

Introduction to Autism

Written and reviewed by the My Child Without Limits Advisory Committee

Autism is a disability that affects the way a person develops. It causes problems with social relationships and communication. Symptoms usually start before age three and can cause delays or problems in many different skills from infancy to adulthood.

What is Autism Spectrum Disorder?

A spectrum disorder is a group of disorders with similar features. Autism is considered a spectrum disorder by health care professionals because people with autism can have different symptoms. Some people with autism have mild symptoms, while others have serious symptoms. But they all still have autism.

The different types of disorders within the Autism Spectrum Disorder are:

- Autistic disorder (also called classic autism)
- Asperger syndrome
- Pervasive Developmental

Who Gets Autism?

Autism occurs in as many as one or two per 1,000 children. It is found four times more often in boys (usually the first-born) and occurs around the world in all races and social backgrounds.

What Causes Autism?

There is reason to believe that the cause of autism is mostly genetic. It has been found that identical twins are more likely to both be affected than twins who are fraternal (not genetically identical). In a family with one autistic child, the chance of having another child with autism is about one in 20, much higher than in the normal population.

Sometimes, relatives of an autistic child have mild behaviors (such as repetitive behaviors and social or communication problems) that look very much like autism. Research also has found that some emotional disorders (such as manic depression) occur more often in families of a child with autism.

At least one group of researchers has found a link between an abnormal gene and autism. The gene may be just one of three to five or more genes that interact in some way to cause the condition. Scientists suspect that a faulty gene or genes might make a person more likely to develop autism when there are also other factors present, such as a chemical imbalance, viruses or chemicals, or a lack of oxygen at birth. In a few cases, autistic behavior is caused by:

- Rubella (german measles) in the pregnant mother
- Tuberosus sclerosis (a rare genetic disorder that causes benign tumors to grow in the brain as well as in other vital organs)
- Fragile X syndrome (the most common inherited form of mental retardation)
- Encephalitis (brain inflammation)
- Untreated phenylketonuria (when the body lacks an enzyme needed for normal metabolism)

In the past few years, there has been interest in a theory that suggested a link between autism and the use of thimerosal, a mercury-based preservative used in the measles-mumps-rubella (MMR) vaccine. Although mercury is no longer found in childhood vaccines in the United States, some parents still have concerns about vaccinations.

However, many well-done, large-scale studies have now been done that have failed to show a link between thimerosal and autism. A panel from the Institute of Medicine is now examining these studies, including a large Danish study that concluded that there was no causal relationship between childhood vaccination using thimerosal-containing vaccines and the development of an autism spectrum disorder,²⁸ and a U.S. study looking at exposure to mercury, lead, and other heavy metals.

How Is Autism Diagnosed?

All children with autism have problems with

- Social Interaction - they way they relate to others
- Verbal and Nonverbal Communication
- Repetitive Behaviors or Interests

Infants with the disorder won't cuddle; they avoid eye contact and don't seem to want or need physical contact or affection. They may become rigid or limp when they are held, cry when picked up, and show little interest in human contact. These children don't smile or lift their arms in anticipation of being picked up. They form no attachment to parents and do not show any normal anxiety toward strangers. They do not learn the typical games of childhood, such as peek-a-boo.

As children with autism get older they often have unusual responses to sensory experiences, such as certain sounds or the way objects look. These symptoms can range from mild to severe - and will be different in different children. For instance, a child may find it easy to learn to read, but have trouble in social situations. However, with autism, each child will display communication, social, and behavioral patterns that are individual but fit into the overall diagnosis of autism.

Children with autism do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems in communication and social skills become more noticeable as the child gets older (between 12 and 36 months) and starts lagging behind other children of the same age.

Some parents report the changes as taking place over a short period of time. They notice that their children suddenly start to reject people, act strangely, and lose language and social skills they had before. In other cases, there is a slowing in the level of progress so that the difference between the child with autism and other children the same age becomes more and more noticeable over a longer period of time.

