Foreword

We have written this Parent's Guide to help families learn how to get help for their young children with special needs (ages birth through 5 years).

We have posed the most asked questions about early intervention services for children ages birth through 2 years old and special education and related services for children ages 3 through 5 years old.

The rules or guidelines for special education in the United States and its territories are outlined in a federal law known as the Individuals with Disabilities Education Act (IDEA), formerly known as the Education of the Handicapped Act (EHA). Each state or territory develops its own policies for carrying out this Act. (You can read more about this law later in this document.)

You'll need to find out what the early intervention or special education policies are in your state and area. The list of agencies and contact people in your state should help you get started. A NICHCY State Resource Sheet for your state is available from NICHCY.

The phrases "children with special needs" or "special needs children" are used throughout this document to refer to children who have disabilities or who are at risk of developing disabilities.

Many of the special education words that appear in this Parent's Guide are defined in the Parent's Dictionary that appears toward the end of this document.

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PART I: Questions and Answers About Early Intervention Services For Infants and Toddlers Who Have a Developmental Delay or Who Are At Risk of a Developmental Delay (Ages Birth Through 2 Years Old)

Note: Many of the words below may be new to you, but they are those that are commonly used in special education. We have used these terms to help you become familiar with them. You can find their definitions in the Parent's Dictionary towards the end of this document.

We have used the term "parent" to mean anyone who is in charge of the care and well-being of a child. These can be guardians, single parents, grandparents, surrogate parents, foster parents, or other family members.

The federal law known as Public Law (P.L.) 102-119 guarantees certain rights to young children (ages birth to 5) with special needs. This law is the most recent amendment to IDEA. (To learn more about this, see the section entitled "Information About IDEA.")

Q: What should I do if I think my child has special needs?

A: First, you'll need to find out if your infant or toddler is eligible for early intervention services. There are many people who can help you with this. We will explain how to get the help you need in the pages that follow.

Q: What are early intervention services?

A: These are services for infants and toddlers that are designed to identify and treat a problem or delay as early as possible. Early intervention services are offered through a public or private agency and are provided in different settings, such as the child's home, a clinic, a neighborhood daycare center, hospital, or the local health department.

Early intervention services can range from prescribing glasses for a two-year-old to developing a complete physical therapy program for an infant with cerebral palsy.

Q: Who do I contact first for help?

A: Each state decides which of its agencies will be the lead agency in charge of early intervention services for infants and toddlers with special needs. In your state, the first contact person may be an early interventionist (an early childhood specialist working with infants and toddlers), someone with the lead agency, or someone in your state's Child Find office.

To find out who can help you in your area, contact the person listed on your State Resource Sheet under "Programs for Infants and Toddlers with Disabilities." If you don't have a State Resource Sheet, call NICHCY at 1-800-695-0285 (Voice/TT). Explain that you want to find out about early intervention services for your child and ask for a name in your area.

Important. Write down the names and phone numbers of everyone you talk to. (You can use the Sample Record-Keeping Worksheet on the last page of this document as a guide.) Having this information available may be helpful to you later on.

Q: What do I say when I talk to my local contact person?

A: Explain that you think your child may need early intervention services and you would like to arrange for an evaluation and assessment. Write down any information you are given.

Q: What is an evaluation and assessment?

A: Evaluation refers to the procedures used to determine if a child is eligible for early intervention services. Assessment refers to the ongoing process of gathering and using information about how a child is developing and determining what kind of help he or she might need.

In regards to your child, this information may come from some or all of the following:

- Doctors' reports;
- Results from developmental tests given to your child;
- Your child's medical history;
- Observations and feedback from all members of the multidisciplinary team, including parents; and
- Any other important observations, records, and/or reports about your child.

Q: Who does the evaluation and assessment?

A: It depends on your state's policies or rules. Ask your local contact person about this. Usually, a team of professionals, which may include a psychologist, an early interventionist, and an occupational or physical therapist, will evaluate a child.

Q: Who pays for the assessment?

A: Under P.L.102-119, evaluations and assessments are provided at no cost to families. Check with your contact person for local guidelines.

Q: Will I have to pay for any services if my child is found eligible?

