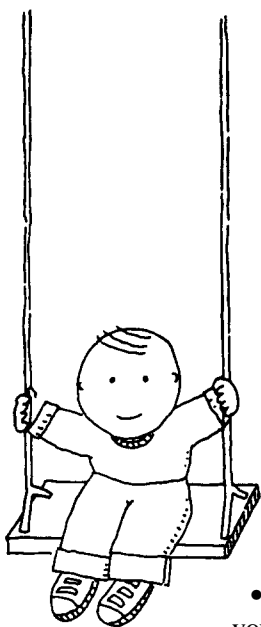
ANGER: Feelings of anger toward a child with special needs is common. A baby with special needs can be irritable, demanding, or difficult to feed. A baby many not respond to a mother's efforts to comfort him or turn away from stimulation as if rejecting her. Parents of an unresponsive baby may feel inadequate and unwanted. Parents who are already tired, upset, and frazzled may react to the baby's fussiness by losing control.

Sometimes relatives and friends may not know how to respond to a family with a child with special needs. You might have noticed a lack of baby gifts or cards that show uneasiness about your child's situation. They may feel uncomfortable bragging about their "normal" children or bringing them over to play. If this happens



to you, it might be interpreted as a rejection, not only of the child, but also of you.

Anger is often viewed as self-defense against guilt and helplessness. There are other explanations. Many people, including physicians and other professionals, do not know how to respond to a parent's needs – especially when they do not have any ready answers. Professionals who are unable to help the child may become defensive, making it almost impossible for them to be supportive. Parents experiencing this insensitivity may become angry or frustrated.



Anger is one of the most powerful emotions. But often behind anger are feelings of powerlessness, fear, guilt, or loneliness. Anger can be used in negative ways through physical or verbal violence or withdrawal. Anger can also be channeled positively in moving a parent into action. If you find yourself feeling angry, it might help to:

- get some help in taking care of yourself;
- let friends or family know how you feel and helping them to be more supportive;
- find others who are understanding of your feelings so that they can be more supportive of you and your family;
- write a letter or take some other positive action; or
- resolve to prove them wrong and get the help that you know you and your child need.

FEAR: Parents who have children with special needs may experience fears about real threats to their child's life and safety related to a medical condition or disability.

They may be fearful of unknowns related to their child's future. This fear often can cause parents to gain more control over their own or child's situation in a number of ways such as:

- finding out more about their child's condition and things that other parents have successfully done for children with similar needs;
- talking to trusted friends, professionals, or other parents about their fears;
- getting needed help or equipment that will help monitor the child or take care of a special need; or
- taking charge in another aspect of the child's or parent's life so that they feel a greater level of control in other areas.

LONELINESS: Parents may also feel more alone than before. At a time help is most needed, no one can be found. Friends, relatives, or even family members who were supportive before may not know how to be helpful in a situation that they do not understand. If you are feeling alone, here are some things that other parents have done to cope with their feelings of loneliness:

- give friends or family members a small task when they say, "Is there anything we can do?" People want to help and like to feel needed.
- reveal your feelings to others. Sometimes telling others about your feelings of loneliness will allow them to let you know that you are not alone.
- find other parents, friends or professionals who will help you out.
- reach out to others. You may find others who are lonely and need help too. If you reach out to them, they may do the same.

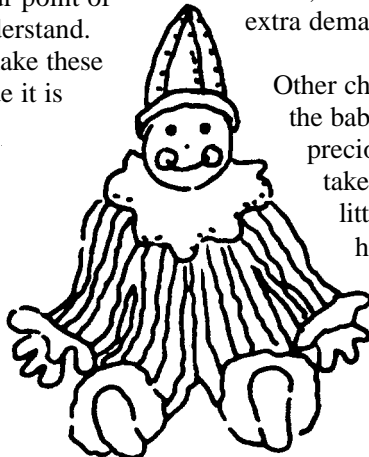
COMMUNICATION

As your child's advocate, you will have to understand and communicate your family's priorities and concerns to professionals, relatives and friends. Parents who have children with special needs may find that communication skills are important on several levels:

- for helping friends and relatives who shared hopes and dreams for your child, and may not know how to respond to you;
- for talking with curious strangers who ask you "What is wrong with your baby?"
- for helping a service provider understand your child's needs;
- for changing a service plan that does not meet your family's needs;
- for explaining a medical bill, when an insurance company denies payment;
- for letting a friend, service provider, or family member know that their efforts are appreciated.

Communicating to others about your child can sometimes be frustrating – especially when they do not share your point of view or do not seem to understand. You can be better able to make these people understand (or decide it is not worth it!) if you:

- are aware of your own feelings;
- have a sense of your own and your family's priorities;



- know what you like about your child - what makes you proud of him;
- have a clear idea of what you want for your child;
- try to understand what others are thinking or feeling.

REMAINING A FAMILY ... IN THE MIDST OF CHAOS

“Early on, I realized that Kimberly was going to take a lot of our time. For instance, it took two hours to give her a tiny bottle of formula. Because she was placing such a demand us, I knew I needed to do something that would help us focus on my oldest daughter's needs. After all, a typical five-year-old can be very demanding.

We started ‘TLC time’ for tender loving care. Every time my oldest daughter felt neglected, I told her to come to me and ask for some “TLC time” and I would stop what I was doing and pay attention to her. This has worked well for our family, and believe it or not, it has not been over-used.”

One of the most important tasks that all babies must accomplish is forming a trustful and loving relationship with their families and the world. For children with special needs, this can be difficult because of the extra demands associated with their needs.

Other children who needed you before the baby still need you. Time is often a precious commodity. Though it may take some extra balancing of time, a little time together each day may help you face challenges in other areas of your lives.

The following are some ideas:

- Parents need to spend time as partners, separate from

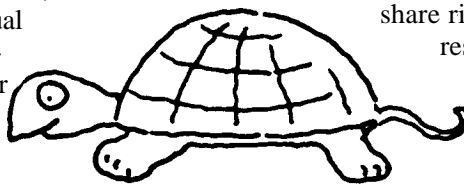
their children. Set aside a few minutes for time together each day and arrange for some time away for just the two of you.

- If you do not have a husband, wife or partner that you can rely upon for support (or even if you do!), talk to a friend or relative or find an enjoyable thing to do with them.
- Try to save a "special time" for other children each day (even if it is only for a few minutes). During "special time," your child has a choice of how that time is spent within the structure you provide. This gives the child an opportunity to have some control, to feel special and nurtured and to let you know what is important to him.
- Keep up with or create new family rituals or special occasions. These are things that you and your family can look forward to. You can also remember these good feelings and experiences when things are not going as well.
- Participate in exercise or a type of recreation that your family enjoys doing.
- It is hard to do, but once in a while, try to take a day off from all of your obligations. Instead of calling it a "sick day," call it a "well day" - for you to renew your energy and indulge yourself. (If you are employed, don't forget to make up a plausible story about just how sick you really were!)
- If it fits with your beliefs, take the time for religious or spiritual renewal. Being with others who share your beliefs can also help you to feel better.

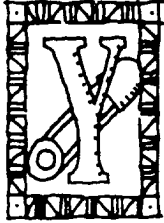
- Remember the positive. You can help your child feel more confident if you remind him of his strengths. Let him help as much as he can, so that he can learn to give to others as well as receive.
- Try to balance your child's needs to be a child (play, love, enjoy life) with his special needs (physical therapy, speech therapy, medical treatment). In addition, those special services will be more beneficial if they are playful or enjoyable.
- Sometimes children with special needs are viewed for what they cannot do or what they need. The positive characteristics that they and their families have are often ignored. On the other hand, some Native American cultures think of children with special needs as people who were placed in this world to teach us. We have much to learn from children with special needs and their families.

Many families have found that the crisis of having a child with special needs makes them stronger. They feel closer and have found more supportive relationships – within and outside the family. They may find themselves to be more organized and competent – their priorities change. They find that many of the little things do not bother them anymore. Parents may find that they are better able to communicate with others and can resolve conflicts.

Many parents have learned a valuable lesson: we are all dependent upon each other and we all have something that we can give. They recognize and appreciate help, share risks and successes and respect differences.



YOU ARE A HOME INFORMATION SPECIALIST



ou were likely raised with at least one parent who knew Dr. Spock's confidence-building words to new parents, "You know more than you think you do!"

When you brought your baby home you, like most all parents, wondered if you could possibly know enough to care for your child.

