

GETTING STARTED

A Guide for Oklahoma Families New to Autism Spectrum Disorders

As the family of a child recently diagnosed with an Autism Spectrum Disorder (ASD) you may be experiencing many emotions and probably have many questions about what the diagnosis will mean for your child and other family members. You may have already received a great deal of sometimes-conflicting information about autism, its causes and its treatment. This guide was developed to give you a general understanding of ASD, to help clarify some of your immediate questions and to help you begin to answer the question “What do we do next?”



WHAT ARE THE CHARACTERISTICS OF AUTISM SPECTRUM DISORDERS?

Autism Spectrum Disorders are neurodevelopmental disorders that affect the brain and disrupt development in several key areas. The term “spectrum” describes how each individual child is affected differently and to varying degrees of intensity, symptoms and behaviors. However, there are several key features these children share. These key features include difficulties with:

- Reciprocal social interactions (seeking comfort, enjoying social play such as peek-a-boo, interest in playing with peers, simple pretend play, imitating the actions of others)
- Language and/or communication difficulties (making their needs known in an age appropriate way, following simple commands)
- Restricted interests or repetitive, stereotyped behaviors (having an obsession with a specific toy or topic, unusual repeated body movements)

WHAT ARE THE DIFFERENT TYPES OF AUTISM SPECTRUM DISORDERS?

Your child may have received one of several diagnoses - Autism, PDD-NOS or Asperger Syndrome, to name a few. **Autism Spectrum Disorder** is an increasingly accepted term that refers to a broad definition of autism that includes a complex group of related disorders. It is sometimes used synonymously with another broad term, **Pervasive Developmental Disorder (PDD)**. To add further confusion, the public school systems use the category of **Autism** to qualify your child for services. Again, Autism is used as the broad “umbrella” term to refer to all the classifications listed below. You will hear these broad terms used interchangeably.

The three primary diagnoses or classifications under the broad terms are:

- **Autistic Disorder**
- **Asperger Syndrome (AS)**
- **Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)**

Autism is the fastest growing developmental disability in the United States

There is no specific medical test for autism, so professionals must rely on information from parents and caregivers and the presence or absence of certain behaviors they observe during the assessment process. Individuals in each classification may exhibit characteristics along the continuum from mild to severe. For example, a child with Autistic Disorder may have fluent speech or be completely nonverbal. Although the individual classification criteria vary somewhat, they all share many of the core characteristics, and regardless of which diagnostic label your child receives, his or her treatment is similar.

Types of Autism Spectrum Disorders

Autistic Disorder – Sometimes referred to as classic autism. Individuals in this classification have significant delays in all three core areas: language, social relations and restricted or repetitive patterns of behaviors and interests.

Asperger Syndrome (AS) – AS differs from autism in that individuals with AS have no significant delay in language acquisition or cognitive development. Individuals with AS have difficulty in two-sided social interaction, non-verbal communication and subtleties of communication, like irony and humor. They are also characterized by restricted and stereotyped interests and activities.

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) – Sometimes referred to as atypical autism. Individuals in this classification do not fully meet the criteria of symptoms and/or do not have the degree of impairments to diagnose any of the specific types of PDD.

WHAT CAUSES ASD?

Simply, we are not sure. It is generally accepted that it is caused by differences in brain structure or function, but there is not a single cause for these differences. Research shows that genetics plays an important role, and that several genes, possibly in combination with the environment and other medical conditions, contribute to ASD.

What we do know is that parents do **not** cause their child to have ASD. It is **not** a result of “bad parenting”, or “spoiled children” who refuse to behave. It is **not** a mental illness or caused by psychological factors. It is **not** contagious and it is **not** anyone’s fault.

HOW COMMON IS ASD?

According to findings released from the Centers for Disease Control and Prevention (CDC) in February 2007, ASD prevalence rates are increasing and the average findings translate to a prevalence rate of 1 in 150 children. ASD is four times more likely to occur in boys than in girls and shows no racial, ethnic or socioeconomic boundaries.

IS THERE A CURE?

While children with a diagnosis of ASD can show significant improvements in many areas, there is no known cure at this time. Early and appropriate interventions can significantly improve the quality of life for individuals with autism.

HOW DO YOU KNOW WHAT TREATMENT IS BEST FOR YOUR CHILD?

The amount of information available regarding different treatment approaches can be overwhelming and you will likely encounter differing opinions regarding the “best” treatment for children with ASD. Also it is important to look for interventions that diminish the core features of ASD and to remember that no two children with ASD are exactly alike. Each child needs a treatment program to meet his individual needs and the needs of his family. Educational interventions, including behavioral strategies, are the cornerstones of ASD treatment. These interventions address communication, social skills, daily-living skills, play and leisure skills, academic achievement, and challenging behaviors.

