

PERVASIVE DEVELOPMENTAL DISORDERS

KEY FACTS

- Two to 5 of every 10,000 individuals have autistic disorder (Zahner and Pauls, 1987, as cited in Volkmar, 1996), but as many as 13 of every 10,000 individuals have conditions that may fall within the autistic–pervasive developmental disorder (PDD) spectrum (Wolraich et al., 1996).
- Approximately 75 percent of children and adolescents with autistic disorder meet criteria for mental retardation (MR) (American Psychiatric Association, 1994).
- Autistic disorder is four to five times more common in males than in females, but affected females are more likely than affected males to suffer from severe MR (American Psychiatric Association, 2000).
- No specific biological marker or precise pathogenic mechanism has been identified for PDDs.

Pervasive developmental disorders (PDDs) are a group of neurobiological disorders characterized by fundamental deficits in social interaction skills or communication skills, or by the presence of stereotyped (purposeless and repetitive) behaviors, interests, or activities (American Psychiatric Association, 2000). Common features include difficulty with transitions or change, unusual sensory interests or sensitivities, an extremely narrow and intense focus of interest, and stereotyped behaviors (e.g., hand flapping, rocking, twirling). Cognitive deficits or uneven skill development are often present. The spectrum of symptoms can range from a limited desire or ability to interact with others to the more severe symptoms seen with autistic disorder. While the symptoms of autistic disorder may be quite evident, children and adolescents with more subtle difficulties (e.g., those with social withdrawal problem; Asperger’s disorder, or a pervasive developmental disorder, not otherwise specified [PDD, NOS]) often go undiagnosed and untreated. Missed opportunities for treatment can adversely affect long-term outcomes and quality of life for these children and adolescents and their families.



DESCRIPTION OF SYMPTOMS

The following descriptive criteria offer a summary of the features of the spectrum of PDDs. Children with a PDD typically begin experiencing difficulties by or before age 3.

Social Withdrawal Problem

(Diagnostic code: V40.3)

Adapted from DSM-PC. Selected additional information from DSM-PC is available in the appendix. Refer to DSM-PC for further description.

Children and adolescents differ in their ability to interact socially and in their desire to do so. Some demonstrate an inability or lack of desire to interact with others. When this inability interferes with their development and functioning, it qualifies as a problem.

Infancy

- May be irritable and difficult to console
- May exhibit repetitive behavior, such as head banging
- May show low levels of social responsiveness; may withdraw in the absence of persistent efforts by parents to encourage social interaction

Early Childhood

- Appears self-absorbed, preferring solitary play to interacting with others
- May exhibit some mildly compulsive or rigid behaviors

Middle Childhood

- Rarely initiates peer interactions; prefers solitary play to group activities
- May be increasingly concerned about following rules and maintaining routines

Adolescence

- Has few friendships; has difficulty in social situations
- May be viewed as a loner; is socially isolated
- May have eccentric hobbies and interests
- Shows little concern for popular styles of dress or behavior

Autistic Disorder

(Diagnostic code: 299.00)

Adapted from DSM-PC and DSM-IV-TR. Selected additional information from DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description. (See also Table 16, p. 324.)

The most important clinical manifestations of autistic disorder are markedly abnormal development in social interaction and communication skills, and patterns of restrictive, repetitive, and stereotyped behavior and interests. These manifestations are

evident in the first 3 years of life but may present differently at various developmental stages. Children and adolescents with autistic disorder may be unable to understand that others have needs or may not be aware of others' feelings or distress. They may treat others as objects, tools, or mechanical aids. In addition, children and adolescents with autistic disorder may show impairment in their nonverbal social behaviors (e.g., lack of eye-to-eye gaze, reciprocal smiling, and affectionate contact) and in their ability

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Description of Symptoms (continued)

Autistic Disorder (continued)

to engage in symbolic or imaginative play. Their erratic sleep patterns and aversion to certain foods may disrupt family life. Self-injurious behavior (e.g., head banging, self-biting, hair pulling) can occur in more severely affected children and adolescents. Some children and adolescents with autistic disorder may have “islets of special abilities” (i.e., highly developed skills in very narrow and specific areas, such as the ability to decode numbers, list things from memory, or draw or play music exceptionally well) that contrast markedly with the level of their general cognitive functioning (Volkmar and Klin, 2000).

Infancy

- Infants with autistic disorder may show little interest in being held, or they may not be comforted by physical closeness with their parents. They have significant limitations in social smiling, eye contact, vocalization, and social play.
- Infants with autistic disorder display little interest in the human face.