You have depended upon many helpers for your family – doctors, social workers, hospital and home care nurses, respiratory therapists, infant development specialists or one of many other care providers. Many parents find themselves, after an initial adjustment period, becoming less dependent on outside helpers. They find out that they do know more than they thought they did.

You are the home information specialist. Every time you meet with a new person who will be involved with your baby and your family, that person will be asking you questions, most of which you have answered many times before. They ask you questions, knowing that you are the expert on your child – you know more about your child and family than anyone else. How can you be sure to share what you believe is valuable to people who are helpers, friends and family?

Since you are the leader on any team that is making decisions about your child, you will want to be ready with information about your baby and family. When your information is organized, you will

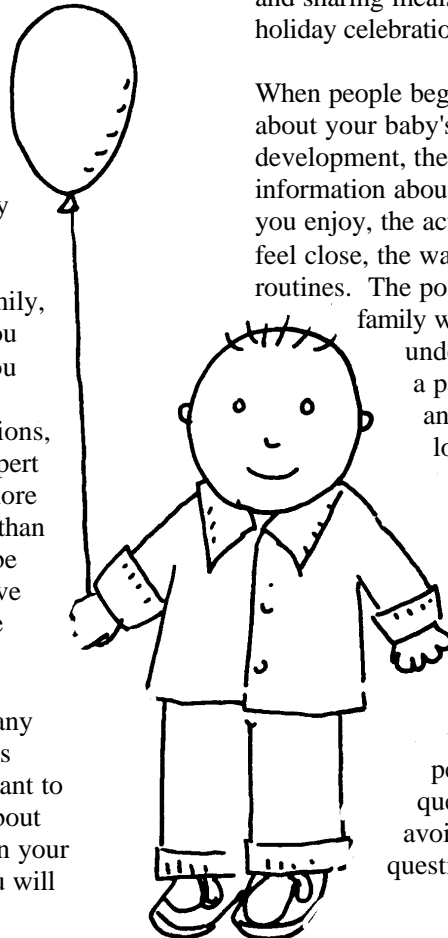
find that you will not be as frustrated answering the same questions over and over with different people, and you will not have to search for it.

ORGANIZING FAMILY INFORMATION

You may say, "How can I organize all that I know about my child and family?" Beginning with your family, the first information you need to consider is what is important to you as a family. What do you as a family enjoy doing together? Is it watching favorite TV programs together? Going out? Playing outdoors? Cooking and sharing meals together? Planning holiday celebrations?

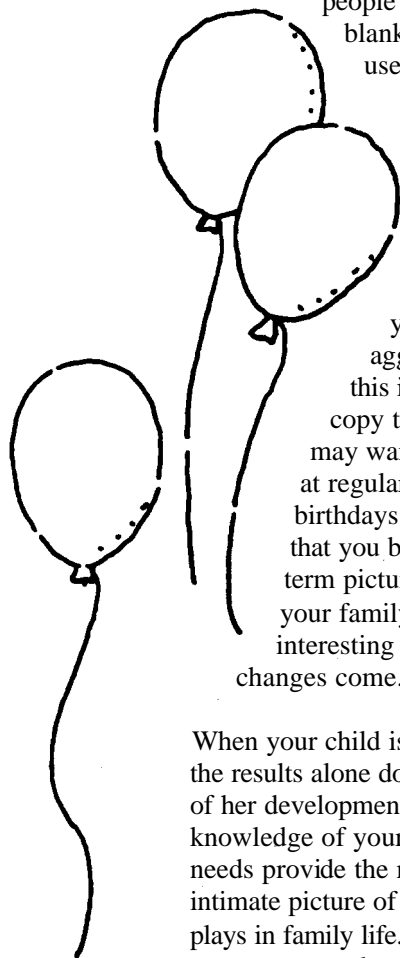
When people begin asking you questions about your baby's health history or development, the best place to start is with information about your family, the things you enjoy, the activities that make you feel close, the ways you build your routines. The positive description of your family will help the other person understand that your baby is a part of a greater family, and one of several that are loved and cared for.

Many families have found that if they fill out a chart about their family and their child such as the one following, they can hand this information in written form to the person asking the questions. In this way they avoid answering the same questions over and over.



Below is the MY CHILD AND MY FAMILY form filled out by Don Smith about his daughter, Kimberly. In the back of this book is a blank form that you can fill out about your child and family. Some

people make copies of the blank form so that they can use it more than once.



After you have completed the MY CHILD AND FAMILY form, you can make several copies, and save yourself the time and aggravation of repeating this information by giving a copy to professionals. You may want to complete this form at regular intervals, such as birthdays or more frequently, so that you begin to build a long-term picture of your child and your family. It is fun and interesting to see how and when changes come.

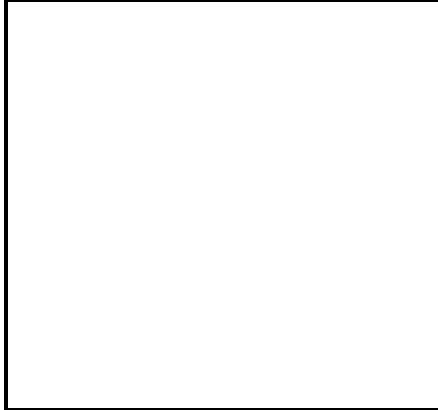
When your child is tested or evaluated, the results alone do not give a full picture of her development. Your experience and knowledge of your child's strengths and needs provide the most colorful and intimate picture of her and the role she plays in family life. You will be able to present a complete picture of your family's strengths and ways you and your baby are growing and changing together.

The form on the next page will help you communicate invaluable information about your child to doctors, infant development specialists, therapists, friends or others who are helping your family and your baby. When you and your baby go for tests, to a meeting to develop an Individualized Family Service Plan, or to see your doctor, you can use these forms to help you in your role as Home Information Specialist. You are your

baby's first and best advocate. An organized advocate is in the best position to bring about positive changes both for your child and your family.

NOTE about form: This is for you. If there are questions, you consider unimportant or private, don't answer them. Likewise when people ask you questions that you consider to be irrelevant, you have the right to challenge them and/or not answer.

MY CHILD AND FAMILY



Date: **March 17**

My Name: **Donald Smith**

Please Call Me: **Don**

My Child's Name: **Kimberly**

Child's Birthday: **1-26-90**

*Photograph of your child or family
or
for fun, you can sketch a picture!*

1. Description of our family (*parent(s), brothers and sisters, grandparents, special friends and relations*).

Our family is composed of grandmother, my wife, two daughters and myself

2. What we enjoy doing as a family is

Playing together; going on walks

During these times together my child

Enjoys being part of the family

3. My child's favorite activity is

playing with family members

Because

It allows her to interact freely

4. My child's least favorite activity is

1 - Going to the Doctor 2 - Taking her medicine

Because

1 - they usually stick her for blood 2 - it tastes bad

5. What I enjoy most about my child is

she is cute, and loves her daddy very much

6. What my child and I enjoy doing the most is **playing together.**

She sits on my lap, facing me, and we touch each other on the hands, arm and face.

7. I am most frustrated when caring for my child when

she doesn't want to take her bottle.

8. My child lets me know when he/she needs something by

kicking the crib or playpen with her foot, or fussing.

9. I could do more for my child if I had

more time to spend with her.

(transportation, someone to talk to and listen to me, time to myself, time for the other children, more information about my baby's condition and about ways to help her, help with medical and other expenses, housing, Supplemental Security Income (SSI), food stamps, etc.)

10. Some changes or progress I've recently noticed in my child

She is focusing on things better, since her eye operation.

11. What I would like to see my child do in the next six months

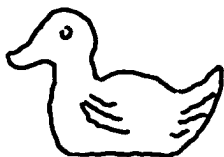
I want Kimberly to push herself into a sitting position.

12. How my family, friends or I can help my child do these things

We can continue to do the physical therapy exercises as instructed by P.T.

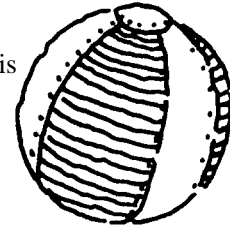
13. Some of my hopes for my child and family are

I want Kimberly to experience life, liberty and happiness, like other children her age. I want the family to understand that Kimberly is a child first, who happens to have special needs.



How often have you had to fumble through all of the cards in your wallet as you sit in the doctor's waiting room trying to fill out the information form required by the doctor? You can fill out the following card, cut it out, fold it and put it in your wallet.