While a person with autism can have symptoms ranging from mild to severe, about 10% of these children have an extraordinary ability in one area, such as mathematics, memory, music, or art. Such children are known as "autistic savants."

Although there are many concerns about labeling a young child with autism, the earlier the diagnosis of autism is made, the sooner actions to help the child can begin. Evidence over the last 15 years has shown that intensive early intervention in optimal educational settings for at least two years during the preschool years results in improved outcomes in most young children with Autism Spectrum Disorder.²

In order to diagnose autism, medical professionals look at a child's specific behaviors. Some of these behaviors may be obvious in the first few months of a child's life, or they may appear at any time during the early years.

In order to be diagnosed with autism the child must have had problems in at least one of these areas: communication, socialization, or restricted behavior before the age of three.

The diagnosis has two stages. The first stage is a developmental screening during "well child" check-ups. The second stage involves a thorough evaluation by a multidisciplinary team.

The Stages of an Autism Diagnosis

The diagnosis of autism has two stages. The first stage is a developmental screening during "well child" check-ups. The second stage involves a thorough evaluation by a multidisciplinary team.

Screening

A "well child" check-up at the doctor should include a developmental screening test. (This test is done to see if the child is developing at a rate that is appropriate for his or her age.) In addition, the parents' own observations and concerns about their child's development is important in helping to screen a child for autism.

Looking at family videotapes, photos, and baby albums can help parents to remember when each behavior first appeared and when the child reached certain developmental milestones.

If a child's doctor sees any of the possible indicators of autism as a result of a screening or a "well child checkup," further evaluation is necessary.

Comprehensive Diagnostic Evaluation

The second type of evaluation must be more detailed in order to make sure the child does, or does not, have autism. This evaluation may be done by a team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with autism.

Because autism is a complicated disorder, a complete evaluation may involve a number of different types of tests. Professionals will test the child's learning skills, social skills, communication skills, listening responses, body movements, hearing, relationships to people, and more.

Lead screening is also essential for children who remain for a long period of time in the oral-motor stage during which they put things into their mouths. Children with an autistic disorder usually have elevated blood lead levels.

Although parents may have been aware that something was not "quite right" with their child, when a diagnosis of autism is given, it is very upsetting. However, as soon as possible after parents learn that their child is autistic, it is important for them to ask questions and get recommendations on what further steps they should take.

What Kinds of Health Problems Do Children With Autism Have?

Different children with autism have different reactions and problems at different levels. Here are some of the problems that frequently accompany autism:

Sensory problems

A great number of children with autism are highly aware of, or even painfully sensitive to, certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin almost unbearable. Some sounds -- a vacuum cleaner, a ringing telephone, a sudden storm, even the sound of waves lapping the shoreline -- will cause these children to cover their ears and scream.

In autism, the brain seems unable to balance the senses appropriately. Some children don't seem to notice extreme cold or pain. One child with autism may fall and break an arm, yet never cry. Another may scream with alarm when lightly touched.

Mental retardation

Many children with autism have some mental dysfunction. When tested, some areas of ability may be normal, while others may be especially weak. For example, a child with autism may do well on the parts of the test that measure visual skills but earn low scores on the language portion.

Seizures

One in four children with autism will develop seizures, which often start either in early childhood or when they become teenagers. Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a "blackout"), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An EEG (electroencephalogram -- a recording of the electric currents developed in the brain by means of electrodes applied to the scalp) can help confirm the seizure's presence.

In most cases, seizures can be controlled by a number of medicines called "anticonvulsants." The dosage of the medication is adjusted carefully so that the least possible amount of medication will be used to be effective.

Fragile X syndrome

Fragile X syndrome is the most common inherited form of mental retardation. It was because one part of the X chromosome has a defective piece that appears pinched and fragile when viewed under a microscope. Fragile X syndrome affects about two to five percent of people with autism.

It is important for children with ASD to be checked for Fragile X, especially if the parents are considering having another child. For an unknown reason, if a child with ASD also has Fragile X, there is a one-in-two chance that boys born to the same parents will have the syndrome. Other members of the family who may be thinking of having a child may also wish to be checked for the syndrome.