A: Usually, services are provided at no cost to the family. You may have to pay for some services, depending on your state's policies. Check with the contact person in your area or state. Some services may be covered by your health insurance, by Medicaid, or by Indian Health Services.

In some areas, you may be charged a "sliding-scale" fee that is based on what you earn. Every effort is made to provide services to all infants and toddlers who need help, regardless of family income.

Q: What is a service coordinator (case manager)?

A: When a child's needs are assessed and the child is found eligible for services, a service coordinator will be assigned to the family. This person should have a background in early childhood development and methods for helping young children who may have developmental delays. The service coordinator should know the policies for early intervention programs and services in your state. This person can help you locate other services in your community, such as recreation, child care, or family support groups. The service coordinator will work with your family as long as your baby is receiving early intervention services and, after your child is 2 years old, the service coordinator will help your family move on to programs for children ages 3 through 5.

Q: What is an IFSP?

A: The family and the service coordinator work with other professionals, as appropriate, to develop an Individualized Family Service Plan, or IFSP. The guiding principal of the IFSP is that the family is a child's greatest resource, that a baby's needs are closely tied to the needs of their family. The best way to support children and meet their needs is to support and build upon the individual strengths of their family. So the IFSP is a whole family plan with the parents as the most important part of the IFSP team. Involvement of other team members will depend on what the baby needs. These other team members could come from several agencies, and may include medical people, therapists, child development specialists, social workers, and others.

The IFSP will describe the following: the child's development levels; family information (with parents' concurrence); the major outcomes expected to be achieved for the child and family; the services the child will be receiving; when and where he or she will receive these services, and the steps to be taken to support his or her transition to another program. The IFSP will identify the service coordinator. The IFSP may also identify services the family may be interested in, such as financial information or information about raising a child with a disability.

Each state has developed specific guidelines for the IFSP. Your service coordinator can explain what the IFSP guidelines are in your state.

Q: Are there any parent groups in my area that can give me more information about early intervention services?

A: There are several types of parent groups, including:

- Support groups (such as Parent-to-Parent) for families of children with disabilities;
- Parent training and information programs funded by the federal government, such as the Technical Assistance

for Parent Programs (TAPP) Project; and
- Groups concerned with a specific disability, such as United Cerebral Palsy Associations, Inc. (UCPA) or the Arc (formerly the Association for Retarded Citizens of the United States).

We have listed some of these groups on the State Resource Sheet.

Parent groups can offer information, support, and/or training to families of children with disabilities to help parents take a more active role in helping their children. Through such groups, families meet other families with similar needs to discuss resources, day-to-day problems, and personal insights.

Your service coordinator or someone at your local school may be able to tell you about nearby groups. For more details on parent groups, contact NICHCY (1-800-695-0285) and ask for our "Parent's Guide to Accessing Parent Programs."

Q: I still have a lot of questions. How can I find out more about special education laws and about early intervention services?

A: See the section of this document entitled Information About IDEA for more information on one of the most important special education laws. Also, see the References for Families section for selected additional information on the development of infants and toddlers with disabilities, on early intervention programs and services, and on raising and caring for a young child with special needs.

As time goes by and your child begins to receive services, you will probably have more questions. For example, you might want to know:

- How do I check on the services my child is getting?
- What do I do if I am not satisfied with my child's assessment, program, or progress?
- What happens to my child once he/she is too old for the program?
- What about private therapists and private schools?

For answers to these and other questions, talk to your service coordinator, contact a parent support and/or training group in your area, or contact NICHCY.

We hope these materials are useful. If you need more help or information from NICHCY, please call us 1-800-695-0285 (Voice/TT), or write to us at this address: NICHCY, P. O. Box 1492, Washington, D.C. 20013-1492.

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PART II: Questions and Answers About Special Education Programs and Services for Preschoolers with Disabilities (Ages 3 Through 5 Years Old)

Note: Many of the words below may be new to you, but they are terms that are commonly used in special education. We have used these terms to help you become familiar with them. You can look up their definitions in the Parent's Dictionary towards the end of this document.

The phrases "special education," "special education programs," "special education services," and "special education programs and services" are used interchangeably in this section.

Below are answers to questions people often ask about special education programs and services for preschool children (ages 3 through 5 years old) who have disabilities.

