

Understanding Autism Spectrum Disorders (ASDs):

An introduction



Autism spectrum disorders (ASDs) are a group of related brain-based disorders that affect a child's behavior, social, and communication skills. They include 3 of 5 disorders known as pervasive developmental disorders (PDDs). These are autistic disorder, Asperger syndrome, and PDD-not otherwise specified (PDD-NOS).

Because most children with ASD will master the early motor skills such as sitting, crawling, and walking on time, delays in social and communication skills may not be as obvious to parents. Looking back, many parents of children with ASD can think of specific examples that suggest something was different, but nothing indicating a serious problem.

Autism spectrum disorders are lifelong conditions with no known cure. However, children with ASD can progress developmentally and learn new skills. Some children may improve so much that they no longer meet the criteria for ASD, although milder symptoms may often persist.

It is important to start an intervention program as soon as possible. The sooner autism is identified, the sooner an intervention program can start. Each child with autism has different needs. What works for one child may not work for another.

The following are excerpts from the American Academy of Pediatrics' (AAP) booklet *Understanding Autism Spectrum Disorders (ASDs)*.

How common are autism spectrum disorders?

Autism spectrum disorders affect an estimated 4 to 6 out of every 1,000 children. The reported number of children with ASD has increased since the early 1990s. The reason for the increase is unclear. It may be because of many factors, including an increased awareness of what ASDs are, more screening tools and services, and/or changes in how ASD has been defined and diagnosed. In the past, only children with the most severe autism were diagnosed (the tip of the iceberg). Now children with milder symptoms are being identified and referred to intervention and educational programs.

What are the symptoms of autism spectrum disorders?

No 2 children with ASD have the exact same symptoms, but the criteria are somewhat standardized. The number of symptoms and how severe they are can vary greatly. The following are examples of how a child with ASD may act:

Social differences

- Doesn't snuggle when picked up, but arches back instead
- Doesn't keep eye contact or makes very little eye contact
- Doesn't respond to parent's smile or other facial expressions
- Doesn't look at objects or events parents are looking at or pointing to
- Doesn't point to objects or events to get parents to look at them
- Doesn't bring objects to show to parents just to share his interest
- Doesn't often have appropriate facial expressions

- Unable to perceive what others might be thinking or feeling by looking at their facial expressions
- Doesn't show concern (empathy) for others
- Unable to make friends

Communication differences

- Doesn't say single words by 15 months or 2-word phrases by 24 months
- Repeats exactly what others say without understanding its meaning (parroting or echolalia)
- Doesn't respond to name being called, but does respond to other sounds (like a car horn or a cat's meow)
- Refers to self as "you" and others as "I" (pronominal reversal)
- Often doesn't seem to want to communicate
- Doesn't start or can't continue a conversation
- Doesn't use toys or other objects to represent people or real life in pretend play
- May have a good rote memory, especially for numbers, songs, TV jingles, or a specific topic
- Loses language milestones, usually between the ages of 15 to 24 months in a few children (regression)

Behavioral differences (stereotypic, repetitive, and restrictive patterns)

- Rocks, spins, sways, twirls fingers, or flaps hands (stereotypic behavior)
- Likes routines, order, and rituals
- Obsessed with a few activities, doing them repeatedly during the day
- Plays with parts of toys instead of the whole toy (for example, spinning the wheels of a toy truck)
- May have splinter skills, such as the ability to read at an early age, but often without understanding what it means
- Doesn't cry if in pain or seem to have any fear
- May be very sensitive or not sensitive at all to smells, sounds, lights, textures, and touch
- Unusual use of vision or gaze—looks at objects from unusual angles
- May have unusual or intense but narrow interests

What are the different types of autism spectrum disorders?

As mentioned earlier, ASD includes 3 of 5 disorders known as PDDs. Pervasive developmental disorders are defined in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* and the revised *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. These manuals are published by the American Psychiatric Association and describe behavioral and mental health conditions. Pediatricians may use the *Diagnostic and Statistical Manual of Mental*

Disorders, Primary Care (DSM-PC) version published by the AAP. Although many doctors use the term PDD as published in the *DSM*, most experts in the field now use the term ASD.

