



Empower Autism

Frequently Asked Questions about Autism

What is Autism?

Autism is a behavioral diagnosis. It describes a set of behaviors. Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders.

What causes Autism?

The simple answer is we don't know. The vast majority of cases of autism are idiopathic, which means the cause is unknown.

The more complex answer is that just as there are different levels of severity and combinations of symptoms in autism, there are probably multiple causes. The best scientific evidence available to us today points toward a potential for various combinations of factors causing autism – multiple genetic components that may cause autism on their own or possibly when combined with exposure to as yet undetermined environmental factors.

While the definitive cause (or causes) of autism is not yet clear, it is clear that it is not caused by bad parenting. Dr. Leo Kanner, the psychiatrist who first described autism as a unique condition in 1943, believed that it was caused by cold, unloving mothers. Bruno Bettelheim, a renowned professor of child development perpetuated this misinterpretation of autism. Their promotion of the idea that unloving mothers caused their children's autism created a generation of parents who carried the tremendous burden of guilt for their children's disability.

In the 1960s and 70s, Dr. Bernard Rimland, the father of a son with autism, who later founded the Autism Society of America and the Autism Research Institute, helped the medical community understand that autism is not caused by cold parents but rather is a biological disorder.

How common is Autism?

Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is not

established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 70 boys is diagnosed with autism.

Source: Autism Speaks

What is a diagnosis?

A diagnosis is a categorical term that describes a group of behaviors or characteristics that, in most cases, are linked with a particular disease or disorder through cause, trajectory and effective treatments.

How is a diagnosis of an Autism Spectrum Disorder (ASD) different from other diagnoses?

Because we do not know the causes, ASD diagnoses are based purely on observations or reports of behaviors. Unlike many medical syndromes, ASDs are not diseases. They are not contagious and are not yet treatable through medication (though medicine can help some symptoms). They are developmental disorders that reflect differences in the way that children develop from very early on (from infancy and toddlerhood) and that usually continue to affect development into adulthood. The primary treatments are educational (e.g., teaching individuals with ASDs ways to do things that may not come as easily for them) and compensatory (e.g., helping individuals learn to use their strengths to make up for areas that are more difficult), as well as behavioral (e.g., helping individuals and families to minimize behaviors that interfere with daily living, such as tantrums or self-injury).

How are Autism Spectrum Disorders defined?

ASDs are defined by difficulty in three areas of behaviors: 1) reciprocal social interaction, 2) communication and 3) repetition and insistence on sameness. Exactly how an individual is impacted across these three areas varies greatly. There is no one behavior that is present in all individuals with ASDs or that would rule out ASDs in every person. Many, but not all, individuals with ASD have language delays. Some individuals with ASD, but not all, have lifelong language disorders. Some, but not all, individuals with ASD also have mental retardation that affects development of nonverbal problem-solving, everyday self-care (e.g., dressing; academics) and language.

Are there different types of ASDs? Are some cases of ASD more severe than others?

Within the category of Autism Spectrum Disorder (sometimes known as Pervasive Developmental Disorders or PDD), there are a number of subtypes that are associated with different levels of severity in different areas.

Autism is the disorder that has received the most study and has been recognized for the longest time. It is defined by the presence of difficulties in each of the three areas listed above (social deficits, communication problems and repetitive or restricted behaviors), with onset in at least one area by age 3 years. It may or may not be associated with language delays or mental retardation.

Asperger Syndrome is a form of ASD that is often identified later (e.g., after age 3, usually after age 5) and is associated with the social symptoms of autism and some repetitive interests or behaviors, but not with language delay or mental retardation. Many parents and professionals use this term with older and/or more verbally fluent individuals with autism because they feel it is less stigmatizing.

Rett Syndrome and Child Disintegrative Disorder are both very rare, severe forms of ASD that have particular patterns of onset, and, in the case of Rett Syndrome, a specific genetic basis.

Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) is a form of ASD used to describe individuals who meet criteria for autism in terms of social difficulties but not in both communication and restricted, repetitive behaviors. It can also be used for children who do not have clearly defined difficulties under age 3 or later. This term is often used by professionals when they are not quite sure of a diagnosis or when the symptoms are mild. Several epidemiological studies have reported that as many or more children have PDD-NOS or less clear symptoms as have classic autism.

The difficulties of children and adults with Asperger Syndrome or PDD-NOS are similar, and milder than those of individuals with autism, suggesting that these distinctions are fairly arbitrary and should not be used to limit services or benefits.

What benefit is a diagnosis of ASD?

A diagnosis should go beyond a description of defining features of a disorder to provide important information about other aspects of behavior or development. For example, where ASDs are concerned, it is essential to know that families with one child with ASD are at greater risk for having another child with ASD, though this risk is probably less than 1 in 5. Also important is the fact that adolescents with ASD are more likely to have a seizure or develop epilepsy than other children their age. Most important of all, a diagnosis often provides children access to services through school systems and early intervention networks. It can also provide adults access to services through vocational programs. A diagnosis can give parents and family members a way to start acquiring information about other children with similar difficulties and ways to find support through local, national and international organizations.

A diagnosis should provide information about effective and ineffective treatments. Though there is no one-size fits all treatment for ASDs, it is clear that low intensity interventions that are not built on engaging a child in social interaction and communication, and that do not involve parents, are not appropriate programs for young children with ASDs. In ASD, many children's behavior problems (e.g., tantrums) are linked to not being able to communicate. Providing the child with a way to let others know what he or she wants (e.g., through words or signs or pictures) and helping the child understand what others are saying (also through pictures or objects or gestures) can decrease problem behaviors greatly. Medications may help treat additional symptoms in ASD, such as hyperactivity, but are often less effective in children with ASD than other children.

A diagnosis is necessary for doing research to find the causes and to improve treatments for ASDs, so that scientists can know who they are studying and can compare findings across different research projects. Because there are probably many subtypes of ASD, researchers need to work with large numbers of children and families in order to have adequate numbers of similar children. This means that researchers need to merge samples, which requires that they agree on common diagnostic procedures (or else they will not know what differences across samples mean if they occur).

Source: Catherine Lord's Frequently Asked Questions about Diagnosis (2007)

What Do I Do Now?

1. *Take care of yourself*

Finding out that your child has autism is a big deal. Hearing the diagnosis can be shocking and emotional, even if you suspected that something was different about your child. It is very common for parents to feel a wide range of emotions about the diagnosis (and the child) including surprise, denial, anger, sadness, grief, numbness, and a sense of being overwhelmed. It is common to feel several of these emotions all at once, or to feel the range of them over time. These emotions are legitimate, and deserve to be acknowledged. Parents who take the time to sort out their own feeling about the diagnosis end up being more useful to their child than parents who do not acknowledge their (very legitimate) reactions.

Many people benefit intensely from attending a few sessions with a therapist themselves. A therapist is a person whose job is to help people process important events and intense emotions. Therapists are for people who have a lot to think about, not just for people who are 'crazy'. Often, insurance companies will cover several sessions of therapy. Investing your time and energy in a few sessions of therapy can really pay off for you and your whole family in both the short and long term.

2. *Read and Ask Questions*

See our basic resources guide for a place to start. Make phone calls and ask questions

3. *Make a Treatment Plan*

Work with your child's doctor, psychiatrist, psychologist, or therapist to develop concrete goals and methods for meeting those goals. This may involve changing the way you do things at home and at school. See our resources guide for more information about treatment.

4. *Make School Plan*

Work with your child's teacher and other school personnel to develop educational goals, and methods of meeting those goals. This may involve changing the way expectations are communicated in school. See our resources guide for more information about education.

5. *Continue to evaluate your plans* and modify them as your child reaches new developmental stages.