A federal law known as Public Law (P.L.) 102-119 guarantees certain rights to young children (ages birth to 5) with special needs. This law is the most recent amendment to Public Law (P.L.) 94-142, The Education For All Handicapped Children's Act, now called the Individuals with Disabilities Act (IDEA).

Q: What should I do if I think my preschool child needs special education?

A: If you think your preschooler needs special education, you will first want to find out if he or she is eligible for a special education program. There are people who can help you with this. Read on, and we will explain how to contact them.

Q: What are special education programs?

A: Special education programs are specially designed programs in public schools offered at no cost to families of children with disabilities. Today, under P.L.102-119, all schools must offer special education services to eligible 3-5 year olds with disabilities.

Q: Who do I contact first for help?

A: The best place to start is your local public elementary school. (In most cases, this would be the school that other children who live near you attend.) Call and ask to speak to the principal or to someone in charge of special education at the school.

If this doesn't work, look on the NICHCY State Resource Sheet under "State Department of Education." Call the Early Childhood Specialist for children ages 3-5 years and ask for the name and phone number of the person in your area in charge of these programs. Explain that you want to find out about special education services for your child. Ask what you need to do to arrange for an evaluation.

Write down the names and phone numbers of everyone you talk to. (As a guide, you can use the Sample Record-Keeping Worksheet at the end of this document.) Having this information available may be helpful to you later on.

Q: What is an evaluation?

A: Evaluation means the procedures used to determine whether a child has a disability and the extend of the special education and related services the child needs. In regards to your child, this information may come from:

- Doctors' reports;
- Results from developmental tests given to your child;
- Your child's medical history;
- Observations and feedback from all members of the assessment team, including parents; and

- Any other important observations, records, and/or reports about your child.

Q: Who conducts my child's evaluation?

A: Your child's evaluation will be conducted by a multidisciplinary team of group of persons. Who is involved will depend on the rules in your state or school district. Ask your school contact person what the policy is for getting an evaluation for your child.

Q: Will I have to pay for the evaluation or for any services my child may be eligible for?

A: Special education services are offered for 3-5-year-olds at no cost to parents. The assessment and evaluation process is considered part of these services and is provided at no cost to families.

Q: Are there any parent groups in my area that can give me more information about special education?

A: There are several types of parent programs, including:

- Support groups (such as Parent-to-Parent) for families of children with disabilities;
- Parent training and information programs funded by the federal government, such as the Technical Assistance for Parent Programs (TAPP) Project; and
- Groups concerned with a specific disability, such as United Cerebral Palsy Associations, Inc. (UPCA), or the Arc (formerly the Association for Retarded Citizens of the United States).

We have listed some of these groups on your State Resource Sheet. You can also check with someone in your local school or call NICHCY.

Parent groups can offer information, support, and/or training to families of children with disabilities to help them take a more active role in their children's education. Through such groups, families meet other families with similar needs to discuss local resources, daily problems, and personal insights. For more details on these and other parent groups, contact NICHCY and ask for our "Parent's Guide to Accessing Parent Groups."

Q: I still have a lot of questions. How can I find out more about special education programs and services?

A: See the section entitled Information About IDEA to learn more about one of the most important special education laws. Also, see the "References" section towards the end of this document for information on raising and caring for a young child with special needs.

Once your child has been found eligible for special education, you will most likely have more questions. For example:

- How do I check on my child's special education program?
- What do I do if I am not satisfied with my child's assessment, placement, program, or progress?
- What happens to my child when he or she is too old for the program?
- What about private therapists and private schools?

For answers to these and other questions, talk to your special education coordinator or school principal or contact a parent support and/or training group in your area.

Also, write to NICHCY and ask for a copy of "Questions Often Asked About Special Education Services" and/or the longer, more detailed "Questions and Answers about the Individuals with Disabilities Education Act." Both documents contain information about special education laws and parents' rights in getting school services for their children with disabilities.

We hope these materials are useful. If you need more help or information from NICHCY, please call us at 1-800-695-0285 (Voice/TT) or write to us at this address: NICHCY, P. O. Box 1492, Washington, D.C. 20013-1492.

