

How Do I Get the Help My Child Needs?

The road ahead will be bumpy. There will be times when your progress stalls or takes an unexpected turn. When it does, try to remind yourself that these are speed bumps, not roadblocks. Take them one at a time. It is important that you start now. There are a variety of services available to treat and educate your child. The article below, from *Does My Child Have Autism?* by Wendy L. Stone, PhD, with Theresa Foy DiGeromino, MEd, explains why:

There is no debate or doubt: early intervention is your child's best hope for the future. Early attention to improving the core behavioral symptoms of autism will give your child – and the rest of the family – several important benefits that you will not gain if you take a wait-and-see approach until your child enters school at age four or five. A good early intervention program has at least four benefits: It will provide your child with instruction that will build on his or her strengths to teach new skills, improve behaviors, and remediate areas of weakness. It will provide you with information that will help you better understand your child's behavior and needs. It will offer resources, support, and training that will enable you to work and play with your child more effectively. It will improve the outcome for your child. For these reasons, an intervention program for your child should be implemented as soon as possible after he or she receives a diagnosis. However, as you probably know by now, it can be very challenging to teach young children with autism. They have a unique profile of strengths and needs and require intervention services and teaching approaches that are sensitive to these needs. That's why strategies that worked for teaching your other children to remain seated at the dinner table, to play appropriately with a toy, or to say words simply don't work as well for your child with autism. In the same way, intervention programs that are generic – rather than autism specialized – are less likely to be effective for your child. That's why as you begin your exploration of early intervention, you must keep in mind that not all interventions are equal.

Early Intervention will improve the outcome for your child.



Accessing Services: Your Child's Rights for Public Education

Every child has the right to a free appropriate education. The **Individuals with Disabilities Education Act (IDEA)**, enacted in 1975, mandates a public education for *all* eligible children and makes the schools responsible for providing the supports and services that will allow this to happen. IDEA was most recently revised in 2004 (and, in fact, renamed the Individuals with Disabilities Education Improvement Act, but most people still refer to it as IDEA). The law mandates that the state provide an eligible child with a free appropriate public education that meets his or her unique individual needs. IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. In addition, the IDEA legislation has established an important team approach and a role for parents as equal partners in the planning for an individual child, and promotes an education in the least restrictive environment. In addition to the IDEA stipulations, the Americans with Disabilities Act of 1990 (ADA) sets forth, as a civil right, protections and provisions for equal access to education for anyone with a disability. Section 504 of the Rehabilitation Act of 1973 is another civil rights law that prohibits discrimination on the basis of disability in programs and activities, public and private that receive federal financial assistance. Generally, the individuals protected by these laws include anyone with a physical or mental impairment that substantially limits one or more life activities.

Advocating for your child's education is a very important role, and at times can seem overwhelming and confusing. Two books that may be helpful are *Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide*, by Pam Wright and Pete Wright and *How to Compromise with Your School District Without Compromising Your Child*, by Gary Mayerson. You will also find additional books and websites at the back of this kit that will also be helpful in this process.

You, as a parent, are entitled to be treated as an equal partner with the school district in deciding on an education plan for your child.

What is a "Free and Appropriate Public Education" (FAPE)?

As described previously, IDEA provides for a "free and appropriate education" for all children with disabilities. Each word in this phrase is important, but "appropriate" is the one that relates specifically to your special needs child. Your child is entitled to an education that is tailored to his or her special needs and a placement that will allow them to make educational progress. Although you and your child's teachers or therapists may want to provide your child with the best and optimal programs and services, the school district is simply required to provide an appropriate education. One of the challenges here is working with the school district to determine what is appropriate and, therefore, what will be provided for your child. This is a collaborative process, and may require considerable negotiation in order to secure the appropriate services from the school.



What is “Least Restrictive Environment” (LRE)?

■ IDEA also provides that children with disabilities are entitled to experience the “least restrictive environment” in schools. This means that a school district is required to educate a student with a disability in regular classrooms, with his non-disabled peers. The child must be educated in the school he or she would attend if not disabled, to the maximum extent appropriate, and supported with the aids and services required to make this possible. This does not mean that every student has to be in a general education classroom, but the objective is to place the student in as natural a learning environment as possible, within his home community. This decision is made by the members of the IEP team, with consideration of the myriad of issues related to appropriate environment and supports for the student. Placements and the LRE for a particular student may change over time.

The participation of children with disabilities in the general education environment is often referred to as “mainstreaming” or “inclusion.” Inclusion does not mean that a child with special needs should be placed into a general education setting just like a typical learner; a variety of special education supports should be provided in order to create a successful environment and positive experience for everyone involved. Careful planning and training are essential to providing modifications or accommodations, and to successfully situating a child with a disability in the least restrictive setting. These supports might include providing a specially trained classroom or one-on-one paraprofessional, altering testing environments or expectations, adapting curriculum, providing visual supports or adaptive equipment, etc. The special education department should provide training, strategies and support for general education staff and others in the general school community who may interact with students with special needs. It is important to note that philosophies about inclusion vary considerably among school districts, staff and parents of students with and without special needs.

IDEA provides for a team approach to planning so that the objectives of all members of the team can be considered, and the necessary supports can be put in place to maximize inclusion. Not all parents will feel that a mainstream environment will enhance the growth and development of their student with special needs, and allowances need to be made to accommodate various perspectives. Additionally, not all students will be ready for full inclusion all of the time. The anxiety and sensory issues related to inclusion may mean that efforts should begin with small steps generate ongoing success and increasing participation within the local student body and community.



