ADRESSING YOUR FINANCIAL CONCERNS
ADDRESSING YOUR FINANCIAL CONCERNS

All families are aware of the expenses involved in raising their children. When a child has a disability, especially when it is one that involves ongoing medical care, a family’s resources can be quickly stretched to the limit. Although your financial challenges may never be completely resolved, there are a few steps you can take as soon as you find out that your child has a disability:

• Organize your financial recordkeeping. You will find that, over time, you will come to have an enormous amount of paperwork. Find a system to keep it organized that works for you. If you are too overwhelmed in the beginning to deal with every piece of paper, start with a box where you can toss new papers to keep everything together.

• Ask for information about any and all financial assistance programs. Take it upon yourself to start learning the terminology, requirements, and benefits of the many, many agencies involved in providing disability services. This will not be easy, but it is in your best interest to learn as much as you can.

The costs associated with your child’s disability will depend on many factors, including the type of disability and your family’s income. Be persistent and try to investigate all your options. Because you will talk to dozens of agencies and people, it’s a good idea to keep a notebook by your side whenever you make telephone calls to write down your notes, contact names, and phone numbers for any referrals you are given. Although your work might seem like an endless paper jungle, you will be rewarded with better understanding of “the system” and the opportunity to find the services your child needs.
U.S. SOCIAL SECURITY ADMINISTRATION (SSA)

Social Security
Social Security is the largest support program of the federal government. Most people who work for any length of time have Social Security contributions deducted from their paycheck, which are matched by contributions by their employers. A part of the money collected in this way is set aside for families who have a member with a disability. If you are a worker who became severely disabled before the age of 65 or if you have met your retirement age, you are eligible for Social Security benefits. In addition, the children of retired, disabled, or deceased workers are also eligible for Social Security benefits, provided that they are either under 18 years of age or had a severe disability before the age of 22 and continue to have the disability.

Supplemental Security Income
The SSA also administers the Supplemental Security Income (SSI) program. Depending on your family income, you will want to apply for SSI benefits on the basis of your child’s disability. In Florida, an application for SSI is also an application for Medicaid.

The basic purpose of SSI is to assure a minimum level of income to people who are elderly, blind, or disabled, and who have limited income and resources. Under SSI, a child is considered “disabled” if:

- The child is under age 18 and has a physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations; and

- The condition(s) must have lasted or be expected to last at least 12 months or end in death.

A child may be eligible for SSI benefits based on a disability from the date of birth (there is no minimum age requirement) and remains eligible until age 18. At 18, your child is reevaluated based on the definition for adults. At any age, a person with a visual impairment may be eligible for SSI benefits if the impairment meets the definition of blindness under the SSI statute.

For information and application forms for Supplemental Security Income, contact your local Social Security office. If you need assistance in locating your local office, contact the SSA at their national...
toll-free number at (800) 772-1213 or visit their website at www.socialsecurity.gov.

U.S. DEPARTMENT OF VETERANS AFFAIRS
Civilian Health and Medical Program (CHAMPVA)
CHAMPVA is a comprehensive health care program for eligible military veterans. If you are a veteran who has a service-related disability, your spouse and/or child may be eligible for CHAMPVA benefits. You can contact the Health Administration Center at the Department of Veterans Affairs for more information at (800) 733-8387 or on the web at www.va.gov/hac/aboutus/programs/champva.asp.

Survivors’ and Dependents’ Educational Assistance Program (DEA)
The DEA Program provides education and training opportunities to eligible dependents of deceased and disabled veterans whose disability is a service-related event. Certain special provisions apply to dependents with disabilities. You can contact the Department of Veterans Affairs for more information at (888) 442-4551 or on the web at www.gibill.va.gov/pamphlets/CH35/CH35_Pamphlet_General.htm.

U.S. DEPARTMENT OF DEFENSE
TRICARE Program (formerly CHAMPUS)
TRICARE is the Department of Defense’s managed health care program for persons who are on active military duty and their families and for retirees from active military duty and their families. If you are currently serving in the military or are retired, your spouse and/or child may be eligible for a health insurance plan which may cover some medical visits, medications, equipment and other supplies. Spouses and children of veterans who were killed in action may also be eligible. You can contact the TRICARE Program at the Department of Defense for more information at (888) 363-2273 or on the web at www.tricare.osd.mil.

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
Medicare
Medicare is the federal health insurance program for people 65 years of age and older, certain younger adults with disabilities, and people with End-Stage Renal Disease. The program is funded through the Medicare taxes paid by employees and their employers throughout their working years. Medicare covers all people 65 and older who are eligible for Social Security
benefits as well as younger adults who have disabilities. Adult children with disabilities who receive Social Security benefits based on their parents’ employment can receive Medicare benefits.

To see if your child is entitled to Medicare, call Social Security at 800-772-1213. If you have questions about claims or what is covered by Medicare, call Medicare at 800-MEDICARE or visit their website at [www.medicare.gov](http://www.medicare.gov).

**Medicaid Services**

Medicaid is administered by the Agency for Health Care Administration (AHCA) and is financed by federal and state funds. Medicaid provides services for persons in financial need who are unable to pay for needed medical and health care services.

Many people are covered by Medicaid. Anyone who receives Temporary Assistance to Needy Families (TANF) or Supplemental Security Income (SSI) is eligible for Medicaid. Under Medicaid, there are many different eligibility categories with varied requirements such as different income and asset levels. To find out more about these eligibility categories, visit the Department of Children and Families website at [www.dcf.state.fl.us/ess/medicaid.shtml](http://www.dcf.state.fl.us/ess/medicaid.shtml).

After receiving a Medicaid card in Florida, individuals will receive information on how to obtain Medicaid services. The Medicaid program will allow children to receive hospital care, nursing home care, laboratory services, physician services, dental care, and other medical services. Medicaid waivers allow for additional services.

To find out more about Medicaid programs, contact the local Medicaid area office nearest you. To obtain a listing of Medicaid area offices in Florida, visit their website at [http://ahca.myflorida.com/Medicaid/Areas/index.shtml](http://ahca.myflorida.com/Medicaid/Areas/index.shtml). You can also find a listing of the area offices in Chapter 10.

**PRIVATE INSURANCE COMPANIES**

Many families have a private insurance policy, usually through the workplace of one or more of its members. If you have private medical insurance, one of your first steps will be finding out exactly what services and supplies are
covered. To do this, you can contact the benefits department of your insurance carrier. Be sure to request all information in writing and take notes on your own, including the name of the person giving the information. It may be helpful to follow up on your telephone conversation with a brief letter stating your understanding of your benefits. Always keep copies for your own files.

When you file a claim, fill out all forms carefully and completely. Provide as much information as possible, including photographs, detailed descriptions, and background medical data. Keep a copy for your records. Always ask to speak with the same claims processor rather than speaking with a different person each time you call. Or ask for a case manager to be assigned to your case, so that one person becomes familiar with your child’s medical history and needs.

OTHER FINANCIAL SUPPORT PROGRAMS
Some additional resources to contact in your search for financial assistance can include:

- Hospital social workers
- Public health department
- Volunteer agencies
- Disability organizations
- State government agencies; in Florida, contact the Agency for Persons with Disabilities at (850) 488-4257.

The search for programs to help you carry the responsibility of meeting your child’s medical needs can be challenging. The best advice other parents have given is to be organized, knowledgeable and persistent. The key is to keep trying, to get more information, to follow up on leads, and to continue applying for various types of financial assistance.

You will find that educational expenses related to a child’s disability are usually not covered by insurance or medical assistance programs. It is important, nevertheless, to keep track of educational expenses, because they are generally deductible on your federal income tax returns.

TAX DEDUCTIONS AND TAX CREDITS
There are many income tax deductions and credits available to parents of children with developmental disabilities, and you will benefit from taking advantage of these special provisions. You will need to keep up-to-date with tax information each year and keep records that will support your deductions. If you need assistance in com-
The greatest glory in living lies not in never falling, but in rising every time we fall.

NELSON MANDELA

ADDRESSING YOUR FINANCIAL CONCERNS

Completing your taxes, you can contact your local Internal Revenue Service Office or visit their website at www.irs.gov.

ESTATE PLANNING

All parents should plan for the future of their children. When a child has a disability, this responsibility becomes even more important. Although you know it’s important, you may feel that you have plenty of time to do this planning as your child gets a little older, or you may want to begin planning, but just can’t seem to find the time or energy to do it. Add to that the reluctance we all have to think about our own death, and you may find yourself postponing your estate planning far longer than you should. Here is some information to get you started:

Carrying life insurance

Make sure you are carrying enough life insurance. Although you are irreplaceable to your child, someone will need to take over for you in the event of your death. Even if it is your child’s siblings or other relatives who step in, they will likely have to pay for at least some of the services that you used to provide. If your estate is not large enough to cover these costs, the amount of available funds can be increased through life insurance proceeds. Premiums for “second to die” insurance (which pays only when the second of two parents passes away) often can be purchased at a reasonable cost.

Setting up a trust

Any funds left for a child with a disability, from an estate or from the proceeds of a life insurance policy, should be held in trust for the child. Leaving money directly to a child with a disability may place their ability to receive government funds (such as SSI) at risk in the future. Specialized trusts, such as “self-sufficiency trusts” or “special needs trusts” allow parents to leave money to a child with a disability without disqualifying the child from government benefits. Because choosing the best type of trust fund for your child can be complex, it is recommended that you choose an attorney with experience in disability law to help you through this process.
Writing a Will and Appointing a Guardian
Choosing a guardian for your minor child (under the age of 18) in the event that you can no longer care for him is an important step you must take. Sometimes the choice is relatively simple, as when a sibling comes forward and asks to be given this role. Other times, the decision will be more difficult, but parents should devote time to this decision while they are able. When your decision is made, your attorney will include the naming of your child’s guardian in your will. When your child reaches adulthood (18 years and older), you may need to petition the court for guardianship if she is unable to make decisions about her future and cannot live on her own.

Writing a Care Plan or Letter of Intention
All parents of children with disabilities are advised to write down what their child’s next guardian would need to know about their child and what their wishes are for their child. Imagine if you went away for an evening and never came back. You have a picture of what you want your child’s future life to look like, but her next caregiver may have a very different picture. By preparing a legal Letter of Intent, you will be able to communicate your wishes and desires for your child to those who will come after you. This document is usually a very personal letter in which you share the intimate details of your hopes for the best possible life for your child.

Coordinating with Other Family Members
Make sure you communicate the legal steps you have taken on behalf of your child to other members of your family so that everyone is aware of your plans. This is important for many reasons. For example, a well-meaning relative may leave money directly to your child that will disqualify him from receiving benefits later on. If this relative had known that you established a trust for your child for this purpose, the damage could be avoided. In addition, by telling many people about your plans, it is less likely that any one person in your child’s life would be able to work against your plans for the future.
FIRST STEPS A Guide for Parents of Young Children with Developmental Disabilities

Educational services for young children with disabilities are superior today to any other time in our nation’s history. Prior to the 1960s, special education services for pre-kindergarten children were uncommon. Today, service delivery systems can be found for all individuals with disabilities from birth through adulthood throughout the United States. Although you may not always receive the exact combination of services you request for your child, you can celebrate the fact that service systems are evolving each year to better serve children based on ever-increasing scientific knowledge and technology. The terminology used to refer to persons with disabilities has also changed over the years, and many outdated terms have been replaced.

THE BEGINNINGS OF SPECIAL EDUCATION SERVICES
The first special education class in the U.S. was established for “the deaf” in Boston in 1869. Nearly 30 years later, in 1896, the first special education class for the “mentally retarded” was organized in Providence, Rhode Island, followed by classes in Chicago and Boston in 1899, and New York City in 1900. A class for “crippled children” was also started in Chicago in 1899. By 1911, more than 100 large city school systems had special day schools and special education classes. By the 1920s, over two-thirds of the large cities in the U.S. had special class programs, but they served only a small percentage of all children with disabilities. Most children with moderate to severe levels of disability were either admitted to institutions or residential schools or they remained at home. Children with less severe levels of disability were often enrolled in regular education classes without any type of additional assistance. Without support, many children eventually dropped out of school.
Special education programs continued to expand until 1930, but then the momentum slowed down. During the 1930s and 1940s, special public school classes gave way to institutionalization and segregation of children with disabilities. Institutions became overcrowded and understaffed with few actual training programs, and the level of care given to the residents was largely custodial.

After World War II, tens of thousands of young men and women came home from war with disabilities. Americans began to change their attitudes because of the return of these young soldiers and became more sensitive to their needs. First, new services were provided for the veterans of war, and then gradually expanded to children and other persons with disabilities. Between 1947 and 1980, the number of students in public school special education programs increased by more than 700 percent!

Today, Americans believe that education is a right of ALL children and is a means for preparing them to meet the demands of their environment, to learn, and to live as fulfilling, productive lives as possible.

ACCESSING SERVICES FOR YOUR CHILD
Since the 1960s, many federal laws have resulted in increased funding, research, grants, teacher training and direct services for children with disabilities. The most significant legislation passed by Congress is Public Law 94-142, The Education for All Handicapped Children Act of 1975, sometimes known as the Bill of Rights for Children with Disabilities.

The Education for All Handicapped Children Act was reauthorized by Congress in 1983 and 1986. When it was reauthorized again in 1990, it was renamed the Individuals with Disabilities Education Act (IDEA), and it is the federal law that currently governs all public education services to children with disabilities in the United States. Each state or territory develops its own policies for carrying out this Act. The IDEA was most recently reauthorized by Congress in 2004, and renamed as the Individuals with Disabilities Education Improvement Act of 2004.

The services that are available to your child will depend on your child’s age. Learning about and getting services for your child can sometimes be complex, but there will be many people to help you along the way.
Many of the words you encounter here may be new to you, but it is important to begin learning them. Many terms are defined in the “Dictionary of Terms” in Appendix C.

In addition to the agencies listed later in this chapter, you can contact the Florida Directory of Early Childhood Services (commonly known as the Central Directory) for information about all disability services in Florida.

**Florida Central Directory**
Children’s Forum
2807 Remington Green Circle
Tallahassee, FL 32308
Toll Free (800) 654-4440
Local (850) 487-6301
Fax (850) 922-9156
lalong@centraldirectory.org
www.centraldirectory.org

**EARLY INTERVENTION SERVICES**
**(BIRTH TO 3 YEARS)**

**What are Early Intervention Services?**
Early intervention services are special services for eligible infants and toddlers and their families made available through “Part C” of the Individuals with Disabilities Education Act (IDEA). These services are designed to identify developmental delays as early as possible and to meet children’s needs in five developmental areas:

- Physical development
- Cognitive development
- Communication
- Social and emotional development
- Adaptive development.

In Florida, the “Part C” program of the IDEA is known as “Early Steps,” and it is administered by Children’s Medical Services (CMS) within the Florida Department of Health, along with guidance from the Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT). The Early Steps network serves Florida’s infants and toddlers up to age 36 months with a developmental delay or a condition that places them at risk for developmental delay. Fifteen local Early Steps sites are located across the state. The toll-free number for the main Early Steps office is (800) 654-4440 and the website is found at [www.cms-kids.com/EarlyStepsHome.htm](http://www.cms-kids.com/EarlyStepsHome.htm).

Part C early intervention is designed to offer services and supports to families to enable them to help their child develop within their communities and can be
offered through a variety of public or private agencies. Services are provided within the “natural environment” or the locations where children without disabilities are found such as at home, early care and education, family child care or community recreation or development programs. Examples of early intervention services and supports include home-based speech and language therapy to help you increase your child’s communication skills, consultation to the child care provider by the physical therapist to help with walking within the classroom and playground, and developmental resources and information for your family to identify natural learning opportunities throughout the day to support your child’s play skills.

**Initial Evaluation**
Under the IDEA, a complete evaluation of your child is necessary to determine whether she is eligible for early intervention services; however, if your child has an “established condition,” which is a condition that has a high probability of resulting in a disability or developmental delay, she will not need an evaluation. You can get the process started by talking to your pediatrician or by contacting the main Early Steps office directly. The evaluation is provided at no cost to you. Once you are in contact with Early Steps, you will be assigned a service coordinator to help guide you through the process. This service coordinator will be familiar with the policies of Early Steps and will be able to help you with your initial questions.

To determine if your child is eligible for Early Steps services, a multidisciplinary team will conduct an evaluation of your child. The evaluation process will also help to identify the nature of your child’s strengths, delays, and difficulties and your priorities for helping your child.

“Multidisciplinary” means that the evaluation team is made up of qualified people who have different areas of training and experience. Together, they have specialized knowledge of children’s speech and language skills, physical abilities, hearing and vision, and other important areas of development. They know how to work with very young children to discover if a child has a developmental delay or is developing within normal ranges. The
team members may evaluate your child individually or as a group.

“Evaluation” refers to the procedures used to determine if your child is eligible for early intervention services. As part of the evaluation, the team members will observe your child, ask your child to do certain things, talk to you and your child, and use other methods to gather information. These procedures will help the team find out how your child functions in all five areas of development. Following the evaluation, you and a team of professionals will meet and review all of the results and reports. The members of the team will talk with you about whether your child meets the criteria for Early Steps services; in other words, whether he has a developmental delay, an established physical or mental condition, or is at risk for having a developmental delay. If so, then your child will probably be found eligible for services.

If found to be eligible and you are interested in services and supports, additional information will be gathered through an assessment. “Assessment” refers to the ongoing process of gathering information and using the information to determine the types of services and supports that match your priorities for your child and family. With your consent, your family’s needs and interests will also be discussed. This process is intended to identify the resources, priorities, concerns, and needs of your family. It also identifies the supports and services you may need to enhance your family’s capacity to meet your child’s developmental needs.

When conducting the evaluation and assessment, the team members may get information from some or all of the following sources:

- Doctor’s reports
- Results of developmental tests given to your child
- Your child’s medical and developmental history
- Observations and feedback from all members of the multidisciplinary team, including you as the parent
- Interviews and conversations with you and other family members or caregivers
- Any other important observations, records, or reports about your child.

**Role of the Service Coordinator**

If your child is found to be eligible for Early Steps services, a service coordinator will assist you with accessing needed services. The service coordinator will be
familiar with the early intervention programs and services in your community. This person can also help you locate other services in your area, such as recreation, child care, respite services, or family support groups. The service coordinator will work with your family as long as your child is receiving early intervention services and, sometime after your child turns 2 years old, the coordinator will help your family prepare to move on to programs for children ages 3 to 5, in a process known as “transition.”

The Individualized Family Support Plan
The family and the service coordinator will work with other professionals, as appropriate, to develop a written “Individualized Family Support Plan,” or IFSP. The guiding principle of the IFSP is that the family is the child’s greatest resource and that a child’s needs are closely tied to the needs

THE INDIVIDUALIZED FAMILY SUPPORT PLAN
Your child’s IFSP must include the following:

- Your child’s developmental levels
- Family information (with your consent), including your resources, priorities, and concerns and those of other family members closely involved with your child
- The major results or outcomes expected to be achieved for your child and family
- The specific services your child will receive
- Where in the “natural environment” of the child (such as in the home or somewhere in the community) services will be provided
- When your child will receive services
- The number of days or sessions your child will receive each service and how long each session will last
- Whether the service will be provided on a one-to-one basis or in a group,
- Who will pay for the services
- The name of the service coordinator overseeing the implementation of the IFSP
- The steps to be taken to support your child’s transition out of early intervention and into another program when the time comes.

The IFSP may also identify services your family may have interest in, such as financial services or finding information about disabilities.

Love is a fruit in season at all times, and within reach of every hand.
MOTHER TERESA
of the family. The best way, then, to support children and meet their needs is to support and build upon the strengths of the family.