WHAT SHOULD YOU LOOK FOR IN AN EDUCATIONAL PROGRAM?

There is no single educational intervention that works all the time for all children with ASD. The success of intervention depends on the program being individualized for your child. Your knowledge and experience of your child is critical to developing an effective program.

In the past 15 years there has been a greater emphasis placed on early intervention for ASD. This is due in part to research that suggests that children with ASD who receive a diagnosis early and enter intervention early often have substantially better outcomes. As a result of the emphasis on early intervention, many of the model programs described in research studies were developed for young children with ASD. While these programs differ in their emphasis (i.e., what skills or behaviors are taught) and in philosophy of how to address intervention, they share many common components. These common components have been reviewed and summarized by such organizations as the National Academy of Sciences (NRC Report, 2001) and serve as an excellent guide for developing a comprehensive intervention program for a child with ASD. These components are summarized in the box below.



A program of intervention should begin as soon as an ASD diagnosis is considered or upon receiving a formal diagnosis and should include the following components:

1. An adequate level of intensity. Intervention for young children can be defined as a combination of professional support and home and community activities to total 25 hours per week. Intensity considerations include:
 - the amount of time spent on intervention
 - the educational validity of the interventions provided
 - the amount of time a child is attending to and actively interacting with others (engagement)
2. Incorporation of a high degree of structure through such elements as:
 - predictable routines,
 - presentation of activities in a manner that is comprehensible to the child (i.e., pictures, symbols, words, schedules)
 - organization of the physical space that clearly communicates expectations and minimizes distractions
3. Repeated, planned teaching interactions that utilize low child-to-adult ratios and are delivered in both individual and small group settings
4. Active involvement of the family in intervention procedures, including family training, to address family priorities and ensure the generalization of skills
5. Regularly scheduled and planned opportunities for interaction with typically developing peers
6. Positive approach to addressing challenging behaviors that:
 - focus on preventing problems from occurring
 - utilize functional assessment procedures
 - emphasize teaching new skills to replace disruptive behavior
7. Specialized assessment procedures and curriculum that focuses on:
 - functional and spontaneous communication
 - social interaction to include skills such as imitation, reciprocal interaction, joint attention, and initiation
 - functional adaptive skills that prepare the child for increased responsibility and independence
 - teaching of play skills
8. The use of appropriate on-going evaluation tools to monitor progress and allow for needed adjustments to program

WHAT ABOUT OTHER TREATMENTS?

Increasing numbers of treatments exist that may be outside of what is typically recommended. They are sometimes referred to as complementary or alternative treatments. It is very understandable that many parents continually seek new treatments in an effort to do everything possible to help their children. Some of these treatments are developed by reputable professionals or by parents of a child with ASD. Although an unproven treatment may help one child, it may not prove beneficial to another and may actually be counterproductive for a child. To be accepted as a proven treatment, the treatment should undergo rigorously controlled randomized studies.

The National Institutes of Health (NIH), National Center for Complementary and Alternative Medicine (NCCAM) explores complementary and alternative healing practices in the context of rigorous science. For more information on these treatments go to nccam.nih.gov. The National Institute of Mental Health, part of NIH, does studies to test how well various biomedical interventions work. Search ClinicalTrials.gov for NIH studies on ASD. A good resource for reviewing the scientific evidence regarding the more common treatments for ASD is the website of the Association for Science in Autism Treatment. This website provides up to date information on the latest treatments (<http://www.asatonline.org/>).

The **Centers for Disease Control** warns that some types of treatments are controversial. Current research shows that as many as one third of children with autism may have tried complementary or alternative medicine treatments, and up to 10% may be using a potentially dangerous treatment. Before starting such a treatment, check it out carefully, and talk to your child's health care professional.

SHOULD YOUR CHILD BE ON MEDICATION?

There is not a medication which can cure autism and no medication that treats the core symptoms (social, communication and repetitive or unusual behaviors) of autism. There are medications that treat certain symptoms associated with autism such as high energy levels, inability to focus, anxiety, depression, seizures or sleep disturbances. A child with ASD may not respond in the same way to medications as typically developing children. It is important that parents work with a qualified medical doctor who has experience with children with ASD and that the child is monitored closely while taking a medication.



WHAT CAN YOU DO TODAY TO HELP YOUR CHILD?

Today, you can begin by making your child's life as predictable as possible. Most children with ASD are confused about what is expected of them. Think of simple, concrete ways you can let your child know where he should be, what he should be doing, when an activity is finished and what happens next.