The following are descriptions of autistic disorder, Asperger syndrome, and PDD-NOS:

Autistic disorder

Autistic disorder is the term used when a child meets all the necessary criteria listed in the *DSM-IV*. Children with autistic disorder have problems with language skills that are absent, delayed, or abnormal; problems relating to others socially; and unusual or repetitive behaviors. While social symptoms are usually present in the first year of life, language problems show up in the second year and stereotypic behaviors show up later. Many of these children will have intellectual deficits; others might *appear* to have deficits when, in fact, scores on intelligence tests are low because of lack of cooperation. Others may have normal scores on intelligence tests, yet they may have trouble with abstract and real-life reasoning. Children with autism are often labeled as *high functioning* when intelligence is in the normal range.

Asperger syndrome

Asperger syndrome is usually not diagnosed until preschool age or later. This is because early speech development, especially language and sentence structure, is relatively normal. Sometimes children with Asperger syndrome speak in an odd way. Some children may speak in the same tone of voice without raising or decreasing the pitch of their voice. Other children may speak in language above what you would expect for their age like “little professors.” They may make little eye contact while talking and may have trouble maintaining a back-and-forth conversation. They usually obsess over 1 or 2 topics and will talk about these topics whether the listener is interested. Children with Asperger syndrome often interpret language literally and may have particular trouble with humor, teasing, and figures of speech. Many may also have problems with motor coordination. Intelligence is normal. Some experts do not consider this a separate disorder from high-functioning autism.

Pervasive developmental disorder-not otherwise specified

Children with PDD-NOS or atypical autism show some signs of autism or other PDD, but don’t meet the criteria to be diagnosed with one specific disorder.

What causes autism spectrum disorders?

No one knows exactly what causes ASD. Years ago “poor, non-nurturing” parenting was thought to be a possible cause of ASD, but this is not the case. Today scientists know from twin and other family studies that genetics play a major role. Although many chromosomal and gene abnormalities have been identified, none of these are present in all children with ASD. If a family already has a child diagnosed with ASD, the chances that siblings might also have some form of ASD are 10 times higher than in the general population. Environmental factors may also play a secondary role, but this has not been proven yet.

Studies have shown that in families with autism, there are often other developmental problems. These problems may include language delays, learning disabilities, anxiety, or mood disorders among family members.

Autism spectrum disorders, particularly autistic disorder, also tend to occur more often in people with certain medical conditions, such as fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU).

Two prescription medicines that have potentially been linked to ASD are thalidomide and valproate.

Current scientific proof does not support a link between the measles-mumps-rubella (MMR) vaccine or any combination of vaccines and ASD. There also is no scientific proof to support a link between thimerosal (a mercury-containing preservative) and ASD. In any event, vaccines no longer contain mercury.

What are the early signs of autism spectrum disorders?

Many children with ASD may show developmental differences throughout their infancy, especially in social and language skills. Because they usually sit, crawl, and walk on time, these more subtle differences often go unnoticed.

Social skills

In looking back on their child’s development, parents will often say that something seemed different from the beginning. For example, a child with ASD may have

- Not smiled back to you or smiled less often or less enthusiastically than you expected.
- Not cuddled like other children.
- Not made as much eye contact with others.
- Not responded to her name being called.
- Seemed to tune others out. At other times, she may have seemed to hear environmental sounds, even very faint ones, perfectly well. This was probably confusing and may have caused you to worry about a hearing problem.

One of the most important developmental differences between children with ASD and other children is a delay or lack of *joint attention*. Looking back and forth between the same object or event and another person and connecting with that person is called joint attention. It is a building block for later social and communication skills. Engaging in many back-and-forth social interactions, such as exchanging lots of emotional expressions, sounds, and other gestures, is called *reciprocal social interaction*. Delays in joint attention skills are found in most children with ASD and rarely seen in children with other types of developmental problems. Thus, joint attention deficits are thought to be among the most characteristic deficits of ASD. There are several stages of joint attention. Children with ASD usually show delays or absent skills at every stage.

Other differences in children with autism spectrum disorders

- **May use fewer gestures or none at all.** For example, they may not wave goodbye, reach up to parents to be held, or play patty-cake.
- **May be attached to hard objects.** Many typically developing children become attached to a comfort item that helps to soothe and console them in times of stress. Usually this is a soft object such as a favorite blanket, stuffed animal, or pillow. However, children with ASD often insist on carrying a hard object with them at all times. The object could be a pen, a piece of string, an action figure from a favorite TV show or video, or sometimes an unusual object like a toilet plunger or soft soap dispenser. The children may have severe temper tantrums if the object is taken away. These unusual attachments often change from one object to another over time.
- **May demonstrate repetitive actions** such as hand flapping, rocking, head banging, twirling, or pacing back and forth across the room.

