

*Developmental
Behavioral
Pediatrics*

A Family Guide
To
Autism Spectrum Disorder

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UNDERSTANDING AUTISM SPECTRUM DISORDER (ASD)

As a parent or caregiver of a child who has been diagnosed with autism spectrum disorder, one of the most valuable things you can do for your child is learn about ASD and how it affects your child and family. The more you know, the better you can advocate for your child and his or her needs. At first the diagnosis may feel overwhelming. *It is important that you take the time you need to take in the information you have just been given.* As you are able, you can read more about ASD in the pages below and from the resources included at the end of this handout. **If you have any questions you can call our office at 312-227-6720.**

What is autism spectrum disorder?

Autism spectrum disorder is a developmental disorder that affects how a child grows and learns in several areas, including speech, social skills and behavior. Children who have problems in these areas are sometimes said to have an autistic spectrum disorder because the severity of symptoms varies greatly. Other names you may hear to describe this disorder may be: pervasive developmental disorder (PDD-NOS), Asperger's syndrome or autism. Up until very recently, we thought that autism, pervasive development disorder and Asperger syndrome were separate disorders, but the latest research indicates that they are likely the same disorder.

What are the symptoms of autism spectrum disorder?

Children with autism spectrum disorder have a number of symptoms, ranging from mild to severe. Symptoms include:

- Difficulty interacting with others and making friends.
- Communication problems, both in understanding what is said and in using spoken language and gestures.
- Behavioral differences including restrictive or repetitive patterns or insistence on sameness and routine.

Each child with autism spectrum disorder is unique, but some common characteristics and behaviors may include:

- Repeats words
- Doesn't play "pretend" games
- Doesn't point at objects or wave "bye-bye"
- Is overly active
- Has frequent temper tantrums
- Avoids eye contact
- Has difficulty starting or maintaining conversation
- Does not respond to being called by name
- Repeats actions again and again
- Focuses on single subject or activity
- Wants to be alone
- Is overly sensitive to the way things feel, sound, taste or smell
- Dislikes being held or cuddled
- Has sleep disturbances
- Lacks fear in risky situations
- Is aggressive
- Hurts himself
- Loses skills (for example, stops saying words he used to say

What causes autism spectrum disorder?

Autism is a disorder that is mostly genetic in origin; however, we don't always know why a specific child may have the disorder. Autism is a disorder of brain development that appears to be associated with subtle abnormalities in specific structures or functions in the brain.

Scientists believe that at least 100 genes on different chromosomes may contribute to ASD. The role environmental factors may play in the development of the disorders remains an area of active research. In a minority of cases, other genetic diseases, such as fragile X syndrome and tuberous sclerosis may play a role.

What does not cause Autism Spectrum Disorder?

Childhood vaccines, including the measles/mumps/rubella (MMR) vaccine, do not cause autism. Some suspect that this vaccine, given around 12 to 15 months of age, contributes to autism because children sometimes begin to display symptoms of autism around the time they are vaccinated. Most likely, this is the age when symptoms of the disorder commonly begin, even if a child is not vaccinated.

Another reason that childhood vaccines were suspected of playing a role in autism spectrum disorder is that, until recently, they included a preservative called thimerosal. Thimerosal is a substance related to mercury. Since 2002, all routine childhood vaccines have been free of thimerosal.

While higher doses of certain forms of mercury may affect brain development, studies show that thimerosal does not. In 2004, an Institute of Medicine panel concluded that neither the MMR vaccine nor thimerosal-containing vaccines are associated with ASD.

Diagnosing Autism Spectrum Disorder

When is Autism Spectrum Disorder diagnosed?

A child with autism spectrum disorder usually does not look different from other children. The child may appear to develop normally for the first year or so of life.

But during the second year of life, some children with ASD begin to fall behind in social skills, fail to develop speech, or even lose skills that they had previously acquired.

Most children with autism spectrum disorders are diagnosed between ages 2 and 5 years old. Children with more mild forms may even be diagnosed later in the school-age years or even in adolescence.

How is Autism Spectrum Disorder diagnosed?

There is no medical test to diagnose ASD. Doctors generally diagnose ASD with the support of occupational therapists, speech therapists, and/or psychologists by observing a child's behavior and by using tests that measure a number of characteristics and behaviors associated with autism spectrum disorder.