Parents are the most important part of the IFSP team, and the IFSP is a plan for the whole family. Other team members will be involved on the basis of the child’s needs and may include medical personnel, therapists, infant and toddler developmental specialists, social workers, and others. The IFSP is reviewed at least every six months and is updated at least once a year. The IFSP must be completely explained to you and your suggestions must be considered. You must give your written consent before any services can begin. If you do not give your consent in writing, your child cannot receive services. The IFSP is different for each child and family, but the services that can be included are:

- Family training, counseling and home visits
- Special instruction
- Speech-language pathology services (commonly known as speech therapy)
- Audiology services (for children with hearing impairments)
- Occupational therapy
- Physical therapy
- Psychological services
- Medical services (but only for diagnostic or evaluation services)
- Health services to enable your child to benefit from the other services
- Social work services
- Assistive technology devices and services
- Transportation
- Nutrition services
- Service coordination services.

The cost of the services your child will receive may be covered by your health insurance, by Medicaid, or by Indian Health Services (for American Indians and Alaska Natives), or they may be provided at no cost to you through Early Steps. Every effort is made to provide services and supports to all infants and toddlers who need them, regardless of family income. Services cannot be denied to a child because the family is not able to pay for them. As time goes by and your child is receiving services, you will probably have more questions, such as:

- How do I know that what I am doing is helping my child?
- What do I do if I am not satisfied with my child’s assessment, services, or progress?
What happens when my child turns 3 and is too old for Early Steps?

Will my child still be eligible for services when she is ready for preschool?

For answers to your questions, you can talk with your service coordinator or contact a parent support group or a professional organization serving young children with disabilities.

**SPECIAL EDUCATION AND RELATED SERVICES (3-5 YEARS)**

**What are Special Education and Related Services?**

Special education is instruction that is specifically designed to meet the educational needs of children with developmental delays or disabilities. It also refers to other services, known as “related services,” that may be needed to help a child benefit from educational programs.

**RELATED SERVICES**

The following services are included within the definition of related services:

- Audiology services
- Psychological services
- Speech and language pathology services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services, including rehabilitation counseling
- Orientation and mobility services (for children with vision impairments)
- Medical services for diagnostic or evaluation purposes
- School health services
- Social work services in schools
- Parent counseling and training
- Transportation.
special education. Special education is provided free of charge through your public school district for eligible children who are 3 through 21 years of age. Pre-kindergarten programs are designed for children 3 to 5 years of age, through the year in which your child “transitions” into kindergarten (the year in which your child turns 5 before September 1). Special education is made available through “Part B” of the Individuals with Disabilities Education Act (IDEA).

Available Related Services
The IDEA defines “related services” as “transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education.”

Children are not eligible for related services until they have been found eligible for special education services. Once eligible, it will be decided which, if any, of the related services are needed by any individual child.

Getting Started with Special Education Services
If your child’s disability was identified before the age of 3 and your family is already receiving early intervention services, your service coordinator will help you move into special education services when your child turns 3. This process is known as “transition” from one program to another, and you and your service coordinator will begin transition planning well before your child turns 3 so that all plans can be in place by the date of your child’s third birthday.

However, if your child has not been participating in early intervention services but it is now suspected that he may have a developmental delay or disability, you will want to seek an evaluation for your child. Again, your pediatrician can help by making a referral for you. You can also contact the Child Find Specialist at your local Florida Diagnostic and Learning Resources System (FDLRS) center, or you can contact the Pre-Kindergarten Exceptional Student Education office in your local school district. FDLRS is a statewide network of centers that provides support services to public school district programs serving children with disabilities and their families. Each center includes specialists in the areas of Child Find, Parent Services, Human Resource Development, and Technology. “Child Find” is the program that can help you get started with the referral process.

In addition, you can begin the referral process by calling 800-654-4440 and speaking with specialists at Early Steps, FDLRS/Child Find or the Central Directory.

Evaluation is Required
Just as with early intervention services, a complete evaluation of your child is required under the IDEA to determine whether she is eligible for special education services. This evaluation is also provided to you at no cost.

“Evaluation” in this case refers to the procedures used to determine whether your child has a disability and the extent of the special education and related services that she needs. The evaluation will be conducted
by school district staff. The evaluation team may include staff members such as a school psychologist, educational diagnostician, social worker, and speech, occupational, and/or physical therapist. The composition of the evaluation team is based on the needs of each child.

The evaluation team will begin by looking at what is already known about your child and may also recommend gathering additional information. They may use the following sources of information:

- Doctor’s reports
- Results of developmental tests given to your child
- Developmental and behavioral checklists
- Your child’s medical history

THE CONTINUUM OF SPECIAL EDUCATION PLACEMENTS IN FLORIDA (AGES 3 THROUGH 21 YEARS)

Each child may require a different combination of services and settings. In Florida, special services are organized so that children can receive instruction in one or more of the following ways:

- Supplementary consultation or related services. Supplementary consultation or related services is the provision of assistance to students in regular, vocational, or special education classes.
- Resource room. Resource room special instruction is supplemental instruction to students who receive their major educational program in other regular or vocational classes.
- Special class. Special class is the provision of instruction to students who receive the major portion of their educational program in special classes located in a regular school.
- Special day school. A special day school is a school which is administratively separate from regular schools and is organized to serve one or more categories of students with disabilities.
- Residential school. A residential school is a special school which, in addition to providing special education and related services, provides room and board.
- Special class in a hospital or facility operated by a non-educational agency.
- Individual instruction in a hospital or home.
- In addition, districts may provide supplementary instructional personnel to public or nonpublic preschool or day care programs for the instruction of pre-kindergarten students with disabilities.

6A-60311 Florida Administrative Code
• Observations and assessments conducted in your child’s current educational setting (if any)
• Observations and feedback from all members of the evaluation team, including you as parents
• Any other important observations, records, or reports about your child.

The Individual Educational Plan

After the evaluation is completed, school district personnel will meet with you to go over the results and determine whether your child is eligible for services. You are a part of this decision.

If your child is found to be eligible for special education services, you and the school district personnel will develop a written plan known as an “Individual Educational Plan,” or IEP. Your child’s IEP is a written statement of the educational program designed to meet your child’s individual needs. Every child who receives special education services must have an IEP, and you will be asked to sign the IEP to indicate your participation in the meeting. If this is the first IEP meeting, you will also be asked to sign a consent for your child to receive special education services. The IEP has two general purposes:

• To set reasonable learning goals for your child, and
• To state the services that the school district will provide for your child.

The IEP will describe what your child can do and knows now, what special education and related services will be provided, the date services will begin, the length of time your child is expected to need the service, how often your child will receive or use the service, where the service will be provided (e.g. regular education class, resource room) and the annual goals that describe what your child needs to learn. The IEP team must consider the least restrictive environment (LRE). This means that your child must be educated to the greatest extent possible with “typically developing” children. The IEP must explain the extent to which your child will not participate with “typically developing” children.

Your child’s IEP team may include these individuals:

• At least one of your child’s regular education teachers (if your child is participating in an educational setting)
• Individuals (invited by you or the school district) with knowledge or special expertise about your child
• An administrator in the school district who knows about special education policies, children with disabilities, the general school curriculum, and available resources
• At least one special education teacher or service provider
• You, as parents or guardians
• Your child, if appropriate
• Someone who understands and can explain the evaluation results (this could be one of the school district staff members listed above)
• Other qualified professionals, as appropriate (such as a school psychologist, occupational therapist, speech therapist, physical therapist, medical specialist or others).

THE RIGHTS OF PARENTS UNDER THE IDEA
The IDEA clearly defines the rights of children with disabilities and their parents. In general, the law guarantees that you, as a parent, have the right to participate in the educational decision-making process for your child. More specifically, your rights include:

• The right to a free, appropriate public education for your child.
• The right to request an evaluation if you think your child needs special education and related services.
• The right to be notified whenever the school wants to evaluate your child, wants to change your child’s educational placement, or refuses your request for an evaluation of your child.
• The right to obtain an independent educational evaluation if you disagree with the outcome of the school’s evaluation.
• The right to “informed consent.” Informed consent means that school staff must have your written consent before they do an individual evaluation of your child, place your child and provide

GETTING READY FOR THE IEP MEETING
• Think about your goals for your child’s long-term future.
• Make a list of things your child can do, likes to do, and needs to learn.
• Make a list of the type of assistance your child needs.
• Ask to see your child’s school records and evaluations. Read them carefully.
• Ask the school for a blank IEP form so you can become familiar with it.
• Let the school know in advance if you will need a translator during the meeting.
• Let the school know in advance if you need to change the meeting time or place.
• Talk to other parents about their IEP experiences.
• Ask a friend, another parent, or an advocate to attend the meeting with you. Let the school know if you have invited someone to attend.
• Ask the names and positions of the school district staff who will be attending.

special education services for the first time, and do individual tests or other evaluation activities as part of a reevaluation of your child. Your consent is voluntary and may be withdrawn before the activity occurs.

- The right to request a reevaluation. The school must reevaluate your child at least once every three years, unless both the parent and the school agree that a reevaluation is not necessary. However, your child’s IEP must be reviewed at least once during each calendar year.

- The right to receive communication in your primary language to the extent possible to ensure that you understand all oral and written communication, including the right to an interpreter if you are hearing impaired or if your primary language is not English.

- The right to review all your child’s school records and obtain copies of these records, although the school may charge you a reasonable fee for making the copies. If you feel any of the information in your child’s records is inaccurate, misleading, or violates the privacy of your child, you may request that the information be changed.

- The right to be fully informed by the school of all rights that are provided to you under the law.

- The right to participate in the development of your child’s IEP, including the placement decision. The school must notify you of the IEP meeting and arrange it at a time and place that is mutually agreeable.

- The right to request mediation or a due process hearing to resolve differences with the school that cannot be resolved informally. Be sure to make your request in writing, date your request, and keep a copy.

THE RESPONSIBILITIES OF PARENTS IN THE EDUCATIONAL PROCESS

Parents of children with disabilities have a vital role to play in the education of their children. Just as you have certain rights, you also have responsibilities. Knowing

A HELPFUL NOTE

As you can see, there is much to learn about early intervention services and special education and related services. Many of the procedures, and especially the IEP process, may seem complex at first. Don’t hesitate to talk with other “experienced” parents to learn more about these services. As is often the case, parents who have already navigated “the system” will be one of your best sources of information and support.
and following through on your responsibilities will help ensure that you are a contributing partner in the decisions made on behalf of your child. Although these responsibilities may vary based on the nature of your child’s disability, you may want to consider these suggestions:

- Develop a partnership with the school.
- Learn as much as you can about your rights and the rights of your child.
- Keep records.
- Ask for clarification on any aspects of your child’s program that are unclear to you.
- Make sure you understand the program specified in the IEP before signing it.
- Monitor your child’s progress.
- Discuss any problems that may arise.
- Join a parent organization.
- When you feel teachers and school personnel are doing a good job, tell them.

**CHOOSING CHILD CARE**

A child care setting may be another part of your child’s daily life. For some children, educational programs may take place in a child care setting, where they spend all of their day receiving early intervention or special education services, along with routine care, meals and rest. Other children may receive their special services in a public or private school classroom during the 6-hour school day, and then be transported to a child care setting for additional hours of care while their parents are working. Some children may need child care services only during the summer months. Given all the possibilities, many parents find that they need child care services for their child at one time or another.

Your need for child care will also depend on your family’s situation. If you are a “stay-at-home” mother or father, you may not need child care on a regular basis, but rather will only need occasional “drop-in” care for a few hours while you tend to an appointment or shopping, or you may need occasional respite care through a respite care program. If your child is receiving early intervention services (birth through 2 years) or special education services (3-5 years), you may or may not need additional child care services, depending on the hours your child is receiving services versus the number of hours...
of care you need for your employment, enrollment in school, or other activities.

You may already know that finding child care is hard work. There are many factors to consider and many visits to be made to find a program that feels right to you. If you have a child who needs special attention or special services due to a disability, your search can be even more challenging.

Prior to the 1990s, there was a limited number of child care services available to young children with disabilities, and the majority of these programs had “segregated” services. In other words, many of these programs provided care and education only for children with disabilities, who were often excluded from other child care programs serving children with typical development.

In January 1990, the Americans with Disabilities Act (the “ADA”) was signed into law in the United States. This civil rights law has many important provisions for all people with disabilities, and it is designed to prevent discrimination in the workplace and in the community. One of the most important implications for young children is that the ADA prohibits family child care homes and child care centers from discriminating against children with special needs on the basis of their disability. All child care providers must make “reasonable accommodations” for your child and, in most cases, may not charge you more for your child’s care than they would charge any other parent. There is much more to know about the ADA, but the main point here is that you can feel confident in approaching all child care providers to discuss the possibility of enrolling your child. That does not mean that every child care setting in your community will be an appropriate one for your child, but it does mean that every provider should be willing to talk with you. Perhaps you have other children who attend child care and you may want all of your children to be enrolled in the same program. That is not an unreasonable expectation and it should now be an option for you in some programs.

There are several different types of child care to investigate. Each one has certain advantages and disadvantages, depending on your wants, needs and family situation.

**Family Child Care Homes**

Family child care homes are operated by a child care provider in his or her own home. In Florida, family child care homes can be either registered or licensed (depending...
on the county) by the Florida Department of Children and Families (DCF). Some counties in Florida require all family child care homes to be licensed; others do not. Friends, neighbors, and relatives can also provide child care as long as they do not care for children from more than one unrelated family in addition to their own children. In this case, the provider is not required to register or obtain a license from DCF.

Family child care homes can provide care for up to a certain number of children (depending on ages and local regulations), and large family child care homes (with 2 or more adults) can provide care for larger numbers of children. Some family child care providers have experience caring for children with disabilities who may be other children in their care or members of their own families. Other providers may be willing to learn to care for your child. Often, family child care providers are able to be a bit more flexible in their hours of operation and their practices than child care centers. Because of this flexibility and smaller group size, family child care homes can often be a good option for young children with disabilities. Of course, you must take great care in selecting and monitoring the care your child receives inside someone else’s private home.

**Child Care Centers**

Child care centers are operated in facilities in the community. In Florida, all child care centers must be licensed by Florida DCF, with the exception of some faith-based facilities that may choose a religious exemption or some programs based in public schools that may choose a public school exemption. Licensing by DCF establishes standards that all centers must meet and maintain. These standards generally address health and safety features of the programs and do not guarantee that the educational program is of high quality. Again, you must bear the responsibility for examining the daily operations of a child care center to make sure it is providing services that meet your expectations. Most experts will advise you to make several visits to a center before making your final decision.

You can also review the licensing inspection reports for each center by contacting the local licensing agency in your county or by accessing them online at www.myflorida.com/childcare and selecting “Provider Search”. These reports can assist you in making your decision. You can also receive help and advice from the educational professionals who are involved with you and your child through your disability services system. Even though you may not have as many options for your child as parents of children without disabilities, you should still be careful choosing the place your child will spend time each day.

You should not be expected to place your child in a setting that makes you feel uncomfortable just because it appears to be
the only one available. Keep asking and keep looking.

**In-Home Caregivers, Babysitters, and Nannies**
These individuals are people who come into your home to care for your child. Generally, you are responsible for finding, interviewing, and hiring such individuals, although some cities in Florida may have established “nanny” services that can do this work for you. Paying for care in your home is often more expensive than either family child care or center care. Great attention should be given to selecting an individual who will provide child care in your home, but using this type of care also gives you the opportunity to find a person who has experience or willingness in caring for a child with a disability. Consider using in-depth interviews, reference checks, and a trial period to determine if an in-home caregiver will be appropriate for your family.

**Shared In-Home Caregiver Arrangements**
In this arrangement, two or more families combine their resources to hire one caregiver who will take care of their children. The care may take place in one home or rotate among homes, and is generally less expensive than each family hiring its own caregiver. You may have friends or co-workers with children who would benefit from this type of arrangement. One benefit for children with disabilities would be having interactions with typical peers while still being part of a relatively small group. Participating parents would need to work out the details of the arrangement to everyone’s satisfaction and would need to carefully interview and screen the potential caregiver.

**In-Home Support Services**
There may be times in your child’s life when you need the services of a trained nurse or support worker in your home. Some of these times might occur when your child returns home from a hospital admission, when your child becomes seriously ill, or when you are unable to perform required medical procedures for your child. In-home support services are generally covered by your private medical insurance or by your child’s Medicaid coverage, administered through the Florida Agency for Persons with Disabilities. In either case, in-home support services are subject to certain limits, generally on an annual basis. In addition, it is important to check with the agency covering your costs for in-home services for restrictions based on age and on certain categories of disability that may not be eligible.
Services for Military Families

You can get information about early intervention services (Birth-2 years) and special education services (3-5 years) for military families from several sources.

The Specialized Training of Military Parents (STOMP) organization provides information and assistance to military families, both in the United States and overseas, who have children with disabilities. The STOMP staff is made up of parents of children with disabilities who are trained to work with other parents. As spouses of members of the military, the staff understands the unique needs of military families.

You can contact STOMP at:

Specialized Training of Military Parents (STOMP)
6316 South 12th Street
Tacoma, WA 98465
(253) 565-2266 (V/TTY)
(800) 5-PARENT (V/TTY)
www.stompproject.org

The U.S. Department of Defense Education Activity (DoDEA) office provides extensive guidance for military families with children with disabilities who are living in the United States or overseas. A good online resource about available services can be found at www.dodea.edu/instruction/curriculum/special-ed/index.htm

You can contact DoDEA at:

Department of Defense Education Activity (DoDEA)
4040 North Fairfax Drive
Arlington, VA 22203
(703) 696-4493
www.dodea.edu

Services for Adoptive and Foster Families with Children with Disabilities

Adoptive Families. In general, the process for getting early intervention services (Birth-2 years) or special education services (3-5 years) for adopted children with disabilities is the same as the process for all children with disabilities.

Adoptive Families of America is an organization with a nationwide family support network of adoptive families. The main focus of this organization is to provide general help and information to all adoptive families, but its bimonthly parent support magazine includes information and resources for families of adopted children who have disabilities.

You can contact this organization at:
Adoptive Families of America, Inc. (AFA)
3333 Highway 100, N
Minneapolis, MN 66422
(612) 535-4829
www.adoptivefamilies.com

Foster Families. Families who provide foster homes for children who have disabilities can contact the Florida Department of Health (Early Steps, Birth-2 years) or the Florida Department of Education (Bureau of Exceptional Education and Student Services, 3-5 years) for information about obtaining services. You may also want to contact the National Foster Parent Association, Inc. (NFPA). This national, nonprofit organization offers information and support to all foster parents. Members of this group receive a bimonthly newsletter and have access to nearly 500 NFPA resource materials. You can contact this organization at:

National Foster Parent Association, Inc. (NFPA)
7512 Stanich Ave. #6
Gig Harbor, WA 98335
(253) 853-4000
(800) 557-5238
(253) 853-4001 fax
www.nfpainc.org

Services for Native American Families Living on Reservations

The IDEA requirements for early intervention services (Birth-2 years) and special educations services (3-5 years) include Native American children living on reservations in Florida. Information on these services is available from the Florida Department of Health (Early Steps, Birth-2 years) or from the Florida Department of Education (Bureau of Exceptional Education and Student Services, 3-5 years). Other sources of information include the office of the tribal leader or the tribal education committee. You may also contact:

Bureau of Indian Affairs
Office of Indian Education Programs
1849 C Street NW,
MS-3512 MIB
Washington, DC 20240
(202) 208-6123
www.oiep.bia.edu
The term “inclusion” is used widely in educational circles and particularly in the disability field, but there is actually no one official definition for this word. The word “inclusion” does not appear in the Individuals with Disabilities Education Act (IDEA), and it has never been defined in federal legislation.

In fact, there is a great deal of confusion about the term “inclusion.” In the past, the words “mainstreaming” and “integration” have been used to talk about bringing children with disabilities into the “mainstream” of life, but neither one really means the same thing as inclusion.