You will find that you won't be as frustrated trying to find the many numbers and codes required! There is a blank FAMILY INFORMATION CARD in the back of the book that you can use.



FAMILY INFORMATION RECORD

Child's name _____ Date of Birth _____
 Birthplace _____ Social Security # _____
 Home address _____
 Home telephone _____ Emergency telephone _____

Mother/legal guardian _____ SS# _____
 Employer _____ Occupation _____
 Work address _____ Work telephone _____

Father/legal guardian _____ SS# _____
 Employer _____ Occupation _____
 Work address _____ Work telephone _____

Primary Medical Coverage _____
 Membership # _____ Group # _____ Effective date _____
 Subscriber _____ Coverage Code _____

Additional Medical Coverage _____
 Membership # _____ Group # _____ Effective date _____
 Subscriber _____ Coverage Code _____

Physician _____ Telephone # _____
 Address _____

Pharmacy _____ Telephone # _____
 Address _____

Other information (*gestation period, allergies, pregnancy or birth complications, etc.*)

By keeping this folded in your wallet, you will have ready access to most questions asked on basic information forms.

FINDING YOUR WAY THROUGH THE EARLY INTERVENTION MAZE

"When I found out that Monica had problems, the doctor referred me to the early intervention program. At first I was overwhelmed. I had to fill out so many forms and answer so many questions - not only about Monica, but my family as well. I didn't understand why they needed all that information about my family... I was asking for help for Monica. I called the service coordinator. She took the time to explain the process to me and told me how important I was to making sure that Monica received the right services. She also convinced me that taking care of our whole family would help Monica.

The service coordinator connected me with another mother who offered to help me through the process. When the time came to write the Individualized Family Service Plan, I felt more comfortable. I was able to talk about what I thought Monica needed. And you know what? They listened!"



As you begin to look for services that will help your child, you may find yourself in a whole new system with unfamiliar terms, acronyms and perspectives.

THE PART C EARLY INTERVENTION PROCESS

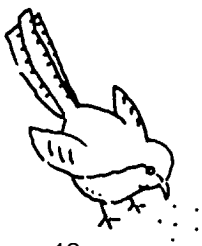
REQUEST FOR SCREENING – A parent or professional can request a screening to identify infants and toddlers who may require a multidisciplinary team evaluation. The team can make referrals to appropriate resources. A screening is not a required part of the eligibility

process, but can be useful as a preliminary assessment.

SCREENING – Screenings must take place within 12 working days from the request. Screening methods may vary by program. They might be conducted during a home visit, in a screening clinic, using parent observation and report, or during a well-baby check. A child who does not appear to meet the eligibility requirements may be referred to other services if the parent has concerns about the child's development and/or is asked to come back at a later date for follow-up. Regardless of the outcome of the screening, if a parent believes that a child is eligible, the parent can request a multidisciplinary evaluation.

IDENTIFICATION – A child may enter into the Part C early intervention system a number of different ways: through parent identification; referral by the hospital, doctor or nurse; well-baby check; or screening.

ASSIGNMENT OF TEMPORARY SERVICE COORDINATOR – Once a public agency receives a referral, it must begin arrangements for an evaluation, and assign a temporary service coordinator within two working days after receiving the referral. The temporary service coordinator will be the main person you talk to during the evaluation process. This person will pull together a team to evaluate your child's developmental levels and will gather information that you and other professionals who have worked with you child provide. In some programs, the service coordinator first assigned to the family is the family's permanent service coordinator.



MULTIDISCIPLINARY

EVALUATION – During the multidisciplinary evaluation, your child's unique strengths and needs to grow and learn are identified. You will provide information about your child and family, your family's concerns and priorities, and what types of early intervention services your child and family need. The multidisciplinary evaluation must take place within 45 calendar days from referral unless you give permission for it to take place later.

ELIGIBILITY DETERMINATION –

After the evaluation is completed, you and the provider members of the multidisciplinary team will meet and decide if your child can receive early intervention services.

Eligibility will be determined based on information you provide and the results of the multidisciplinary evaluation, which will indicate whether your child meets any of the requirements below:

- is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas:
 - ✓ cognitive development
 - ✓ physical development
 - ✓ language and speech development
 - ✓ psychosocial development, or
 - ✓ self-help (adaptive) skills, or
- has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

At a state's discretion, individuals from birth through age 2 may be eligible if they are at risk of having substantial developmental delays if early intervention services are not provided.

DEVELOPMENT OF AN INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP) – After

evaluation and eligibility, if your child is found eligible to receive services, you and your team will come up with a plan for addressing the unique needs of your child and family. The plan is called an Individualized Family Service Plan and must be written within 45 calendar days after referral. The IFSP contains a description of your child's level of development, a description of your family's strengths and priorities (*not mandatory, and you may choose not to include this section in the IFSP*), what you expect for your child to do in the next few months and the next year, and specific services your child and family needs to meet those outcomes. The IFSP may also include, if appropriate, medical and other services necessary for your child's development (*but not required under Part C*), and steps to be taken to secure services through public or private resources. A permanent service coordinator will be assigned at the meeting if not previously assigned.

COSTS FOR SERVICES – The following services are to be provided at no *direct* cost to parents:

- child evaluation
- IFSP development
- service coordination

States determine policies regarding costs of early intervention services.

EVALUATIONS— COPING AND HOPING

Evaluations offer useful information about your child's development. You and early intervention providers will identify areas to which you will want to pay the most attention.



Evaluations also help you to look objectively at your child's progress, by identifying milestones and developmental levels your child has mastered. Even so, going through the evaluation process can be trying for you and your child. You may find it helpful to prepare for the process because preparation can help reduce your stress and give evaluators information that can help them get more accurate results.

BEFORE THE EVALUATION— People get ready for evaluations in different ways. Some parents may find helpful professionals who are willing to prepare them for the process by explaining unfamiliar terms and concepts. Another parent might read all the available information about early intervention and what might be appropriate for his child. He might visit other programs or talk to other parents about their experiences and seek their advice on getting appropriate services. A third parent might bring another family member or friend along to the evaluation. She might write questions down, decide what she wants out of the meeting, or plan what role to play. And, a fourth parent might do all of the above!



- Do I need to bring anything? (*food, toys, immunization forms, other reports*)
- What role do parents usually play? What role should I play?
- How soon will I know the results of the tests? In what way is this information usually given?
- How do the evaluators use information if my child does something at home that he does not do during the evaluation?

AFTER THE EVALUATION — Evaluators often will give you preliminary results of tests immediately following the evaluation. You may be pleasantly surprised, or disappointed that your child has not progressed as much as you had hoped. In some cases you may not agree with the evaluators or feel like they have the whole picture of your child.

How do you cope? People respond in different ways. Here are some of the reactions that parents have mentioned to us.

"After they told me everything that was wrong with Marcie, I asked them what was right. I was pleasantly surprised when they said that many children with her condition are not doing nearly as well."

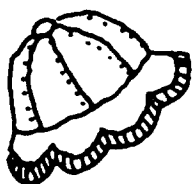
"I go out and buy a new pair of shoes after every evaluation. You should see my closet!"

"My best friend, Betty Lou calls me after every important meeting. Most of the time we have a good cry together. Pretty soon we're laughing too!"

"After a few of these tests I know better. I always plan something unrelated to my son's problems, that I will enjoy doing

Here are some questions that might help you for your next evaluation:

- When is my child at his best? (*After he eats, when I am out of the room, in the early afternoon?*)
- Who will be involved in the evaluation? What are their roles?
- What tests will be used? What types of things do these tests measure?
- How are evaluations usually conducted? Is there any flexibility if I have any suggestions?



afterward. I figure if there is something to celebrate, I'll be prepared for that too."

"I did not get mad, I got even. I say, 'Now that we know about all of Joey's problems, what are we all going to do about it?' It got people's minds off Joey as a test score and moved them to finding ways that will help him."

Your first instinct might be to hide all those pieces of paper in a drawer somewhere. This might be okay for a while. But you may want to take charge of all that paper before it takes charge of you. You will also come into contact with a whole new group of people: parents, specialists, physicians, insurance claims adjusters, to name a few. How will you keep track of all that information?

KEEPING TRACK

Not long after you find that your child may need special help, you may find yourself in a mountain of paperwork: bills, reports, notes, advice, questionnaires, and appointment slips.