Tuberous Sclerosis

Tuberous sclerosis is a rare genetic problem that causes benign (not cancerous) tumors to grow in the brain as well as in other important organs. One to four percent of people with autism also have tuberous sclerosis.

What Are Common Treatment Options for Autism?

There is no single best treatment package for all children with autism. However, most professionals agree that early treatment is important and that most people with autism respond well to highly structured, specialized programs.

Before making decisions about a child's treatment, parents should learn as much as possible about the different options that are available. Some of the questions parents can ask about programs for their children include:

- How successful has the program been for other children with autism?
- How many children have been placed in a regular school and how have they performed?
- Do staff members have training and experience working with children and adolescents with autism?

- How are activities planned and organized?
- Are there regular daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

What Medicines Are Used to Treat Autism?

Medications are often used to treat the behavioral problems, such as aggression, self-harming behavior, and severe tantrums, that keep someone with autism from functioning more effectively at home or school. The medications used are those that have been developed to treat similar symptoms in other disorders. Many of these medications are prescribed "off-label." This means they have not been officially approved by the Food and Drug Administration (FDA) for use in children. However, the doctor prescribes the medications anyway if he or she feels they are appropriate for the child. Further research needs to be done to make sure these medicines are both effective and safe when used in the treatment of children and adolescents.

A child with autism may not respond to medications in the same way as children without autism. Therefore a child should be monitored closely while taking a medication. It is important that parents work with a doctor who has experience with children with autism. The doctor will prescribe the lowest dose possible to be effective.

Parents should ask doctors about any side effects the medication may have and keep a record of how the child responds to the medication. It will be helpful for parents to read the "patient insert" that comes with the medication. Some people keep the patient inserts in a small notebook to be used as a reference. This is most useful when several medications are prescribed.

SSRIs

The selective serotonin reuptake inhibitors (SSRIs) are medications most often prescribed for symptoms of anxiety, depression, and/or obsessive-compulsive disorder (OCD). Only one of the SSRIs, fluoxetine, (Prozac®) has been approved by the FDA for both OCD and depression in children age seven and older. Three that have been approved for OCD are fluvoxamine (Luvox®), age eight and older; sertraline (Zoloft®), age six and older; and clomipramine (Anafranil®), age 10 and older.⁴ Treatment with these medications have been shown to decrease the repetitive, ritualistic behavior and help improve eye contact and social contacts. The FDA is studying data to better understand how to use the SSRIs safely, effectively, and at the lowest dose possible.

Antipsychotic Medications

Antipsychotic medications have been used to treat severe behavioral problems. These medications work by reducing the activity in the brain of the neurotransmitter dopamine. Among the older, typical antipsychotics, such as haloperidol (Haldol®), thioridazine, fluphenazine, and chlorpromazine, haloperidol was found in more than one study to be more effective than a placebo (fake drug) in treating serious behavioral problems.²⁶ However, haloperidol, while helpful for reducing symptoms of aggression, can also have negative side effects, such as drowsiness, muscle stiffness, and abnormal movements.

Studies of the newer antipsychotics are being conducted on children with autism. The first study was on risperidone (Risperdal®).²⁷ Results of the eight-week study were reported in 2002 and showed that risperidone was effective and well tolerated for the treatment of severe behavioral problems in children with autism. Further long-term studies are needed to determine any long-term side effects. Other antipsychotics that have been studied recently with encouraging results are olanzapine (Zyprexa®) and ziprasidone (Geodon®).

Seizure Medications

Seizures are found in one in four persons with autism, especially in those who have a low IQ or who cannot speak. They are treated with one or more of the anticonvulsants. These include such medications as carbamazepine (Tegretol®), lamotrigine (Lamictal®), topiramate (Topamax®), and valproic acid (Depakote®). The level of the medication in the blood should be monitored carefully and adjusted so that the least amount possible is used to be effective. Although medication usually reduces the number of seizures, it cannot always eliminate them.