“Mainstreaming” became a popular term in the early 1970s, when efforts to include children with disabilities in regular programs and classrooms first began to gain recognition. At that time, children still usually received most of their education in a separate setting but were “mainstreamed” for a part of their day into a regular education setting. The term “integration” was borrowed from the civil rights movement of the 1960s on behalf of African-American citizens. This movement helped the nation realize that segregation wasn’t good for anyone, including children with disabilities. But the term “integration” didn’t quite capture the essence of being fully included in society, and so the word “inclusion” came into use.

WHAT IS INCLUSION?
In a sense, inclusion is a philosophy. It is a value that supports the right of all children, regardless of their abilities, to participate actively in “natural settings” in their communities. “Natural settings” are those places where a child would spend time had he not had a disability. These settings include, but are not limited to home, preschool
programs, Head Start programs, kindergartens, public school classrooms in the child’s home school zone, child care centers, places of worship, recreational sites (such as community playgrounds), and other settings that all children and families enjoy (restaurants, theaters, hotels, and so on). In general, inclusion is full participation in family and community life for all people, including persons with disabilities.

When talking about education for children, inclusion means placement in the programs and classrooms where a child would be enrolled had she not had a disability, which means a regular child care center, a regular preschool program, or a regular classroom in the school for which she is zoned. Even though the word “inclusion” is not specifically mentioned, there is legal support for inclusion in the IDEA in the concept of “least restrictive environment.”

The search for the “least restrictive environment” for every child begins with a regular education classroom in the child’s home school; therefore, that is the first option that the IFSP or IEP committee must consider. Only after it is determined that the child cannot be successful in a regular education class, even with “appropriate aids and supports,” can the committee recommend a more restrictive placement for the child.

Inclusion has become an issue of much discussion in recent years. On one hand, advocates of inclusion have evidence – legal, educational, social, and moral – that inclusion is the best way to serve children in our schools and communities. On the other hand, there are organizations and individuals who are concerned about the movement toward inclusion. Some school administrators worry about placing children in regular classrooms without the supports and services they need to succeed. They also worry about the effects of such placements on teachers and other children. Some teacher organizations are concerned that regular education teachers do not get adequate training in their college classes to prepare them to meet the educational needs of children with disabilities. It is likely that almost everyone agrees with inclusion in theory, but when it comes to making decisions about individual children, some disagreement can be expected.

This is also true for the parents of children with disabilities. As a parent, you no doubt
want your child to be fully accepted in society. Yet when it comes to enrolling him in a regular child care center, for example, you may have doubts or concerns. Other parents, though, strongly believe in the value of inclusion for their children and work for inclusion as actively as they can.

Does that mean that one view is right and the other is wrong? No, not at all. There is not just one right answer for every family. You will come to your own decisions about the value of inclusion for your child, and your decision will be based on many factors. The severity of your child’s disability will probably be one factor. Your perceptions about available services and supports will be another, and your beliefs about people and society in general will also figure into your feelings about inclusion. In general, American society is moving toward greater inclusion of persons with disabilities, and most people would agree this is right and good. In fact, virtually all parents of children with disabilities would agree that the philosophy of inclusion is a good one; nevertheless, those parents who are not seeking inclusion for their own children have shared these reasons:

- Parents believe that the type or severity of their child’s disability will prevent him from benefiting from being in a regular education classroom. Parents have cited characteristics such as medical needs, sensory impairments, lack of self-help skills, lack of language, the presence of seizures, and the presence of multiple disabilities as reasons why they feel regular classroom placement would not be appropriate for their children.
- Parents believe that inclusion would overburden teachers or have a negative impact on other children in the class. Because a child with a disability might require additional care or attention, some parents feel that teachers could not adequately meet the needs of all children. Parents may also have concerns about the lack of specially-trained teachers and assistants.
- Parents may believe that their child’s needs could not be met in a classroom that has an emphasis on an academic curriculum of reading, writing, math, and so on. These parents often report that they would prefer to have their children in an environment that emphasizes basic living or functional skills.
- Parents may be fearful that their children would be mistreated, harmed, or ridiculed by other children in regular education settings.
• Parents worry that their children, in general, would be neglected or at the least would not receive the individualized attention or specialized services they need in a regular education classroom.
• Parents believe that there is a benefit to having other children with similar needs and disabilities in their child’s classroom for the formation of friendships and enjoyment of similar activities.
• Parents report that such relationships can be important in their child’s life. This line of thinking supports the idea that friendships between children with disabilities are no less valuable than friendships with non-disabled peers.

Other parents are strong supporters of inclusion programs for their child’s education. These parents tend to place great emphasis on the social and emotional aspects of their child’s daily experience. They are not necessarily parents of children with less severe levels of disability, because we know that parents with children at all levels of disability can be devoted advocates for inclusion. Parents have reported these as some of the reasons for supporting inclusion for their children:

• Parents believe that other children in regular education will become more sensitive and knowledgeable about disabilities, thereby leading to a greater acceptance of persons with disabilities in the general society as these children grow up.
• Parents believe that their children will learn more in regular education programs due to higher expectations and the presence of peers with typical developmental skills as role models.
• Parents believe that their children will grow in their social development, even if they don’t show as much improvement in their academic work, meaning that parents believe that having typical friends and being included in society is more important in the long run than any other consideration.
• Parents want their child with a disability to go to the same school as their other children or with other children in the neighborhood.
• Parents believe that inclusion is the right thing to do, and that children with disabilities should not be segregated in separate classrooms.
The truth is, there are no simple answers about inclusion for individual families. Just as the individuality of each child must be respected in the planning of educational services, so must the individual nature of families be respected as well. One size does not fit all. Given support and information, families will generally make decisions for their children that best serve their family system and priorities.

WHAT DOES INCLUSION LOOK LIKE?
There is still much to be done to make inclusive school settings available to all children. The encouraging news is that educators do know how children with disabilities can best be served in regular education settings. Even though it is not yet happening in all places, the practice of inclusion has been studied for more than 30 years.

It is now known that a number of conditions must be present in order for inclusion to be successful for everyone involved. These conditions can be organized into five categories:

**Attitudes and Beliefs**
- Regular education teachers believe that children with disabilities belong in their classrooms.
- All regular education staff accept responsibility for the educational outcomes of children with disabilities. They do not believe it’s someone else’s job.
- Regular education teachers are given preparation and information that a child with a disability will be joining the class.
- Children are helped to understand their classmates’ disabilities, and interactions among the children are supported.
- Parents are kept informed and support their child’s placement in the regular education setting.
- All special education staff are committed to working together with the regular education staff.
- All school staff (including paraprofessionals, counselors, lunch room staff, bus drivers, etc.) receive training in the value and practice of inclusion.

**Services and Accommodations**
- All services needed by the child are available, such as speech therapy, occupational therapy, physical therapy, transportation, additional staff member in the classroom and behavioral supports, and so on.
- Accommodations needed by the child can be made, such as accessibility to
the classroom and playground, adaptive toys and equipment, environmental modifications (such as noise levels) and assistive devices.

**School Support**
- The director, administrator, or principal understands the needs of children with disabilities and supports their inclusion in the program.
- Adequate numbers of personnel are available.
- Policies and procedures are put into place to support and monitor the progress of children with disabilities.

**Collaboration**
- Special education staff are part of the planning and instructional team.
- A team approach is used for problem-solving and implementing programs.

**Instructional Methods**
- Teachers have the knowledge and skills needed to adapt the curriculum to meet the individualized needs of all children.
- A variety of instructional methods are available.
- Teachers create a cooperative learning environment and promote socialization among all children.

If all these conditions could be met in every classroom, you probably would agree that it would be a good place for your child. If everyone can agree on that, then everyone can probably agree that this “ideal situation” is what we must work toward for all of our children.

**THE RESPONSIBILITIES OF PARENTS**

Historically, parents have played an important role in the United States in gaining services for their children with disabilities. Even though it may not always feel that way, you can have a big impact on getting improved services for your child and on improving services for all children over time.

You may have already realized that you are the most important advocate your child will ever have. From seeking medical care to advocating for inclusive settings, you have an important role to play in making changes in the systems that serve children with dis-
abilities. It may not be a role you asked for, but it is a role you now have. You may even surprise yourself when you find out how passionate you can be when you are advocating for your child’s rights and needs. Inclusion for your child refers to much more than her educational setting, but this will be one of the first places you will come face-to-face with decisions about inclusion.

As you think about a regular education setting for your child, keep this thought in mind: It is not your child’s job to be “ready” for a regular classroom; it is the school’s job to make the classroom ready for your child. Technically, your child may never be “ready” for an inclusive class if that means she has to be walking, or toilet-trained, or so on. The point of inclusion is that everyone is ready, and “everyone belongs.”

Some parents seek inclusive education for their child, and others do not. If you decide that you are not ready for inclusion for your child, or that a regular education classroom is not in your child’s best interest at this time, it is okay to say so to your child’s planning team. The team members may try to explain why a regular education classroom is best for your child, or they may agree with you that the services your child needs cannot be provided in any of their current classrooms. If you agree to place your child in a special education setting, it does not mean you can’t change your mind later. You have the right to ask to have your child’s progress reviewed at any time.

Try to keep your mind open to the benefits of inclusion. No one wants to go back to the days of institutions and an “out of sight, out of mind” way of thinking. If you choose a special education setting or residential school for your child, try to think of other ways that you can expose your child to his typical peers, such as at the playground, in play groups, or other programs in the community.

On the other hand, you may want a regular class placement for your child, only to find that no regular settings are available for your child’s specific needs in your community. The number of inclusive programs varies from community to community, and may be more difficult to find if you live in certain areas. Most educational programs will try to respond to your needs, especially if you are persistent. In some cases, you may need to be very persistent to make certain your child is receiving the most time possible...
with typical peers. Always try to keep your goals for your child in the front of your mind and make each decision you face based on those goals.

THE BENEFITS OF INCLUSIVE EDUCATION

You may or may not agree that your child will receive the best educational experience in a regular education setting at this time. Many experts agree, however, that when inclusive education is done well, there are many benefits that can be expected. These benefits can affect not only children with disabilities but also children with typical development, their families, classroom teachers, and the community at large according to these categories:

Children with special needs may
• Experience a more complex environment that stimulates developmental progress.
• Increase their social skills and language through interaction with typically developing peers.
• Develop a better understanding of the real world.
• Be better accepted within the community if they participate in a natural setting, thus growing up feeling included rather than excluded.

Children with typical development may
• Learn about differences in human growth and development.
• Become more accepting of their own limitations.
• Become more accepting of individual differences as they learn to work and play with a wider range of children.
• Learn how children with special needs can be models for perseverance and determination in spite of adversity.
• Learn how children with special needs are similar to all other children.

Families of children with special needs may
• Develop more positive attitudes toward their children.
• Gain understanding about a real-world perspective for interpreting their children’s accomplishments and challenges.
• Increase their knowledge of typical child development.
• Learn about age-appropriate activities.
• Feel less socially isolated.
• Improve their perception of themselves as parents.

Families of typically developing children may
• Have opportunities to teach their children about differences in growth and development.
• Develop a greater understanding of persons with disabilities.
• Become more sensitive to the needs of families with children who have disabilities.
• Become advocates for community integration.

Classroom teachers may
• Receive additional training, such as learning how to enhance social interactions, which will help them with all children.
• Develop positive, realistic attitudes toward inclusion.
• Develop new relationships with professional colleagues from various disciplines.
• Receive the personal satisfaction of helping all children make progress and become friends.

The community may
• Understand that if the potential of all children is maximized, children with disabilities are helped to become productive members of society.
• Understand that providing intervention early in a child’s life saves money in the long run, because the effects of disabilities can be modified to varying degrees, enabling children to become more independent.

FOSTERING FRIENDSHIPS FOR YOUR CHILD

All parents know that having friends is an important aspect of a child’s life. Like all parents, parents of children with disabilities want their children to be loved, feel a sense of belonging, and share experiences with their siblings and other children.

Children with disabilities are sometimes at risk of having social interactions only with the adults who work with them, but all children need to interact with other children. Although some friendships develop naturally, it is still important to provide opportunities where friendships can get started. Because your young child can’t make these arrangements for himself, you will need to help him. Here are some ways you can use to expand your child’s social circle:
• Find activities your child enjoys. Learning does not end when the school day ends. By building on your child’s strengths and interests, you can help him find friends who enjoy the same things. Identify activities that keep your child’s attention, bring out the best in him, and bring a smile to his face.

• Use resources in your community. Find out what classes, organizations, and programs are available in your community. Many communities offer a variety of weekend or after-school classes such as swimming, soccer, horseback riding, martial arts, music, dance and art. Other community resources include churches, libraries and parks.

• Share information and raise awareness. It is useful to share information about your child with caregivers, baby sitters, Sunday school teachers, and so on, especially if they have not had experience with children with disabilities. Sharing might include specific information about your child’s strengths, preferences, and ways to encourage her participation in activities.

• Encourage a variety of social relationships. Create different opportunities for your child to connect with other children. For example, you may set up a regular “play date” at your house for one or two other children in the neighborhood. Be sure to prepare in advance to make certain the experience is a positive one. Choose toys that bring children together, such as balls or bubbles or water play, instead of toys that encourage children to play alone, such as books or crayons. You might want to organize a specific activity like baking cookies or a trip to the park. Keep play dates relatively short, so children want to come back soon.

• Identify children who show an interest in your child. Find out who your child plays with at school or which children show a special interest in him. Use this information to decide which children you may want to invite for play dates or other ways to socialize with families in your neighborhood.

• Teach your child specific social skills. Before an interaction can take place, someone must initiate it. Learning how to greet others with a hello, a wave, or a smile is a skill that children can use throughout their lives in many different situations. If your child has difficulty with mobility or speech, you can try
talking to other children and suggesting specific ways they can talk or interact with your child. If your child is able, you can practice some basic social skills at home together, like walking up to each other and saying “hi” or offering to trade one toy for another.

THE IMPORTANCE OF ASSISTIVE TECHNOLOGY

Assistive technology refers to any device that helps a person with a disability to complete everyday tasks. If you break your leg, a TV remote control can be assistive technology. If you have poor eyesight, your glasses are assistive technology.

Assistive technology includes many specialized devices as well, such as “typing telephones” (TTY) for people who are deaf and motorized wheelchairs for people with limited mobility. Assistive technology can be “low-tech” (simple and low-cost), like a pencil grip, or “high-tech” (sophisticated and higher-cost), like a computer. Assistive technology can be critical for the person using it. As an example, if you are dependent on your eyeglasses, think how hard it would be to get through a day without them. Assistive technology assists people with disabilities to be a part of their homes, schools, and communities.

When the Individuals with Disabilities Education Act (IDEA) was revised in 1997, it recognized the importance of assistive technology for children in special education programs. Now, IEP teams must consider your child’s need for devices to help her function as a better “student,” “family member,” or “friend.” If the need for assistive technology seems likely, the school district must provide these services:

- A qualified evaluator must conduct an assistive technology evaluation.
- If the evaluator recommends a device, it must be provided.
- If you, your child, or the staff in your child’s classroom need training to use the device, that training must be provided as well.

Types of Assistive Technology

There are many types of assistive technology. These are some examples:

- **Access and Environmental Controls:** Switches, special keyboards or mice, and remote controls that allow a child with a physical disability to control things in his or her environment. This also includes things that help people get around the community, like ramps, automatic door openers and Braille signs.
• **Aids to Daily Living:** Special tools for daily activities, like brushing teeth or dressing, and specially designed toilet seats for children who need help with self-care.

• **Assistive Listening:** Hearing aids, cochlear implants, FM systems, sound field systems, amplifiers, captions on TV, and typing telephones that help a child who is deaf or has a hearing loss.

• **Computer-Based Instruction:** Software to help children with learning difficulties in reading, writing, math and other subject areas.

• **Mobility:** Wheelchairs, walkers, and adapted bicycles that allow a child with a physical or visual disability to move safely through the community.

• **Positioning:** Adjustable chairs, tables, standers, wedges and straps that help a child with a physical disability remain in a good position for learning without becoming tired.

• **Visual Aids:** Large-print books, books on tape, magnifiers, talking computer software, and Brailers that give a child who is blind or has low vision access to information.

• **Augmentative/Alternative Communication:** Picture boards, battery-operated communication devices, communication software and computers that allow a child who cannot speak, or whose speech is not understood by others, to communicate.

**Augmentative and Alternative Communication (AAC)**

Augmentative and Alternative Communication is one of the most essential forms of assistive technology. All children have the right to express what they want and how they feel, but this is not always easy for every child. Some children are not able to speak clearly enough for people to understand them, while others are not able to speak at all. Using AAC, parents and caregivers can help children with communication difficulties find ways to express what they want, need and think.
Augmentative and alternative communication refers to any strategy that helps a child communicate with others. Some strategies may be as simple as having your child point to a picture or use a gesture or some basic sign language. For example, a child might point to a picture of a glass of juice as a way of telling you that she wants juice. As her abilities develop, more and more pictures can be put together on a “communication board,” including pictures of both objects and emotions. Symbols can also be used in place of pictures to extend the types and complexity of thoughts your child wants to express.

Other strategies are considered more “high-tech” and are more complicated than pictures or symbols on a communication board. For example, on a “voice output communication aid” (VOCA), a child can press a button or picture on the device and a prerecorded voice will speak the word or message. If your child pressed pictures of herself, drink and juice, the device will create a message spoken by the computer, saying “I want juice,” in a voice easily understood by others.

If you believe your child might benefit from AAC, request an IEP meeting to discuss a reevaluation of your child’s need for assistive technology. If your child is already receiving speech therapy, you can talk with your therapist about the evaluation. If your child is not currently receiving any speech or language services, you can contact the pre-kindergarten program office in your local school district. If there is one in your area, you can also contact a college or university that offers speech and language therapy services. Many times these schools can provide AAC evaluations or can help you find someone who is qualified to conduct the evaluation.
BEGINNING EARLY

Even though your child may still be quite young, you probably think about the future sometimes. What will the future hold? What will my child’s life be like as an adult?

Actually, now is exactly the right time to begin making plans for your child’s future. The way you think about and interact with your child now will have big implications for his future. It will affect the way others relate to him and, most importantly, it will affect the way he thinks about himself.

You may be familiar with the story of Christy Brown who was born with cerebral palsy to a large Irish family in Dublin in 1932. At the time, no one knew that his physical limitations were due to a diagnosis of cerebral palsy. Against doctor’s recommendations, his mother took him home and treated him just like all of her other children. Eventually, with voluntary control over only one foot, Christy became a gifted author, painter and poet. He gave credit to his mother and to a therapist for shaping his life with their unconditional love, support, and belief in his potential in his 1954 book *My Left Foot*, which was also made into a 1989 movie.

Many other adults with disabilities have written and spoken about the profound effect their parents have had on their lives. Most often, they credit their ability to take part in the mainstream of life to the fact that their parents expected them to be a part of the big, wide world, with all its joy and all its pain.

You may begin to hear the word “normalization.” This term was first used in the early 1970s, when many people with disabilities were still living in large residential
facilities, and it refers to making all aspects of life as “normal” or “typical” as possible for persons with disabilities. Use of the term “normalization” is not as common as it once was, since long-term custodial care is no longer seen as an appropriate option for people with disabilities; nevertheless, the concept of normalization is still a powerful one.

Normalization does not mean “normalizing” people; it means normalizing environments, and it is everyone’s responsibility. Schools are responsible for normalizing education settings for all students, employers are responsible for normalizing employment settings for all workers, and all of us are responsible for normalizing community settings for all citizens. But parents have a special responsibility for normalizing the early lives of their children with disabilities. As your child’s advocate, you are in the best position to influence the way in which your child learns to see herself, her abilities, and her disabilities. Your child will look to you to see how you react to her efforts and her behaviors, just as we all learn about ourselves from the way others in our lives react to us. If your child sees only anxiety and protectiveness coming from you, she will soon learn that she is someone who needs protection and special treatment. In addition to a physiological disability, your child may also develop a “hidden disability” of low self-esteem or overdependency on others.