Early Childhood

- Children may not follow (shadow) their parents at home, preferring to be alone. They may not show

anxiety in being separated from their parents but may become noticeably agitated in response to minor changes in their environment or routine. They often display echolalia (stereotyped repetition of another person’s words or phrases), repetitive motor behavior, and unusual attachments to objects. As they grow older they tend not to make friends and do not exhibit social or emotional reciprocity.

- Children commonly demonstrate delays in or total lack of development of spoken language.

Middle Childhood

- Children rarely share pleasure or excitement with others, and their social and vocal expressions and interactions are limited.

Adolescence

- Adolescents show significant deficits in understanding social expectations and have few or no friendships. They may exhibit unusual affect and perseverative (persistent and repetitive), ritualistic speech or behaviors.

Rett’s Disorder

(Diagnostic code: 299.80)

Adapted from DSM-PC and DSM-IV-TR. Selected additional information from DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description.

Rett’s disorder shares the same diagnostic code as pervasive developmental disorders, not otherwise specified (PDDs, NOS) and Asperger’s disorder. This X-linked dominant disorder has been reported only in females

and is usually associated with severe to profound mental retardation (MR). Rett’s disorder is characterized by normal functioning through the first 5 months of life, with subsequent development of the following severe deficits:

- Deceleration of head growth between 5 and 48 months
- Loss of purposeful hand movements between 5 and 30 months, and development of stereotyped mid-

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Description of Symptoms (continued)

Rett's Disorder (continued)

- line hand movements (e.g., hand wringing, hand washing)
- Cessation of social engagement
- Poorly coordinated gait or trunk movements
- Severe impairments in language development, with severe psychomotor retardation

By age 5, MR is frequently severe. Serious medical concerns include seizures, respiratory problems (including periods of apnea and hyperventilation), and risk of sudden cardiac death. Motor problems and scoliosis may also be present. Individuals with Rett's disorder have progressive neurodegeneration but can survive to adulthood (Volkmar and Klin, 2000).

Childhood Disintegrative Disorder

(Diagnostic code: 299.10)

Adapted from DSM-PC and DSM-IV-TR. Selected additional information from DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description.

This disorder is characterized by normal development until at least age 2 and thereafter by progressive loss (before age 10) of skills in communication, social interaction, behavior, self-help, and adaptive functioning. Childhood disintegrative disorder is associated

with severe mental retardation (MR) and with an increased risk of seizure disorder.

The majority of children and adolescents with childhood disintegrative disorder eventually stabilize and cease to deteriorate. Occasionally, they may recover some previously attained developmental skills. A minority of children and adolescents with childhood disintegrative disorder have progressive neurodegeneration and die early, but most have a normal life expectancy (Volkmar and Klin, 2000).

Asperger's Disorder

(Diagnostic code: 299.80)

Adapted from DSM-PC and DSM-IV-TR. Selected additional information from DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description.

Asperger's disorder shares the same diagnostic code as pervasive developmental disorder, not otherwise specified (PDD, NOS), but children and adolescents with Asperger's disorder can be identified by the following symptoms:

- Impaired social interaction

- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities
- No significant delay in language or cognitive development (may be cognitively high functioning), adaptive skills (other than in social interactions), or curiosity about their environment
- Clumsiness (in many but not all cases)

Long-term outcomes of Asperger's disorder are not well defined, but impairment in social interaction is believed to be a lifelong problem for individuals with this disorder.

Description of Symptoms (continued)

Pervasive Developmental Disorder Not Otherwise Specified

(Diagnostic code: 299.80)

Adapted from DSM-PC and DSM-IV-TR. Selected additional information from DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description.

A wide range of developmental patterns are currently diagnosed as pervasive developmental disorder, not otherwise specified (PDD, NOS), which is consid-

ered a residual diagnostic category. Compared with children and adolescents who have social withdrawal problem, children and adolescents with PDD, NOS exhibit more extensive impairment in reciprocal social interactions; such impairment is associated with impaired verbal or nonverbal communication skills and/or stereotyped interests or behaviors that can interfere with developmental activities.