The following forms can help you organize information. Forms are in the appendix so you can copy them. The key people chart is a quick reference guide. The phone call record can be used to document phone calls, meetings, or other conversations.

KEY PEOPLE CHART

I HEALTH

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Primary Care Physician		
Other Specialists		
Hospital		
Nursing Advice Line		
Public Health Nurse		
Pharmacy		

CHAPTER III

II EARLY INTERVENTION

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Service Coordinator	_____	_____
Specialists	_____	_____
_____	_____	_____
_____	_____	_____

III FAMILY SUPPORT

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Parent Support Line	_____	_____
Sitter or Other Helper	_____	_____
_____	_____	_____

IV. FINANCIAL

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Insurance	_____	_____
Medicaid	_____	_____
Supplemental Security Income	_____	_____
Emergency Services	_____	_____
Other	_____	_____



V. OTHER CONTACTS: FRIENDS, CHURCH, FAMILY, CONSULTANTS

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
_____	_____	_____
_____	_____	_____

PHONE CALL RECORD

Who: _____ Date: _____
_____ Phone: _____

Notes:

Need to follow up? _____ No Who _____
_____ Yes When _____

Who: _____ Date: _____
_____ Phone: _____

Notes:

Need to follow up? _____ No Who _____
_____ Yes When _____

Who: _____ Date: _____
_____ Phone: _____

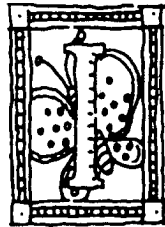
Notes:

Need to follow up? _____ No Who _____
_____ Yes When _____



MAKING FAMILY PLANS

"What a meeting! I could hardly believe the way they listened to me! I had my lists of questions, concerns, hopes and dreams and everyone there treated my ideas with respect. What a difference from other times I have been with professionals who act as if they have all the answers!"



Is this what you will say after your next IFSP meeting? When the time comes for you and other key people to write an Individualized Family Service Plan (IFSP) you, again, will have preparations to make. You will be asked many questions about your concerns, what you think is important to your child and family, and what you want for the future.

child in the near future – perhaps six months down the road. The first four categories allow for descriptions of your child's development. As you think about your hopes and dreams, also consider what kinds of help or assistance you will need to help fulfill them.

The second section asks for family hopes and dreams, now and in six months. In each of these parts you are asked to think about who can help you and what services you will need to realize these dreams now and in the future.

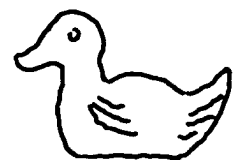
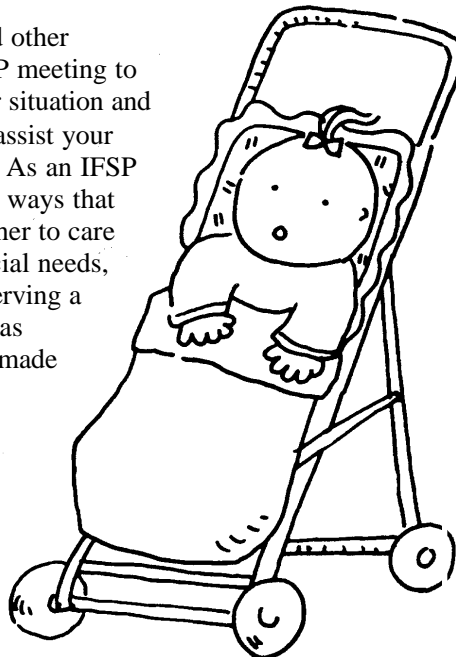
Below is the HOPES AND DREAMS EXERCISE that Mary Jackson filled out before she went to an IFSP meeting. It might give you some ideas before you use the one in the back of this book.

PREPARING FOR THE IFSP MEETING

One of the unique aspects of the IFSP is that parents are the primary decision makers. You are in the driver's seat.

The service coordinator and other professionals are at the IFSP meeting to help you think through your situation and to solve problems that will assist your child's growth and change. As an IFSP team you will discover new ways that your family can work together to care for your child who has special needs, while at the same time preserving a family life that is as normal as possible. Decisions will be made about the kinds of help and services you will require.

To prepare for your IFSP meeting, you can fill out the HOPES AND DREAMS EXERCISE. The first section helps you think of goals you have for your



HOPES AND DREAMS EXERCISE

HOPES AND DREAMS FOR MY CHILD IN SIX MONTHS

Independence: *(i.e. feeding, toileting, doing things without help, etc.)*

Eat with a spoon. Decide which toy to play with.

Movement: *(i.e. grasping, creeping, using motorized wheelchair, etc.)*

Hold onto cart and walk across the room.

Social: *(i.e. smiling, recognizing mother, having friends, sharing toys, etc.)*

Play with children at nursery school (at church).

Communication: *(i.e. understanding words, letting you know when hungry, using a touch-talker, etc.)*

Point at object or food he wants.

Services and supports my child will need to realize these hopes and dreams: **Maxwell will need someone to help him hold his spoon correctly and encourage him to make his own choices. Nursery school teachers will need to help him enter activities with other children.**

HOPES AND DREAMS FOR MY FAMILY RIGHT NOW

Things we can do together:

Go to church on Sundays – Go to restaurants together.

What I can do with individual children:

I want some time to play with Sarah and not worry about Maxwell.

Things just for my partner and me:

We need some time on our own once in awhile.

Supports we need to realize our hopes and dreams: *(i.e. service providers, relatives, church, other assistance, etc.)* **Nursery school teachers need some help so they can care for Maxwell during church. We need help so Maxwell won't scream through every meal. We need a trained – dependable – babysitter.**

HOPES AND DREAMS FOR MY FAMILY IN SIX MONTHS

Things we can do together:

Take a week's vacation at the beach this summer.

What I can do with individual children:

I want to help Sarah's soccer team – Maybe coach a little.

Things just for my partner and me:

We'd like to go somewhere alone overnight.

Supports we will need to realize future hopes and dreams: **We need some help for Maxwell so he can sit and play in the sand and water and enjoy it. We need reliable, trained babysitters.**

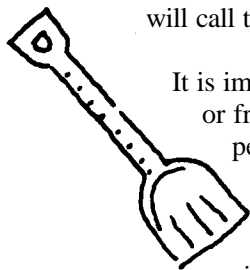
The HOPES AND DREAMS EXERCISE

will help you prepare for your IFSP meeting. You will find that your family values and routines are an important aspect of planning. It is important that you let others know what is important to you and what you want for your family. The IFSP must be responsive to your family's strengths, areas of concern, and priorities. The plan must be respectful of your family's routines. All planning will be in your family's own language so that everyone can understand the plans and outcomes. As possible, services must also take place in your family's natural environments – that is where you would be and what you would do if your child did not have special needs.

PARTICIPATING IN THE IFSP MEETING

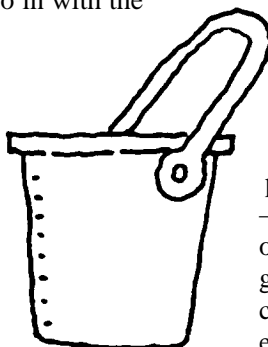
What happens at an IFSP meeting?

People related to services you may need will be at the meeting. Either a temporary service coordinator or the person who has been designated as the service coordinator will call the meeting.



It is important to take a family member or friend with you as a support person – to listen with you, to help you explain some of your wishes and your point of view, and to take notes if you feel you might need them later. Before the meeting, go over your HOPES AND DREAMS EXERCISE with your support person so both of you will go in with the same agenda.

When the IFSP meeting is over you and your support person could go out for pizza or home for a cup of coffee to talk about what happened at the meeting.



THE IFSP DOCUMENT

An IFSP is a written document that has nine required parts.

1. Information about your child's current development – includes both your home information and the evaluation results about his health, vision, hearing, language, speech, social, self-help and intellectual development.

2. Information about your family – includes what you believe to be the strengths, concerns, and priorities you and your family have in helping with your child's development, and areas in which you need help. You do not have to give this information unless you choose to do so.

3. Expected outcomes - includes your hopes and dreams for your child and family, and how you will progress toward reaching these outcomes, and how to handle changes in these outcomes or services in order to reach your goals.

4. Early intervention services – help you achieve the outcomes you have written. This section must also describe where, when and for what length of time each session of the services will be given as well as who has responsibility for payment. Services are listed in the box on the following page.

