



National Dissemination Center for Children with Disabilities

A publication of the National Dissemination Center for Children with Disabilities

Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities

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Note from NICHCY: October, 1997

Dear Reader:

The Individuals with Disabilities Education Act (IDEA) has been amended! This is the law that guides how schools deliver special education and related services to students with disabilities.

You will be reading about the IDEA in this publication. This note is to alert you that, while much of the law remains essentially the same, some aspects have changed as a result of the amendments passed in June, 1997. Bear this in mind as you read about the IDEA in this publication.

If you have questions about the new amendments, please feel free to contact NICHCY.

Introduction

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).

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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.

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 the Individuals with Disabilities Education Act (IDEA) guarantees certain rights to young children (ages birth to 5) with special needs. (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 the NICHCY [State Resource Sheet](#) under "Programs for Infants and Toddlers with Disabilities." If you don't have a State Resource Sheet and/or can't download the one for your state from our Web site, 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 at the end 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 IDEA, 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 Alliance for Parent Centers \(the Alliance\); and](#)
- [Groups concerned with a specific disability, such as United Cerebral Palsy Associations \(UCPA\) 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, take a look at our "[Parent's Guide to Accessing Parent Programs](#)" or contact us at 1.800.695.0285 and ask us to send you a copy.

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. NICHCY also has many publications on the law and how to raise and care for a child with special needs. These are available on our Web site and by contacting us at 1.800.695.0285.

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/TTI); write to us at this address: NICHCY, P. O. Box 1492, Washington, D.C. 20013-1492; or email us at nichcy@aed.org.

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NICHCY *Parent Guides* are published several times a year in response to questions from individuals and organizations that contact us. We encourage you to [share your ideas](#) and feedback with us!

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