COMMONLY ASSOCIATED PROBLEMS AND DISORDERS

Table 15. Comparison of Pervasive Developmental Disorder Diagnoses

Features	Autistic Disorder	Asperger's Disorder	Rett's Disorder	Child Disintegrative Disorder
Age at onset	< 3 years, usually in first year	Typically > 3 years; no delays in language and cognitive development	Deceleration of head growth, 5–48 months; loss of purposeful hand skills, 5–30 months	2–10 years; normal development prior to 2 years of age
Gender	4–5 times more likely in males than in females	At least 5 times more likely in males than in females	Reported almost exclusively in females	Occurs in slightly more males than females
Relationship to mental retardation (MR)	Typically mild to profound MR; females likely to exhibit more severe MR	None	Severe to profound MR	Severe MR
Degenerative	No	No	Yes	In most children, degeneration stabilizes; occasionally some skills regained
Seizures	Occur in up to 25% of children and adolescents; more common in adolescence	No	Yes	Increased risk of seizures
Examples of associated conditions	Fragile X syndrome; tuberous sclerosis; neurofibromatosis; chromosomal aberrations	Chromosomal aberrations; obsessive compulsive disorder; depression; attention deficit hyperactivity disorder	Not applicable	Metachromatic leukodystrophy; Schilder's disease

Source: American Psychiatric Association, 2000; Klin and Volkmar, 1997.

INTERVENTIONS

Early identification and intensive early intervention during early childhood result in improved outcomes for most children with PDDs (Lovaas, 1987; McEachin et al., 1993; Ozonoff and Cathcart, 1998; Rogers, 1998; Sheinkopf and Siegel, 1998, as cited in Filipek et al., 2000). Interventions should be informed by an ongoing assessment of each child's or adolescent's needs and level of functioning, as these characteristics will change as the child or adolescent develops.

Children and adolescents with PDDs usually require interventions from a team of professionals that can include neurologists, psychiatrists, psychologists, social workers, audiologists, speech and language therapists, physical therapists, and occupational therapists (Volkmar et al., 1999). The primary care health professional plays a critical role in coordinating services and working with the child or adolescent and family over time to support the child's or adolescent's development and functioning. The following guidelines can help the primary care health professional identify and support children and adolescents with PDDs.

Child or Adolescent

1. At health supervision visits, assess all children and adolescents for developmental delays. Obtain a detailed history, including a developmental and family history, from parents as soon as impairments in social interaction or communication skills are noted. See Table 16: Signs of Autism in Infancy and Later. Screening tools such as the Ages and Stages Questionnaire (ASQ) (Bricker and Squires, 1999), the Child Development Inventories (CDIs) (Ireton, 1992), and the

Parents' Evaluation of Developmental Status (PEDS) (Glascoe, 1997) can provide baseline information (Filipek et al., 1999, 2000). Reviewing family-made home videos may also be helpful.

2. PDDs can co-occur with a variety of medical conditions. In particular, autistic disorder can be associated with genetic disorders such as fragile X syndrome, neurofibromatosis, tuberous sclerosis, and phenylketonuria. PDDs can also be confused with other conditions such as schizophrenia and syndrome of acquired aphasia with seizure disorder. Consider further medical evaluation as indicated (e.g., genetic screening; neurological, auditory, and ophthalmological assessments).
3. If initial assessment of a child or adolescent raises concerns about PDDs, refer the child or adolescent for neuropsychological testing and psychiatric evaluation of cognitive functioning, adaptive behavior, and social and communicative skills.
4. Assess the quality of social interactions for each child or adolescent as she develops over time, as children with subtler social withdrawal problems or milder forms of a PDD may not manifest symptoms until they are older.
5. Monitor the child or adolescent for any evidence of underlying psychiatric difficulties (e.g., anxiety, mood disorders), especially if behavioral problems appear suddenly.
6. Collaborate with a mental health professional (e.g., child psychologist, child psychiatrist, social worker) or a developmental-behavioral pediatrician about ongoing management of associated behavioral and emotional difficulties

