

Autism and Related Disorders

What is autism?

Autism, more commonly referred to as autism spectrum disorder (ASD) by clinicians and families, is a biological condition that limits a child's ability to develop social relationships and communicate. As a result, children often have significant problems in learning and experience many behavioral difficulties. The condition is usually life-long, although overall outcome is improving.

Children with ASD have difficulty interpreting what others are thinking or feeling and do not respond "normally" to their parents or caregivers. While a typical child will respond to changes in his/her parents' tone of voice or facial expressions, a child with ASD will often not do so. Also, children with ASD tend to start speaking later than other children, have difficulties in playing with peers and engage in ritualistic and repetitive behaviors that can consume much of the child's time and energy. Difficulties with change and new things and situations also are common.

In 2007, the Centers for Disease Control and Prevention (CDC) found that autism spectrum disorders were diagnosed in one in 150 children in the United States and affected four times as many boys as girls. Since then, studies have found that 1 percent of children are affected by an autism spectrum disorder. Classical autism, if strictly defined, is seen in perhaps 1 in 800 children.

A report published in 2009 in American Academy of Pediatrics' journal *Pediatrics* found the prevalence among children ages 3 – 17 to be higher than that reported by the CDC. In this study, one in 91 American children was found to have ASD, including one in 58 boys. The authors of the 2009 study suggest the increase is due to more inclusive survey questions, heightened awareness by the public and improved screening and identification by providers.

The most frequently recognized types of autism spectrum disorders include:

- **Autistic Disorder** (also called "classic" autism or what most people think when hearing the word "autism") — People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.
- **Asperger Syndrome** — People with Asperger syndrome usually have some milder symptoms of autistic disorder. However, they typically do not have problems with language or intellectual disability.
- **Pervasive Developmental Disorder** — Not Otherwise Specified (PDD-NOS; also called "atypical autism") — People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with PDD-NOS. People with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder.

What are the symptoms of autism?

The hallmark feature of ASD is impaired social interaction. The child's primary caregivers are usually the first to notice signs of ASD. As early as infancy, a baby with ASD may be unresponsive to his/her parents or siblings and focus intently on one item to the exclusion of others for long periods of time. Some children, perhaps 20 percent to 25 percent with ASD develop normally until age 18 to 24 months then stop gaining new skills, or lose skills they once had. A diagnosis may be delayed because parents may not detect changes until they become dramatic.

Symptoms include:

- Not responding to one's name by 12 months
- Not pointing at objects to show interest (such as an airplane in the sky) by 14 months
- Not playing "pretend" games by 18 months

- Avoiding eye contact and wanting to be alone
- Trouble understanding other people's feelings or talking about their own feelings
- Delayed speech and language skills
- Repeating words or phrases over and over and other obsessive behavior
- Giving unrelated answers to questions
- Being upset by minor changes

How is autism diagnosed?

Currently, there are no laboratory or other medical tests for autism. Diagnosis is based on observation and educational and psychological testing by experienced clinicians. Diagnosing autism requires a two-stage process: developmental screening during “well child” check-ups and a comprehensive evaluation by a multidisciplinary team, which is usually comprised of a psychologist, neurologist, psychiatrist and speech therapist.

Because ASD varies widely in its severity and symptoms, autism may go unrecognized for years, especially in mildly affected individuals or in those with multiple handicaps. Children who display aggressive symptoms, such as head banging, and have other symptoms that are worrisome to parents, such as not speaking or ignoring them, are diagnosed more quickly since parents want to get help and treatment as soon as possible. Asperger syndrome is often not apparent until the child interacts with peers in school/preschool because the child's social vulnerabilities can be masked for a time by better verbal (vocabulary) skills.

According to the American Academy of Pediatrics, from birth to at least 36 months of age, every child should be screened by his/her pediatrician for developmental milestones during routine “well child” visits. If concerns about a child's development are raised, the pediatrician should refer the child to a specialist for a developmental evaluation. Hearing and lead exposure screenings should be performed to rule out other causes for the symptoms displayed and an autism-specific screening tool, such as the Modified Checklist of Autism in Toddlers (MCHAT) should be used.

The MCHAT is a checklist that asks the parent/caregiver to report on 23 behaviors. The answers to the questions help determine whether a child needs to be referred to a specialist for further evaluation. Other tests for autism include the Screening Tool for Autism in Two-Year-Olds (STAT) and the Social Communication Questionnaire (SCQ) (for children 4 years of age and older) for children who do not have the classical symptoms of autism.

Once the diagnosis is made by the specialist, the multidisciplinary team will help determine the degree of impairment and recommend treatment options.

New NARSAD-supported research to improve the diagnosis of autism includes:

- Finding better ways to diagnose autism
- Understanding the various subtypes and complexities of autism
- Better understanding of how children with autism learn tasks and behave compared to “normal” children

How is autism treated?

Two treatments that have been scientifically researched and proven to be effective in treating autism are: Applied Behavioral Analysis (ABA), an educational and behavioral intervention, and Risperdal (risperidone), an antipsychotic medication that is the only drug approved by the Food and Drug Administration for autism.

Applied Behavioral Analysis (ABA) is an intensive system of reward-based training, that can be performed at home by a caregiver parent, counselor, or certified behavior analyst. ABA focuses on teaching particular skills, improving social interactions, modifying the learning environment and reducing behaviors that interfere with functioning in society, such as self injury.