Who is at risk of Autism Spectrum Disorder?

Autism occurs in all racial, social and educational groups. Boys are about 4 times as likely as girls to be affected. Siblings of an affected child may be at increased risk for autism spectrum disorder, though the risk appears fairly low (2 to 8 percent).

TREATMENT FOR AUTISM SPECTRUM DISORDER

Although there is no single known cause or cure, autism spectrum disorder is treatable. It is important to have hope for your child, because with the right interventions and support, people with autism spectrum disorder can live full, healthy and meaningful lives. The types of intervention your child needs are as unique as your child, and may change over time. It is helpful to know about what treatment options are available so that you and the professionals working with your child can choose interventions tailored to your child's individual strengths, needs and challenges.

Treatment for autism spectrum disorders typically focuses on building self-help and communication skills as well as on decreasing disruptive and challenging behaviors. The most commonly recommended treatment options for children with autism spectrum disorder include therapies and education services.

Therapies can occur individually or in groups. They can occur in a child's home, in a therapist's office setting, or at school, and may include the following:

- Speech therapy
- Occupational therapy
- Developmental therapy
- Physical therapy
- Social skills training
- Behavioral therapy
- Music therapy
- *Specific therapies for autism spectrum disorder:*
 - Applied Behavioral Analysis (ABA), also known as Discrete Trial Training. This highly-structured therapy focuses on 1-on-1 teaching with rewards. This form of therapy has the most scientific evidence to support its use.
 - Verbal behavior therapy is similar to ABA but focuses on learning to use language in natural environments.
 - Relationship Developmental Intervention (RDI). This family-centered approach focuses on skill-building through a child's natural relationships.
 - DIR/Floortime (Developmental, Individual Differences, Relationship-Based) Model. This model focuses on following a child's natural emotions and interests rather than on specific skills or behaviors.
 - TEACHH (Treatment and Education of Autistic and related Communication Handicapped Children). This highly-structured teaching program focuses on helping children with ASD to adapt to the world.

Medicines There are no known medicines that cure autism, but some medicines can be used to help manage behaviors that interfere with a child's progress, like hyperactivity, inattention, irritability, aggression, self-injury, repetitive behaviors, mood disturbances, anxiety and sleep problems.

Complementary and Alternative Medical Treatments (CAM) Many families try complementary and alternative treatments for their child, including nutritional supplements, diet changes, or other medications and therapies. These treatments may not have been scientifically studied. If you are interested in using any of these treatments, you should discuss them with your child's pediatrician. It is important to understand all

of the potential benefits and risks of any chosen treatment, as well as the potential financial costs that may be involved.

SCHOOL CONSIDERATIONS

School-aged children with autism spectrum disorder are entitled by law to an education program that is tailored to their unique strengths and needs. This often includes having an Individualized Education Program (IEP) that identifies their specific strengths and challenges; goals for the child and school staff to address; and services or accommodations needed to help the child reach his or her full potential.

Enrolling your child in school is an important step in ensuring that your child is getting the services and supports he or she needs. Children 5 years old and older by September 1st are eligible to enroll in Kindergarten. Children 3-5 years old may be eligible for your local school district's Early Childhood Education programs. There are different types of early childhood education programs for children aged 3-5 and they vary by school district. You will need to contact your local school district to find out what is offered in your area.

Illinois' Early Intervention Program

- Free to children who qualify from birth to 3 years old with diagnosed disabilities, developmental delays or substantial risk of significant delays.
- Receive resources and supports that assist in maximizing their child's development
- To apply: Use the **DHS Office Locator** to find an Early Intervention office in your local area. <http://www.dhs.state.il.us/page.aspx?module=12>
- Or Call 1-800-447-6404 (Voice/TTY). For automated service, call 1-800-323-GROW (4769).

Pre-Kindergarten/Pre-School Programs

- Free, low-cost, and tuition-based programs for children from 3-5 years-old
- Potty training not required
- If your child could benefit from special education services, contact your public school system's department of special education services for more information

To find out more about these programs you can contact:

Illinois State Board of Education Division of Early Childhood

217-524-4835 (direct line) or 866-262-6663 (they can connect you)

<https://www.isbe.net/Pages/Early-Childhood.aspx>

For a directory of state early childhood programs:

https://www.isbe.net/documents/pfa_contact_list.pdf

If you live in the City of Chicago

For children 3-5 years old, you can contact the Chicago Early Learning Hotline at (312) 229-1690 or go to <https://chicagoearlylearning.org/>

If your child has not been evaluated for special education services through the school system, please also attend a Child Find Team Screening Site to obtain a free developmental screening. If a screening indicates a need for further evaluation then you

will be referred to the Office of Diverse Learner Supports and Services (ODLSS). Please contact ODLSS at 773-553-1800 for Child Find Screening locations and dates/times.