Table 16. Signs of Autism in Infancy and Later

Signs in Infancy				
Motor	Perceptual	Socioemotional	Language	Mental Representation
<p>Inactive</p> <ul style="list-style-type: none"> • Flaccid muscle tone • Rarely cries • Irritable • Inconsolable • Soothed only when in constant motion • Rigid when held • Arches away from close physical contact • May have lost an acquired skill 	<ul style="list-style-type: none"> • Mix of hyper and hypo sensitivities to sensory stimuli <p>Auditory</p> <ul style="list-style-type: none"> • Appears deaf to voices, but jolts or panics at environmental sounds <p>Tactile</p> <ul style="list-style-type: none"> • Prefers smooth surfaces • Refuses food with rough texture • Adverse reaction to wool fabrics and seams <p>Visual</p> <ul style="list-style-type: none"> • Sensitive to light • May panic at changes in light levels • Preoccupied with observing own hand and finger movements 	<ul style="list-style-type: none"> • Unresponsive • Late, rare, or absent social smile • Avoids eye contact when held • Fleeting eye contact at a distance • Lack of anticipatory response to being picked up • Fails to show normal 8-month stranger anxiety • Lack of gaze monitoring • Does not follow a point • Seems to dislike being held • Seems content to be left alone • Fails to visually follow comings and goings of parents • Doesn't play peek-a-boo or pat-a-cake or wave good-bye • Fails to form strong personal attachments 	<ul style="list-style-type: none"> • Delayed or absent coo and/or expressive vocalization • Failure to imitate sounds or babble • Little use of communicative gestures • Lack of pointing and pointing to obtain an object; instead brings adult's hand to desired object or tries to get desired object on own • May have lost an acquired skill 	<ul style="list-style-type: none"> • Decreased visual pursuit of objects or people • Object permanence develops slowly

Table 16. Signs of Autism in Infancy and Later (continued)

Signs Beyond Infancy				
Motor	Perceptual	Socioemotional	Language	Mental Representation
<ul style="list-style-type: none"> • Toe-walking • Rocking • Head banging • Whirling without dizziness • Perseverative movements • Sniffing • Other stereotypics 	<ul style="list-style-type: none"> • Withdraws from environmental stimulation • Engages in self-stimulation • Becomes preoccupied with spinning objects • Suddenly ceases activity and stares into space, often with neck hyperextended 	<ul style="list-style-type: none"> • Moves adult's hand like a tool • Insists on sameness and ritualizes routines • Unable to identify with another's feelings or point of view • Lack of pointing to direct another's attention to an interesting object or event 	<ul style="list-style-type: none"> • Speech is delayed or absent, or shows precocious advances followed by failure to use previously learned words • Limited ability to follow directions • Unable to point to body parts, objects, or pictures when named • Lack of pointing and pointing to obtain an object; instead leads adult to desired object or gets desired object on own • Immediate echolalia • Delayed echolalia unrelated to social context • Pronoun reversals • Atonal, hollow, rhythmic voice 	<ul style="list-style-type: none"> • No representational play • Little appropriate use of toys • Preoccupied with impersonal invariant information (e.g., television commercials) • Unable to solve false-belief problems ("Sally and Ann Test")

Source: Adapted from Kalmanson B, Pekarsky JH. 1987. Infant-parent psychotherapy with an autistic toddler. *Zero to Three* 7(3):1-6. Copyright 1987, ZERO TO THREE: National Center for Infants, Toddlers, and Families. Adapted with permission of the copyright holder.



(e.g., aggression, hyperactivity, self-injurious behaviors, anxiety symptoms, emotional distress with transitions).

7. If behavioral or self-injurious behaviors, anxiety, or mood symptoms persist, consult with a child psychiatrist or a developmental-behavioral pediatrician about pharmacological interventions.
8. Refer the child or adolescent for a comprehensive speech and language assessment. Advocate for ongoing speech and language services as indicated.
9. Refer the child or adolescent for physical therapy and occupational therapy evaluations, including assessment of any sensory sensitivities.
10. Incorporate an understanding of the child's or adolescent's communicative abilities into dealings with the child or adolescent (e.g., a child or adolescent whose receptive language skills exceed her expressive abilities may not be able to verbalize questions or distress but can benefit from an explanation of each step of the physical exam).
11. Identify the child's or adolescent's strengths, and focus on these when trying to find ways to help him interact more with his environment.

Family

1. Help families engage long-term supports, for example,
 - Community supports (e.g., family members and friends)
 - Agency and organizational supports (e.g., the Department of Developmental Disabilities, state and local agencies, Supplemental Social Security Income, the Autism Society of America) (See Resources for Families, p. 328.)
 - Physical and mental health professionals
2. Help families develop behavioral modification programs in the home setting (usually with the collaboration of a behavioral therapist specializing in developmental disorders) to strengthen adaptive behaviors (e.g., increased social interactions) and to decrease maladaptive behaviors (e.g., aggression, self-injurious behaviors).
3. For children and adolescents whose symptoms are less severe and involve more subtle difficulties with social communication and interactions, help families structure activities to maximize their child's or adolescent's opportunities to engage in positive social experiences (e.g., suggest that the child or adolescent participate in organized clubs or sports that have close adult supervision and in structured activities with one or two supportive peers).



Friends

1. In addition to encouraging the types of day-to-day social opportunities described above, consider making a referral for social skills training via programs such as weekly social skills groups or peer tutoring programs.