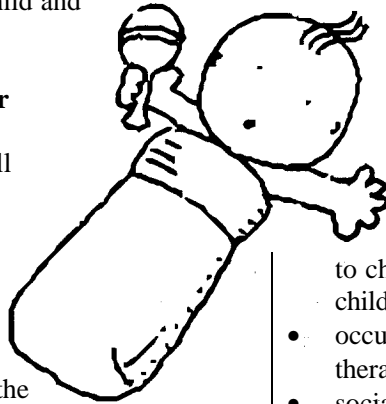
5. Statement of how and where will be provided – Services have to be provided where the child would normally be if he didn't qualify for services, such as home, daycare center, parks, etc. However, if the IFSP team determines that services should not be provided in a child's natural environment – for example, in a center or office where only children with developmental delays go – the IFSP must state why services cannot be provided in natural environments.

6. Other services – includes, if appropriate, medical or other needs of your child that are not required under the IFSP, but will help in planning and securing services for your child.

7. Dates and duration of services – states when the services will begin and how long they will last.

8. Service Coordinator – helps you to coordinate the various services required. This person has the appropriate training to meet the needs of your child and family.

9. Transition plan for your child – includes statements about what will happen after your child leaves early intervention (no later than his third birthday) should he still need services. For example, those statements may describe the private and public preschools in your area.



If possible, IFSP meetings need to be conducted in the native language of the family. This can often be done through the help of a professional, family member or resource person who can act as an interpreter. Taking all suggestions and points of view into consideration, specific contents of the IFSP will evolve at the meeting. The contents of the IFSP are determined at the meeting with the points of view of all the people considered. You, as the parent, are the one who makes the final decision, and without your consent the IFSP will not be put into effect.

Remember, you are in charge of deciding what goes into the IFSP. IFSP meetings

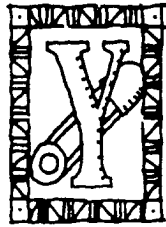
must be conducted annually and reviewed every six months or more frequently if necessary or if the family requests a review. If you decide it has to be changed before that, you can ask your service coordinator.

Early intervention services might include:

- audiology services to help with your child's hearing and communication skills;
- health, medical or nursing services to prevent, diagnose, or treat medical problems;
- nutritional services to help you figure out ways to choose foods and to feed your child;
- occupational, speech, or physical therapies;
- social work or psychological services to help in your child's development or your family's coping;
- special instruction or teaching for your child or your family that will help you achieve your hopes and dreams;
- service coordination to give you assistance you need in gaining access and managing the services required.
- vision services;
- assistive technology devices and services;
- transportation and related costs that are necessary to enable your child and family to receive early intervention services.

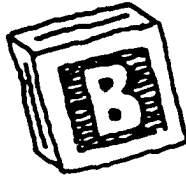
MAKING IT WORK FOR YOUR FAMILY

WHEN SERVICES BEGIN



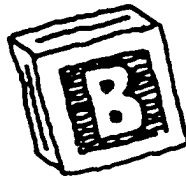
You might think that once your IFSP is written you can sit back, try to relax, and let things happen. This is not so. Now is the time for the important work outlined in your IFSP to start and to help your child and family move forward on the pathway toward growth and change.

Depending upon the services described on the IFSP, your involvement will help to ensure the outcomes. Working as a partner with the service providers helps you build a support group. In addition, the service providers or your service coordinator can link you to other families who are living and coping with a family situation similar to yours.



When Edna Parkins and her family found out that Keith had Down Syndrome, the early intervention specialist told her of the Roberts family who lived not far away.

Their son, Jacob, is close to Keith's age. Jacob has some developmental problems that so far have no diagnosis. The Roberts and the Jacksons have compared notes on family life and have enjoyed picnics together on weekends.

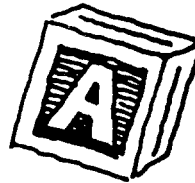


BUILDING RELATIONSHIPS

Families have found different ways to become partners with people who are there to help them. Some of the professionals are skilled not only in their areas of expertise but also in their abilities to communicate with you. Others, though

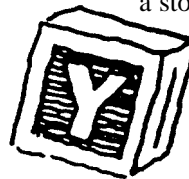
competent in their field, may not show warmth and sensitivity.

The most important way to build partnerships with people who will be helping you and your family is practicing good communication techniques. Sometimes a professional is talking about your child, and you do not hear a single word said. Understanding and remembering information is difficult when you are anxious. If this happens, you can ask to come back another time to discuss things further. You can set up a time when someone else can care for your child, so that your full attention can be on the discussion. Try to bring another adult with you to the meeting so that between the two of you, you can remember most of what is said. Your partner may even wish to take notes.



Good communication requires careful building of relationships. There are many ways to strengthen relationships with people who provide services – most take little time. "Thank you" in person, on the telephone or in a short note show you care and are very much appreciated by providers. These ways to show appreciation mean a lot to people.

A second suggestion is to go back to the information you filled out in Chapter 2 of this booklet, the MY CHILD AND FAMILY form. Getting a session off to a positive start is easy if you use an icebreaker. The best and easiest is simply a story about your child, especially a humorous or uplifting one. If you can, mention in a story some positive or humorous link with the professionals in the room. For example:



"Remember, Lynn, when you were teaching Maria how to tear paper last week and you were wondering if she got the message? You'll be glad to know that I found her in the bathroom with a whole pile of torn and shredded toilet paper next to her. I think she learned her lesson."

This approach can also prepare a positive relationship for later; if concerns or criticisms must be aired, they will be heard in the context of a give and take relationship.

The relationships you build will help you in checking on your child's progress and solving problems that arise. The time and effort you take to write a card, have a professional over for a cup of tea, make a call that tells of your child's success, or writing a positive letter to the person's supervisor or Board, will pay good dividends in the long run.

WHEN DISAGREEMENTS ARISE

In the best of relationships disagreements arise. When you have made the effort to build a parent/professional partnership these disagreements have a good chance of being resolved quickly and satisfactorily.

Children, parents and families have certain rights in early intervention programs. Rights under early intervention programs assure that:

- parents and families are served by programs that are conducted in a voluntary and nondiscriminatory way;
- parents and family members have access to the information they need to know in order to participate in early intervention programs and to make clear decisions; and

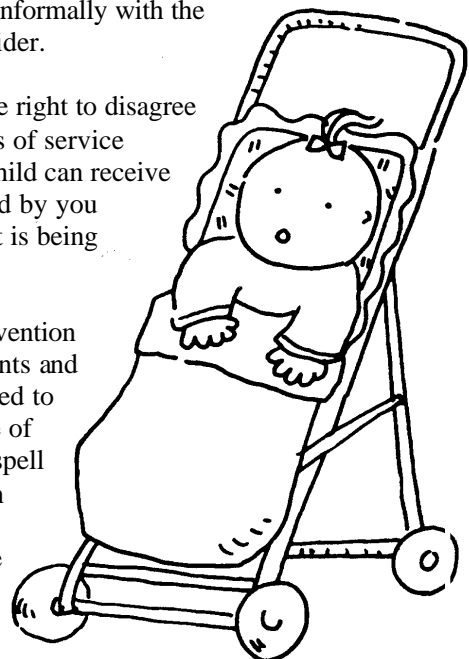
- family members' preferences and choices are respected regarding the services for their child and their family.

You, your child and family are protected by your right to:

- give permission when your child is to be evaluated;
- be given notice, in writing, of actions proposed by the service providers;
- see copies of, and correct records about your child and family;
- have providers keep confidential any private information about your child or your family;
- have a service coordinator who will assist you in pulling together the information and people needed to develop an IFSP;
- and have a service coordinator help you go through a mediation or formal hearing process if there are disagreements or complaints that can't be resolved informally with the service provider.

You also have the right to disagree with certain parts of service plans, but your child can receive services approved by you while the conflict is being resolved.

Every early intervention program for infants and toddlers is required to give you a notice of these rights that spell out your rights in greater detail. Many states have put into place a mediation

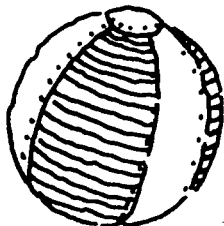


system for disagreements. In this situation, your right to a formal hearing is not delayed or given up; you and the party with whom you disagree can identify areas of disagreement and work with a mediator to reach an agreement. This will help avoid a more formal hearing.