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PART III: Questions and Answers About Programs and Services for Rural, Native American, Adoptive/Foster, and Military Families and Their Young Children With Disabilities

Q: What about services for families in remote or rural areas?

A: The goals of early intervention or special education programs and services for young children with special needs is the same for both rural and urban families. However, the ways in which these services are offered may be different. Two groups that may be able to offer information specifically about services for rural families are:

American Council on Rural Special Education (ACRES)
University of Utah
Department of Special Education
Milton Bennion Hall
Salt Lake City, UT 84112
Telephone: (801) 585-5659

Rural Institute on Disabilities
52 Corbin Hall
The University of Montana
Missoula, MT 59812
Telephone: (800) 732-0323

Q: What about services for Native American families living on reservations?

A: The lead agency for the state is responsible for seeing that early intervention programs and services are provided to infants and toddlers (ages birth through two years) with special needs in the state. The State Education Agency (SEA) is responsible for seeing that programs and services are provided to preschool children (ages three through five) with special needs. These requirements include Native American infants, toddlers, and children living on reservations. Information on these services is available from the lead agency, from the SEA, or by contacting the office of the tribal leader or the tribal education committee. Local public or BIA schools and Indian Health Service (IHS) offices and clinics are also possible sources of information.

Q: What information and support groups are available to help families?

A: There are several types of parent groups including:

- Support groups (such as Parent-to-Parent) for families of children with disabilities;
- Parent training and information programs funded by the federal government, including some specializing in services for Indian families; and
- Groups concerned with a specific disability, such as United Cerebral Palsy Associations, Inc. (UCPA) or the Arc (formerly the Association for Retarded Citizens of the United States).

Q: What additional information do families of adopted or foster children with disabilities need about early intervention or special education services?

A: In general, the process for getting early intervention or special education programs and services for adopted children with special needs is the same as it is for all children with special needs.

An organization that has a nationwide family support network of adoptive families is Adoptive Families of America (AFA). While the main focus of this organization is to provide general help and information to all adoptive families, its bimonthly parent support magazine includes information and resources for families of adopted children who have special needs.

Their address is:

Adoptive Families of America, Inc. (AFA)
3333 Highway 100, North
Minneapolis, MN 55422
Telephone: (612) 535-4829

Families who provide foster homes to children who have disabilities or who are at risk of developing disabilities may want to contact the National Foster Parent Association, Inc. (NFPA). This national, non-profit group offers information and support to all foster parents. Members of the group receive a bimonthly newsletter and have access to nearly 500 NFPA resource materials.

For the Information/Services Office of NFPA, contact:

National Foster Parent Association, Inc.
Information/Services Office
226 Kilts Drive
Houston, TX 77024
Telephone: (713) 467-1850
Fax: (713) 827-0919

Q: How do I find out about programs and services for military families whose young children have special needs?

A: One way is through a project known as Specialized Training of Military Parents (STOMP). This organization provides information and help to military families (both in the U.S. and overseas) who have children with special needs.

The STOMP staff is made up of parents of children with special needs who are trained to work with other parents of children with special needs. As spouses of members of the military, the staff understands the unique needs of military families.

To contact STOMP, call or write:

Specialized Training of Military Parents (STOMP)
12208 Pacific Highway, S.W.
Tacoma, WA 98499
Telephone: (206) 588-1741 (Parents can call collect.)

Another way to learn more about early intervention and special education programs and services for children in military families stateside is to contact the Community Service Center (also called Family Service Center or Family Resource Center) or the assigned community contact person on your installation.

While most children of military families attend (or will attend) public schools, some are in Section VI schools. Section VI schools provide early intervention services and special education services in accordance with the Interim Final Rules issues in the Federal Register on October 6, 1993 (Federal Register, Volume 58, Number 192, pages 51996-52010). As of July 1994, a final Department of Defense Instruction in this regard is anticipated. Once this Instruction is issued, copies should be available at each local military installation, Section VI school, Superintendent's Office.