Community and School

1. Support families in requesting appropriate educational interventions. Children and adolescents with PDDs are eligible for early interven-

tion and special education services through the Individuals with Disabilities Education Act (IDEA). Legal mandates specify that all children and adolescents ages 3–21 who are diagnosed with a PDD receive appropriate educational services at no cost based on the child's or adolescent's Individualized Education Program (IEP). (See Tool for Families: Individualized Education Program [IEP] Meeting Checklist, *Mental Health Tool Kit*, p. 120.) Before age 3, services may be provided by other agencies through an Individualized Family Service Plan. Parents should be aware that their child or adolescent may also qualify for services under Section 504 of the Rehabilitation Act.

For further information about eligibility and services, families can consult the school's special education coordinator, the local school district, the state department of education's special education division, the U.S. Department of Education's Office of Special Education Programs (<http://www.ed.gov/offices/OSERS/OSEP>), the IDEA '97 Web site (<http://www.ed.gov/offices/OSERS/IDEA>), or the U.S. Justice Department's Civil Rights Division (<http://www.usdoj.gov/crt/edo>).

2. Be aware of how to help the family and the school access information about meeting the child's or adolescent's educational and developmental needs. An individualized intervention program should be carried out by professionals experienced in working with children and adolescents with PDDs. A child or adolescent with a PDD may require intensive and individualized instruction and interventions. Educational programs based on the Treatment and Education of Autistic and

Related Communication Handicapped Children (TEACCH) system (Campbell et al., 1995) have shown promise for children and adolescents with PDDs and are based on the following principles:

- Improving each child's or adolescent's overall adaptation by improving skills and developing appropriate environmental adaptations
 - Using both formal measures (e.g., the Psychoeducational Profile-Revised [PEP-R] [Schopler et al., 1990]) and informal observation to design individualized educational programs
 - Using cognitive and behavioral theory to inform interventions
 - Assessing and enhancing skills, while recognizing areas of weakness
 - Using visual teaching techniques
 - Using a multidisciplinary team to address the child's or adolescent's needs, and engaging consultants as indicated
3. Support the school and the family in maximizing a child's or adolescent's communication skills and in generalizing these skills to multiple settings.
 4. Refer for additional services (e.g., speech and language therapy, occupational therapy, vocational training) as indicated.

Resources for Families

Academy for Educational Development National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492

Washington, DC 20013

Phone: (800) 695-0285

Web site: <http://www.nichcy.org>

NICHCY is funded by the Office of Special Education Programs, U.S. Department of Education. It provides access to resources, including state- and local-level agencies and resources.

Administration for Children and Families
Administration on Developmental Disabilities
U.S. Department of Health and Human Services
Mail Stop: HHH 300-F

370 L'Enfant Promenade, S.W.

Washington, DC 20447

Phone: (202) 690-6590

Web site: <http://www.acf.dhhs.gov/programs/add>

American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)

8630 Fenton Street, Suite 410

Silver Spring, MD 20910

Phone: (301) 588-8252

Web site: <http://www.aauap.org>

Autism Society of America (ASA)

7910 Woodmont Avenue, Suite 300

Bethesda, MD 20814-3015

Phone: (800) 3AUTISM (328-8476), ext. 150;

(301) 657-0881

Web site: <http://www.autism-society.org>

Local ASA chapters can serve as an important resource for families.

Di Lima SN, Niemeier S, eds. 1997. *Caregiver Education Guide for Children with Developmental Disabilities*. Gaithersburg, MD: Aspen Publishers. Phone: (800) 317-3113; Web site: <http://www.aspenpub.com>.

National Institute of Child Health and Human Development (NICHD)
31 Center Drive, Building 31, Rooms 2A32, MSC2425
Bethesda, MD 20892-2425
Web site (for autistic disorder references):
<http://www.nichd.nih.gov/autism>
Phone: (800) 370-2943

The NICHD Clearinghouse provides access to information and referral services.

National Library of Medicine's electronic resource guide on autism Web site:<http://www.nlm.nih.gov/medlineplus/autism.html>

Office of Special Education and Rehabilitative Services
U.S. Department of Education
330 C Street, S.W., Room 3132
Washington, DC 20202-2524
Phone: (202) 205-8241
Web site: <http://www.ed.gov/offices/OSERS>

This office includes the Office of Special Education Programs and the Rehabilitative Services Administration.

Social Security Administration/Supplemental Security Income (SSI)
Phone: (800) 772-1213
Web site: <http://www.ssa.gov/pubs>

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