Early Intervention Services (EI) – For Children under the Age of 3

The IDEA provides states with federal grants to institute early intervention programs. Any child younger than age three who has a developmental delay, or a physical or mental condition likely to result in a developmental delay, is eligible to receive early intervention services through these programs. EI services can vary widely from state to state and region to region. However, the services should address your child's unique needs and should not be limited to what is currently available or customary in your region. The document that spells out your child's needs and the services that will be provided is the **Individual Family Service Program (IFSP)**. The IFSP should be based on a comprehensive evaluation of your child. It should describe your child's current levels of functioning and the anticipated goals. It should also list the specific services that will be provided to your child and your family. EI services are aimed at minimizing the impact of disabilities on the development of your child. Services for your child may include, but are not limited to, speech and language instruction, occupational therapy, physical therapy, Applied Behavior Analysis (ABA) and psychological evaluation. Services for families may include training to help reinforce the affected child's new skills and counseling to help the family adapt.

Information about the Legal Rights and Procedures for Early Intervention in your state can be found in the Autism Speaks Resource Guide

www.autismspeaks.org/community/fsdb/search.php.

Click on your state and you will find the information under Early Intervention/State Information

In this same section of the Autism Speaks Resource Guide you will also find state specific information on the process of transitioning from Early Intervention Services to Special Education Services.

Special Education Services – For Children Ages 3 – 22

Special education services pick up where early intervention services leave off, at age 3. Your local school district provides these services through their special education department. The focus of special education is different from that of early intervention. While early intervention addresses your child's overall development, special education focuses on providing your child with an education, regardless of disabilities or special needs. The document that spells out your child's needs and how these needs will be met is the Individualized Education Program (IEP). Like the IFSP, the IEP describes your child's strengths and weaknesses, sets goals and objectives, and details how these can be met. Unlike the IFSP, the IEP is almost entirely related to how



the needs of your child will be met within the context of the school district and within school walls.

Information about the Legal Rights and Procedures for Special Education Services (both Pre-school and School Age Services) in your state can be found in the Autism Speaks Resource Guide

www.autismspeaks.org/community/fsdb/search.php.

Click on your state and you will find the information under Pre-School Services or School Age Services/ State Information

You can also view the Autism Speaks School Community Toolkit at www.autismspeaks.org/community/family_services/school_kit.php

Extended School Year (ESY) Services

■ If there is evidence that your child experiences a substantial regression in skills during school vacations, he or she may be entitled to ESY services. These services would be provided over long breaks from school (summer vacation) to prevent substantial regression, but not to acquire new skills. It is important for the family to remain involved in determining appropriate goals, communicating with the educational team about progress, and working to provide consistency between home and school.

“I was overwhelmed in the beginning by all the evaluations and paperwork. Watching the changes in Samantha as she learns and grows, we know our efforts are paying off.”

How Do I Get Services Started for My Child?

■ For Early Intervention Services, if your child is under the age of three, call your local Early Intervention Agency. In most states Early Intervention is provided by the Department of Health. Contact information is included in the local resource guide of this kit. For Special Education Services, if your child is three or older, contact your local school district, and more specifically the Office of Special Education within the school district. In some cases, you may need to put the request in writing that you would like your child evaluated for special education services. Refer to “Assembling Your Team” in this kit for more information. You’ll find more information at the *Autism Speaks* web site, www.AutismSpeaks.org/community/fsdb/search.php and in the Action Plan section of this kit.



Before Service can be provided, it may be necessary to complete further assessments and evaluations. These may include:

- *An Unstructured Diagnostic Play Session*
 - *A Developmental Evaluation*
 - *A Speech - Language Assessment*
 - *A Parent Interview*
 - *An Evaluation of Current Behavior*
- *An Evaluation of Adaptive or Real Life Skills*

You may find yourself spending some time in waiting rooms with your child when you are completing additional evaluations. You have probably already figured out how helpful it is to bring some snacks for your child, his or her favorite toy, or some other form of entertainment to help pass the time. Having to wait for the completion of these additional evaluations, which may be required by the school district or Early Intervention, may be frustrating. There are sometimes waiting lists, and so it is important to start the process as soon as possible. The additional evaluations will provide much more in-depth information about your child's symptoms, strengths and needs, and will be helpful for accessing and planning therapy services in the long run.

It can also sometimes be difficult to read some of the evaluations about your child's strengths and challenges. It's helpful to remember that this is the same child as before the diagnosis and all of the evaluations.

The purpose of the evaluations is to understand your child's challenges so that he can get the appropriate services that he needs. The Organization for Autism Research's *A Parent's Guide to Assessment* can be helpful in explaining the results of the evaluations and what they mean for your child.

The guide can be found at

www.researchautism.org/resources/reading/documents/AssessmentGuide.pdf

If you find you are spinning your wheels waiting for the results, there are things you can be doing in the meantime. Talk to other parents about what services have been helpful for their children.

Investigate the therapies outlined in this kit. Start reading about autism. (There is a list of suggested books and web sites at the end this kit, as well as in the Autism Speaks Resource Library at www.autismspeaks.org/community/resources/index.php#library)

"While we were waiting for EI to complete the 'evals', my husband and I picked up two copies of the same book about autism and raced each other through it. By the time the tests were done, we'd learned a lot!"

