



Autism / PDD

◇ Ryan's Story ◇

Ryan is a healthy, active two-year-old, but his parents are concerned because he doesn't seem to be doing things they expect him to do, things that his older sister did at this age. He hasn't started talking, yet; although sometimes, he repeats, over and over, words that he hears others say. He doesn't really 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, since he's started throwing a tantrum whenever his routine has the smallest change. More and more, his parents feel helpless, never knowing what will trigger Ryan's next upset .

Sometimes, Ryan doesn't seem to 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 a form of autism. As painful as this is for his parents to learn, the early intervention staff try to encourage them. 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 are a little relieved. They now know that they aren't alone and they're getting Ryan getting the help he needs.



*NICHCY is the
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for Children with Disabilities.*

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❖ What is Autism / PDD? ❖

Autism and Pervasive Developmental Disorder (PDD) are developmental disabilities that share many of the same characteristics. Usually evident by age three, autism and PDD are neurological disorders that affect a child's ability to communicate, understand language, play, and relate to others.

In the diagnostic manual used to classify disabilities, the *DSM-IV-TR* (American Psychiatric Association, 2000), "autistic disorder" is listed as a category under the heading of "Pervasive Developmental Disorders." A diagnosis of autistic disorder is made when an individual displays 6 or more of 12 symptoms listed across three major areas: (a) social interaction, (b) communication, and (c) behavior. When children display similar behaviors but do not meet the criteria for autistic disorder, they may receive a diagnosis of Pervasive Developmental Disorder-NOS (not otherwise specified, or PDD-NOS). Although the diagnosis is referred to as PDD-NOS, throughout the remainder of this fact sheet, we will refer to the diagnosis simply as PDD, as it is more commonly known.

Autistic disorder is one of the disabilities specifically defined in the Individuals with Disabilities Education Act (IDEA), the federal legislation under which children and youth with disabilities receive special education and related services. IDEA, which uses the term "autism," defines the disorder as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences." [See 34 *Code of Federal Regulations* §300.7(c)(1).]



Don't Be Shy!

All of our publications and resource lists are online—help yourself! Visit us at:

www.nichcy.org

If you'd like personalized assistance, email or call us:

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1.800.695.0285 (v/tty)



Due to the similarity of behaviors associated with autism and PDD, use of the term Pervasive Developmental Disorder has caused some confusion among parents and professionals. To add to the confusion, there are also a number of different diagnostic terms that fall within the broad meanings of autism or PDD, such as:

Autism Spectrum Disorders,
Aspergers' syndrome,
Rett's syndrome, and
Childhood Disintegrative Disorder.

While there are subtle differences and degrees of severity among these conditions, the treatment and educational needs can be very similar for all of them.

◇ How Common is Autism / PDD? ◇

Information from the National Institute of Mental Health indicates that between 2 and 6 per 1,000 people have some form of autism / PDD. These disorders are four times more common in boys than in girls.

The causes of autism and PDD are unknown. Currently, researchers are investigating areas such as brain development, structure, genetic factors and biochemical imbalance in the brain as possible causes. These disorders are not caused by psychological factors.

◇ What are the signs of Autism / PDD? ◇

Some or all of the following characteristics may be observed in mild to severe forms:

- Communication problems (e.g., using and understanding language);
- Difficulty relating to people, objects, and events;
- Unusual play with toys and other objects;
- Difficulty with changes in routine or familiar surroundings; and
- Repetitive body movements or behavior patterns.

Other Helpful Things to Know

These NICHCY publications talk about topics important to parents of a child with a disability.

Parenting a Child with Special Needs

Your Child's Evaluation

Parent to Parent Support

Questions Often Asked by Parents About Special Education Services

Developing Your Child's IEP

All are available in English and in Spanish—on our Web site or by contacting us.

Early diagnosis and appropriate educational programs are very important to children with autism or PDD.

Want More Info?

NICHCY *State Resources Sheets* list organizations in each state addressing autism, special education, and other disability-related issues and concerns.

Our “*A to Z Topics*” include connections to a treasure trove of links to the latest research, publications, conferences and more!

Just two of the many resources available to you online—help yourself!



Children with autism or PDD vary widely in abilities, intelligence, and behaviors. Some children do not speak; others have language that often includes repeated phrases or conversations. Children with more advanced language skills tend to use a small range of topics and have difficulty with abstract concepts. Repetitive play skills, a limited range of interests, and impaired social skills are generally evident as well. Unusual responses to sensory information—for example, loud noises, lights, certain textures of food or fabrics—are also common.