Other treatments besides ABA include speech, occupational, physical, play and developmental therapies that are designed to increase emotional, social and intellectual abilities. A handful of other approaches to structured teaching and intervention have been reviewed in “Educating Children with Autism” by the National Research Council, an independent organization that provides policy recommendations to the government.

Medications have an important role in the treatment of behavioral difficulties and, for older and more able individuals, associated psychiatric problems like depression. These medications do not treat the underlying social vulnerability but may help a child profit from educational interventions. Drug treatment is particularly prescribed for children who display aggressive behavior that can result in injuries to themselves and others or who suffer from depression and other conditions. A significant minority of children with autism also exhibit seizures which may respond to drug treatment.

The drugs most commonly prescribed to people with autism are antipsychotics such as Risperdal which treat aggression, agitation or insomnia; anticonvulsants

(Tegretol, Depakote, Dilantin) to control seizures; anti-anxiety medications such as alprazolam (Xanax), clonazepam (Klonopin) and diazepam (Valium) and Selective Serotonin Reuptake Inhibitors (SSRIs) such as fluoxetine (Prozac), fluvoxamine (Luvox) paroxetine (Paxil) and sertraline (Zoloft) for depression or compulsive behaviors. However, recent studies suggest that SSRIs do not work well in children with autism as they do for adults and some adolescents with autism.

▶ **New NARSAD-supported research to improve the treatment of autism includes:**

- Understanding which existing drugs work for autism
- Finding new medications to treat autism
- Identifying better behavioral treatments for autism

What causes autism?

There is no known cause of autism. A disproven but formerly popular theory that it is caused by bad parenting unfortunately led to enormous guilt in many parents. It is now known that autism is a biological disorder with a strong genetic basis.

A small number of cases can be linked to inherited genetic disorders or problems during pregnancy. Fragile X is the most common genetic disorder associated with autism (perhaps 1 or 2 children out of every 100 children with autism). It can also cause mental retardation and learning disabilities.

Many parents believe autism is linked to childhood vaccinations, especially the measles, mumps and rubella (MMR) vaccine. However every well controlled scientific study to date has failed to find a link between childhood vaccines and autism. But, because many vaccines are given during the time that autism is first diagnosed as well as the widespread media coverage of the theory and its embrace by some celebrities, it has been a hard perception to overcome.

Researchers think multiple genetic components may interact to produce autism. There may be a role for some environmental factors but this is controversial and has yet to be convincingly shown. However, much more research is needed in all areas.

▶ **New NARSAD-supported research to understand the causes of autism include:**

- Identifying genes that can cause autism
- Understanding the neurobiology of autism
- Understanding why boys are more prone to autism than girls

For a child with autism, living in a world where one cannot communicate or understand one's surroundings is often frightening and lonesome.

Living with OCD—from diagnosis to daily life

Anyone who has had a child knows that parents worry about their children. During pregnancy, mothers pray for a normal baby with a normal delivery. When an infant does not appear to be developing in the way that seems normal, parents are naturally concerned.

Some children with autism do not smile, do not answer to their names or are hostile. These behaviors cause confusion, anger and sadness to family members. For a child with autism, living in a world where one cannot communicate or understand one's surroundings is often frightening and lonesome.

Parents of autistic children speak about feelings of denial, guilt and shame about producing a child who is "not normal". Many parents resent the child and are deeply troubled by the behaviors their children display, which can include head banging and angry outbursts or total withdrawal. Teenagers and adults with autism have trouble forming relationships and succeeding in school or at work. Siblings often resent the attention paid to their brother or sister with autism often at their expense. Divorce is common among parents of children with autism over issues of treatment, financial pressures and the strain of caring for an autistic child, which can result in lack of sleep, lack of time for oneself and depression.

The CDC has called autism a national public health crisis for which we still need effective treatments and whose causes need to be better understood. We know that autism is a spectrum of illnesses and some people with autism function very well in society while some people end living in assisted living or with their families for the rest of their lives. However, increased funding for research about autism and heightened awareness of autism have led families and scientists to believe that better treatments are within reach.

Help support NARSAD's research on autism

For the past 23 years, NARSAD has been at the forefront of research on mental illness. From 1987 through 2009, NARSAD has given more than \$252 million in grants to support innovative research by more than 2,800 scientists at leading universities, medical centers and research institutions around the world. Besides autism, NARSAD funds research on schizophrenia, depression, bipolar disorder, and childhood mental illness.

For autism research specifically, NARSAD has provided:

- **107 grants** to researchers studying autism and related disorders
- **\$7.4 million dollars** for those research grants

NARSAD supports research on all aspects of autism and other mental illnesses — the causes and nature of the disease, structural and functional changes in the brain, chemical abnormalities, genetics, pharmacological and non-pharmacological treatments, and social and behavioral aspects of the illness.

NARSAD's grantmaking program is guided by its Scientific Council, a volunteer group of 116 leading neuroscientists, which reviews and recommends research proposals for funding.

NARSAD relies on the generosity of thousands of donors and volunteers to support this research, which has yielded great progress in the understanding, diagnosis and treatment of mental illnesses. Formerly known as the National Alliance for Research on Schizophrenia and Depression, NARSAD is a 501 (c)(3) organization that receives no government support. All donations are tax-deductible. To donate to NARSAD and to learn more about our work, please call (800) 829-8289, write to info@narsad.org, or visit our website.

For more information, go to www.narsad.org

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