The best thing any parent can give a child is a good, strong sense of self. Children with disabilities can be especially vulnerable to feelings of “being different,” and they may need the assistance of the important adults in their lives to build their identity. By “normalizing” your child’s world, you can begin to help him develop good self-esteem at an early age.

What does that mean? Normalizing your child’s world means:

- Expecting behavior as normal as possible from birth onward.
- Using discipline and managing your child’s behavior as you would for any other child.
- Exposing your child to other children and encouraging him to socialize as normally as possible from infancy onward.
• Treating your child as any other child in your family would be treated.
• Exposing your child to the whole of life and the activities of the community in the same way you would any other child.
• Exposing your child to inclusive environments where he will be challenged to develop typical language and behavior patterns to the extent possible.
• Encouraging your child to participate in typical community activities and programs as much as possible.
• Expecting your child to accept personal responsibility for his own actions to the extent possible.
• Encouraging your child to become as self-sufficient as possible at every age.
• Encouraging your child to reach for the highest level of functioning possible.
• Helping your child to recognize personal limitations, but not to use them as an excuse for every shortcoming.

• Considering your child’s mental health to be as important as his physical and intellectual development.

You may be thinking that interacting with your child in these ways would sometimes be difficult. Indeed, it is. Treating your child as any other child includes letting her try something new and falling down and scraping her knee. It includes allowing your child to approach a group of peers knowing that her feelings may get hurt. The truth is that self-esteem does not grow by doing things that are easy or routine. Think about the last time you did something that made you feel really good about yourself. Most likely it happened when you tried something that was hard or scary for you and you succeeded. It doesn’t matter how big or how small the task; the important factor is the sense of accomplishment. Without the opportunity to try and fail, we never learn how to persist at a task and we never get to savor that sweet taste of success. Yes, it’s hard, but next to your love, it’s probably the best gift you can give to your child.

THE RIGHT TO SELF-DETERMINATION
When children are given the opportunity to be a part of their community and the chance to move toward increasing independence, they are already starting down the road to “self-determination.” Self-determination refers to the right of people with disabilities to take charge of and responsibility for their lives. With self-determination, it is the
individual, not “the system,” who decides where he will live and with whom, what types of services he requires and who will provide them, how he will spend his time, and how he will relate to his community.

Disability advocates often refer to five principles of self-determination:

1. **Freedom** – to live a meaningful life in the community
2. **Authority** – over dollars needed for support
3. **Support** – to organize resources in ways that are life-enhancing
4. **Responsibility** – for the wise use of public dollars, and
5. **Confirmation** – of the important leadership role that self-advocates have in this process.

The concept of self-determination arose in the 1990s when dissatisfaction reached a peak with national and state support systems for people with disabilities. More and more, it became evident that using public money to make people “fit the system” was not an efficient or responsible use of these funds. Why not use the same funds to assist individuals in deciding what they need rather than telling them what they need?

Viewing disability services in this way requires a change in thinking, and change rarely comes easily. In the last ten years, many states have begun to make changes in the way services are delivered, but there is still much to be done.

Even though your child may be very young right now, there are many things you can do to make sure she is ready for the opportunity to direct her own life later on. At the very center of self-determination is choice-making. If individuals are going to be able to make good choices as adults, they need to be exposed to choice-making from infancy onward. How can you give choices to young children? Consider these examples:

- **Infancy.** Allow your child to decide when he has had enough to eat. If he turns away before the bowl is empty, respect his choice to stop eating.

- **Toddlerhood.** Give simple either/or choices all day long. Do you want cereal or oatmeal? Do you want to wear the red shirt or the blue shirt? Do you want to look at the book or play with blocks?
• Preschool-Age. Continue offering choices throughout the day, expanding the activities over which your child is able to have control. Be careful, however, to only offer “real” choices. Do not ask, “Do you want to go to bed now?” if bedtime is not really an option.

Offering children the opportunity to make choices about the things that happen to them builds many important qualities:

• Self-Esteem – I can do things myself!
• Sense of Control – I am powerful and I can make things happen!
• Independence – Look what I can do!

Self-determination is not all or nothing. Some individuals with disabilities will live completely independent lives in their own homes, with their own income and their own problem-solving skills. Others will not. The essence of self-determina-

tion, however, is being able to communicate your own preferences, and everyone has preferences. Every individual can move closer to directing some events in their lives, even if they cannot become fully independent.

ADOLESCENCE AND SEXUALITY
When your child is very young, you can see frequent signs that he is growing and changing. You will notice increases in weight, or mobility, or efforts to talk. You will observe the development of his unique personality and temperament. And you will realize that one day your little child will become a teenager and young adult.

What can you expect as your child matures? During adolescence, the developmental tasks for all young people include strengthening a sense of identity as an individual apart from the family, assuming the male or female sexual role, and achieving some measure of independence.

Many parents have difficulty with the changing behaviors of their children during adolescence, particularly with regard to the child’s developing sexuality. When a child has a developmental disability, the challenge of dealing with sexual feelings and behavior may be even more difficult. It will help to remember that sexuality is a part of all human development and should be considered a normal part of growth.
Sometimes there is conflict between the rights and needs of parents and the rights and needs of children. As a parent, you may feel uncomfortable about your child’s sexual interest or activity; yet, your child has a right to express sexual feelings, in both physical and emotional ways. You may want to protect your child from harm or criticism by the community. You may be worried about pregnancy, abuse, or exploitation of your child or you may believe that your child is not capable of managing a relationship that might include sex.

Your child may have concerns of her own as well, but learning to deal with her own sexuality is an important step in the developmental process. Obviously, there may be real problems to be faced as your child matures, and many times there are no easy solutions.

Fortunately, there is much more openness today about sexuality in our society. You will be able to find organizations that offer assistance and information about sexuality, birth control, privacy rights, sex education, marriage, having children, and parenting. As your child grows toward adulthood, you will gain a better sense of the nature of the issues you and your child will face together as she becomes a mature individual.

**ADULT RELATIONSHIPS**

As your child grows into adulthood, his need for relationships with other adults outside of his family will also become increasingly important. Upon leaving high school, your child’s opportunities to interact with peers may become less frequent, and it will become important for new friendships and relationships to develop. If you started to include your child in the life of the community early on, your child may already know how to seek out new relationships by the time he reaches adulthood. Employment options and community living options will also provide opportunities to meet new people and develop new friendships. The more involved your child becomes in the mainstream of life in the early years, the more prepared he will be to participate with others later in life.

**ADULT LIVING ARRANGEMENTS**

As their children leave the high school years and transition to the adult world, many parents begin to think about the significance of living in the community for their children. Some parents think of community-based living as an exciting step in their children’s lives that will widen their world. Other parents face this decision with great concern, anxiety or sadness. At this time, it may be helpful to remember the principle of normalization. It is “normal” or “typical” in our culture for young adults to move to alternate living arrangements sometime in their early- to mid-20s. It is a part of the typical cycle of life. Although your family home is usually the best place for a young child to live, it may or may not be best for an adult child.
There is no “right time” for your child to move out of your family home. Indeed, depending on the resources available in the community, your child may find that the best living arrangement is in the family home, where she can receive needed services from the agencies that support her. The situation will be different for every individual. Sometimes, the age of the parents will be a factor, when caring for a child simply becomes too difficult for elderly caregivers. Sometimes, it will be the wish of the child to live in the community, and parents can move their child toward independence by helping him to make this a reality. It is important to remember that, with the right services and supports, every individual can live in the community. The range of living arrangements beyond the family home includes:

- **Independent Living.** The individual lives in the community and manages all activities on his own, with or without the informal support of friends or family.

- **Supported Living.** The individual receives an array of formal services and supports that allow him to establish and maintain his own household in the community. The intensity of the support can range from a few hours of drop-in assistance on a monthly, weekly, or daily basis to arrangements in which paid personal assistants live in the home with the individual.

- **Group Home Living.** The individual lives in a residential home in the community with paid staff and other individuals with disabilities. Again, the intensity of the support he receives there varies according to his own need for support.

- **Residential Living.** The individual lives in a facility with paid staff and other individuals with disabilities. The facility itself is not a personal residence and is likely to provide a home for a larger number of individuals than would typically be found in a family dwelling. Residential programs can be publicly or privately funded. Living in a large residential facility is not typically considered to be “community-based” living.

**EMPLOYMENT**

Looking for a job can be challenging and frustrating for anyone. Fortunately, recent federal laws have helped to make the process less difficult for people who also have disabilities.

The Vocational Rehabilitation Act of 1973 (amended in 1992) created the state grant programs that provide vocational rehabilitation, supported employment, and independent living services to all persons with disabilities. In Florida, these services are administered by the Florida Department of Education. Within the Department, the Division of Vocational Rehabilitation provides these major programs:
• **General Vocational Rehabilitation Program.** Assists individuals with disabilities, including Floridians with the most severe disabilities, to pursue meaningful careers appropriate to their abilities and capabilities.

• **Florida Alliance for Assistive Services and Technology (FAAST).** Provides a supportive partnership between Florida businesses and government to provide assistive technology products and services which will enable persons with disabilities to participate in independent living, education, work and recreation.

• **Independent Living Program.** Provides services through a statewide network of private nonprofit, locally-based and consumer-controlled Centers for Independent Living.

• **Migrant and Seasonal Farm Worker Program.** Funds projects that provide vocational rehabilitation services to individuals with disabilities who are migrant or seasonal farm workers, and to the family members who are residing with these individuals, including transportation services and services to maintain the family.

• **Bureau of Rehabilitation and Re-employment Services for Injured Workers.** Provides appropriate and necessary re-employment services to assist injured employees in their return to employment.

• **Adults with Disabilities Grant Program.** Provides school districts and community colleges with funding to enable adults with disabilities and senior citizens the opportunity for enhancement of skills consistent with their abilities and needs.

The Workforce Investment Act of 1998 (WIA) reorganized the U.S. job training system in order to give everyone easier access to services, especially groups who face serious barriers in seeking and gaining employment, such as youth and adults with disabilities.
The WIA provides for a system of “one-stop workforce centers” designed to provide job training, education, and employment services at a single neighborhood location. A key idea behind WIA is that every individual, including people with disabilities, has the right to access basic or “core” services that include:

- skill assessment services
- information on employment and training opportunities
- unemployment services, such as job search and placement assistance and up-to-date information on job vacancies.

All adults age 18 and older are eligible for core services. Services are also provided to “transition-age youth” who are ages 14 to 21 and meet certain income requirements. In Florida, the One-Stop Workforce Centers are administered by the Florida Agency for Workforce Innovation.

The Americans with Disabilities Act of 1990 (ADA) gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. The ADA has far-reaching implications for people with disabilities in the workforce, guaranteeing certain work adaptations and accommodations found to be necessary and reasonable for their inclusion in the workplace. The ADA is administered at the federal level by the U.S. Department of Justice, Division of Civil Rights. ■
By now, you may be feeling overwhelmed by the amount of information found in these pages. The good news is that you do not need to learn everything all at once. As you travel along in this journey, you will need different information at different times in your life and your child’s life. Some information found in this First Steps booklet will be useful to you now. Other sections may seem too far removed from the issues you are facing today. Keep it handy, though; you may find that you’ll come back to it in the future.

In this Chapter, many sources of additional information can be found on a variety of topics. The resources listed here represent only a portion of the resources that are available to you; there are many, many more. As you learn more about your child’s disability and about the disability community in general, you will become an expert in your own right. These resources will help to get you started.

**Note:** Telephone numbers are designated as Voice (V) or as Text Telephone (TTY) for persons with hearing or speech impairments. Many agencies and organizations also offer services and materials in Spanish.
STATE OF FLORIDA RESOURCES

STATE AGENCIES
AND ORGANIZATIONS

By federal law, all states have all the types of agencies shown below. The following list indicates where each type of service is located within Florida’s governmental structure.

The information listed for these agencies and organizations was correct at the time of publication, but may change at any time. If you want to check for changes, you can visit http://www.nichcy.org/stateshe/fl.htm for a current listing.

State Department of Education: Special Education

Bureau of Exceptional Education and Student Services
Florida Department of Education
325 W Gaines Street, Suite 614
Tallahassee, FL 32399-0400
850-245-0475
http://www.fldoe.org

Clearinghouse Information Center
Bureau of Exceptional Education and Student Services
Florida Department of Education
325 W Gaines Street, Suite 628
Tallahassee, Florida 32399-0400
850-245-0477
cicbiscs@fldoe.org
http://www.firm.edu/doe/commhome/cler-home.htm

Florida Diagnostic and Learning Resources System (FDLRS)
Bureau of Exceptional Education and Student Services
Florida Department of Education
325 W Gaines Street, Suite 601
Tallahassee, Florida 32399-0400
850-245-0478
http://www.paec.org/fdlrsweb/index.htm

Programs for Infants and Toddlers with Disabilities: Ages Birth through 2

Children’s Medical Services
Department of Health
4052 Bald Cypress Way, Bin A-06
Tallahassee, FL 32399-1707
850-245-4200; 800-654-4440

Bureau for Early Interventions
Early Steps
Children’s Medical Services
Florida Department of Health
4052 Bald Cypress Way, Bin A-06
Tallahassee, FL 32399-1707
850-245-4444
http://www.cms-kids.com/earlystepshome.htm

Florida’s Central Directory
Florida Directory of Early Childhood Services
2807 Remington Green Circle
Tallahassee, FL 32308-3752
850-487-6301; 800-654-4440
http://www.centraldirectory.org

Programs for Children with Disabilities: Ages 3 through 5

Bureau of Exceptional Education and Student Services
Florida Department of Education
325 W Gaines Street, Suite 601
Tallahassee, FL 32399-0400
850-245-0478
http://www.fldoe.org

Florida’s Central Directory
Florida Directory of Early Childhood Services
2807 Remington Green Circle
Tallahassee, FL 32308-3752
850-487-6301
800-654-4440
http://www.centraldirectory.org

State Agency for Workforce Innovation/Office of Early Learning Programs

Office of Early Learning
Florida Agency For Workforce Innovation
107 E Madison Street, MSC 140
Tallahassee, FL 32399
850-921-3180
http://www.floridajobs.org/earlylearning/index.html

State Vocational Rehabilitation Agency

Division of Vocational Rehabilitation
Department of Education
2002 Old St. Augustine Road, Building A
Tallahassee, FL 32301-4862
850-245-3399
800-451-4327 (V/TTY)
http://www.rehabworks.org

School-To-Work Transition Services
Division of Vocational Rehabilitation
Department of Education
2002 Old Saint Augustine Road, Building A
Tallahassee, FL 32301
850-245-3360
http://www.rehabworks.org

Career and Technical Education for Students with Disabilities

Career Education for Students with Special Needs
Division of Community Colleges & Workforce Education
Department of Education
325 W Gaines Street, Room 701
Tallahassee, FL 32399-0400
850-245-9022
http://www.myfloridaeducation.com/commhome

State Medicaid Office

Agency for Health Care Administration
2727 Mahan Drive, Mail Stop 8
Tallahassee, FL 32308
850-488-3560
http://ahca.myflorida.com/Medicaid

If you want to check for changes in the listing of the Medicaid Area Offices, you can visit http://ahca.myflorida.com/Medicaid/Areas/index.shtml

State Medicaid Area Offices (11)

Area 1. 160 Governmental Center, Room 510
Pensacola, FL 32502
850-595-5700
800-303-2422

Area 2A. 651 West 14th Street, Suite K
Panama City, FL 32401
850-872-7690
800-699-7068

Area 2B. 2727 Mahan Drive, Building 2
Tallahassee, FL 32308
850-921-8474
800-248-2243

Area 3A. 14101 NW Highway 441, Suite 600
Alachua, FL 32615
386-418-5350
800-803-3245

Area 3B. 2441 W Silver Springs Boulevard
Ocala, FL 34475
352-732-1349
877-724-2358

Area 4. 921 N Davis Street, Building A, Suite 160
Jacksonville, FL 32209
904-353-2100
800-273-5880
State Mental Health Agency

Mental Health Programs Office
Department of Children and Families
1317 Winewood Boulevard
Building 6 Tallahassee, FL 32399-0700
850-488-8304
http://www.state.fl.us/cf_web

State Mental Health Representative for Children and Youth

Mental Health Programs Office
Department of Children and Families
1317 Winewood Boulevard
Building 6, Room 290
Tallahassee, FL 32399-0700
850-488-8304
http://www.state.fl.us/cf_web

State Developmental Services

Agency for Persons with Disabilities
4030 Esplanade Way, Suite 380
Tallahassee, FL 32399-0950
850-488-4257
http://apd.myflorida.com/

Council on Developmental Disabilities

Florida Developmental Disabilities Council, Inc.
124 Marriott Drive, Suite 203
Tallahassee, FL 32301-2981
850-488-4180; (800) 580-7801 (in FL)
http://www.fddc.org

Protection and Advocacy Agency

Advocacy Center for Persons with Disabilities
2671 Executive Center Circle West,
Suite 100
Tallahassee, FL 32301-5092
850-488-9071 (V)
800-346-4127 (TTY)
800-342-0823
800-350-4566
(Spanish and Creole Speaking Clients)
info@advocacycenter.org
http://www.advocacycenter.org
**Client Assistance Programs**

**Programs for Children with Special Health Care Needs**

Children’s Medical Services  
Department of Health  
4052 Bald Cypress Way, Bin A-06  
Tallahassee, FL 32399-1707  
850-245-4200  
800-654-4440
http://www.myflorida.com

**State Children’s Health Insurance Program (CHIP) Program**

Florida KidCare  
Agency for Health Care Administration  
P.O. Box 980  
Tallahassee, FL 32302-0980  
888-540-5437  
http://www.floridakidcare.org

**Programs for Children and Youth who are Blind or Visually Impaired**

Division of Blind Services  
Department of Education  
1320 Executive Center Drive  
Tallahassee, FL 32399  
850-245-0322; 800-342-1828 (in FL)  
http://myflorida.com/dbs/index.shtml

**Programs for Children and Youth who are Deaf or Hard of Hearing**

Deaf and Hard of Hearing Services  
Division of Vocational Rehabilitation  
Department of Education  
2002 Old St. Augustine Road, Building A  
Tallahassee, FL 32301-4862  
850-245-3353; 850-245-3403 (V)  
850-245-3413; 850-245-3404 (TTY)  
http://www.rehabworks.org

**Telecommunications Relay for People who are Deaf, Hard of Hearing, Deaf/Blind, or Speech Impaired**

Florida Telecommunications Relay, Inc.  
1820 E Park Avenue, Suite 101  
Tallahassee, FL 32301  
http://www.ftri.org  
800-222-3448 (V) (questions or comments)  
888-447-5620 (TTY)  
To use the relay dial 711 or the following toll-free numbers:  
800-955-8771 (TTY)  
800-955-8770 (Voice)  
800-955-3771 (ASCII)  
877-955-8260 (Voice Carry Over-Direct)  
877-955-5334 (Speech to Speech)  
877-955-8773 (Spanish)  
877-955-8707 (French Creole)

**State Education Agency Rural Representative**

Exceptional Student Education Program  
Development and Services  
Bureau of Exceptional Education and Student Services  
Florida Department of Education  
325 W Gaines, Suite 601  
Tallahassee, FL 32399-0400  
850-245-0478  
http://www.fldoe.org

Outreach Services/Parent Infant Program  
Florida School for the Deaf and the Blind  
207 San Marco Avenue  
St. Augustine, FL 32084  
904-827-2233  
http://www.fsdb.k12.fl.us/outreach_services
Regional ADA & Information Technology Technical Assistance Center

Southeast Disability and Business Technical Assistance Center
Center for Assistive Technology and Environmental Access
Georgia Technological Institute
490 10th Street
Atlanta, GA 30318
404-385-0636
800-949-4232 (V/TTY)
http://www.sedbtac.org

