



# Autism Spectrum Disorders

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## Ryan's Story

Ryan is a healthy, active two-year-old, but his parents are concerned because he doesn't seem to be doing the same things that his older sister did at this age. He's not really talking yet, although sometimes he repeats, over and over, words that he hears others say. He doesn't use words to communicate, though. It seems he just enjoys the sounds of them. Ryan spends a lot of time playing by himself. He has a few favorite toys, mostly cars, or anything with wheels on it! And sometimes, he spins himself around as fast as he does the wheels on his cars. Ryan's parents are really concerned, as he's started throwing a tantrum whenever his routine has the smallest change. More and more, his parents feel stressed, not knowing what might trigger Ryan's next upset.

Often, it seems Ryan doesn't notice or care if his family or anyone else is around. His parents just don't know how to reach their little boy, who seems so rigid and far too set in his ways for his tender young age.

After talking with their family doctor, Ryan's parents call the Early Intervention office in their community and make an appointment to have Ryan evaluated.

When the time comes, Ryan is seen by several professionals who play with him, watch him, and ask his parents a lot of questions. When they're all done, Ryan is diagnosed with autism, one of the five disorders listed under an umbrella category of "Pervasive Develop-

mental Disorders"—a category that's often referred to as simply the "autism spectrum."

As painful as this is for his parents to learn, the early intervention staff encourage them to learn more about the autism spectrum. By getting an early diagnosis and beginning treatment, Ryan has the best chance to grow and develop. Of course, there's a long road ahead, but his parents take comfort in knowing that they aren't alone and they're getting Ryan the help he needs.

## What are the Characteristics of Autism Spectrum Disorders?

Each of the disorders on the autism spectrum is a neurological disorder that affects a child's ability to communicate, understand language, play, and relate to others. They share some or all of the following characteristics, which can vary from mild to severe:

- Communication problems (for example, with the use



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or comprehension of language);

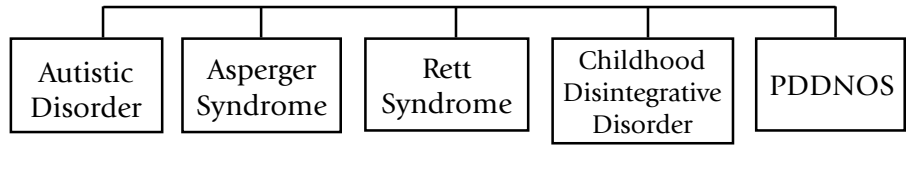
- Difficulty relating to people, things, and events;
- Playing with toys and objects in unusual ways;
- Difficulty adjusting to changes in routine or to familiar surroundings; and
- Repetitive body movements or behaviors.<sup>1</sup>

These characteristics are typically evident before the age of three.

Children with autism or one of the other disorders on the autism spectrum can differ considerably with respect to their abilities, intelligence, and behavior. Some children don't talk at all. Others use language where phrases or conversations are repeated. Children with the most advanced language skills tend to talk about a limited range of topics and to have a hard time understanding abstract concepts. Repetitive play and limited social skills are also evident. Other common symptoms of a disorder on the autism spectrum can include unusual and sometimes uncontrolled reactions to sensory information—for instance, to loud noises, bright lights, and certain textures of food or fabrics.



## Pervasive Developmental Disorders (PDD)



Current Classification Scheme in the DSM-IV-TR

### What are the Specific Disorders on the Autism Spectrum?

There are five disorders classified under the umbrella category officially known as Pervasive Developmental Disorders, or PDD. As shown above, these are:

- autism;
- Asperger syndrome;
- Rett syndrome;
- childhood disintegrative disorder; and
- Pervasive Developmental Disorder Not Otherwise Specified (often referred to as PDDNOS).<sup>2</sup>

Although there are subtle differences and degrees of severity between these five conditions, the treatment and educational needs of a child with any of these disorders will be very similar. For that reason, the term “autism spectrum disorders”—or ASDs, as they are sometimes called— is used quite often now and is actually expected to become the official term to be used in the future (see the box on the next page).<sup>3</sup>

The five conditions are defined in the *Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV-TR)* of the American Psychiatric Society (2000). This is also the manual used to diagnose autism and its associated disorders, as well as a wide variety of other disabilities.