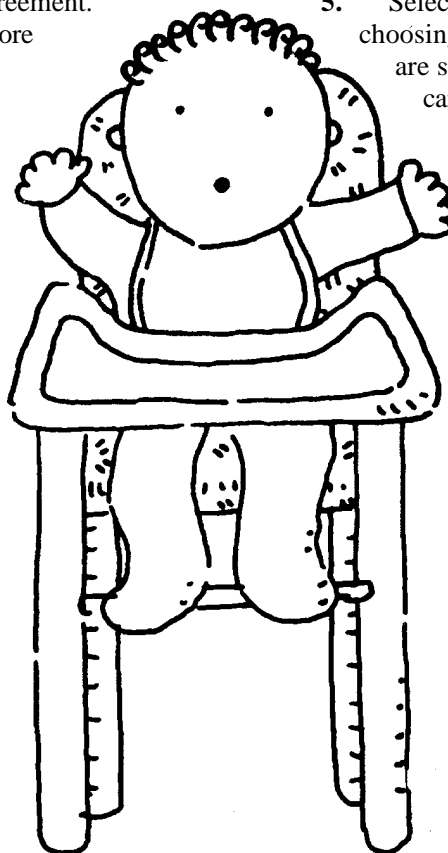
PROBLEM SOLVING WITH SERVICE PROVIDERS

When you reach a time when you can't seem to think your way through a situation either in your relationship with another person or as you make choices, a problem solving approach can be very helpful.

Solving a problem requires two stages. First, clarify the situation, identifying what you believe to be unsatisfactory. Second, make a plan of action by exploring various alternatives and deciding which of these to pursue. There are five steps in the problem solving process.



1. Clarify the situation by examining the facts and expressing the feelings associated with the problem.
2. Define the problem by making a clear, concise statement about the situation.
3. Set the goal by choosing the behavior, situation or attitude that can be realistically changed and attainable.



4. Plan the action by examining and evaluating the alternatives available.
5. Select steps to take by choosing actions which are specific, can be carried out in the short-term, and which are individually rewarding so that all can feel a sense of accomplishment.



This problem solving method is effective not only with complications or disagreements that may arise, but can be used when you are deciding alternative services or courses of action. If you can find a friend or partner to go through these steps with you, and/or write them down, you will be in the driver's seat – for that is where you should be!

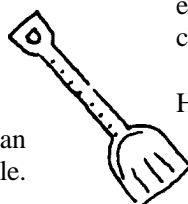
MAKING TRANSITIONS

Why is it that every time you feel life is just getting settled into some kind of routine, things change?



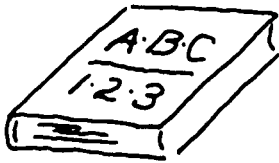
Perhaps an infant development specialist working with your child goes on maternity leave, or your child is reaching the age where he must change from early intervention to preschool, or your family must move due to a new job. Transitions are part of life. But they can seem especially problematic when you have a child with special needs.

How do you prepare for these changes in the lives of your child and family? There are several suggestions that can



ease these transitions.

- Gather as much information as possible about the proposed change.
- Think about how the proposed change fits in with your hopes and dreams for your child and his place in your family and your community.
- Find out about possible program alternatives in order to select one or two of the best choices.
- Find another family who has had experience in the services or programs that you are considering and learn from them about their experiences.
- Find out who is in charge of the new program or service and talk to this person.



- Visit the new person or program in advance of the change.

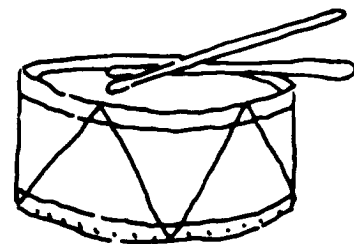
- Talk about your experiences in the old situation and your expectations for the new.
- Ask for written materials and learn the procedures for entering and participating in the new service or system.
- Evaluate carefully the proposed change and realize that you are in charge and can say either "yes" or "no" to the services recommended for you child or your family.

When the time comes for the actual change, you will want to think of ways to prepare yourself, your child and your family for the change in routine.

- A visit to the new program or service to help your child become acquainted with the people and the new place will help to ease the way.
- On the first day, send something familiar with him to make him more comfortable in the new situation.
- Prepare other family members for changes in their routines brought on by the new situation.

You will find, as time goes on, that changes present many of the same problems you have already worked through successfully. The past can certainly help to prepare you for new experiences. What you have learned in early intervention can be applied in your preparation for the day when he enters school programs.

As in all of the decisions you have been and will be making, the more information you have gathered, the stronger the relationships that you have developed, the smoother the transition will be for you and your family.



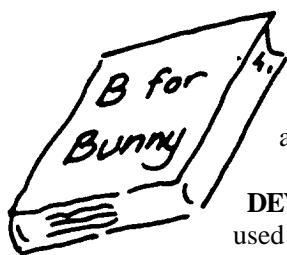
COMMON WORDS USED IN EARLY INTERVENTION

AT-RISK: Term used to describe children who are considered likely to have difficulties because of medical problems at birth, home life circumstances, or other factors, and who may need early intervention services to prevent future difficulties.

CHILD FIND: A state and local program mandated by the Individuals with Disabilities Education Act (IDEA) to identify individuals with special needs between the ages of birth and twenty-one and to direct them to appropriate early intervention or educational programs.

COGNITIVE: A term that describes the process people use for remembering, reasoning, understanding, and judging.

CONFIDENTIALITY: The limiting of access to a child or family's records to only personnel having direct involvement with the child. Parents must give permission for professional staff to share information with other agencies.



DEVELOPMENTAL: Having to do with the steps or stages in growth and development before the age of 18.

DEVELOPMENTAL DELAY: Term used to describe slower than usual development of an infant or child in one or more areas.

DUE PROCESS: A system of procedures that ensure an individual will be notified of decisions made about him or a minor child, and have the opportunity to contest those decisions. In Part C (early intervention) and Part B (special education) of IDEA, due process refers to the legal right to appeal any decision regarding any portion in the process of getting and receiving services for eligible children.

EARLY INTERVENTION: Providing services and programs to infants and toddlers with developmental delays, from birth until their third birthdays, in order to minimize or eliminate the developmental delays as they mature. Services may include:

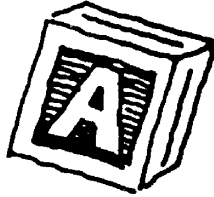
- family training, counseling and home visits
- special instruction
- speech pathology and audiology
- occupational therapy
- physical therapy
- psychological services
- service coordination
- medical services only for diagnostic or evaluation purposes
- early identification, screening, and evaluation services,
- health services necessary to enable the infant or toddler to benefit from the other early intervention services
- assistive technology services and devices

ELIGIBILITY: The determination of whether or not a child qualifies to receive services based on meeting established criteria.

ELIGIBILITY CRITERIA FOR PART C: Federal eligibility for Part C identifies infants and toddlers from birth to age 2, inclusive, who need early intervention services because they:

- are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas:

- ✓ cognitive development
- ✓ physical development
- ✓ language and speech development
- ✓ social or emotional development
- ✓ self-help skills



or

- have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.

Such term may also include, at a State's discretion, individuals from birth through age 2, who are at risk of having substantial developmental delays if early intervention services are not provided.

EVALUATION: (*also called assessment*) Obtaining detailed information about a child's developmental levels and needs for services. In early intervention, families are important contributors to the evaluation process and can define ways that professionals can assist them in helping their child. Under Part C, evaluations must occur at least yearly.

EXPRESSIVE LANGUAGE: The ability to communicate through speech, writing, augmentative communication or gestures.

FINE MOTOR SKILLS: Body movements which use small muscles; for example picking up a small object, putting it into or taking it out of a container, or pouring liquid.

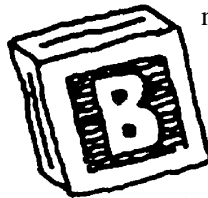
GROSS MOTOR SKILLS: Body movements which use the large muscles; for example, sitting, crawling, walking or climbing.

INDIVIDUALIZED EDUCATION PROGRAM (IEP): A written statement for each student in special education

(provided through the schools for students 2-21) describing present levels of performance; annual goals including short-term objectives; specific special education and related services the student is to receive; dates for beginning and duration of service; and how the IEP will be evaluated.