For children ages 5 and up, Call Chicago Public Schools to find your home school, at 773-553-2060

You can find your home school and enrollment information via their website:
http://www.cps.edu/Schools/Enroll_in_a_school/Pages/Enrollinaschool.aspx

For more information about special education laws and advocacy see:

Equip for Equality

<http://www.equipforequality.org/issues/special-education/>

Call the Free Special Education Helpline: **1-866-KIDS-046** (1-866-543-7046)

Family Resource Center on Disabilities

Phone: 312-939-3513

<https://frcd.org/>

ADDITIONAL RESOURCES FOR FAMILIES

- *Autism Speaks* **www.autismspeaks.org** or 1-888-AUTISM-2
Autism Speaks provides a wealth of information and resources for families, including video clips about autism and the 100-Day Kit, a free resource to guide families through the first 100 days following a new diagnosis. This kit can be downloaded or ordered through their website or by phone, and personalized to include local resources for your family. Autism Speaks also maintains an online resource search engine, helpful for finding resources based on your zip code:
<https://www.autismspeaks.org/family-services/resource-guide>
- *Autism Society of America* **www.autism-society.org** or 1-800-3-AUTISM
The Autism Society of America is the oldest support organization for autism and provides detailed information about autism spectrum disorders as well as resources for families, information and referrals, and advocacy for individuals with ASD.
- *The Autism Program of Illinois (TAP)* **www.theautismprogram.org**
217-525-8332 (Springfield Main Office).
TAP is a statewide network of resources for Autism Spectrum Disorder, providing information, training, consultation and support for parents and professionals.
- *Rush Autism Resource Center* **<https://www.rush.edu/services-treatments/psychiatry/autism-resource>**
The Rush Autism Resource Center maintains an online directory of Chicago area resources for individuals with autism spectrum disorders. It includes resources for diagnosis, treatment, family support and other services such as special needs dentist

- *Illinois Autism Law*: An Illinois law passed in December 2008 requires insurance companies to pay for therapies for children with autism, but only if the company you work for is not self-insured. Your human resources department can provide you with information about your insurance policy. For more information about the law see: **<http://insurance.illinois.gov/HealthInsurance/AutismFactSheet.pdf>**
- *Funding for Services in Illinois*: The Children's Waiver Program provides additional funding for therapy, respite care and other supports for children 3-21 who qualify. In order to apply for this funding, families must register with the PUNS database. To find out how you can register with PUNS and apply for the waiver contact the **Illinois Division of Developmental Disabilities Hotline at 1-888-337-5267**. You can also contact the **Family Support Network** for more information 708-331-7370 or at **www.familysupportnetwork.org**.
- *Social Security for Children with Disabilities*: SSI (social security) provides monthly payments to families of children with qualifying disabilities who also meet certain financial criteria. For more information on SSI call the Social Security Administration at 1-800-772-1213 or visit their website at **www.ssa.gov/disability**.
- *Resource Center on Autism and Developmental Delay*- is a UIC Center for Literacy initiative established to provide resources, referral information, education, and training for parents and teachers of children with developmental disorders. RCADD is staffed by professionals who work with families and providers to identify and prioritize current needs and select or create appropriate resources for children with disabilities. Resources include books, software, games, home teaching kits, and visual supports. The library's resources are available to check out free of charge to provide community members and professionals with access to current, innovative, supportive services and materials.

RCADD also conducts workshops that are designed to support family members of children newly diagnosed with an Autism Spectrum Disorders (ASD). (See workshop schedules included in this packet)

RCADD South: King Community Center
4314 S. Cottage Grove Ave. #106 CHICAGO, IL 60653
312-747-8571

RCADD West
at the Garfield Community Center
10 S. Kedzie Ave., Room 205
Chicago, IL 60612
(312) 747-8571