Technology-Related Assistance

Florida Alliance for Assistive Service and Technology (FAAST)
325 John Knox Road, Building 400, Suite 402
Tallahassee, FL 32303
850-487-3278
888-788-9216
850-922-5951 (TTY)
faast@faast.org
http://faast.org

State Mediation System

ESE Program Administration and Quality Assurance
Bureau of Exceptional Education and Student Services
Florida Department of Education
325 W Gaines Street, Suite 614
Tallahassee, FL 32399
(850) 245-0476
http://www.myfloridaeducation.com/commhome

Special Format Library

Florida Bureau of Braille and Talking Book Library Services
420 Platt Street
Daytona Beach, FL 32114
386-239-6000; 800-226-6075
800-955-8771 (TTY)

DISABILITY-SPECIFIC ORGANIZATIONS

Attention Deficit Disorder
To identify an ADD group in your locality, contact either:

Children and Adults with Attention-Deficit/Hyperactivity Disorder
8181 Professional Place, Suite 150
Landover, MD 20785
301-306-7070
800-233-4050 (Voice mail to request information packet)
http://www.chadd.org

Attention Deficit Disorder Association
P.O. Box 543
Pottstown, PA 19464
484-945-2101
http://www.add.org

Autism

Autism Society of Florida, Inc.
P.O. Box 970646
Coconut Creek, FL 33097
954-349-2820
http://www.autismfl.com

Autism Recovery Network
maximom@yahoo.com
http://www.autismrecoverynetwork.org

Centers for Autism and Related Disabilities (CARD)
Six regional centers for autism and related disabilities
To identify the CARD serving your region, visit
http://www.card.ufl.edu/state.html

The Alexis Foundation
P.O. Box 916263
Longwood, FL 32779
407-862-8833
admin@alexisfoundation.org
http://www.alexisfoundation.org
### Blindness/Visual Impairments

**American Foundation for the Blind-National Literacy Center**  
100 Peachtree Street, Suite 620  
Atlanta, GA 30303  
404-525-2303  
literacy@afb.net  
http://www.afb.org

### Brain Injury

**Brain Injury Association of Florida**  
North Broward Medical Center  
201 E Sample Road  
Pompano Beach, FL 33064  
954-786-2400; 800-992-3442 (in FL)  
info@biaf.org  
http://www.biaf.org

### Cerebral Palsy

**United Cerebral Palsy of Florida**  
http://www.ucpflorida.org

### Challenging Behaviors

**Positive Behavioral Interventions and Supports-Florida Partner**  
University of South Florida  
Louis de la Parte Florida Mental Health Institute  
Department of Child and Family Studies  
13301 Bruce B. Downs Boulevard  
Tampa, FL 33612  
813-974-7684  
kincaid@fmhi.usf.edu  
http://www.fmhi.usf.edu/cfs/cfsinfo/cfsdetails.cfm?projectID=36

### Down Syndrome

**Broward Gold Coast Down Syndrome Organization**  
10250 NW 53rd Street  
Sunrise, FL 33351  
954-577-4122  
jmaia@aol.com  
http://www.bgcdownsindrome.org

**Down Syndrome Association of Central Florida**  
1137 Edgewater Drive, Suite 101  
Orlando, FL 32804  
407-540-1121  
info@dsacf.org  
http://www.dsacf.org

**Down Syndrome Association of Tallahassee**  
2910 Kerry Forest Parkway D4-212  
Tallahassee, FL 32309  
850-893-7334  
jackkeou@aol.com  
http://dsatallahassee.org

### Epilepsy

**Epilepsy Services Program**  
Florida Department of Health  
4052 Bald Cypress Way, Bin A-18  
Tallahassee, FL 32399-1744  
850-245-4330, ext. 4366  
sheryl_mosley@doh.state.fl.us  
http://www.floridaepilepsy.org  
http://www.doh.state.fl.us/family/epilepsy/index.html

### Learning Disabilities

**Learning Disabilities Association of Florida**  
331 E Henry Street  
Punta Gorda, FL 33950  
941-637-8957  
ldaf00@sunline.net  
http://www.lda-fl.org

### Mental Health

**Center for Child and Adolescent Resources**  
NAMI-Florida  
911 E Park Avenue  
Tallahassee, FL 32301  
850-671-4445, ext. 23  
helpline@namifl.org  
http://www.namifl.org
Florida Association for Infant Mental Health  
c/o Florida State University Center for Prevention & Early Intervention Policy  
1339 East Lafayette Street  
Tallahassee, FL 32301  
850-922-1300  
ann.kelley@directionsmh.org  
http://www.cpeip.fsu.edu/faimh

Mental Retardation and Related Developmental Disabilities  
ARC/Florida  
2898 Mahan Drive, Suite 1  
Tallahassee, FL 32308  
850-921-0460  
arcofflorida@comcast.net  
http://www.arcflorida.org

Speech and Hearing  
Florida Association of Speech-Language Pathologists and Audiologists  
P.O. Box 150127  
Altamonte Springs, FL 32715-0127  
407-774-7880  
800-243-3574  
tkautter@kmgnet.com  
http://www.flasha.org

Spina Bifida  
Spina Bifida Association of Florida of Jacksonville, Inc.  
807 Children’s Way Jacksonville, FL 32207  
904-390-3686  
800-722-6355  
sbaj@sbaq.org  
http://www.sbaj.org

TRANSITION  
Career Development and Transition Project  
University of Florida  
P.O. Box 117050  
Gainesville, FL 32611-7050  
352-392-0701  
transitionscenter@coe.ufl.edu  
http://www.thetransitioncenter.org

Florida’s Transition Project  
401 SW 42nd Street  
Gainesville, FL 32607  
352-372-2573  
http://www.floridatransitionproject.com

Training and Technical Assistance System (TATS)  
University of Central Florida  
4000 Central Florida Boulevard  
Teaching Academy, Suite 403  
Orlando, FL 32816-1250  
407-823-3058  
http://www.tats.ucf.edu/

STATE PARENT ORGANIZATIONS  
Parent Training and Information Center (PTI)  
Family Network on Disabilities of Florida, Inc.  
Parent Education Network  
2735 Whitney Road  
Clearwater, FL 33760-1610  
727-523-1130  
800-825-5736 (In Florida)  
pen@fndfl.org  
http://www.fndfl.org

Parent-To-Parent  
Parent to Parent of Florida  
Family Network on Disabilities of Florida, Inc.  
2735 Whitney Road  
Clearwater, FL 33760-1610  
727-523-1130  
800-825-5736 (In Florida)  
http://fndfl.org/

Community Parent Resource Center  
Parent to Parent of Miami, Inc.  
Community Parent Resource Center  
7990 SW 117th Avenue, Suite 201  
Miami, FL 33183  
305-271-9797; 800-527-9552  
info@ptopmiami.org  
http://www.ptopmiami.org
INDEPENDENT LIVING

To find contact information for the Statewide Independent Living Council (SILC) in Florida, contact:

Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
2323 South Sheppard, Suite 1000
Houston, TX 77019
713-520-0232 (V)
713-520-5136 (TTY)
ilru@ilru.org
http://www.ilru.org

To find contact information for Centers for Independent Living (CILs) in Florida, contact:

National Council on Independent Living
1710 Rhode Island Avenue, NW, 5th Floor
Washington, D.C. 20036
877-525-3400 (V)
202-207-0340 (TTY)
ncil@ncil.org
http://www.ncil.org

LEGAL ASSISTANCE

Advocacy Center for Persons with Disabilities, Inc.
2671 Executive Center Circle West, Suite 100
Tallahassee, FL 32301
800-342-0823 (V)
800-346-4127 (TTY)
info@advocacycenter.org
http://www.advocacycenter.org

Florida Bar Lawyer Referral Service
The Florida Bar
651 E. Jefferson Street
Tallahassee, FL 32399
850-561-5600 (V)
http://www.floridabar.org

Florida Statewide Advocacy Council
2727 Mahan Drive, MS-57
Tallahassee, Florida 32308
800-342-0825 (V)
Sherri.McVay@myflorida.gov
http://www.floridasac.org

OTHER ORGANIZATIONS

Easter Seals Florida
2010 Mizell Avenue
Winter Park, FL 32792
407-629-7881
info@fl.easterseals.com
http://www.fl.easterseals.com

Florida Association of Rehabilitation Facilities, Inc.
2475 Apalachee Parkway, Suite 205
Tallahassee, FL 32301-4946
850-877-4816
http://www.floridaarf.org

Florida Head Start State Collaboration Office
600 S Calhoun Street, Suite 202
Tallahassee, Florida 32399-02400
850-921-3467
http://www.floridaheadstart.org

Florida Inclusion Network
Home Office/Florida State University City Center
227 N Bronough Street, Suite 1125
Tallahassee, Florida 32301
888-232-0421
http://www.floridainclusionnetwork.com/

Florida Respite Coalition
2699 Lee Road, Suite 230
Winter Park, Florida 32789
866-FL-RELIEF (357-3543)
407-740-8909
http://www.floridarespite.org
NATIONAL RESOURCES

AGENCIES AND ORGANIZATIONS

Advocacy

Disability Rights Education and Defense Fund
2212 Sixth Street
Berkeley, CA 94710
510-644-2555 (V/TTY)
http://www.dredf.org

TASH (formerly the Association for Persons with Severe Handicaps)
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204
410-828-8274 (V)
410-828-1306 (TTY)
http://www.tash.org

Wrights Law
http://www.wrightslaw.com

Americans with Disabilities Act (ADA)
U.S. Department of Justice
Civil Rights Division
950 Pennsylvania Avenue, NW
Disability Rights Section - NYAV
Washington, DC 20530
800-514-0301 (V)
800-514-0383 (TTY)
http://www.ada.gov

U.S. Equal Employment Opportunity Commission
1801 L Street, NW
Washington, DC 20507
For publications
800-669-3362 (V)
800-800-3302 (TTY)
For questions
800-669-4000 (V)
800-669-6820 (TTY)
http://www.eeoc.gov

Assistive Technology/Devices

AbleNet, Inc.
2808 Fairview Avenue North
Roseville, MN 55113
800-322-0956 (V)
http://www.ablenetinc.com

Alliance for Technology Access (ATA)
2175 East Francisco Boulevard, Suite L
San Rafael, CA 94901
707-778-3011 (V)
707-778-3015 (TTY)
http://www.ataccess.org

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
1700 North Monroe Street, Suite 1540
Arlington, VA 22209
703-524-6686 (V)
703-524-6639 (TTY)
http://www.resna.org

United States Society for Alternative and Augmentative Communication
P.O. Box 10906
Baltimore, MD 21234
877-887-7222
http://www.ussaac.org

Blindness/Visual Impairments

American Council of the Blind
1155 15th Street NW, Suite 1004
Washington, DC 20005
800-424-8666 (V/TTY)
http://www.acb.org

American Printing House for the Blind
1839 Frankfort Avenue
Louisville, KY 40206
800-223-1839 (V)
http://www.aph.org

American Foundation for the Blind (AFB)
11 Penn Plaza, Suite 300
New York, NY 10001
800-232-5463 (V)
212-502-7662 (TTY)
http://www.afb.org
Blind Children’s Center
4120 Marathon Street
Los Angeles, CA 90029
800-222-3566 (V)
http://www.blindcntr.org

Lighthouse International
The Sol and Lillian Goldman Building
111 East 59th Street
New York, NY 10022
800-829-0500 (V)
212-821-9713 (TTY)
http://www.lighthouse.org

National Association of Parents
of the Visually Impaired
P.O. Box 317
Watertown, MA 02471
800-562-6265 (V)
http://www.napvi.org

National Federation of the Blind
1800 Johnson Street
Baltimore, MD 21230
410-659-9314 (V)
http://www.nfb.org

Prevent Blindness America
211 West Wacker Drive
Suite 1700
Chicago, IL 60606
800-331-2020 (V)
http://www.preventblindness.org

Recording for the Blind & Dyslexic
National Headquarters
20 Roszel Road
Princeton, NJ 08540
866-732-3585 (V)
http://www.rfbd.org

Challenging Behaviors
National Technical Assistance Center
on Positive Behavioral Intervention
and Supports (PBIS)
U.S. Department of Education
http://www.pbis.org/main.htm

Child Abuse
National Child Abuse Hotline
800-422-4453 (800-4-A-CHILD)

Parents Anonymous Inc.
675 West Foothill Boulevard,
Suite 220
Claremont, CA 91711
909-621-6184
http://www.parentsanonymous.org

Prevent Child Abuse America
500 N Michigan Avenue, Suite 200
Chicago, IL 60611
312-663-3520 (V)
http://www.preventchildabuse.org

Cognitive Disabilities
American Association on Mental Retardation
444 North Capitol Street, NW
Suite 846
Washington, DC 20001
800-424-3688 (V)
http://www.aamr.org

The ARC of the United States (formerly the
Association for Retarded Citizens of the U.S.A.)
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
800-433-5255 (V)
http://www.thearc.org

Communication Disorders
National Institute on Deafness
and Other Communication Disorders
National Institutes of Health
31 Center Drive, MSC 2320
Bethesda, MD 20892
800-241-1044 (V)
800-241-1055 (TTY)
http://www.nidcd.nih.gov

Stuttering Foundation of America
3100 Walnut Grove Road, Suite 603
P.O. Box 11749
Memphis, TN 38111
800-992-9392 (V)
http://www.stuttersfa.org
Deafness/Hearing Impairments

Alexander Graham Bell Association for the Deaf
3417 Volta Place NW
Washington, DC 20007
202-337-5220 (V)
202-337-5221 (TTY)
http://www.agbell.org

American Deafness and Rehabilitation Association
P.O. Box 480
Myersville, MD 21773
http://www.adara.org

American Society for Deaf Children
ASDC Headquarters
3820 Hartzdale Drive
Camp Hill, PA 17011
800-942-2732 Hotline
866-895-4206 (V/TTY)
http://www.deafchildren.org

Better Hearing Institute
515 King Street, Suite 420
Alexandria, VA 22314
800-327-9355 (V/TTY)
http://www.betterhearing.org

Deafness Research Foundation (DRF)
2801 M Street, NW
Washington, DC 20007
866-454-3924 (V)
888-435-6104 (TTY)
http://www.drf.org/

Gallaudet University Laurent Clerc National Deaf Education Center
800 Florida Avenue, NE
Washington, DC 20002
202-651-5031 (V)
202-651-5636 (TTY)
Carla.Hanyzewski@gallaudet.edu
http://clerccenter.gallaudet.edu

John Tracy Clinic
806 West Adams Boulevard
Los Angeles, CA 90007
800-522-4582 (V/TTY)
http://www.jtc.org

National Association of the Deaf (NAD)
8630 Fenton Street, Suite 820
Silver Spring, MD 20910
301-587-1788 (V)
301-587-1789 (TTY)
http://www.nad.org

Education/Special Education

Head Start Bureau Administration on Children, Youth and Families
U.S. Department of Health and Human Services
370 L’Enfant Promenade, SW
Washington, DC 20013
http://www.acf.dhhs.gov/programs/hsb

Office of Special Education Programs (OSEP)
Office of Special Education and Rehabilitative Services
U.S. Department of Education
400 Maryland Avenue, SW
Washington, DC 20202
202-245-7459
http://www.ed.gov/about/offices/list/osers/osep/index.html?src=mr

Employment

U.S. Equal Employment Opportunity Commission
P.O. Box 7033
Lawrence, Kansas 66044
800-669-4000 (V)
800-669-6820 (TTY)
http://www.eeoc.gov

Job Accommodation Network
Office of Disability Employment Policy
U.S. Department of Labor
P.O. Box 6080
Morgantown, WV 26506
800-526-7234 (V/TTY)
http://www.jan.wvu.edu/

Hospice

Children’s Hospice International
1101 King Street, Suite 360
Alexandria, VA 22314
800-242-4453 (V/TTY)
http://www.chionline.org
Hospicelink (Hospice Education Institute)  
P.O. Box 98  
Machiasport, ME 04655  
800-331-1620 (V)  
http://www.hospiceworld.org

Inclusion

Circle of Inclusion  
University of Kansas  
Department of Special Education  
521 J.R. Pearson  
Lawrence, KS 66045  
785-864-0685  
http://www.circleofinclusion.org

National Early Childhood Technical Assistance Center (NECTAC)  
Frank Porter Graham Child Development Institute  
University of North Carolina at Chapel Hill  
Campus Box 8040, UNC-CH  
Chapel Hill, NC 27599  
919-962-2001 (V)  
919-843-3269 (TTY)  
http://www.nectac.org/topics/inclusion/default.asp

Independent Living

Research and Training Center on Independent Living  
University of Kansas  
4089 Dole Building  
Lawrence, KS 66045  
785-864-4095 (V/TTY)  
http://www.rtcil.org

Learning Disabilities

International Dyslexia Association  
Chester Building, Suite 382  
8600 LaSalle Road  
Baltimore, MD 21286  
800-222-3123 (V)  
http://www.interdys.org

Learning Disabilities Association of America (LDA)  
4156 Library Road  
Pittsburgh, PA 15234  
888-300-6710  
http://www.ldanatl.org

Medical Organizations

National Easter Seal Society  
230 West Monroe Street, Suite 1800  
Chicago, IL 60606  
800-221-6827 (V)  
312-726-4258 (TTY)  
http://www.easter-seals.org

March of Dimes Birth Defects Foundation  
1275 Mamaroneck Avenue  
White Plains, NY 10605  
914-428-7100  
http://www.modimes.org

Muscular Dystrophy Association (MDA)  
3300 East Sunrise Drive  
Tucson, AZ 85718  
800-572-1717 (V)  
http://www.mdausa.org

Shriners of North America  
Shriners Hospitals for Children  
International Headquarters  
2900 Rocky Point Drive  
Tampa, FL 33607  
800-237-5055 (V)  
http://www.shrinershq.org

Mental Health

National Mental Health Association  
2000 N Beauregard Street, 6th Floor  
Alexandria, VA 22311  
Mental Health Resource Center  
800-969-6642 (V)  
800-433-5959 (TTY)  
http://www.nmha.org
Parent Organizations and Support Groups

Beach Center on Disability
University of Kansas, Haworth Hall
1200 Sunnyside Avenue, Room 3136
Lawrence, KS 66045
785-864-7600 (V)
785-864-3434 (TTY)
http://www.beachcenter.org

The Father’s Network
Washington State Fathers Network
Kindering Center
16120 NE Eighth Street
Bellevue, WA 98008
425-747-4004
http://www.fathersnetwork.org

Family Resource Center on Disabilities
20 East Jackson Boulevard, Room 900
Chicago, IL 60604
312-939-3513 (V)
312-939-3519 (TTY)
http://www.frcd.org/contact.html

Family Village Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705
http://www.familyvillage.wisc.edu

Family Voices
2340 Alamo SE, Suite 102
Albuquerque, NM 87106
888-835-5669
http://www.familyvoices.org

Federation of Families for Children’s Mental Health
9605 Medical Center Drive
Rockville, MD 20850
240-403-1901 (V)
http://www.ffcmh.org

Parents Helping Parents: The Parent-Directed Family Resource Center for Children with Special Needs
3041 Olcott Street
Santa Clara, CA 95054
408-727-5775
http://www.php.com

Sibling Support Project of the Arc of the United States
6512 23rd Ave NW, Suite 213
Seattle, WA 98117
206-297-6368
http://www.thearc.org/siblingsupport/

Technical Assistance Alliance for Parent Centers
PACER Center
8161 Normandale Blvd
Minneapolis, MN 55437
888-248-0822 (V/TTY)
http://www.taalliance.org

Physical Disabilities

National Spinal Cord Injury Association (NSCIA)
6701 Democracy Boulevard
Suite 300-9
Bethesda, MD 20817
800-962-9629
http://www.spinalcord.org