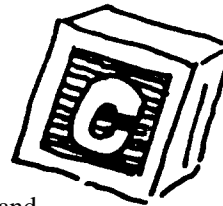
INDIVIDUALIZED FAMILY

SERVICE PLAN (IFSP): A written statement developed by a team of people who have worked with the child (including the family) for an infant or toddler receiving early intervention services. Plan must include the child's developmental level, strengths and needs and may include, with the family's permission, family-identified concerns and priorities. Also included are resources, specific services, goals and outcomes for the child and family, and a transition plan for the child into services for children over age two.



INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA):

This law covers early intervention and special education for infants, toddlers, children, and youth, from birth through age 22 who require services to meet their special developmental and educational needs. Part C of the law (formerly Part H) concerns education for infants and toddlers through age 2, and Part B of the law concerns special education provided by public schools through age 21.



INFANT STIMULATION: Refers to a program designed to provide specific activities that encourage growth in developmental areas such as movement, speech and language, etc., in infants with developmental delays.

INTERAGENCY COORDINATING COUNCIL (ICC): A federal, state or local group consisting of parents, advocates and professionals who serve in an advisory capacity to plan and implement Part C – Early Intervention Services for Infants and Toddlers with Disabilities and their Families – of the Individuals with Disabilities Education Act (IDEA).

LEAD AGENCY: State agency that has been designated by the governor to administer and implement a statewide comprehensive, coordinated, multidisciplinary, interagency service delivery system for infants and toddlers with developmental delays and their families.

LEARNING STYLE: An individual's unique way of learning: for example by playing games, imitating, or handling objects. Most children learn through a combination of processes.

MEDICAID: A Federal/State program which provides medical services primarily to low-income individuals. Local Departments of Social Services determine eligibility. Provisions under the Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program raises the allowable household income for eligibility for young children. Certain waiver programs allow services regardless of family income, to individuals who might otherwise be hospitalized or institutionalized.

MEDIATION: A formal intervention between parents and early intervention system personnel to achieve reconciliation, settlement or compromise.

MENTAL RETARDATION: A broad term describing delayed intellectual development resulting in delays in other area such as academic learning, communication, social skills, rate of maturation and physical coordination.

MULTIDISCIPLINARY EVALUATION: An evaluation to determine a child's developmental level in a variety of areas, conducted by two or more professionals, such as infant development specialists, speech therapists, physical therapists, occupational therapists, social workers, nurses, etc.

NATURAL ENVIRONMENTS: A term that defines where and how infants and toddlers receive services. Part C services must be provided in keeping with where the infant or toddler would be and what he would be doing if he did not have special needs.

OCCUPATIONAL THERAPY (OT): Activities focusing on fine motor skills and perceptual abilities that assist in improving physical, social, psychological and/or intellectual development e.g., rolling a ball, finger painting, sorting objects.

PHYSICAL THERAPY (PT): Activities or routines designed to increase gross motor skills.

RECEPTIVE LANGUAGE: The process of receiving and understanding written, gestured or spoken language.

REFERRAL: A formal notification to an early intervention system that a child may need early intervention services. A parent or professional working with the child may make the referral.

SERVICE COORDINATOR: Someone who acts as a coordinator of a child's and family's services and works in partnership with the family and other service providers.

SPECIAL NEEDS: a term to describe a child who has developmental delays, a disability, or chronic illness; or is at risk for developing disabilities and who needs services or treatment to progress.

SPEECH-LANGUAGE

PATHOLOGIST: A professional who evaluates and develops programs for individuals with speech or language problems.

SPEECH THERAPY: Activities or routines designed to improve and increase communication skills.

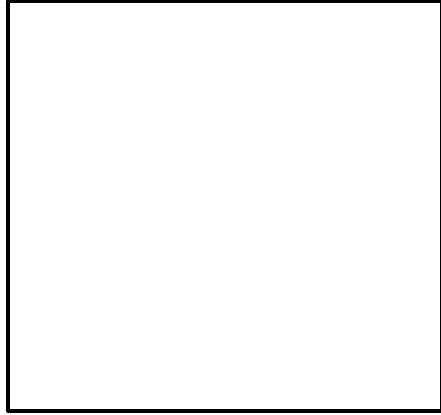
SUPPLEMENTAL SECURITY

INCOME (SSI): A federal program administered through the Social Security Administration that provides payments to individuals who are aged and/or disabled. A Supreme Court decision (Zebley vs. Sullivan) expanded the eligibility criteria to allow more children with disabilities to qualify for the program.

TRANSITION: The movement of children and families into and out of programs or services.



MY CHILD AND FAMILY



*Photograph of your child or family
or
for fun, you can sketch a picture!*

Date: _____

My Name: _____

Please Call Me: _____

My Child's Name: _____

Child's Birthday: _____

1. Description of our family (*parent(s), brothers and sisters, grandparents, special friends and relations*).

2. What we enjoy doing as a family is

During these times together my child

3. My child's favorite activity is

Because

4. My child's least favorite activity is

Because

5. What I enjoy most about my child is

6. What my child and I enjoy doing the most is

7. I am most frustrated when caring for my child when

8. My child lets me know when he/she needs something by

9. I could do more for my child if I had

(transportation, someone to talk to and listen to me, time to myself, time for the other children, more information about my baby's condition and about ways to help her, help with medical and other expenses, housing, Supplemental Security Income (SSI), food stamps, etc.)

10. Some changes or progress I've recently noticed in my child

11. What I would like to see my child do in the next six months

12. How my family, friends or I can help my child do these things

13. Some of my hopes for my child and family are

FAMILY INFORMATION RECORD

Child's name _____ Date of Birth _____
Birthplace _____ Social Security # _____
Home address _____
Home telephone _____ Emergency telephone _____

Mother/legal guardian _____ SS# _____
Employer _____ Occupation _____
Work address _____ Work telephone _____

Father/legal guardian _____ SS# _____
Employer _____ Occupation _____
Work address _____ Work telephone _____

Primary Medical Coverage _____
Membership # _____ Group # _____ Effective date _____
Subscriber _____ Coverage Code _____

Additional Medical Coverage _____
Membership # _____ Group # _____ Effective date _____
Subscriber _____ Coverage Code _____

Physician _____ Telephone # _____
Address _____

Pharmacy _____ Telephone # _____
Address _____

Other information (gestation period, allergies, pregnancy or birth complications, etc.)

By keeping this folded in your wallet, you will have ready access to most questions asked on basic information forms.

KEY PEOPLE CHART

I HEALTH

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Primary Care Physician		
Other Specialists		
Hospital		
Nursing Advice Line		
Public Health Nurse		
Pharmacy		

II EARLY INTERVENTION

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Service Coordinator		
Specialists		

APPENDIX

III FAMILY SUPPORT

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Parent Support Line		
Sitter or Other Helper		

IV. FINANCIAL

<i>Name</i>	<i>Address</i>	<i>Telephone</i>
Insurance		
Medicaid		
Supplemental Security Income		
Emergency Services		
Other		

V. OTHER CONTACTS: FRIENDS, CHURCH, FAMILY, CONSULTANTS

<i>Name</i>	<i>Address</i>	<i>Telephone</i>

PHONE CALL RECORD

Who: _____ Date: _____

_____ Phone: _____

Notes:

Need to follow up? _____ No Who _____

_____ Yes When _____

Who: _____ Date: _____

_____ Phone: _____

Notes:

Need to follow up? _____ No Who _____

_____ Yes When _____

Who: _____ Date: _____

_____ Phone: _____

Notes:

Need to follow up? _____ No Who _____

_____ Yes When _____

HOPES AND DREAMS EXERCISE

HOPES AND DREAMS FOR MY CHILD IN SIX MONTHS

Independence: *(i.e. feeding, toileting, doing things without help, etc.)*

Movement: *(i.e. grasping, creeping, using motorized wheelchair, etc.)*

Social: *(i.e. smiling, recognizing mother, having friends, sharing toys, etc.)*

Communication: *(i.e. understanding words, letting you know when hungry, using a touch-talker, etc.)*

Services and supports my child will need to realize these hopes and dreams:

HOPES AND DREAMS FOR MY FAMILY RIGHT NOW

Things we can do together:

What I can do with individual children:

Things just for my partner and me:

Supports we need to realize our hopes and dreams: *(i.e. service providers, relatives, church, other assistance, etc.)*

HOPES AND DREAMS FOR MY FAMILY IN SIX MONTHS

Things we can do together:

What I can do with individual children:

Things just for my partner and me:

Supports we will need to realize future hopes and dreams:

WHERE TO GET MORE INFORMATION

A number of resources exist for finding more information about your child's special needs, early intervention, and support. If you are already connected with an early intervention program, that is a good place to start. They might also be able to help you contact a parent who has had a similar experience or who is an expert in the early intervention system. Your school district may also have resources and information. Libraries, information and referral programs, your physician or hospital may also have helpful information. Also, many state Part C offices provide useful information for parents.