Medications for Inattention and Hyperactivity

Stimulant medications such as methylphenidate (Ritalin®), used for people with attention deficit hyperactivity disorder, have also been prescribed for children with autism. These medications may decrease impulsivity and hyperactivity especially in higher functioning children. Several other medications have been used to treat ASD symptoms; among them are other antidepressants, naltrexone, lithium, and some of the benzodiazepines such as diazepam (Valium®) and lorazepam (Ativan®). The safety and effectiveness of these medications in children with autism has not been proven.

Are There Dietary Treatments for Autism?

Some diets have been reported to be helpful to some children with autism. However it's important to keep in mind that the effectiveness and safety of these diets have not been proven.

There are people who believe that food allergies cause symptoms of autism. There is also a belief among some people that not getting enough of a certain vitamin or mineral can cause some autistic symptoms. If parents decide to put an autistic child on a special diet, they should make sure that their child's nutritional status is measured carefully.

A diet that some parents have found helpful to their autistic child is a gluten-free, casein-free diet. Gluten is a casein-like substance that is found in the seeds of various cereal plants -- wheat, oat, rye, and barley. Casein is the principal protein in milk. Since gluten and milk are found in many of the foods we eat, following a gluten-free, casein-free diet is difficult.

A vitamin supplement that some parents feel could help an autistic child is Vitamin B6, taken with magnesium (which makes the vitamin effective). The result of research studies is mixed; some children respond positively, some negatively, some not at all or very little.⁵

There has also been discussion in the last few years about the use of secretin, a substance approved by the Food and Drug Administration (FDA) for a single dose normally given to aid in diagnosis of a gastrointestinal problem. Non-scientific reports have noticed improvement in autism symptoms, including sleep patterns, eye contact, language skills, and alertness. However, several clinical trials conducted in the last few years have found no real improvements in symptoms between patients who received secretin and those who did not.²⁵

Applied Behavior Analysis

Applied Behavior Analysis (ABA) is the most common treatment for people with with autism. An effective ABA treatment program will build on the child's interests, offer a predictable schedule, teach tasks as a series of simple steps, actively engage the child's attention in highly structured activities, and provide regular reinforcement of behavior.

Parental involvement is also believed to be a major factor in treatment success. Parents work with teachers and therapists to identify the behaviors that need to be changed and the skills that should be taught. Recognizing that parents are the child's earliest teachers, more programs are beginning to train parents to continue the therapy at home.

As soon as a child's disability has been identified, instruction should begin. Effective programs will teach early communication and social interaction skills.

In children younger than three years of age, appropriate interventions usually take place in the home or a child care center. These interventions target specific problems with learning, language, imitation, attention, motivation, behaving, and interacting with others. Included are behavioral methods, communication, and therapy along with social play interventions.

Children older than three years usually have school-based, individualized, special education. The child may be in a separate class with other autistic children, or may be placed in a class with children without disabilities for at least part of the day. Different schools may use different methods but all should help the children learn social skills and communication. In these programs, teachers often involve the parents, giving useful advice on how parents can help their child use the skills or behaviors learned at school when at home.

What Does the Future Hold For Someone With Autism

Some adults with autism, especially those who are high-functioning or who have Asperger syndrome, are able to work successfully in mainstream jobs.

However, communication and social problems often cause difficulties in many areas of life. These people will continue to need encouragement and moral support in their struggle for an independent life.

Many others with autism are able to work in special environments especially if they are supervised by managers trained in working with persons with disabilities. A nurturing environment at home, at school, and later in job training and at work, helps persons with autism continue to learn and to develop throughout their lives.

The public schools' responsibility for providing services ends when the person with autism reaches the age of 22. The family is then faced with the challenge of finding living arrangements and employment to match the particular needs of their adult child, as well as the programs and facilities that can provide support services to achieve these goals.



Autism Resources

National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov

Centers for Disease Control and Prevention

www.cdc.gov

Autism Speaks

www.autismspeaks.org

Autism Society

www.autism-society.org