National Scoliosis Foundation
5 Cabot Place
Stoughton, MA 02072
800-673-6922
http://www.scoliosis.org

Spina Bifida Association of America
4590 MacArthur Boulevard NW, Suite 250
Washington, DC 20007
800-621-3141 (V)
http://www.sbaa.org

United Cerebral Palsy Association, Inc.
1660 L Street NW, Suite 700
Washington, DC 20036
800-872-5827 (V/TTY)
http://www.ucpa.org
Rare Disorders

Genetic Alliance, Inc.
4301 Connecticut Avenue, NW
Suite 404
Washington, DC 20008
202-966-5557 (V)
http://www.geneticalliance.org

National Organization for Rare Disorders (NORD)
55 Kenosia Avenue
P.O. Box 1968
Danbury, CT 06813
203-744-0100 (V)
203-797-9590 (TTY)
800-999-6673 (voicemail only)
http://www.nord-rdb.com

Recreation

American Therapeutic Recreation Association
1414 Prince Street, Suite 204
Alexandria, Virginia 22314
703-683-9420 (V)
http://www.atra-tr.org

North American Riding for the Handicapped Association, Inc.
P.O. Box 33150
Denver, CO 80233
800-369-7433 (V)
http://www.narha.org

Special Olympics International
1325 G Street, NW, Suite 500
Washington, DC 20005
202-628-3630 (V)
http://www.specialolympics.org

Respite Care

Access to Respite Care and Help (ARCH)
National Respite Center
800 Eastowne Drive, Suite 105
Chapel Hill, North Carolina 27514
919-490-5577
http://www.archrespite.org

National Respite Locator Service
http://www.respitelocator.org

Social Security Income (SSI)

Social Security Administration
Office of Public Inquiries
Windsor Park Building
6401 Security Boulevard
Baltimore, MD 21235
800-772-1213 (V)
800-325-0778 (TTY)
http://www.ssa.gov

Specific Disabilities and Special Health Care Needs

Alliance of Genetic Support Groups
4301 Connecticut Avenue, NW, Suite 404
Washington, DC 20008
800-336-4363 (V/TTY)
http://www.geneticalliance.org

American Brain Tumor Association
2720 River Road
Des Plaines, IL 60018
800-886-2282 (Patient Services)
http://www.abta.org

American Diabetes Association
1701 North Beauregard Street
Alexandria, VA 22311
800-342-2383 (V)
http://www.diabetes.org

American Heart Association- National Center
7272 Greenville Avenue
Dallas, TX 75231
800-242-8721 (V)
http://www.americanheart.org

American Lung Association
1701 North Beauregard Street
Alexandria, VA 22311
800-586-4872 (V)
http://www.lungusa.org

Angelman Syndrome Foundation
3015 E New York Street, Suite A2265
Aurora, IL 60504
800-432-6435
http://www.angelman.org
Aplastic Anemia Foundation of America, Inc.
P.O. Box 613
Annapolis, MD 21404
800-747-2820 (V)
http://www.aplastic.org

Asthma and Allergy Foundation of America
1233 20th Street, NW, Suite 402
Washington, DC 20036
800-727-8462 (V)
http://www.aafa.org

AMC Cancer Research Center
1600 Pierce Street
Denver, CO 80214
800-321-1557 (V)
http://www.amc.org

Autism Speaks
2 Park Avenue, 11th Floor
New York, NY 10016
212-252-8584 (V)
http://www.autismspeaks.org

Cancer Information and Counseling Line
800-525-3777 (V)

Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD)
8181 Professional Place, Suite 201
Landover, MD 20785
800-233-4050
http://www.chadd.org

Children’s Craniofacial Association
13140 Coit Road, Suite 307
Dallas, TX 75240
800-535-3643 (V)
http://www.ccakids.com

Cleft Palate Foundation
1504 East Franklin Street, Suite 102
Chapel Hill, NC 27514
800-242-5338 (V)
http://www.cleftline.org

Cooley’s Anemia Foundation National Office
330 Seventh Avenue, Suite 900
New York, NY 10001
800-522-7222 (V)
http://www.thalassemia.org

Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street, Suite 100
Avon, CT 06001
800-223-8355 (V)
http://www.cdlsusa.org

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, Maryland 20814
800-344-4823 (V)
http://www.cff.org/home

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
800-332-1000
http://www.epilepsyfoundation.org

Hydrocephalus Association
870 Market Street, Suite 705
San Francisco, CA 94102
888-598-3789
http://www.hydroassoc.org

International Rett Syndrome Association
9121 Piscataway Road, Suite 2B
Clinton, MD 20735
800-818-7388
http://www.rettsyndrome.org

Leukemia & Lymphoma Society
1311 Mamaroneck Avenue
White Plains, NY 10605
800-955-4572
http://www.leukemia.org

Little People of America, Inc.
5289 NE Elam Young Parkway
Suite F-100
Hillsboro, OR 97124
888-572-2001 (V)
http://lpaonline.org

Magic Foundation (Growth Disorders)
6645 W North Avenue
Oak Park, IL 60302
800-362-4423
http://www.magicfoundation.org
National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447
763-553-0020
http://www.ataxia.org

National Attention Deficit Disorder Association (ADDA)
P.O. Box 543
Pottstown, PA 19464
484-945-2101
http://www.add.org

National Cancer Institute
6116 Executive Boulevard
Room 3036A
Bethesda, MD 20892
800-422-6237 (V)
800-332-8615 (TTY)
http://www.cancer.gov

National Down Syndrome Congress
1370 Center Drive, Suite 102
Atlanta, GA 30338
800-232-6372 (V)
http://www.ndsccenter.org

National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012
800-221-4602 (V)
http://www.ndss.org

National Fragile X Foundation
P.O. Box 190488
San Francisco, California 94119
800-688-8765 (V)
http://www.nfxf.org

National Multiple Sclerosis Society
733 Third Avenue
New York, NY 10017
800-344-4867
http://www.nmss.org

Children’s Tumor Foundation
95 Pine Street, 16th Floor
New York, NY 10005
800-323-7938
http://www.nf.org

National Organization on Fetal Alcohol Syndrome (NOFAS)
418 C Street NE
Washington, DC 20002
800-666-6327
http://www.nofas.org

National Organization for Albinism and Hypopigmentation
P.O. Box 959
East Hampstead, NH 03826
800-473-2310
http://www.albinism.org

National Reye’s Syndrome Foundation
P.O. Box 829
Bryan, OH 43506
800-233-7393 (V)
http://www.bright.net/~reyessyn

Tuberous Sclerosis Alliance
801 Roeder Road, Suite 750
Silver Spring, MD 20910
800-225-6872 (V)
http://www.ntsa.org

Prader-Willi Syndrome Association
5700 Midnight Pass Road, Suite 6
Sarasota, FL 34242
800-926-4797 (V)
http://www.pwsausa.org

Sudden Infant Death Syndrome Alliance
1314 Bedford Avenue, Suite 210
Baltimore, MD 21208
800-221-7437 (V)
http://www.sidsalliance.org

Tourette Syndrome Association
4240 Bell Boulevard
Bayside, NY 11361
800-237-0717 (V)
http://www.tsa-usa.org

Vestibular Disorders Association
P.O. Box 13305
Portland, OR 97213
800-837-8428
http://www.vestibular.org
Therapies

American Occupational Therapy Association (AOTA)
4720 Montgomery Lane
P.O. Box 31220
Bethesda, MD 20824
301-652-2682 (V)
http://www.aota.org

American Physical Therapy Association (APTA)
1111 North Fairfax Street
Alexandria, VA 22314
800-999-2782 (V)
703-683-6748 (TTY)
http://www.apta.org

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
800-638-8255 (V/TTY)
http://www.asha.org

Vision Connection (Orientation and Mobility)
111 East 59th Street
New York, NY 10022
800-829-0500 (V)
212-821-9713 (TTY)
http://www.visionconnection.org/Content/VisionRehabilitation/VisionRehabilitation-Services/OrientationandMobilityTraining/default.htm

Trauma

American Trauma Society
8903 Presidential Parkway, Suite 512
Upper Marlboro, MD 20772
800-556-7890 (V)
http://www.amtrauma.org

Brain Injury Association
105 North Alfred Street
Alexandria, VA 22314
800-444-6443 (V)
http://www.biausa.org

CLEARINGHOUSES

Clearinghouse on Child Abuse and Neglect/Family Violence Information
800-394-3366 (V)

Clearinghouse on Disability Information
Office of Special Education and Rehabilitative Services
550 12th Street, SW, Room 5133
Washington, DC 20202
202-245-7307 (V)
202-205-5637 (TTY)
http://www.ed.gov/about/offices/list/osers/codi.html

DB-LINK: National Information Clearinghouse on Children Who Are Deaf-Blind
345 N Monmouth Avenue
Monmouth, OR 97361
800-438-9376 (V)
800-854-7013 (TTY)
http://www.tr.wou.edu/dblink

ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children
1110 N Glebe Road, Suite 300
Arlington, VA 22201
888-232-7733 (V)
866-915-5000 (TTY)
http://ericc.org

HEATH Resource Center (National Clearinghouse on Post-Secondary Education for Individuals with Disabilities)
One DuPont Circle, NW, Suite 800
Washington, DC 20036
800-544-3284 (V/TTY)
http://www.acenet.edu/programs/HEATH/home.html

National Clearinghouse for Alcohol and Drug Information (NCADI)
P.O. Box 2345
Rockville, MD 20847
800-729-6686 (V)
800-487-4889 (TTY)
http://www.health.org
REFERENCES

The authors wish to acknowledge the use of material from the following resources in writing this publication.

CHAPTER ONE: Getting a Diagnosis


CHAPTER TWO: Managing Your Feelings


CHAPTER THREE: Understanding Developmental Disabilities

Federal and state laws and statutes were accessed online at U.S. Government and State of Florida websites.
CHAPTER FOUR: Making Individual and Family Adjustments


CHAPTER FIVE: Knowing the Rights and Responsibilities of Parents and of Children with Disabilities


CHAPTER SIX: Addressing Your Financial Concerns


CHAPTER SEVEN: Navigating the Educational System


CHAPTER EIGHT: Recognizing the Value of Inclusion


**CHAPTER NINE: Planning for the Future**


**CHAPTER TEN: Finding the Information You Need**


Developmental milestones are specific skills or tasks that most children can do within a certain age range. Milestones are used to help determine if a child is developing within expected limits. Although each milestone has an age range, the actual age when a typically developing child reaches that milestone can vary quite a bit. Each child is unique.

Developmental milestones are important because they give us a way to check the ongoing development of the child from infancy onward. Milestones that are delayed are often the first sign that a child may be in need of early intervention services.

You have probably seen many lists of the skills and behaviors that children should acquire by certain ages. Another way to think about these skills is to look at the ones that are critical to the healthy development of your child. The American Academy of Pediatrics and the National Center on Birth Defects and Developmental Delay (U.S. Centers for Disease Control and Prevention) have developed the lists below to help parents know when they should alert their doctor if their child has not begun to show certain skills.

When using these charts with children who are born prematurely, be sure to use a child’s “adjusted age.” A premature baby who is 4 months old is not developmentally the same as a full-term baby who is 4 months old. As you watch your premature baby grow, it’s helpful to keep in mind his “gestational age” (the number of weeks since he was conceived) and adjusted age (his age minus the amount of prematurity). A full-term baby is 40 weeks old at birth. When that full-term baby is 1 month old he will have the same gestational age as a 4 month-old preemie who was born 3 months prematurely, meaning that they were both conceived at the same time. Even though the “preemie” has been out of the womb longer, both babies have a gestational age of 44 weeks. However, the premature infant will have an adjusted age of 1 month (instead of 4 months since his date of birth). It is this adjusted age that should be used when evaluating the infant’s skills and abilities, at least during the first few years of life.
DEVELOPMENTAL HEALTH WATCH CHARTS

BY THE END OF THE FIRST MONTH

If, during the second, third or fourth weeks of your baby’s life, he shows any of the following signs of developmental delay, notify your pediatrician.

- Sucks poorly and feeds slowly
- Doesn’t blink when shown a bright light
- Doesn’t focus and follow a nearby object moving side to side
- Rarely moves arms and legs; seems stiff
- Seems excessively loose in the limbs, or floppy
- Lower jaw trembles constantly, even when not crying or excited
- Doesn’t respond to loud sounds

BY THE END OF THREE MONTHS

Although each baby develops in her own individual way and at her own rate, failure to reach certain milestones may signal medical or developmental concerns requiring special attention. If you notice any of the following signs in your infant at this age, discuss them with your pediatrician.

- Doesn’t seem to respond to loud sounds
- Doesn’t notice hands by 2 months
- Doesn’t smile at the sound of your voice by 2 months
- Doesn’t follow moving objects with eyes by 2 to 3 months
- Doesn’t grasp and hold objects by 3 months
- Doesn’t smile at people by 3 months
- Cannot support head well at 3 months
- Doesn’t reach for and grasp toys by 3 to 4 months
- Doesn’t babble by 3 to 4 months
- Doesn’t bring objects to mouth by 4 months
- Begins babbling, but doesn’t try to imitate any of your sounds by 4 months
- Doesn’t push down with legs when feet are placed on a firm surface by 4 months
- Has trouble moving one or both eyes in all directions
- Crosses eyes most of the time (Occasional crossing of the eyes is normal in these first months)
- Doesn’t pay attention to new faces, or seems very frightened by new faces.
- Experiences a dramatic loss of skills she once had
BY THE END OF SEVEN MONTHS

Because each baby develops in his own particular manner, it’s impossible to tell exactly when or how your child will perfect a given skill. Developmental milestones will give you a general idea of the changes you can expect, but don’t be alarmed if your own baby’s development takes a slightly different course. Alert your pediatrician; however, if your baby displays any of the following signs of possible developmental delay for this age range.

- Seems very stiff with tight muscles
- Seems very floppy, like a rag doll
- Head still flops back when body is pulled up to a sitting position
- Reaches with one hand only
- Refuses to cuddle
- Shows no affection for the person who cares for him
- Doesn’t seem to enjoy being around people
- One or both eyes consistently turn in or out
- Persistent tearing, eye drainage or sensitivity to light
- Does not respond to sounds around him
- Has difficulty getting objects to mouth
- Does not turn head to locate sounds by 4 months
- Doesn’t roll over in either direction (front to back or back to front) by 5 months
- Seems impossible to comfort at night after 5 months
- Doesn’t smile on his own by 5 months
- Cannot sit with help by 6 months
- Does not laugh or make squealing sounds by 6 months
- Does not actively reach for objects by 6 to 7 months
- Doesn’t follow objects with both eyes at near (1 foot) and far (6 feet) ranges by 7 months
- Does not bear some weight on legs by 7 months
- Does not try to attract attention through actions by 7 months
- Does not babble by 8 months
- Shows no interest in games of peek-a-boo by 8 months
- Experiences a dramatic loss of skills he once had
**BY THE END OF TWELVE MONTHS**

Alert your pediatrician if your child displays any of the following signs of possible developmental delay for this age range.

- Does not crawl
- Drags one side of body while crawling (for over one month)
- Cannot stand when supported
- Does not search for objects that are hidden while he watches
- Says no single words (“mama” or “dada”)
- Does not learn to use gestures, such as waving or shaking head
- Does not point to objects or pictures
- Experiences a dramatic loss of skills he once had

**BY THE END OF TWO YEARS**

Alert your pediatrician if your child displays any of the following signs of possible developmental delay for this age range.

- Cannot walk by 18 months
- Fails to develop a mature heel-toe walking pattern after several months of walking, or walks exclusively on his toes
- Does not speak at least 15 words by 18 months
- Does not use two-word sentences by age 2
- By 15 months, does not seem to know the function of common household objects (brush, telephone, bell, fork, spoon)
- Does not imitate actions or words by the end of this period
- Does not follow simple instructions by age 2
- Cannot push a wheeled toy by age 2
- Experiences a dramatic loss of skills she once had
BY THE END OF THREE YEARS

Alert your pediatrician if your child displays any of the following signs of possible developmental delay for this age range.

- Frequent falling and difficulty with stairs
- Persistent drooling or very unclear speech
- Cannot build a tower of more than four blocks
- Difficulty manipulating small objects
- Cannot copy a circle by age 3
- Cannot communicate in short phrases
- No involvement in “pretend” play
- Does not understand simple instructions
- Little interest in other children
- Extreme difficulty separating from mother or primary caregiver
- Poor eye contact
- Limited interest in toys
- Experiences a dramatic loss of skills he once had

BY THE END OF FOUR YEARS

Alert your pediatrician if your child displays any of the following signs of possible developmental delay for this age range.

- Cannot throw a ball overhand
- Cannot jump in place
- Cannot ride a tricycle
- Cannot grasp a crayon between thumb and fingers
- Has difficulty scribbling
- Cannot stack four blocks
- Still clings or cries whenever parents leave
- Shows no interest in interactive games
- Ignores other children
- Doesn’t respond to people outside the family
- Doesn’t engage in fantasy play
- Resists dressing, sleeping, using the toilet
- Lashes out without any self-control when angry or upset
- Doesn’t use sentences of more than three words
- Doesn’t use “me” and “you” correctly
- Experiences a dramatic loss of skills she once had
BY THE END OF FIVE YEARS

Alert your pediatrician if your child displays any of the following signs of possible developmental delay for this age range.

- Acts extremely fearful or timid
- Shows extremely aggressive behavior
- Is unable to separate from parents without major protest
- Is easily distracted and unable to concentrate on any single activity for more than five minutes
- Shows little interest in playing with other children
- Refuses to respond to people in general, or responds only superficially
- Rarely uses fantasy or imitation in play
- Seems unhappy or sad much of the time
- Doesn’t engage in a variety of activities
- Avoids or seems aloof with other children and adults
- Doesn’t express a wide range of emotions
- Has trouble eating, sleeping or using the toilet
- Can’t differentiate between fantasy and reality
- Seems unusually passive
- Cannot understand two-part commands using prepositions (“Put the cup on the table and get the ball under the couch.”)
- Can’t correctly give first and last name
- Doesn’t use plurals or past tense properly when speaking
- Doesn’t talk about her daily activities and experiences
- Cannot build a tower of six to eight blocks
- Seems uncomfortable holding a crayon
- Has trouble taking off clothing
- Cannot brush her teeth efficiently
- Cannot wash and dry her hands
- Experiences a dramatic loss of skills he once had
APPENDIX B: CATEGORIES OF DISABILITIES

There are many ways to think about the different types of disabilities that can occur, and there are many ways they can be grouped into categories. You may see examples of these various categories in the publications you read.

No attempt will be made to define every type of disability in these pages because there are literally hundreds of medical diagnoses that can apply to the conditions of children. Instead, the disability categories that can qualify infants, toddlers, children, and youth for services under the Individuals with Disabilities Education Act (IDEA) of 2004 will be presented here.

Under the IDEA, states are responsible for meeting the special needs of eligible children with disabilities. To find out if a child is eligible for services, he must first receive a full and individual evaluation, as discussed in Chapter 7. The two main purposes of the evaluation are:

- to determine if the child has a disability, as defined by IDEA, and
- to learn in more detail what his special needs may be.

Infants and Toddlers, Birth Through Two

Under the IDEA, “infants and toddlers with disabilities“ are defined as children from birth through age two who are in need of early intervention services because they are experiencing developmental delays in one or more of the following areas:

- cognitive development,
- physical development, including vision and hearing,
- communication development,
- social or emotional development, or
- adaptive development,

or they may be eligible for services because they have a diagnosed physical or mental condition (an “established” condition) that has a high probability of resulting in developmental delay.
Children and Youth, Ages 3 Through 21

The IDEA lists a number of disability categories under which 3 through 21-year-olds may be eligible for services. For a child to be eligible for services, the disability must affect the child’s educational performance; that is, it must be “educationally relevant”. The disability categories found in the IDEA are:

- autism,
- deaf-blindness,
- emotional disturbance,
- hearing impairment (including deafness),
- mental retardation,
- multiple disabilities,
- orthopedic impairment,
- other health impairment,
- specific learning disability,
- speech or language impairment,
- traumatic brain injury,
- visual impairment (including blindness), and
- developmental delay (for children ages 3 through 5).