There are a number of federal information programs you can contact. Below is a list of federal information programs and websites provided by private non-profits that can get you started in looking for resources.

National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492
Washington, D.C. 20013
(800) 695-0285
www.nichcy.org

A national clearinghouse that provides answers to individual disability issues, referrals to specific organizations, information packets, technical assistance and publications on current issues. Publications may also be downloaded through the Internet.

NICHCY can also give you the contact person for your state office responsible for Part C early intervention services.

National Early Childhood Technical Assistance System (NEC*TAS)

www.nectas.unc.edu

A consortium of six organizations, NEC*TAS provides information about the Individuals with Disabilities Education Act (IDEA) and educating infants and toddlers with developmental delays.

National Organization for Rare Disorders (NORD)

P.O. Box 8923
New Fairfield, CT 06812-8923
Phone: (800) 999-6673
www.rarediseases.org

NORD is a clearinghouse for information about rare disorders and links families with similar disorders together for mutual support.

National Health Information Clearinghouse (NHIC)

P.O. Box 1133
Washington, D.C. 20013
800/336-4797
nhic-nt.health.org

NHIC is an information and referral agency that puts people with health and medical questions in contact with organizations that can respond.

Zero to Three: National Center for Infants, Toddlers and their Families

734 15th Street, NW, Suite 1000
Washington, DC 20005
(202) 638-1144
www.zerotothree.org

ZERO TO THREE, a non-profit charitable organization, is a resource on the first three years of life. Their aim is to promote the healthy development of babies and toddlers.



The Family Village

Waisman Center,
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705-2280
www.familyvillage.wisc.edu

Sponsored by the Joseph P. Kennedy Jr. Foundation, the website integrates information, resources, and communication opportunities on the Internet for persons with special needs, for their families, and for those that provide them services and support. The website includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, and disability-related media and literature.

Parent Training and Information Centers

The Parent Training and Information Centers are based on a strong philosophical foundation, viewing parents as full partners in the educational process and a significant source of support and assistance to each other. The projects are funded by the Division of Personnel Preparation, Office of Special Education Programs (OSEP), U.S. Department of Education, "to provide training and information to parents to enable them to participate more effectively with professionals in meeting the educational needs of their children with disabilities." The Parent Training projects help parents to:

- Better understand the nature their child's special needs;
- Provide follow-up support for the educational programs of their child with special needs;
- Communicate more effectively with special and regular educators,

administrators, related services personnel, and other relevant professionals;

- Participate in educational decision-making processes, including the development of the family's individualized family service plan (IFSP) and the child's individualized education program (IEP);
- Obtain information about the programs, services, and resources available to their child with special needs and the degree to which those programs, services and resources are appropriate.

Each state has a Parent Training and Information Center. In Virginia, that center is the Parent Educational Advocacy Training Center (PEATC).

PEATC

1-800-869-6782 or 703-923-0010
www.peatc.org

To help you find a Parent Training and Information Center in another state, contact the Technical Assistance Alliance for Parent Centers.

Alliance Coordinating Office:

PACER Center
4826 Chicago Avenue South
Minneapolis, MN 55417-1098
(612) 827-2966 voice
(612) 827-7770 TTY
(612) 827-3065 fax
1-888-248-0822 (toll-free nationally)
E-mail: alliance@taalliance.org
Web site: www.taalliance.org

BOOKS

EP: Exceptional Parent

This magazine is an excellent source of information for parents of exceptional children. Featured articles are always on current topics. Each issue has a special focus and there are regular features that appear monthly and annually. The annual resource guide is an invaluable resource for parents.

You can subscribe to the magazine by calling (877) 372-7368 or visiting their website at www.eparent.com, itself an excellent resource.

Woodbine House

Woodbine House is a small publishing house that specializes in books for families of children with special needs. They also have a few books available in Spanish. You can receive a current catalog by calling (800) 843-7323 or visiting their website at www.woodbinehouse.com.

Some of their books include:

Babies with Down Syndrome, Children with Autism, Children with Cerebral Palsy, Children with Down Syndrome, Children with Facial Differences, Children with Fragile X, Children with Mental Retardation, Children with Spina Bifida, Children with Tourette Syndrome, and Children with Visual Impairments, are guides to specific special needs geared to families.

Negotiating the Special Education Maze (third edition) is a guide for parents as they negotiate special education for their children with special needs. This book

was co-written by Winifred Anderson, an author of this guide.

My Brother Matthew, Andy and His Yellow Frisbee, We'll Paint the Octopus Red, and Russ and the Firehouse are some of Woodbine children's books that feature children with special needs and can answer children's questions.

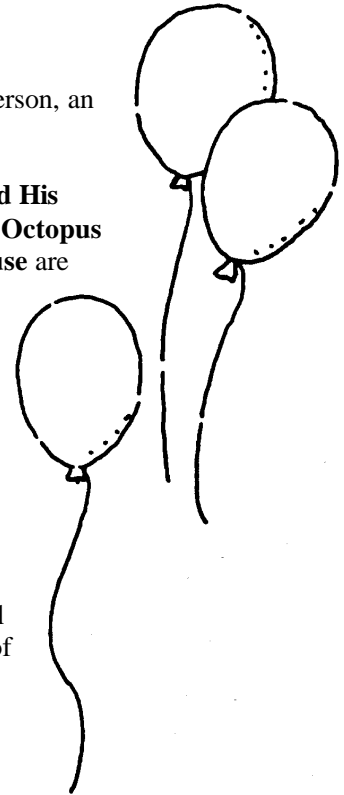
Views from Our Shoes is a compilation of brief stories by brothers and sisters of children with special needs. **Uncommon Fathers** is also a compilation of stories about children with special needs, but from the perspective of fathers.

Paul H. Brookes

Paul H. Brookes also publishes many books about individuals with special needs and their families. You can receive a catalog by calling (800) 638-3775 or visiting their website at www.pbrookes.com.

Two of their books include:

The Special Child: A Source Book for Parents of Children with Developmental Disabilities. Written for parents, *The Special Child* contains a great deal of medical information, including descriptions of various disabilities, procedures and treatments, tests, and adaptive equipment. At the same time, an overview of parents' feelings and concerns and the need for parent-professional partnerships are presented. A description of early intervention programs and an introduction to special education and legal issues are also covered. An excellent



source of basic information, presented clearly and succinctly. The book includes a list of organizations and further reading.

Nobody's Perfect: Living and Growing with Children Who Have Special Needs.

Nobody's Perfect contains the candid, inspiring, and often humorous reflections of four mothers who are raising children with disabilities. It offers parents who have children with special needs strategies for success in balancing their lives, developing a parenting partnership, interacting with children, friends, relatives, providers, and others.

Other books to consider are as follows:

Greenspan, S. I., & Wieder, S., The Child With Special Needs. Addison-Wesley, 1998. The subtitle of the book - "Encouraging Emotional and Intellectual Growth" – reflects the book's main idea that parents can best help their children by helping them grow emotionally and intellectually. The book looks on the individual needs of children and how a parent can build on a child's specific strengths, and work with the child's specific needs, all within family relationships and routines.

A Parent's Guide: Accessing Programs For Infants, Toddlers, and Preschoolers with Disabilities.

The National Information Center for Children and Youth with Disabilities, August 1994.

This parent's guide answers questions about early intervention programs, special education, and programs for special groups (i.e. rural, American Indians, adoptive/foster, and military families). It includes an overview of the Individuals with Disabilities Education Act (IDEA), a glossary, references, and a record keeping worksheet. The guide can be downloaded from their website at www.nichcy.org. It is also available in Spanish.

Taking Charge: A Parent's Guide to Health Care for Children with Special Needs. Parent Educational Advocacy Training Center, 1993.

This booklet helps readers become organized so that they can manage their children's complex needs (including paperwork, bills, schedules, plans, reports and procedures) and make their way through the unfamiliar world of medical diagnoses and terminology.

The booklet is available by contacting PEATC at 1-800-869-6782 or 703-923-0010 or on the web at www.peatc.org.



Parent Educational Advocacy Training Center

6320 Augusta Drive, 12th Floor

Springfield, Virginia 22150

(703) 923-0010

(703) 569-6200 (en español)