- **May not engage in pretend or make-believe play** with dolls or stuffed animals as if they were having a tea or birthday party.

On the other hand, some children with ASD may be especially talented in putting complex puzzles together or playing computer games.

Language delays

All children with autism show significant language delays. Those children later diagnosed with Asperger syndrome will seem to have met language milestones during the toddler years, but use of language may be abnormal.

Regression in developmental milestones

About 25% of children will seem to have normal development until about 18 months, after which they will gradually or suddenly

- Stop talking (if they had begun to say a few words).
- Stop waving goodbye.
- Stop turning their heads when their names are called.
- Withdraw into a shell and seem more distant and less interested in their surroundings.

However, a careful review of home videos of these children taken at their 1-year-old birthday parties (*before* they actually regress) often shows subtle signs of ASD that were missed at the time. One of the most common signs in these videos is children not consistently turning their heads when their names were called.

How is the diagnosis made?

Diagnosis of ASD involves many factors. There are no specific lab tests for ASD, so pediatricians must rely on information from parents and what can be observed during well-child checkups. The condition is complex and symptoms are different for each child.

When an ASD is suspected as a cause of language and social delays, a full evaluation should follow. This may be done by a doctor or psychologist who has expertise in the diagnosis of ASD or, preferably, by a team of specialists that may include developmental pediatricians, child neurologists, child psychiatrists, psychologists, speech or language pathologists, occupational or physical therapists, educators, and social workers. Typically, an evaluation will include the following:

- **Careful observation of play and child-caregiver interactions.**
- **Detailed history and physical exam.**
- **Developmental assessment of all skills** (motor, language, social, self-help, cognitive). Autism spectrum disorders are suspected when the child's social and language functioning is significantly more impaired than the overall level of motor, adaptive, and cognitive skills.
- **Standardized autism-specific tool.** Special training is usually needed to administer a standardized behavioral or developmental tool that has been specifically developed to help diagnose ASD. There may be few clinicians in a given community with these qualifications. However, every school district should have at least one professional (usually a child psychologist) that can administer an autism-specific tool. Tools may include the Childhood Autism Rating Scale, Gilliam Autism Rating Scale, Autism Diagnostic Interview-Revised, and Autism Diagnostic Observation Schedule.
- **Hearing test.** All children with any speech delays or those suspected of having ASD should have their hearing evaluated by a pediatric audiologist.
- **Language evaluation** that provides standardized scores of expressive language (including speech) and receptive language, as well as an evaluation of pragmatic language (social use of language) and articulation (pronunciation).

Medical tests

In fewer than 10% of children diagnosed, ASD may be associated with a known syndrome or medical condition. Lab tests may be needed to rule out other possible medical causes with similar symptoms. Your pediatrician will recommend what's best based on your child's history and physical exam. Tests should be ordered only if the results will provide useful information. Your child may be referred to other specialists, such as a geneticist or a pediatric neurologist, to help with this search for an underlying cause.

Living with autism spectrum disorders

There are many different strategies and techniques to help children with ASD interact with others and learn new skills that will help them talk, interact, play, learn, and care for their needs. So far, no one technique has been proven significantly better than others. However, effective programs should be intense, address behavior management as well as communication and social skills development, and encourage parents to get involved. The ultimate goal of all programs should be the successful integration of the child with ASD into inclusive environments with typically developing peers as early as possible.

According to an expert panel writing for the National Academy of Sciences, effective educational programs designed for children with ASD from birth to 8 years of age should

- **Offer choices.** The program should offer a variety of behavioral, language, social, play, and cognitive strategies that are individualized to the child. If possible, the child should also receive direct speech, occupational, and physical therapies.
- **Have clear goals.** An individualized plan should include specific, observable, and measurable goals and objectives in each developmental and behavioral area of intervention.
- **Be intense.** The program should be intense, with 20 to 25 hours of planned intervention or instruction per week. It should be given year-round. The majority of children benefit from a staffing ratio of 1:1 or 1:2 with an adult. For each child there should be 1 teacher, and there should be no more than 2 children per teacher.
- **Encourage parents to be fully involved.** Siblings and peers should also be part of the program. Children often learn best by modeling typically developing children in inclusive settings.
- **Take place in everyday settings.** To promote generalization of newly acquired skills, interventions should take place in everyday settings. Natural reinforcers should also be used.
- **Address behavior problems.** A functional analysis of behavior should be done when there are behavior problems. Information gained should be used to design a behavior management plan.
- **Monitor progress often.** If goals and objectives are not being met in a reasonable amount of time, the program should be evaluated and revised as needed.

