



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 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 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 take comfort in knowing that they aren't alone and they're getting Ryan the help he needs.



*NICHCY is the
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✧ What is Autism / PDD? ✧

Autism/Pervasive Developmental Disorder (PDD) is a neurological disorder that affects a child's ability to communicate, understand language, play, and relate to others. PDD represents a distinct category of developmental disabilities that share many of the same characteristics.

The different diagnostic terms that fall within the broad meaning of PDD, include:

- Autistic Disorder,
- Asperger's Disorder,
- Rett's Disorder,
- Childhood Disintegrative Disorder, and
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

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

In the diagnostic manual used to classify mental disorders, the *DSM-IV-TR* (American Psychiatric Association, 2000), "Autistic Disorder" is listed under the heading of "Pervasive Developmental Disorders." A diagnosis of autistic disorder is made when an individual displays 6 or more of 12 symptoms across three major areas: (a) social interaction, (b) communication, and (c) behavior. When children display similar behaviors but do not meet the specific criteria for autistic disorder (or the other disorders listed above), they may receive a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified, or PDD-NOS.

Autism is one of the disabilities specifically defined in the Individuals with Disabilities Education Act (IDEA), the federal legislation under which infants, toddlers, children, and youth with disabilities receive early intervention, special education and related services. IDEA 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



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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* §300.8(c)(1).

✧ **How Common is Autism / PDD?** ✧

Information from the National Institute of Mental Health and the Center for Disease Control and Prevention (CDC) indicates that between 2 to 6 per 1,000 children (from 1 in 500 to 1 in 150) have some form of autism/PDD. These disorders are four times more common in boys than in girls, although Rett's Disorder has only been reported and diagnosed in girls.

The causes of autism or 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.

Children with autism/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.

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/PDD.

✧ *What Research is Being Done?* ✧

Want More Info?

NICHCY's *State Resources Sheets* list organizations in each state related to autism, early intervention, special education, parent centers, and other disability-related issues and concerns. Help yourself!

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 and at no cost from NICHCY.)



Thanks to federal legislation—the Children's Health Act of 2000 and the Combating Autism Act of 2006—nearly \$1 billion over the next five years (2007-2012) has been authorized to combat autism through research, screening, early detection, and early intervention. The National Institutes of Health and the CDC are the lead entities conducting and coordinating multiple research activities. On the education front, the PDA Center at the University of Washington has several sites around the country that provide training and support to schools and families for students with autism spectrum disorders. Research on instructional interventions for children with a broad range of needs is an ongoing national endeavor. Check NICHCY's Research to Practice database and OSEP's discretionary projects directories on our web site to learn more. Additional information can also be found on the web sites included in the list of Organizations at the end of this publication.

✧ *What about School?* ✧

Early diagnosis and intervention are very important for children with autism/PDD. Under the Individuals with Disabilities Education Act (IDEA), children with autism/PDD 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 autism/PDD (ages 3 to 22) 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 autism/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. Consistency and continuity are very important for children with autism/PDD, 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 autism/PDD grow to live, work, and participate fully in their communities.

✧ Tips for Parents ✧



- ❑ Learn about autism/PDD. The more you know, the more you can help yourself and your child. Your State's PTI can be especially helpful. You'll find resources and organizations at the end of this publication and in NICHCY's online *State Resources Sheet*.
- ❑ 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 never-ending 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.

✧ Tips for Teachers ✧

- ❑ Learn more about autism/PDD. Check out the research on effective instructional interventions and behavior on NICHCY's web site. The resources and 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/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. 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. (Phone: 800.843.7323; Web: 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. (Phone: 877.782.7347; Web: 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. (Phone: 800.777.4643; Web: 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 (Phone: 800.638.3775; Web: www.brookespublishing.com)

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

Tsai, L.Y. (1998). *Pervasive developmental disorders*. Washington, DC: NICHCY. (Available online at: www.nichcy.org/pubs/factshe/fs20txt.htm)

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. (Web: 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. (Phone: 919.743.0204; Web: www.autismbookstore.com)

✧ Organizations ✧

(★ indicates member of OSEP's Technical Assistance and Dissemination Network)

Autism Information Center at CDC
Phone: 800.311.3435
Web: www.cdc.gov/ncbddd/autism/index.htm

Autism Society of America
Phone: 800.328.8476
Web: www.autism-society.org

Autism Treatment Network
Web: www.autismtreatmentnetwork.org

★ Center on Positive Behavioral Interventions and Supports (PBIS)
Web: www.pbis.org

★ Center for Implementing Technology in Education (CITED)
Web: www.citededucation.org

Cure Autism Now
Phone: 888.828.8476
Web: www.cureautismnow.org

★ Family Center on Technology and Disability
Web: www.fctd.info/

Indiana Resource Center for Autism
Web: www.iidc.indiana.edu/irca

Interactive Autism Network
Web: www.ianproject.org/

MAAP Services for Autism & Asperger Syndrome
Web: www.asperger.org

National Alliance for Autism Research
Phone: 888.777.6227
Web: www.naar.org/

NIH Autism Research Network
Web: www.autismresearchnetwork.org/AN/

★ NIMAS Development and Technical Assistance Centers
Web: <http://nimas.cast.org>

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

★ Professional Development in Autism Center
Web: depts.washington.edu/pdacent/

Yale Developmental Disabilities Clinic
Web: www.autism.fm



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