The office of Department of Defense Dependent Schools (DODDS) overseas issues a handbook for military families with children who have special needs and who are receiving, or are eligible to receive, a free appropriate public education through DODDS overseas. To order the handbook, write or call:

Department of Defense Dependent Schools
4040 North Fairfax Drive
Arlington, VA 22203-1635
Telephone: (703) 696-4493

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Information About IDEA

For the past 25 years, laws have been passed by Congress instructing states to provide education for children and youth with disabilities. Public Law 94-142, the Education For All Handicapped Children Act (EHA), was passed by Congress and signed into law by President Ford in 1975. This law is well known; it required states to fully educate all children with disabilities. It has been amended several times. In 1986, the EHA was amended through P.L. 99-457 to, among other things, lower the age at which children can receive special services to three years old. It also established the Handicapped Infants and Toddlers Program (Part H), which is for children who need help from birth to their third birthday. The amendments of 1990 and 1991 brought about more changes, among which was a change in the name. Now the EHA will be called IDEA, the Individuals with Disabilities Education Act.

Information About Programs for Children Ages 3-21

IDEA requires that all states and territories provide a public school education to children with disabilities from ages 3 to 21, no matter how severe their disabilities are.

There are several basic rights that this law promises to children with disabilities (ages 3 to 21) and their parents:

- The right to a "free appropriate public education" at public expense (in some cases, this may include placing a child in a private school);

- The right to an educational placement that is based on an assessment and evaluation of each child's own special needs;

- The right of children with disabilities to receive teaching or instruction that is designed to meet their needs; these needs are to be clearly written and included in an Individualized Education Program (IEP) for each child, with statements about what services the child will receive;

- The right to a full range of educational services that may include related services such as counseling, special transportation, speech/language pathology, or occupational or physical therapy;

- The right of parents (or guardians) to be included in making decisions about their child's educational needs and to approve the educational plans for their child; and

- The right of parents (or guardians) to appeal any decisions made about the identification, evaluation, and placement of the child through a due process procedure.

Finally, IDEA requires that children with disabilities be educated in the "Least Restrictive Environment" (LRE), that is, in a setting with children who have no disabilities, with special help provided to those who need it.

Information About Programs for Very Young Children

Under the IDEA, early intervention services are to be made available to infants and toddlers with disabilities, ages birth through two years. Services are not the same in all areas. To find out what is available where you live, call the early childhood specialist in your school system or check under "Programs for Infants and Toddlers with Disabilities" on NICHCY's State Resource Sheet. You can also call NICHCY at 1-800- 695-0285 (Voice/TT) ask for assistance.

Congress made funds available to help states and territories plan a comprehensive service system to provide the following services:

- Early intervention services to infants and toddlers (ages birth through 2 years) with disabilities. If a state chooses to, it can also serve infants and toddlers at risk of developing disabilities; and

- Special education programs and related services to preschoolers (ages 3 through 5 years) who have disabilities.

Services for children 3 years old and up are provided by the state department of education. However, programs for children under age 3 are provided by different agencies in different states. Sometimes the department of education will handle all these programs; in other states it may be the health department or another agency.

The term "infants and toddlers with disabilities" in the law refers to children (ages birth through 2 years) who need early intervention services in any of the following areas:

- Physical,
- Cognitive,
- Communication,
- Social or emotional, and/or
- Adaptive development.

Early intervention services must be provided by people who are qualified to work with infants and toddlers who have disabilities or who are at risk of developing disabilities. Any services provided must be written into an Individual Family Service Plan (IFSP) that is reviewed every 6 months.

For more information about the laws that affect children with disabilities and their families, call NICHCY at 1-800-695-0285 (Voice/TT).

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Parent's Dictionary of Terms Used in Special Education*

*****Note: The following definitions have been compiled from a variety of sources. The contents of this dictionary do not necessarily represent definitions endorsed by the U.S. Department of Education.

adaptive development -
: development of the child in comparison to other children the same age. This might include the child's ability to dress himself, feed himself, toilet training, how he/she plays with other children, how he/she plays alone, understanding dangers in crossing the street, how he/she behaves if mother leaves the room, etc.