By establishing clear routines that you follow each day your child's world will make more sense to him. Pictures and other visual cues can help with this. Whenever possible, prepare your child ahead of time when something new or different will happen. For example, show your child a picture of friends or relatives before they arrive for a visit. You can also make places and activities in your home organized and predictable. Make a special place where certain activities will take place. Safety issues should be a priority and putting extra childproofing and prevention plans in place may be necessary.

Finally, take a deep breath and remember that your child is the same wonderful, unique individual he was before receiving a diagnosis. Love him, encourage him and expect him to develop to the best of his abilities.

WHAT DO YOU DO NEXT?

1. GET SUPPORT

Many families find one of the most helpful things they can do is to meet and talk with other families of children with ASD. Other families who may have a few years of experience in raising a child with ASD can provide priceless information about resources in your area and share their experience in navigating the system. It may also be helpful to know you are not alone and there are others who can support and encourage you over the rough spots. Oklahoma has several autism family support groups. To locate one in your area or to get information to start a new group, contact the Oklahoma Autism Network at **1-877-228-8476**

Website: okautism.org Email: okautism@ouhsc.edu

2. LOCATE SERVICES

If your child is under 3...

SoonerStart is Oklahoma's early intervention program for infants and toddlers birth to three years old with developmental delays. This program is funded through various state and federal sources. SoonerStart service providers support children in their natural environments at no cost to the family. Services are organized through an Individualized Family Service Plan (IFSP) and may include an array of supports, which can be provided in the home and/or community setting. SoonerStart will also assist in your child's transition to school at age three. Contact the Oklahoma State Department of Education, Special Education Services at **(405)521-4155**, or to the website at www.sde.state.ok.us to locate services.

If your child is 3 to 21...

Once your child reaches the age of three, your local school district will provide services through their special education program. The school team will review any information you provide them and collect additional information, if needed, in order to have a comprehensive picture of your child including strengths and weaknesses. After this evaluation process, eligibility is established and an Individualized Education Plan (IEP) will be developed to outline your child's services. Contact your local school district special education office for services.

Explore other resources

After getting services through SoonerStart or your school you may wish to contact the Oklahoma Autism Network to learn about other services your child may be eligible for. The network can help you locate providers, find out about free parent training programs and obtain information about financial resources available.

3. LEARN ALL YOU CAN ABOUT ASD

Information about ASD is abundant but you can't learn everything all at once. Take one step at a time and concentrate on how ASD affects your individual child. We have provided a few important books and websites to get you started.

4. BE AN INFORMED CONSUMER

We live in an age of information with increased access to resources at our fingertips. While this is good, too much information can be overwhelming. Distinguishing misinformation from accurate information can be a very challenging task. Be open-minded and don't hesitate to ask critical questions about treatment and intervention approaches.

5. SHARE WITH OTHERS

Family members, friends, neighbors, church members and others can be a source of support for you and your family. Helping them learn about ASD and your child's unique strengths and challenges will allow them to understand your child and provide support to you. A good resource for this would be *Ten Things Every Child with Autism Wishes You Knew* by Ellen Notbohm and published Future Horizons (2005).

6. TAKE CARE OF YOURSELF

It's natural to feel urgent about helping your child, especially when you first get the diagnosis. Parents who have been at this a long time often say that one of the best things you can do is take one step at a time. You can't learn everything all at once and neither can your child. Allow yourself some "time out" to nurture yourself so that you can nurture and advocate for your child.

RESOURCES

FIRST BOOKS

Children with Autism: A Parent's Guide, Powers, M., Woodbine House (2000)

A Parent's Guide to Asperger Syndrome and High-Functioning Autism: How to Meet the Challenges and Help Your Child Thrive, Ozonoff, S., Dawson, G., & McPartland, J., Guilford Publications, Inc. (2002)

FIRST WEBSITES

Oklahoma Autism Network

www.okautism.org

Autism Society of America

www.autism-society.org

Autism Speaks

www.autismspeaks.org

American Academy of Pediatrics

www.aap.org

Online Asperger Syndrome Information and Support (OASIS)

www.udel.edu/bkirby/asperger

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National Institute of Mental Health. (April 3, 2008). Retrieved May 7, 2008, from <http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>

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**This publication was developed in Spring 2008 by
The University of Oklahoma Health Sciences Center
Child Study Center
Project PEAK and Early Foundations**

**Special Acknowledgements for funding and assistance to:
University of Oklahoma Health Sciences Center
Center for Learning and Leadership,
Oklahoma's University Center for Excellence in Developmental Disabilities (UCEDD)**

**Oklahoma State Department of Education
Special Education Services**

Oklahoma Autism Network

This publication was partially funded by a grant from the US Administration on Developmental Disabilities (Grant # 90DD0543).