Definitions of the IDEA Disability Categories

The IDEA provides definitions of the existing disability categories. The actual names of the categories may vary from state to state. In Florida, for example, the category of “autism” will be changed to “autism spectrum disorder” in 2006. In addition, the descriptions of the categories may differ in Florida from the federal descriptions listed here:

1. **Autism.** Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, and adversely affecting educational performance. Characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to changes in daily routines or the environment, and unusual responses to sensory experiences. The term autism does not apply if the child’s educational performance is adversely affected primarily because the child has emotional disturbance, as defined in #3 below. A child who shows the characteristics of autism after age 3 could be diagnosed as having autism on the basis of evaluation.
2. **Deaf-Blindness.** Deaf-blindness means simultaneous (“at the same time”) hearing and visual impairments, so that the combination results in communication and educational needs that cannot be met in special education programs solely for children with deafness or for children with blindness alone.

3. **Emotional Disturbance.** Emotional Disturbance means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child’s educational performance:

   (a) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
   (b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
   (c) Inappropriate types of behavior or feelings under normal circumstances.
   (d) A general pervasive mood of unhappiness or depression.
   (e) A tendency to develop physical symptoms or fears associated with personal or school problems.

   The term “emotional disturbance” includes schizophrenia, but does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

4. **Hearing Impairment, including Deafness.** Deafness means a hearing impairment so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, and that adversely affects a child’s educational performance.

   Hearing Impairment means impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance but is not included under the definition of “deafness.”

5. **Mental Retardation.** Mental Retardation means general intellectual functioning that is significantly below average, exists at the same time with deficits in adaptive behavior, becomes evident during the developmental period, and adversely affects a child’s educational performance.

6. **Multiple Disabilities.** Multiple Disabilities means impairments that occur together (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.) so that the combination results in educational needs that cannot be met in a
special education program solely for one of the impairments. The term does not include deaf-blindness.

**Note:** Florida does not recognize a category of “multiple disabilities.” Instead, Florida school districts may designate primary and secondary categories of eligibility.

7. **Orthopedic Impairment.** Orthopedic Impairment means an physical impairment that adversely affects a child’s educational performance. The term includes impairments caused by a congenital anomaly (e.g. clubfoot, absence of a limb, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).

8. **Other Health Impairment.** Other Health Impairment means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

(a) is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and

(b) adversely affects a child’s educational performance.

9. **Specific Learning Disability.** Specific Learning Disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an impaired ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include learning problems that are primarily the result of visual, hearing, or motor disabilities; of mental retardation; of emotional disturbance; or of environmental, cultural, or economic disadvantage.

10. **Speech or Language Impairment.** Speech or Language Impairment means a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child’s educational performance.
11. **Traumatic Brain Injury.** Traumatic Brain Injury means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child’s educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not include brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

12. **Visual Impairment, including Blindness.** Visual Impairment means impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness.

13. **Developmental Delay (for children ages 3 through 5 years).** The category of “developmental delay” may be used in Florida for children ages 3 through 5 years. By the time a child reaches the 6th birthday, he will be reevaluated to determine if eligibility for services will continue under one of the other disability categories listed above.

Children in this age range may be included as an eligible “child with a disability” when they are experiencing developmental delays in one or more of the following areas:

- cognitive development,
- physical development, including vision and hearing,
- communication development,
- social or emotional development, or
- adaptive development, and when they are found to be in need of special education and related services because of the developmental delay.

The IDEA’s definitions of disability categories help states, schools, service providers, and parents decide if a child is eligible for early intervention or special education and related services. The definitions can also help you understand why your child may not be eligible for services in your local community.
APPENDIX C: DICTIONARY OF TERMS

The terms listed here are adapted from these sources:

• The Dictionary for Parents of Children with Disabilities. This list was compiled and developed by: “Building a Winning Team: The M.V.P. (Most Valuable Parent) Project,” under the direction of Juli Schlaht, Parent Information Specialist, and is supported by the South Dakota Department of Special Education and Cultural Affairs: Office of Special Education. The full list of terms can be found at http://www.usd.edu/cd/publications/dictionary.pdf

• The Tools for Parents of Children with Disabilities and Special Needs Glossary of Terms. This list was compiled by James J. Messina, Ph.D. and Constance M. Messina, Ph.D., authors of the coping.org website. The full list of terms can be found at http://www.coping.org/specialneeds/glossary.htm

For a glossary of terms specific to Florida’s Early Intervention Program (Early Steps), visit pages 47 through 50 of the document found at http://www.cms-kids.com/EarlySteps/EarlyStepsPolicy.pdf

For a glossary of terms specific to Florida’s Exceptional Student Education Program, visit http://www.cpt.fsu.edu/ESE/glossary.html

A

accommodation: A change made in teaching methods or materials to assist a child in fully taking part in the life and activities of the classroom.

activities of daily living (ADL): Basic life activities such as bathing, toileting, dressing, eating, socializing, communication, mobility, and so on.

acute: Intense and of short duration, usually said of a disease or health condition. Marked by sudden onset, sharp rise, and lasting a short time, demanding prompt attention.

adaptive equipment: Devices or additions to equipment that allow an individual to access his environment. Examples include wheelchairs, adaptive seating, and specialized desks and tables.

adjusted age: Age in weeks from conception. Computed by subtracting the amount of prematurity from the infant’s actual age since birth. Used with premature infants.
advocacy: The process of actively speaking out, writing in favor of, supporting, and/or acting on behalf of oneself, another person, or a cause. Advocacy can be any action to assure the best possible services for or intervention in the service system on behalf of an individual or group.

advocate: 1. Anyone who speaks or acts on behalf of oneself, another person, or a cause. 2. In relation to estate planning, a person or institution that will serve as a friend and look out for the best interests of an individual with a disability.

age appropriate: Activities, materials, curriculum, and environment consistent with the chronological age of the child being served.

ambulatory: Being able to move from place to place with or without assistive devices.

amendment: A change, revision, or addition made to a law.


amniocentesis: A prenatal assessment of a fetus which involves analysis of amniotic fluid.

amnioscopy: A prenatal diagnostic procedure in which the fetus is seen by use of a fibro-optic light.

amniotic fluid: Fluid that surrounds and protects the developing fetus. This fluid is sampled through amniocentesis.

APGAR score: An evaluation of a newborn’s physical condition after birth that enables professionals to quickly identify an infant at risk. It is the sum of ratings (0, 1, & 2) on five criteria: appearance or coloring, pulse (heart rate), grimace (responsiveness to stimuli), activity (muscle tone), and respiration. The first letter in each word combines to make the acronym APGAR. Ratings are taken at one minute and again at five minutes after birth.

appropriate: 1. Able to meet a need; suitable or fitting. 2. In special education, often refers to as the “most normal” setting possible. An “appropriate education” refers to an individualized educational program specially designed to meet the unique needs of a child with a disability.

articulation: The ability to make specific speech sounds: i.e., the “g” in gum, the “b” in bear, the “s” in snake.
articulation disorders: Difficulties with the way sounds are formed and strung together, usually characterized by substituting one sound for another (wabbit for rabbit), omitting a sound (han for hand), adding a sound (galue for glue) or distorting a sound (shlip for sip).

assessment: 1. A collecting and bringing together of information about a child’s educational needs which includes the use of social, psychological, and educational measurements and is designed to plan the child’s educational program. 2. The ongoing observations and monitoring of progress at various levels by qualified personnel to track the child’s unique needs, the family’s strengths and needs related to development of the child, and the nature and extent of the services needed by the child and the child’s family to best support the development of the child.

assistive device: Any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of a person with a disability. Examples include visual alerting systems for a person with a hearing impairment or a Braille printer for a person who is blind.

assistive technology: The systematic application of technology, engineering methodologies, or scientific principles to meet the needs of, and address the barriers confronted by, persons with disabilities in areas including education, employment, supported employment, transportation, independent living, and other aspects of daily life. The term includes assistive technology devices and assistive technology services.

at risk: A term used with children who have, or could have, developmental disorders that may affect later learning.

attending behavior: The ability to pay attention to a task. Attending behavior includes alertness, stimulus selection, focusing, and vigilance.

attention: The ability to focus on relevant information, screen out distractions, or stay on task.

audiogram: A graph on which the results of a person’s hearing test are recorded. Usually performed by an audiologist using an instrument called an audiometer.

audiologist: A professional educated in the study of normal and impaired hearing. The audiologist determines if a person has a hearing impairment, what type of impairment it is, and how the individual can make the best use of remaining hearing. If a person will benefit from using a hearing aid or other listening device, the audiologist can assist with the selection, fitting, and purchase of the most appropriate aid and with training the individual to use the aid effectively.
audiology: 1. The science or study of hearing. 2. Detection and management of aural (hearing) factors associated with communication.

audiometer: An electric device used to detect a person’s response to sound stimuli.

auditory brainstem response (ABR): A highly reliable test used when more information is needed to complete an in-depth evaluation of hearing or the auditory system, or when other methods of evaluation have not given reliable results. Most commonly used with infants and other individuals who are hard to test and can be performed while they are sleeping. Also referred to as “auditory evoked potentials measurement” or “brainstem evoked response audiometry.”

augmentative/alternative communication: Any approach designed to support, enhance, or supplement the communication of individuals who cannot communicate verbally and independently in all situations. Use of a communication board is an example.

B

barrier-free facility/environment: A building or other structures or settings that are designed and constructed so that people with mobility disabilities (such as those using wheelchairs) can move freely throughout and access all areas and features without encountering architectural obstructions.

behavior management: To develop, strengthen, maintain, decrease or eliminate behaviors in a planned or systematic way. May include a behavior management plan.

behavior modification: A technique of changing behavior based on the theory of reinforcement. Careful observation of events preceding and following the behavior in question is made, and the environment is changed to reinforce the desired responses, thereby bringing about the desired change in behavior.

behavioral intervention: Making accommodations in the child’s environment that include positive behavioral supports or a behavior management system. May include use of predictable routines, clear rules, consistent enforcement, and regular consultation and review.

C

caregivers: Any persons who have input into the care of the child, such as a babysitter, extended family, child care personnel, hospital personnel (nurses, aides, etc.).

case history: Information gathered, typically from care provider or parent, regarding a child’s developmental, medical and family history.
**Case Management:** 1. A service that assists persons to obtain and coordinate community resources such as income assistance, education, housing, medical care, treatment, vocational preparation, and recreation. 2. The planning, implementation, and monitoring of a person’s program from diagnosis through treatment. 3. Also referred to as “service coordination”.

**Case Management Activities:** 1. The activities carried out by a service coordinator to assist and enable a child and family to receive the rights, procedural safeguards, and services that are authorized to be provided. 2. Activities to establish a long-term process for coordinating the range of assistance needed by persons with disabilities and their families that is designed to ensure accessibility, continuity of supports and services, and the ability of persons with disabilities to achieve maximum independence, productivity, and inclusion in the community.

**Case Manager:** An individual who assists and coordinates the evaluation and treatment services for individuals and families. Also referred to as a “service coordinator.”

**Child Development Associate (CDA):** A competency-based training and certification program for child care personnel.

**Child Find:** A publicly-funded program under the Individuals with Disabilities Education Act of 1990 (IDEA) designed to locate, identify and evaluate young children with potential developmental delays or disabilities. Directed by the Department of Education in each state. May include public education about the importance of child development and parenting techniques.

**Child Protective Services (CPS):** State or county agency responsible for addressing issues of child abuse and neglect. In Florida, the Department of Children and Families is responsible for Protective Services for children.

**Chorionic Villus Sampling (CVS):** A prenatal assessment of a fetus which involves analysis of a small sample of the placenta.

**Chromosomal Abnormalities:** Defects or damage in the chromosomes of an individual.

**Chromosomes:** Threadlike materials within each cell that carry the genes of that individual. Play a central role in tissue development and inherited characteristics.

**Chronic:** Marked by long duration or frequent recurrence of a disease or health condition.

**Chronological Age:** Age of a child in years, months, and days since birth.

**Civil Rights:** With regard to education, the rights of a citizen of the United States that deal with protections related to due process, informed consent, appeal, petition for change, equal protection under the law, educational services, equal opportunity, and opportunities in the least restrictive setting.
**cognitive:** A term that describes mental processes such as remembering, reasoning, understanding, problem solving, evaluating, and using judgment.

**cognitive development:** The development of skills necessary for understanding and organizing the world, including such perceptual and conceptual skills as discrimination, memory, sequencing, concept formation, generalization, reasoning, and problem solving.

**communication:** The process of transmitting or receiving thoughts or messages from one person to another in a way that both understand, using facial expressions, body language, gestures, sign language, speech pictures, written words, etc.

**communication disorders:** Difficulties of speech, language or hearing that interfere with effective communication.

**community supports:** Providing activities, services and other assistance to persons with disabilities, their families and their communities which are designed to: (a) assist neighborhoods and communities to be more responsive to the needs of persons with disabilities, (b) develop local networks which can provide informal support, and (c) make communities accessible and enable communities to offer their resources and opportunities to persons with disabilities and their families. Community supports include community education, personal assistance services, vehicular and home modifications, support at work, and transportation services.

**confidentiality:** The process of protecting private information and notifying involved persons for permission prior to the sharing of information.

**congenital:** Present at birth. A condition or disease existing at birth.

**continuum of placements:** A range of educational settings available, as appropriate, for children with disabilities, including such options as regular classrooms, regular classrooms with itinerant or resource teachers, special classes, home instruction, and instruction in hospital or residential institutions.

**crisis:** A turning point in the course of one’s life; a decisive or crucial time; a difficult stage or event.

**crisis intervention:** Short-term therapy or counseling with individuals, families, groups, communities, and/or organizations that have experienced a substantial loss or change.
**D**

**delayed language:** A language disorder in which there is a noticeable slowness in the development of the vocabulary and grammar necessary for expressing and understanding thoughts and ideas.

**delayed speech:** Failure of speech to develop at the expected age. A deficit in the use of speech so that the child performs below age-level expectations, as a younger child would be expected to perform.

**development:** Growing both physically and mentally. Having to do with the steps or stages in growth and development before the age of 18.

**developmental age (DA):** The age score a child receives based on actual performance within a specific developmental area as compared to the chronological age.

**developmental assessment:** Standardized tests that are intended to document the emergence of a sequence of behaviors, skills, or abilities over a period of time.

**developmental delay:** When a child’s development progresses at a slower rate than the development of most children.

**developmental disability (DD):** 1. A physical or mental impairment originating before the age of 18 which may be expected to continue indefinitely and to result in substantial limitations to major life activities (See Chapter 3). 2. When applied to children birth to age 5, inclusive, refers to substantial developmental delays or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

**developmental domains:** Areas of child development that refer to different types of skills, such as gross motor development, fine motor development, social development, language development, and so on.

**developmental history:** The developmental progress of a child over time with regard to such skills as sitting, walking, and talking during the period from birth to 18 years.

**developmental milestones:** Specific skills or tasks that most children can do within a certain age range, such as sitting up, crawling, walking, saying a first word, etc. Stages of growth that are sequential in order and expected to occur by a certain age as a sign of typical maturation.

**developmental period:** 1. The time between conception and 18 years of age, during which physical and mental growth occurs.

**developmental screening:** The process used to determine if a child may have a developmental delay and be in need of further evaluation.
developmental tests: Standardized tests that measure a child’s development as it compares to the development of all other children at that age.

developmentally appropriate practice (DAP): Instructional practices that are appropriate for the age of the children within the group and is implemented with attention to the different needs and developmental levels of those individual children.

diagnosis: 1. Identifying the nature or cause of a physical or mental disorder by looking at its symptoms. 2. The process of identifying specific mental or physical disorders.

disability: A physical or mental impairment which substantially limits one or more major life activities. The preferred term instead of “handicap” when referring to a physical or mental impairment of an individual. A “disability” refers to the actual impairment of the body. A “disability” only becomes a “handicap” when it prevents the individual from performing certain skills or tasks or when others assume that the individual cannot perform these skills because of the disability.

discrimination: 1. Any action which limits or denies a person or a group of persons opportunities, privileges, roles or rewards on the basis of their sex, age, race, disability, national origin and/or religious affiliation.

DOE: Department of Education.

due process: A legal term referring to actions that protect a person’s rights under the law; in special education, this applies to actions taken to protect the educational rights of children with disabilities.

due process hearing: A formal legal proceeding presided over by an impartial public official who listens to both sides of the dispute and renders a decision based upon the law.

early childhood specialist: An individual who specializes in early childhood development, usually having a Master’s degree or Ph.D. in an area related to early childhood education or child development.

early childhood teacher: An individual trained in child development

early childhood special education teacher: An individual trained in child development and the education of young children with disabilities.

early interventionist: An individual who provides early intervention services to young children (birth-2 years) with disabilities and their families with the intent of enhancing the developmental outcomes of children.
early intervention programs or services: Programs or services designed to meet
the developmental needs of eligible infants and toddlers and their families under
Part C of the IDEA and also to meet the needs of the family as they relate to the
child’s development.

Early, Periodic Screening, Diagnosis and Treatment Program (EPSDT): A pro-
gram within the Medicaid Program for children under 21 years of age which promotes
prevention and/or early detection and treatment of special health care needs and con-
ditions through periodic health screening.

echohalia: The repetition or imitation of words or phrases spoken by others that tends
to be ongoing and persistent and is used without any apparent communication value.

educationally relevant: Generally applies to physical and occupational therapy; even
though therapy may be medically necessary, school-based therapy services may not
be considered educationally necessary unless needed to help the child benefit from her
educational program.

empowerment: The interaction of professionals with families in such a way that
families maintain or acquire a sense of control over their lives and attribute posi-
tive changes that result from early intervention to their own strengths, abilities,
and actions.

environment: The world around you.

environmentally at risk: Early life events associated with less than optimal develop-
ment outcomes (e.g., poor nutrition, low social support, or high levels of family/par-
enting stress).

equal access: 1. The elimination of barriers that prohibit a child with a disability from
participating in activities typically engaged in by other children. 2. In general, pro-
viding the same opportunities for persons with disabilities to have the same access to
schools, work environments and community facilities as the general population.

established condition: A physical or mental condition of a child that has a high prob-
ability of resulting in a disability or developmental delay.

evaluation: A way of collecting information about a child’s learning needs, strengths,
and abilities which includes testing, observations, and parental input and is designed
to determine the child’s eligibility for early intervention or special education programs
and services.

Exceptional Student Education: The term used in Florida to refer to special educa-
tion programs and services for children with disabilities or children who are gifted
and/or talented.
expressive language: The ideas, concepts and feelings the child is able to share through speech, signing, gestures, etc.

expressive language skills: Skills required to produce language for communication with other individuals. Speaking, signing and writing are expressive language skills.

extended school year (ESY): Refers to school programs for children with disabilities that extend beyond 180 days. The IEP team must consider every child’s need for extended school year services (during the summer months) as part of the IEP process.

eye contact: Looking someone “in the eye” while talking to them. Generally a natural, although not a constant, interaction of the speaker’s eyes with those of the listener. May vary according to a person’s cultural background.