◇ What About School? ◇

Early diagnosis and appropriate educational programs are very important to children with autism or PDD. The Individuals with Disabilities Education Act (IDEA) includes autism as a disability category. Children with autism and PDD are eligible for an educational program appropriate to their individual needs. Educational programs for students with autism or PDD focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning sometimes require the assistance of a professional who is particularly knowledgeable in the autism field, who develops and helps to 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 autism or PDD 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. To overcome frequent problems in generalizing skills learned at school, it is very important to develop programs with parents, so that learning activities, experiences, and approaches 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 autism or PDD grow up to live and work successfully in the community.

◆ Tips for Parents ◆



- ❑ Learn about autism/PDD. The more you know, the more you can help yourself and your child. See the list of resources and organizations at the end of this publication.
- ❑ 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 melt-downs 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 try not to turn your lives into one round of therapy after another.
- ❑ 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 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 school to develop an IFSP or an IEP that reflects your child's needs and abilities. Be sure to include assistive technology, related services, and supplementary aids and supports, if your child needs these. Don't forget about a positive behavior plan, if needed.
- ❑ Be patient, and keep your hopes up. Your child, like every child, has a whole lifetime to learn and grow.

◆ Tips for Teachers ◆

- ❑ Learn more about autism/PDD. The resources and organizations listed in this publication will help you.
- ❑ 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/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 professional resources (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. Reward students for each small success.
- ❑ 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.



✧ Resources ✧

Baldi, H., & Detmers, D. (2000). *Embracing play: Teaching your child with autism* [Video]. Bethesda, MD: Woodbine House. (800-843-7323; www.woodbinehouse.com)

Beytien, A. (2004). *Family to family: A guide to living life when a child is diagnosed with an autism spectrum disorder* [Video]. Higganum, CT: Starfish Specialty Press. (877-782-7347; www.starfishpress.com)

Bondy, A., & Frost, L. (2002). *A picture's worth: PECS and other visual communication strategies in autism*. Bethesda, MD: Woodbine House. (See contact information above.)

Bruey, C.T. (2003). *Demystifying autism spectrum disorders: A guide to diagnosis for parents and professionals*. Bethesda, MD: Woodbine House. (See contact information above.)

Cafiero, J.M. (2005). *Meaningful exchanges for people with autism: An introduction to augmentative & alternative communication*. Bethesda, MD: Woodbine House. (See contact information above.)

DuCharme, R., & Gullotta, T.P. (Eds.) (2004). *Asperger syndrome: A guide for professionals and families*. New York: Springer Publishers. (800-777-4643; www.springeronline.com)

Glasberg, B. (2005). *Functional behavior assessment for people with autism: Making sense of seemingly senseless behavior*. Bethesda, MD: Woodbine House. (See contact information above.)

Journal of Autism and Developmental Disorders. New York: Springer Publishers. (See contact information above.)

Mesibov, G.B., Shea, V., & Schopler, E. (2004). *The TEACCH approach to autism spectrum disorders*. New York: Springer Publishers. (See contact information above.)

O'Brien, M., & Daggett, J.A. (2006). *Beyond the autism diagnosis: A professional's guide to helping families*. Baltimore, MD: Brookes Publishing (800-638-3775; www.brookespublishing.com)

Richman, S. (2000). *Raising a child with autism: A guide to applied behavior analysis for parents*. London: Jessica Kingsley Publishers. (www.jkp.com/)

Volkmar, F.R., & Wiesner, L.A. (2003) *Healthcare for children on the autism spectrum: A guide to medical, nutritional, and behavioral issues*. Bethesda, MD: Woodbine House. (See contact information above.)

Wiseman, N.D. (2006). *Could it be autism?* New York: Broadway Books. (www.broadwaybooks.com)

For more information, books, and videos on autism spectrum disorders, the *Autism Society of North Carolina Bookstore* has over 400 titles in their collection. (919.743.0204; www.autismbookstore.com)

✧ Organizations ✧

Autism Information Center
Centers for Disease Control and Prevention
404-639-3534; 800-311-3435
www.cdc.gov/ncbddd/dd/ddautism.htm

Autism Society of America
301-657-0881; 800-328-8476
www.autism-society.org

Autism Treatment Network
503-783-2710
www.autismtreatmentnetwork.org

Cure Autism Now
323-549-0500; 888-828-8476
www.cureautismnow.org

Indiana Resource Center for Autism
Indiana Institute on Disability & Community
812-855-6508; 812-855-9396 (TTY)
www.iidc.indiana.edu/irca

MAAP Services for Autism & Asperger Syndrome
219-662-1311
www.asperger.org

National Alliance for Autism Research
888-777-6227
www.naar.org/

National Institutes of Health
Autism Research Network
www.autismresearchnetwork.org/AN/

O.A.S.I.S. Online Asperger Syndrome
Information and Support
www.aspergersyndrome.org/

Professional Development in Autism Center
206- 543-4011
<http://depts.washington.edu/pdacent/>

Yale Child Study Center
Yale Social Learning Disabilities Project
www.autism.fm

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