At the moment, according to the 2000 edition of the *DSM-IV*, a diagnosis of autistic disorder (or “classic” autism) is made when a child displays 6 or more of 12 symptoms across three major areas:

- **social interaction** (such as the inability to establish or maintain relationships with peers appropriate to the level of the child’s development,
- **communication** (such as the absence of language or delays in its development), and
- **behavior** (such as repetitive preoccupation with one or more areas of interest in a way that is abnormal in its intensity or focus).

When children display similar behaviors but do not meet the specific criteria for autistic disorder, they may be

diagnosed as having one of the other disorders on the spectrum—Aspergers, Rett’s, childhood disintegrative disorder, or PDDNOS. PDDNOS (Pervasive Developmental Disorder Not Otherwise Specified) is the least specific diagnosis and typically means that a child has displayed the least specific of autistic-like symptoms or behaviors and has not met the criteria for any of the other disorders.

Terminology used with autism spectrum disorders can be a bit confusing, especially the use of PDD and PDDNOS to refer to two different things that are similar and intertwined. Still, it’s important to remember that, regardless of the specific diagnosis, treatments will be similar.

### How Common are ASDs?

According to the National Institute of Mental Health (NIMH) and the Centers for Disease Control and Prevention (CDC), some form of autism affects 2 - 6 of every 1,000 children, with the most recent statistic being 1 in 110.<sup>4</sup> ASDs are four times more common in boys than in girls, although Rett Syndrome has only been diagnosed in girls.<sup>5</sup>

### What Causes an ASD?

The causes of autism and the other disorders on the spectrum are not known. Researchers are currently studying such areas as neurological damage and chemical imbal-

ances within the brain. These disorders are not due, however, to psychological factors or, as has been widely reported in the press, to childhood vaccines.<sup>6</sup>

### Is There Help Available?

Yes, there’s a lot of help available, beginning with the free evaluation of the child. The nation’s special education law, the Individuals with Disabilities Education Act (IDEA), requires that all children suspected of having a disability be evaluated *without cost to their parents* to

determine if they *do* have a disability and, because of the disability, need special services under IDEA. Those special services are:

- **Early intervention** | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families.
- **Special education and related services** | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).



### A Look at ASD Diagnoses in the Future

In early 2010, the American Psychiatric Association released draft revisions to its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and invited comments from both professionals and the general public. The final and official fifth revision of the DSM is expected to be published in May 2013.<sup>7</sup>

When published, the DSM-5 is expected to affect how autism and associated disorders are diagnosed. Among the proposed revisions are:

- changing the name of the diagnostic category to Autism Spectrum Disorders;
- including Asperger Syndrome, Childhood Disintegrative Disorder, and PDDNOS under the diagnosis of Autism Spectrum Disorders, rather than defining them separately and a bit differently, as is now the case;
- removing Rett Syndrome from the DSM entirely (and, thus, from the autism spectrum).<sup>8</sup>

All this is to say...stay tuned. The criteria for diagnoses of ASDs are in the process of changing.

## Definition of "Autism" under IDEA

Under IDEA, *autism* is defined as:

.....a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance.

Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term autism does not apply if the child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in IDEA.

A child who shows the characteristics of autism after age 3 could be diagnosed as having autism if the criteria above are satisfied. [34 CFR §300.8(c)(1)]

Under IDEA, children with a disorder on the autism spectrum are usually found eligible for services under the category of "autism." In the fall of 2005, more than 160,000 school-aged children (3-21) received special education and related services in the public schools under the "autism" category.<sup>9</sup> IDEA specifically defines "autism" as shown in the box above.

To have a child evaluated to see if he or she has a disability, including one on the autism spectrum, *or* to access early intervention services for a child up to his or her 3rd birthday, we recommend consulting NICHCY's *State Resource Sheet* for your state (available online at: <http://www.nichcy.org/families-community/states/>). You'll find a listing for early intervention under the first

section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To have a school-aged child evaluated for an ASD *or* to access special education services for a school-aged child, we recommend getting in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

### What about School?

Early diagnosis and intervention are very important for children with an ASD. As we've mentioned, under IDEA children with an ASD may be eligible for early intervention services (birth to 3) and an educational program appropriate to their individual needs.

In addition to academic instruction, special education programs for students with ASDs focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning often require the assistance of a professional who is particularly knowledgeable in the autism field to develop and help implement a plan which can be carried out at home and school.