advocate -
: someone who takes action to help someone else (as in "educational advocate"); also, to take action on someone's behalf

amendment -
: a change, revision, or addition made to a law

appeal -
: a written request for a change in a decision; also, to make such a request

appropriate -
: able to meet a need; suitable or fitting; in special education, it usually means the most normal situation possible

assessment -

a collecting and bringing together of information about a child's needs, which may include social, psychological, and educational evaluations used to determine services; a process using observation, testing, and test analysis to determine an individual's strengths and weaknesses in order to plan his or her educational services

assessment team -

a team of people from different backgrounds who observe and test a child to determine his or her strengths and weaknesses

at risk -

a term used with children who have, or could have, problems with their development that may affect later learning

Child Find -

a service directed by each state's Department of Education or lead agency for identifying and diagnosing unserved children with disabilities; while Child Find looks for all unserved children, it makes a special effort to identify children from birth to six years old

cognitive -

a term that describes the process people use for remembering, reasoning, understanding, and using judgement; in special education terms, a cognitive disability refers to difficulty in learning

comprehensive service system -

refers to a list of 14 areas each participating state is to provide under early intervention services. These 14 points range from definition of developmentally delayed, to guidelines for identification, assessment, and provision of early intervention services for the child and family, and include timelines and quality control

counseling -

advice or help given by someone qualified to give such advice or help (often psychological counseling)

developmental -

having to do with the steps or stages in growth and development before the age of 18 years

developmental history -

the developmental progress of a child (ages birth to 18 years) in such skills as sitting, walking, talking, or learning

developmental tests -

standardized tests that measure a child's development as it compares to the development of all other children at that age

disability -

the result of any physical or mental condition that affects or prevents one's ability to develop, achieve, and/or function in an educational setting at a normal rate

due process (procedure) -

action that protects a person's rights; in special education, this applies to action taken to protect the educational rights of students with disabilities

early interventionist -

someone who specializes in early childhood development, usually having a Master's degree or Ph.D. in an area related to the development of infants, toddlers, and preschoolers

early intervention policies -

see policy/policies

early intervention services or programs -

programs or services designed to identify and treat a developmental problem as early as possible, before age 3 (services for 3-5 year olds are referred to as preschool services)

eligible -

able to qualify

evaluation -

(as applied to children from birth through two years of age) the procedures used to determine if a child is eligible for early intervention services; (as applied to preschool and school-aged children) the procedures used to determine whether a child has a disability and the nature and extent of the special education and related services the child needs

free appropriate public education [often referred to as FAPE] -

one of the key requirements of IDEA, which requires that an education program be provided for all school-aged children (regardless of disability) without cost to families; the exact requirements of "appropriate" are not defined, but other references within the law imply the most "normal" setting available

handicap -

see disability

identification -

the process of locating and identifying children needing special services

Individualized Education Program (IEP) -

a written education plan for a school-aged child with disabilities developed by a team of professionals (teachers, therapists, etc.) and the child's parents; it is reviewed and updated yearly and describes how the child is presently doing, what the child's learning needs are, and what services the child will need; (For children ages birth through 2 years, the IFSP is used.)

Individualized Family Service Plan (IFSP) -

a written statement for an infant or toddler (ages birth through 2 years old) developed by a team of people who have worked with the child and the family; the IFSP must describe the child's development levels; family information; major outcomes expected to be achieved for the child and family; the services the child will be receiving; when and where the child will receive these services; and the steps to be taken to support the transition of the child to another program; the IFSP will also list the name of the service coordinator assigned to the child and his/her family

lead agency -

the agency (office) within a state or territory in charge of overseeing and coordinating service systems for children ages birth through 2

Least Restrictive Environment (LRE) -

an educational setting or program that provides a student with disabilities with the chance to work and learn to the best of his or her ability; it also provides the student as much contact as possible with children without disabilities, while meeting all of the child's learning needs and physical requirements

multidisciplinary -

a team approach involving specialists in more than one discipline, such as a team made up of a physical therapist, a speech and language pathologist, a child development specialist, an occupational therapist, or other specialists as needed

occupational therapy -

a therapy or treatment provided by an occupational therapist that helps individual developmental or physical skills that will aid in daily living; it focuses on sensory integration, on coordination of movement, and on fine motor and self-help skills, such as dressing, eating with a fork and spoon, etc.