The types and quality of services may vary depending on where you live. Unfortunately, few communities have programs with all, or even most, of these recommendations. Usually this is because there isn't enough public funding and/or experienced staff. Efforts are being made nationally to increase funding and training, but such changes will take time. However, many children will still benefit from a limited program versus no program at all. Often this is possible because of a team effort from staff and parents.

In general, whichever techniques are used, the more and sooner, the better. Children should be referred to an appropriate program as soon as a delay is suspected. Parents should not wait for a definitive diagnosis of autism

because this may take quite some time. When ASD or another developmental disability is diagnosed, the program can be changed to best meet the needs of the child and family. Keep in mind that this can be an ongoing process as additional signs and symptoms become noticeable or others improve.

Although *all* children with ASD will need developmental and educational services and most will need therapy and behavioral interventions, only certain children may need medicine. Medicine may be needed to control behaviors that could interfere with ASD interventions. Aggressive or disruptive behaviors can become a problem when they cause physical harm to others (or to the child himself) or when they prevent him from cooperating with therapists or teachers.

Parents are encouraged to learn as much as they can about all the different treatments available. Treatment should focus on supporting the child to succeed in the real world.

The future

Children with ASD are affected by many factors that will shape their future. Overall, the long-term outcomes of children with ASD have been improving. In general, the sooner ASD is identified, the sooner appropriate intervention programs can begin and the better the outcomes. However, children may be limited in what they can do depending on their intelligence, the severity of autistic symptoms, and whether they have associated medical problems such as seizures.

Children with intelligence in the normal range and milder autistic symptoms generally have better outcomes. Those with Asperger syndrome are thought to have somewhat better outcomes than children with other types of ASD if they don't have additional medical or emotional problems.

The goal of all parents, whether their child has a disability, is to try their very best to help their child reach his full potential with the help of all available resources.

Resources

Books

Gabriels RL, Hill DE. *Autism: From Research to Individualized Practice*. London, England: Jessica Kingsley Publishers; 2002

Gray C, McAndrew S. *My Social Stories Book*. London, England: Jessica Kingsley Publishers; 2002

Howlin P, Baron-Cohen S, Hadwin J. *Teaching Children with Autism to Mind-Read: A Practical Guide for Teachers and Parents*. Chichester, England: John Wiley and Sons; 1999

Naseef RA. *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*. Rev ed. Baltimore, MD: Paul H. Brookes Co; 2001

Ozonoff S, Dawson G, McPartland J. *A Parent's Guide to Asperger Syndrome and High Functioning Autism: How to Meet the Challenges and Help Your Child Thrive*. New York, NY: Guilford Press; 2002

Schopler E. *Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders*. New York, NY: Plenum Press; 1995

Siegel B. *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders*. New York, NY: Oxford University Press; 1996

Szatmari P. *A Mind Apart: Understanding Children With Autism and Asperger Syndrome*. New York, NY: Guilford Press; 2004

Volkmar FR, Wiesner LA. *Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional and Behavioral Issues*. Bethesda, MD: Woodbine House; 2004

Wetherby AM, Prizant BM. *Autism Spectrum Disorders: A Transactional Developmental Perspective*. Baltimore, MD: Paul Brookes; 2000

Wheeler M. *Toilet Training for Individuals With Autism and Related Disorders: A Comprehensive Guide for Parents and Teachers*. Arlington, TX: Future Horizons; 1998

Wrobel M, Rielly P. *Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People With Autism*. Arlington, TX: Future Horizons; 2003

Web sites

American Academy of Pediatrics National Center of Medical Home Initiatives for Children With Special Needs

www.medicalhomeinfo.org/health/autism.html

Autism Society of America

www.autism-society.org

Centers for Disease Control and Prevention Autism Information Center

www.cdc.gov/ncbddd/dd/ddautism.htm

Cure Autism Now

www.cureautismnow.org

National Alliance for Autism Research

www.naar.org

Please note: Listing of resources does not imply an endorsement by the American Academy of Pediatrics (AAP). The AAP is not responsible for the content of the resources mentioned in this brochure. Web site addresses are as current as possible, but may change at any time.

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From your doctor

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of Pediatrics



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