The classroom environment should be structured so that the program is consistent and predictable. Students with an ASD learn better and are less confused when information is presented visually as well as verbally. Interaction with nondisabled peers is also important, for these students provide models of appropriate language, social, and behavioral skills. Consistency and continuity are very important for children with an ASD, and parents should always be involved in the development of their child's program, so that learning activities, experiences, and approaches will be most effective and can be carried over into the home and community.

With educational programs designed to meet a student's individual needs and specialized adult support services in employment and living arrangements, many children and adults with a disability on the autism spectrum grow to live, work, and participate fully in their communities.

## Tips for Parents

- Learn about autism spectrum disorders—especially the specific disorder of your child. The more you know, the more you can help yourself and your child. Your state’s Parent Training and Information Center (PTI) can be very helpful. You’ll find your PTI listed on NICHCY’s online *State-Specific Information* (under “Organizations Especially for Parents”). We’ve also listed organizations on page 6 that can help you become knowledgeable about your child’s disorder.
- Be mindful to interact with and teach your child in ways that are most likely to get a positive response. Learn what is likely to trigger a melt-down for your child, so you can try to minimize them. Remember, the earliest years are the toughest, but it does get better!
- Learn from professionals and other parents how to meet your child’s special needs, but remember your son or daughter is first and foremost a child; life does not need to become a neverending round of therapies.
- If you weren’t born loving highly structured, consistent schedules and routines, ask for help from other parents and professionals on how to make it second nature for you. Behavior, communication, and social skills can all be areas of concern for a child with autism and experience tells us that maintaining a solid, loving, and structured approach in caring for your child, can help greatly.
- Learn about assistive technology (AT) that can help your child. This may include a simple picture communication board to help your child express needs and desires, or may be as sophisticated as an augmentative communication device.
- Work with professionals in early intervention or in your child’s school to develop an IFSP or an IEP that reflects your child’s needs and abilities. Be sure to include related services, supplementary aids and services, AT, and a positive behavioral support plan, if needed.
- Be patient and stay optimistic. Your child, like every child, has a whole lifetime to learn and grow.



## References

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- <sup>9</sup> U.S. Department of Education. (2007). *27th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2005* (Vol. 2). Washington, DC: Author.

## Tips for Teachers



- Learn more about the autism spectrum. Check out the research on effective instructional interventions and behavior on NICHCY's website. The organizations listed in this publication can also help.
- Make sure directions are given step-by-step, verbally, visually, and by providing physical supports or prompts, as needed by the student. Students with autism spectrum disorders often have trouble interpreting facial expressions, body language, and tone of voice. Be as concrete and explicit as possible in your instructions and feedback to the student.
- Find out what the student's strengths and interests are and emphasize them. Tap into those avenues and create opportunities for success. Give positive feedback and lots of opportunities for practice.
- Build opportunities for the student to have social and collaborative interactions throughout the regular school day. Provide support, structure, and lots of feedback.
- If behavior is a significant issue for the student, seek help from expert professionals (including parents) to understand the meanings of the behaviors and to develop a unified, positive approach to resolving them.
- Have consistent routines and schedules. When you know a change in routine will occur (e.g., a field trip or assembly) *prepare* the student by telling him or her what is going to be different and what to expect or do.
- Work together with the student's parents and other school personnel to create and implement an educational plan tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

## Organizations: Your Gateway to Information, Connection, and Research

For incredible amounts of information on ASDs, visit the organizations listed below.

### Autism Society of America

1.800.3AUTISM (1.800.328.8476)

[http://www.autism-society.org/site/PageServer?pagename=about\\_home](http://www.autism-society.org/site/PageServer?pagename=about_home)

### First Signs

<http://www.firstsigns.org>

### Autism Speaks

888-AUTISM2 (288-4762)

<http://www.autismspeaks.org/>

### OASIS @ MAPP

Online Asperger Syndrome Information and Support (OASIS) and MAAP Services for Autism and Asperger Syndrome.

<http://www.aspergersyndrome.org>

### Exploring Autism

Information in English and Spanish.

<http://www.exploringautism.org/>

### Autism Collaboration

<http://www.autism.org/>

### Interactive Autism Network

<http://www.ianproject.org/>

### OAR | Organization for Autism Research

<http://www.researchautism.org/>

### CDC | Centers for Disease Control and Prevention

Information in English and Spanish.

[www.cdc.gov/ncbddd/autism/index.html](http://www.cdc.gov/ncbddd/autism/index.html)

### National Autism Center

1.877.313.3833

<http://www.nationalautismcenter.org/index.php>