F

facilitate: To make easy or easier. To assist someone in a task or process.

family centered/focused model: Providing intervention services for children with special needs within the context of the family for the purpose of enhancing the child’s developmental outcomes. Recognizes that the family is the foundation of a child’s life and that service systems and personnel must support, respect, encourage, and enhance the strength and competence of the family.

family counseling: Support to families in responding to the impact of a family member with special needs on the family’s activities and ability to function.

family needs: Refers to various family necessities, such as basic resources, specialized child care, personal and family concerns, financial and medical resources, education, meal preparation, financial budgeting and household support.

family resources: 1. Refers to family wealth, assets, available money or property; 2. Also refers to the family’s strengths, knowledge, contacts, abilities, etc. (things without intrinsic value).

family strengths: Characteristics that family members identify as contributing to the growth and development of the child and family, such as good coping strategies, nurturing relationships, open communication, religious or personal beliefs, family competence, and family/community interconnectedness.

family support programs/services: Services, supports, and other assistance to families in providing care for their children or adult members with developmental disabilities so they can remain in the home. These services are designed to (a) strengthen the family’s role as primary caregiver, (b) prevent inappropriate out-of-home placement
and maintain family unity, and/or (c) reunite families with members who have been placed out of the home. Services may include respite care, assistive technology, personal assistance, parent training and counseling, support for elderly parents, vehicular and home modifications, and assistance with extraordinary expenses associated with the needs of the person with a disability.

**family support plan:** see “Individualized Family Service Plan.”

**family systems:** The family as a unique, interactive social system whose characteristics reflect the region, economic status, ethnicity, and individual features of its members.

**family therapy:** A therapeutic technique in which family members participate together in order to improve family communication and create more satisfying interactions and relationships.

**fine motor:** The use of small muscle groups for controlled movements, particularly in object manipulation. Includes movements of the hands, how we hold onto things, move our fingers for reaching and grasping, etc.

**free appropriate public education (FAPE):** A key requirement of federal legislation (Public Law 94-142 and its amendments) which requires that special education and related services are provided to all eligible children, and meet the following requirements: (a) Provided at public expense, under public supervision and direction, and without charge; (b) Meet the standards of the state board of education and the laws pertaining thereto; (c) Include preschool, kindergarten, elementary school, and secondary school education; and (d) Provided in conformity with an individual educational program (IEP) designed to address the unique needs of each child and each child’s need for interaction with typical peers.

**functional:** Represents a skill that is necessary for success in daily activities, now or in the future. See also “activities of daily living.”

**functional academic curriculum:** Curriculum that teaches academic material (reading, math, etc.) with content that is most relevant and necessary for a child’s daily living activities. See also “functional life/compensatory curriculum.”

**functional age:** An individual’s level of ability to perform various tasks relative to the average age of others who can perform the same tasks.
G

generalization: The ability to apply a set of skills or knowledge learned under one set of conditions to other conditions or environments.

genes: The parts of the chromosome that direct the way in which body tissue develops, from the formation of all body parts to the color of the hair.

 genetic counseling: A process of giving parents the information they need to make decisions regarding the medical treatment of their children and the possibility of having additional children with disabilities. Often done when there is reason to believe a genetic abnormality may be present.

 genetic screening: Testing of a group of people to identify those at risk for a specific genetic disorder or at risk for transmitting a disorder to their children.

gestational age: The estimated age of a fetus expressed in weeks, calculated from the first day of the last normal menstrual period.

 gross motor: Movement that involves balance, coordination and large muscle activity as required in rolling over, sitting, walking, running, skipping, climbing, jumping and other physical activities.

H

handicap: A limitation imposed on an individual by the environment or by society and the person’s capacity to manage that limitation. See also “disability.”

 home-based services: When a teacher, early interventionist, or therapist goes to individual homes (or other comfortable settings, e.g., child care center) on a regular basis to provide a needed service to children or their family members.

 human rights: Rights of a citizen of a country that deal with the life activities such as choice, freedom of movement, freedom of religion, access to humane living conditions, medical care, pursuit of happiness, etc.

I J K

IDEA: See “Individuals with Disabilities Education Act”.

IEP: See “Individual Educational Plan”.

IFSP: See “Individualized Family Service Plan”.
inclusion: With regard to education, the practice of providing a child’s educational program in a regular education classroom, with the supports and accommodations needed by that child and ideally takes place at the child’s neighborhood school. “Full inclusion” occurs when children receive their entire education in the regular education setting. “Partial inclusion” occurs when children with disabilities spend part of their day in regular education while they receive instruction in special education classrooms or resource rooms for other portions of their school day.

individual supports: Services, supports, and other assistance that enable persons with developmental disabilities to be independent, productive, and integrated into their communities, and that are designed to: (a) enable people to control their environment, permitting the most independent life possible, (b) prevent placement into a more restrictive living arrangement than is necessary, and (c) enable people to live, learn, work and enjoy life in the community. Individual supports may include personal assistance services, assistive technology, vehicular and home modifications, support at work, and transportation.

Individual Educational Plan (IEP): A written plan to identify the annual goals, objectives, and special education and related services needed to meet the individual needs of a child ages 3 through 21 with a disability. Developed by teachers, parents, the child, and others as appropriate, and reviewed annually.

Individualized Family Service Plan (IFSP): A plan of intervention for a child ages birth through 2 with a disability or developmental delay and her family, similar in content to the IEP and developed by a team of individuals involved with the child, including the family. Contains statements regarding the child’s present development level, strengths, and needs; the family’s strengths and needs; major goals of the plan; a description of specific interventions and delivery systems to accomplish outcomes, statement of natural environments, dates of initiation and duration of services, dates for evaluation of the plan, and a transition plan. The IFSP is known as a Family Support plan (FSP) in Florida.

Individuals with Disabilities Education Act (IDEA): The Individuals with Disabilities Education Act, which provides grants to states and local jurisdictions to support the planning of service systems and the delivery of services to children who have or are risk of developmental delays or disabilities. Funds are provided for infants and toddlers (birth through 2 years) through Part C of the IDEA, and for children 3 through 21 years of age through Part B.

integration: For persons with disabilities, integration means living, learning, working, and enjoying life in regular contact with citizens without disabilities in their home communities. More commonly referred to today as “inclusion.”
intelligence quotient (IQ): A score obtained from an intelligence test that provides a measure of mental ability in relation to age.

interdisciplinary team: Individuals involved in assessment and recommendations for persons with disabilities. Team consists of persons from a wide variety of disciplines including, but not limited to, medical experts, educators, speech language pathologists, occupational therapists, rehabilitation engineers, care providers, psychologists, counselors, and social workers. Team members may not necessarily work together.

intervention: Action taken to correct, remediate, or prevent identified or potential medical or developmental delays or disorders.

language delay: A term used when a child’s rate of language development is proceeding more slowly than expected for his age.

language development: Growth of expressive and receptive communication. Also includes the development of skills related to understanding and production of language.

language disorder: A term used when the quality and sequence of language development is significantly disrupted.

least restrictive environment (LRE): 1. An educational setting or program that provides a child with disabilities with the chance to learn and progress to the best of her ability. Also provides the child with as much interaction as possible with children without disabilities, while meeting all the child’s learning needs and physical requirements. 2. As defined in special education legislation: A learning environment for a child in need of special education and/or related services that includes to the maximum extent appropriate children who are not in need of special education or special education and related services, as determined through the child’s individual educational program.

legal rights: Rights which are given to citizens of a country because of specific laws which have been passed so that their human and civil rights can be protected.

limited English proficiency: Refers to individuals for whom English is their second language and, as a result, who have sufficient difficulty speaking, reading, writing or understanding the English language as to deny them the opportunity to learn successfully in classrooms where the language of instruction is English or to participate fully in everyday life.
**local education agency (LEA):** A school district, board of education, or other public authority under the supervision of a state educational agency having administrative control and direction of public elementary or secondary schools in a city, county, township, school district, or political subdivision in a state.

**M**

**mainstream:** The regular education setting, where children without disabilities receive their education. To “mainstream” a child is to place him in a regular education class rather than in a self-contained special class. See also “mainstreaming”.

**mainstreaming:** The process of including children with disabilities in regular educational or other community programs. Term has largely been replaced by the term “inclusion.”

**major life activities:** Functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.

**manipulation:** How a person uses his/her hands with objects, such as writing or drawing with a crayon.

**manipulatives:** Toys that children play with using their hands.

**manual communication:** Use of sign language and fingerspelling as the primary mode of communication, with or without use of oral/aural communication, by deaf and hearing impaired individuals.

**medically necessary:** The frequency, extent and types of services or supplies that represent appropriate medical care and are generally accepted by qualified professionals as reasonable and adequate for the diagnosis and treatment of illness, injury, or maternity and well-baby care.

**mental age:** A child’s age equivalent score on tests of mental ability. See also “developmental age.”

**motor:** Movement of muscles and joints.

**motor development/skills:** The skills and performance of patterns related to the development and use of muscles or limbs.

**multidisciplinary evaluation/assessment (MDE):** An evaluation of a child’s strengths and weaknesses from a variety of professional points of view using a number of different sources of information, and involving the child’s parents.
**multidisciplinary:** A team approach in which specialists from more than one discipline (such as educators, psychologists, physicians, therapists, and others) work together and share information in order to evaluate, assess, and develop educational plans for children who are referred for evaluation. Team members work together, usually on an ongoing basis.

**N**

**natural environment:** Environment where individuals with disabilities would live, work, and play if they did not have a disability.

**natural learning environments:** Places where children experience everyday, typically occurring learning opportunities that promote behavioral and developmental growth.

**neonatal intensive care unit (NICU):** A special unit of a hospital providing advanced technology and trained healthcare professionals for infants in distress.

**noncompliant/noncompliance:** Not following directions or rules. Refers to children who exhibit troublesome or challenging behaviors.

**normal:** A general term applied to behavior or abilities that fall within the average or typical range of human development.

**normalization principle:** 1. Making an individual’s life and surroundings as culturally normal as possible. 2. The principle that children and families should have access to services provided in as usual a fashion and environment as possible, to help children and families become or remain part of their community.

**O**

**objectives:** Small steps taken to meet goals.

**occupational therapist (OT):** A person who practices occupational therapy and who may be licensed, registered, certified, or otherwise regulated by law.

**occupational therapy (OT):** Therapy designed to develop adaptive or physical skills to aid in daily living and improve interactions with a person’s physical and social world. Focuses on developing functional skills related to sensory-motor integration, coordination of movement, fine motor skills, self-help skills (dressing, self-feeding, etc.), adaptive devices/equipment, computer keyboarding, body positioning for school or work, and potential work-related activities.
orientation: Awareness of where one is in relation to time, place, and person.

orientation & mobility (O & M): Refers to training for persons who are blind/visually impaired that helps to familiarize her with her surroundings and enable her to travel safely and independently throughout the environment.

orientation and mobility specialist: An individual trained to teach travel concepts and techniques to persons who are blind or visually impaired.

orthosis/orthotics: An orthopedic appliance used to support, align, prevent or correct deformities or to improve the functioning of movable parts of the body. Common orthoses for children are “AFO’s,” or ankle-foot orthoses.

P Q R

peer buddy/tutor: A peer who helps a child with a disability learn or perform activities or move about through the learning environment.

people-first language: A respectful way of talking or writing about persons with disabilities that identifies and emphasizes the “person first” and the disability as a secondary characteristic. Requires that all references about a person’s needs, disabling condition, use of specialized equipment, etc., are stated following the reference to the person. Example: Instead of saying, “A crippled boy confined to a wheelchair,” say, “A boy with cerebral palsy who uses a wheelchair.”

perception: A person’s ability to consciously recognize and interpret what is seen, heard, or felt. More specifically, the process of organizing or interpreting information obtained through the senses.

perceptual disorders: The inability to interpret information received through one or more of the senses (despite adequate vision, hearing, and other sensory processes) and to perform appropriate actions in response to that information.

perseveration: 1. The tendency to continue an activity once it has been started and to be unable to modify or stop the activity even though it has become inappropriate. 2. Persistent repetition of words, ideas or subjects so that, once an individual begins speaking about a particular subject or uses a particular word, it continues to occur.

physical therapist (PT): A person who is licensed to assist in the examination, testing, and treatment of persons who have physical disabilities through the use of massage, exercise, manipulation, application of heat or cold, use of sonar waves, and other specialized techniques.
physical therapy (PT): Instructional support and treatment of physical disabilities provided by a trained physical therapist, under a doctor’s prescription, to help a person improve the use of bones, muscles, joints, and nerves. Assists in maximizing a person’s general fitness, sensorimotor development, muscular and skeletal function, and ability to perform daily life activities.

pincer grasp: Bringing together the thumb and the tip of the index finger so that a small object can held skillfully.

positive behavioral supports: A comprehensive approach to addressing challenging behaviors using a “proactive” or preventative approach based on several assumptions about the nature and function of the behaviors.

prematurity: Underdevelopment, as in the condition of an infant born too soon. Refers to infants delivered before 37 weeks from the first day of the last menstrual period.

prenatal: The time before birth, while a baby is developing during pregnancy. The period of time between the conception and birth of an infant.

present levels of performance: Statements in an IEP that describe what a child can do or what he knows.

procedural safeguards: 1. Laws that protect the rights of children with disabilities and their families. 2. The requirements of a law with regard to such issues as evaluation policies, parental consent, placement, due process, mediation, notification of meetings, etc.

prognosis: A forecast or prediction as to the course or outcome of a condition or disease.

pull-out: A term applied to interventions (such as therapies) that remove a child with a disability from the assigned classroom to a separate area for the delivery of services for part of the school day.

receptive language disorders: Difficulties in comprehending what others say.

regular classroom: The classroom and school a child with a disability would attend if she did not have a disability, along with the typical peers from her neighborhood.

related services: Services that are necessary for a child to benefit from special education services. May include transportation and supportive services such as speech pathology, audiology, psychological services, physical and occupational therapy, recreation, early identification and assessment, counseling, interpreters for persons with
hearing impairments, medical services for diagnostic or evaluation purposes, school health services, social work services in schools, and parent counseling and training.

**residential school program:** An approved, specialized educational program provided in a facility that a child attends 24 hours a day.

**residential treatment:** Live-in facilities that provide treatment and care for children with emotional/behavioral disabilities who require continuous medication and/or supervision or relief from environmental stress.

**resilience:** The tendency for a child, adult, or family to rebound from stressful circumstances or events and be able to resume usual activity. The power of recovery.

**resource room:** A room separate from the regular classroom in which children with disabilities can receive specialized assistance during a portion of their school day to reinforce and supplement regular classroom instruction.

**resource teacher:** A specialist who works with children with disabilities and acts as a consultant to other teachers, providing materials and methods to help children who are having difficulty within the regular classroom. May work from a centralized resource room within a school where appropriate materials are housed.

**respite:** Temporary care given to an individual for the purpose of providing a period of relief to the primary caregivers. Used to decrease stress in the homes of persons with disabilities, thereby increasing caregivers’ overall effectiveness, or to provide care in emergency situations.

**S**

**Section 504:** A part of the Rehabilitation Act of 1973 which states that no program or activity receiving federal funds can exclude, deny benefit to, or discriminate against any person on the basis of a disability. Also requires access for persons with disabilities to all public buildings. Also known as “504.”

**Section 504 plan:** An individualized plan for a student with a disability who may not meet the eligibility criteria for exceptional student education (ESE) programs but who requires accommodations under Section 504 of the Rehabilitation Act of 1973 and thereby receives identification, evaluation, provision of services, parental notification, and procedural safeguards.

**segregated educational facilities:** Educational facilities that are separate from the typical placements of peers without disabilities, often termed “special schools”.

**self esteem:** A person’s feelings of self-worth and value.
**self-advocacy**: Having the opportunity to know one’s rights and responsibilities, stand up for them, and make choices about one’s own life.

**self-care skills/self-help skills**: Abilities related to personal hygiene, eating, dressing, and generally taking care of oneself.

**self-contained special education classroom**: A separate classroom where children with disabilities receive the majority of their school instruction, often with some opportunity to interact with their non-disabled peers during nonacademic activities and/or on the playground.

**self-determination**: The extent to which persons with developmental disabilities exert control and choice over their own lives.

**self-fulfilling prophecy**: The philosophy that a person will tend to behave on the basis of the expectations demonstrated by those around him. The idea of a person becoming what he is labeled to be based on other people’s expectations.

**sensorimotor skills**: An individual’s ability to interpret information received through the senses (vision, hearing, touch) and then perform appropriate movements or motor actions in response to that information.

**sensory**: Relating to the various sensory systems: tactile (touch), kinesthetic (movement), olfactory (smell), visual (sight), auditory (hearing), gustatory (taste), vestibular (balance).

**sensory integration**: Neurological processes which enable one to effectively interpret and use sensory input. Organization of the brain to make “sense” out of environmental information and coordinate it with information from the body and past experiences to produce an adequate adaptive response.

**sensory modality**: Sensory modality refers to any one of the five sensory avenues for receiving information: seeing, hearing, touching, tasting, and smelling.

**shared responsibility**: Concept that regular education and special education systems both have responsibilities, as partners, for the best education of children with disabilities.

**short attention span**: Inability to focus attention on a task for a sustained period of time, meaning more than a few seconds or minutes, depending upon the age of the child.

**sign language**: A form of manual communication in which words and concepts are represented by hand positions, finger spelling, body language, and facial expressions.

**special education classroom**: See “self-contained classroom.”
special education: Refers to instruction specifically designed to meet the needs of children with disabilities and may include classroom instruction, home instruction, and instruction in hospitals and residential facilities.

special education programs/services: Programs, services, or specially designed instruction offered at no cost to families for children ages 3 through 21 years with special educational needs who are found eligible for these services.

speech therapist/speech pathologist: See “speech-language pathologist”.

speech-language pathologist (SLP): A specialist in the field of human communication, its development, and its disorders, including articulation errors; language deficits; vocabulary, pitch or voice problems, and swallowing disorders. Also devise alternative communication methods for individuals who are nonverbal.

speech/language therapy: Treatment of speech, language and communication difficulties and disorders to enhance the communication ability of the individual.

stress: Internal and external factors that interfere with a person’s emotional, cognitive, and social functioning.

supported employment (SE): Vocational training and ongoing support provided to an individual with a disability who is working competitively at a job site in the community.

syndrome: A combination of symptoms which occur together and define a disease or disorder.

telecommunication device for the deaf (TDD): An electronic keyboard device that sends, receives, and prints typed messages over telephone lines so that individuals with hearing and/or speech impairments can communicate over the telephone. Used interchangeably with “TTY.”

teletypewriter (TTY): A typewriter that converts typed letters into electric signals which are then sent through telephone lines and printed on another typewriter connected to a phone on the other end so that individuals with hearing and/or speech impairments can communicate over the telephone. Used interchangeably with “TDD.”

transition: The process of bridging the time and environments between two settings, programs, or life situations (e.g., from home to school, school to school, or from school/home to employment/independent living) to ensure a smooth change-over to the new setting.
**transition plan:** A designed program outlining the transition activities required to identify the services needed by the individual, the steps that must occur prior to the change to the new setting, and the timelines and responsibilities for completion of these activities.

**typical peers:** The same-aged peers of a child with a disability who are not identified as having a disability.

**U V W X Y Z**

**ultrasound:** A prenatal evaluation procedure which employs high-frequency sound waves that are bounced through the mother’s abdomen to reveal certain characteristics of the developing fetus.

**visual acuity:** The sharpness or clearness of vision.

**visual perception:** The capacity to identify, organize, and interpret or give meaning to what is seen.

**vocational education/instruction:** Organized instruction which is designed to prepare individuals for employment in a specific occupation or group of closely related jobs in an occupational field, and which is especially and particularly suited to the needs of those individuals.

**vocational rehabilitation specialist:** A professional who specializes in designing and implementing programs to assist persons with disabilities to obtain and hold employment.

**vocational rehabilitation (VR):** The service of providing diagnosis, guidance, training, physical restoration, and placement to persons with disabilities for the purpose of preparing them for and involving them in employment that helps them to live with greater independence. Also known as “rehabilitation services.”

**well-baby care/well child care:** Preventive and routine care to protect and assess the general health of children, including immunizations.