

# 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:

## Early Intervention is Your Child's Best Hope for the Future

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

Your special needs child has the right to a free and appropriate education. The Individuals with Disabilities Education Act (IDEA), which was first enacted in 1975 and most recently revised in 2004, mandates that each state provide all eligible children with a public education that meets their individual needs.

The Individuals with Disabilities Act (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 all eligible children with a free and appropriate public education that meets their unique individual needs.

IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. If your child has been diagnosed with a form of autism, the diagnosis is generally sufficient to gain access to the rights afforded by IDEA. The IDEA legislation has established an important role for parents in their children's education. 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 and his or her individual needs. This enables you to be a powerful advocate for your child. It also means that you must be an informed, active participant in planning and monitoring your child's unique program and legal rights.

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## 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 or optimal program and services, the school district is not required to provide the best or optimal but rather 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 that may involve considerable negotiation to secure the services from the school.

## What is "Least Restrictive Environment" (LRE)?

As specified in the IDEA, your child is also entitled to experience the "least restrictive environment." This means that your child should be placed in the environment in which he or she has the greatest possible opportunity to interact with children who do not have a disability and to participate in the general education curriculum. This is commonly referred to as mainstreaming or inclusion. In the general education setting, providing the least restrictive environment can sometimes be accomplished with accommodations, such as using a one-on-one aide who is trained to work with children with autism. While it may be true that seeking the least restrictive environment is beneficial for children with autism, it's important to consider whether or not an option such as inclusion is right for your child. It may or may not be more appropriate for your child to be placed in a special education program, in a school for children with special needs, or in a home instruction program.

# Early Intervention Services (EI)

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. If your child is determined to be eligible, these early intervention services must be provided to you at no cost.

EI services can vary widely from state to state and region to region. However, the services should address your child's unique needs rather than being limited to what is currently available or customary in your area. The document that spells out your child's needs and the services that will be provided is the Individual Family Service Plan (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.

# Special Education Services

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.

# 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. Contact information is included in the local resources guide of this kit.

For Special Education Services, if your child is three or older, contact your local school district. 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](http://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. Often, they 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.

If you find you are spinning your wheels, waiting for them, there are things you can be doing to 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 in this kit.)

“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!”