parent training and information programs -

programs that provide information to parents of children with special needs about acquiring services, working with schools and educators to ensure the most effective educational placement for their child, understanding the methods of testing and evaluating a child with special needs, and making informed decisions about their child's special needs

physical therapy -

treatment of (physical) disabilities given by a trained physical therapist (under doctor's orders) that includes the use of massage, exercise, etc. to help the person improve the use of bones, muscles, joints, and nerves

placement -

the classroom, program, service, and/or therapy that is selected for a student with special needs

policy/policies -

rules and regulations; as related to early intervention and special education programs, the rules that a state or local school system has for providing services for and educating its students with special needs

private agency -

a non-public agency which may be receiving public funds to provide services for some children

private therapist -

any professional (therapist, tutor, psychologist, etc.) not connected with the public school system or with a public agency

program(s) -

in special education, a service, placement, and/or therapy designed to help a child with special needs

psychologist -

a specialist in the field of psychology, usually having a Master's degree or Ph.D. in psychology

public agency -

an agency, office, or organization that is supported by public funds and serves the community at large

Public Law (P.L.) 94-142 -

a law passed in 1975 requiring that public schools provide a "free appropriate public education" to school-aged children ages 3-21 (exact ages depend on your state's mandate), regardless of disabling condition; also called the Education For All Handicapped Children Act, with recent amendments now called the Individuals with Disabilities Education Act (IDEA)

Public Law (P.L.) 102-119 -

passed in 1991, this is an amendment to the Individuals with Disabilities Education Act (IDEA), which requires states and territories to provide a "free appropriate public education" to all children ages 3-21; and provides funds for states and territories to plan a comprehensive service system for infants and toddlers (ages birth through 2 years) with disabilities

related services -

transportation and developmental, corrective, and other support services that a child with disabilities requires in order to benefit from education; examples of related services include: speech pathology and audiology, psychological services, physical and occupational therapy, recreation, counseling services, interpreters for the hearing impaired, and medical services for diagnostic and evaluation purposes

service coordinator -
someone who acts as a coordinator of an infant's or toddler's services, working in partnership with the family and providers of special programs; service coordinators may be employed by the early intervention agency

services/service delivery -
the services (therapies, instruction, treatment) given to a child with special needs

special education -
see special education programs and services

special education coordinator -
the person in charge of special education programs at the school, district, or state level

special education programs/services -
programs, services, or specially designed instruction (offered at no cost to families) for children over 3 years old with special needs who are found eligible for such services; these include special learning methods or materials in the regular classroom, and special classes and programs if the learning or physical problems indicate this type of program

special needs -
(as in "special needs" child) - a term to describe a child who has disabilities or who is at risk of developing disabilities and who, therefore, requires special services or treatment in order to progress

speech/language pathology -
a planned program to improve and/or correct communication problems

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References for Families

Books

Batshaw, Dr. Mark L. (1991). *Your Child Has a Disability: A Complete Sourcebook of Daily and Medical Care.* Boston: Little, Brown and Company. (Available from Little, Brown and Company, Attention: Order Department, 200 West Street, Waltham, MA 02154. Telephone: 1-800-759-0190.)

A book that offers practical information to help parents meet the daily physical and emotional needs of their child with a disability. Includes information on finding the right doctor, the daily and long-term care requirements of different disabilities, behavior management techniques, nutrition, the use of medications, and much more.

Callahan, Charles. (1990). *Since Owen: A parent-to-parent guide for care of the disabled child.* Baltimore, MD: Johns Hopkins University Press. (Available from Johns Hopkins University Press, Hampden Station, Baltimore, MD 21211. Telephone: 1-800-537-5487.)

A book which addresses the challenges of raising a child with a disability by offering both the author's personal experiences and practical suggestions and insights. Discusses the life span of issues, including genetic counseling for parents, issues associated with hospitalization of children with disabilities, their transition from the hospital to home, the family's emotions and stress, support resources, the special education system, and the child's transition to adult life.

Dickman, Irving. (1993). *One miracle at a time: Getting help for a child with a disability (rev. ed.).* New York: Simon and Schuster. (Available from Simon and Schuster, 200 Old Tappan Road, Old Tappan, NJ 07675. Telephone: 1-800-223-2336.)

A book which offers emotional and practical support to parents of children with disabilities. Shares the struggles, strategies, and successes of other parents in regard to caring for a child with disabilities, working with medical professionals, collaborating with school personnel, being an effective advocate, identifying and using assistive technology devices, and providing for the needs of family members. Includes a wealth of information about disability resources.

Krahl, Rhonda. (1990). *Rebuilding your dream: Family life with a disabled child.* Iowa City: Author. (Available from Publications Order Department, 100 Oakdale, M105, Iowa City, IA 52242-5000. Telephone: 1-800-235-2665.)

A book for parents of children with disabilities.. Deals with the many emotions that parents experience when they find their child has a disability. Suggestions are given for adjusting and adapting, maintaining the marriage relationship, meeting the needs of other children in the family, helping grandparents, facing the world, and working with professionals.

Lawrence, K., Johnson, G., and Stepanek, J. (Eds.). (1994). *Parent resource directory (5th ed.).* Bethesda, MD: Association for the Care of Children's Health. (Available from the Association for the Care of Children's Health, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (301) 654-6549.)

Directory which helps locate family members who are willing to share their interests, experiences, and expertise. Has been used to find parent- to-parent support, identifying parents with specific types of expertise related to program development, policy formulation, and legislative and other advocacy activities. Lists more than 450 parents/caregivers, including contact information and their child's condition and areas of interest/expertise. Organized/indexed by state/province, names, types of conditions, and topical areas.

Miller, N.B. (1994). *Nobody's perfect: Living and growing with children who have special needs.* Baltimore, MD: Paul H. Brookes. (Available from Paul H. Brookes, P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: 1-800-638-3775.)

A book for parents that is filled with the voices of other parents who have children with special needs. Discusses the range of emotions many parents experience in raising a child with a disability and offers strategies and emotional support to help parents address parenting issues, work effectively with professionals, and take care of themselves and their children.

Turnbull, A.P., Patterson, J.M., Behr, S.K., Murphy, D.L., Marquis, J.G., and Blue-Banning, M.J. (Eds.). (1993). *Cognitive coping, families, and disability.* Baltimore, MD: Paul H. Brookes. (Available from Paul H. Brookes, P.O. Box 10624, Baltimore, MD 21285-0624. Telephone: 1-800-638-3775.)

A book which offers parents and family members a set of strategies for coping with and successful addressing the daily challenges of disability. Based on the findings of research and the personal experiences of parents, discusses cognitive coping, its impact upon family adjustment and adaptation to stress, and its power to help families enhance their senses of esteem, control, meaning, and well-being.

Other Printed Materials

The Exceptional Parent. A magazine published twelve times a year for parents, individuals, organizations, librarians, schools, and agencies. (Available from The Exceptional Parent, P.O. Box 3000, Denville, NJ 07834. Telephone: 1-800-562-1973.)

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Parent's Record-keeping Worksheet

The sample record-keeping worksheet below can help you start a file of information about your child. As you contact different people and places, it's a good idea to keep records of people you've talked with and what was said. As time goes by, you will want to add other information to your file, such as:

- Letters and notes (from doctors, therapists, etc.);
- Medical records and reports;
- Results of tests and evaluations;
- Notes from meetings about your child;
- Therapist(s') reports;
- IFSP and IEP records;
- Your child's developmental history, including personal notes or diaries on your child's development;
- Records of shots and vaccinations; and
- Family medical histories.

Make sure you get copies of all written information about your child (records, reports, etc.). This will help you become an important coordinator of services and a better advocate for your child. Remember, as time goes on, you'll probably have more information to keep track of, so it's a good idea to keep it together in one place.

Sample Record-Keeping Worksheet

Problem/Topic:

Name of person or agency you talked to: Name of your contact person (may be same as above):

Date you called: Phone number:

Results of discussion:

Action taken (if any):

Person not helpful on this topic, but may be helpful regarding (list topics/areas/issues):

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Credits

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

P.O. Box 1492
Washington, DC 20013
1-800-695-0285 (Voice/TT)
Washington, DC

Parent Guide is published once a year; single copies are provided free of charge. In addition, NICHCY disseminates other materials and can respond to individual requests for information. All services and publications are free. For further information and assistance, or to receive a NICHCY Publications List, contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-695-0285 (Voice/TT) and (202) 884-8200 (Voice/TT).

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