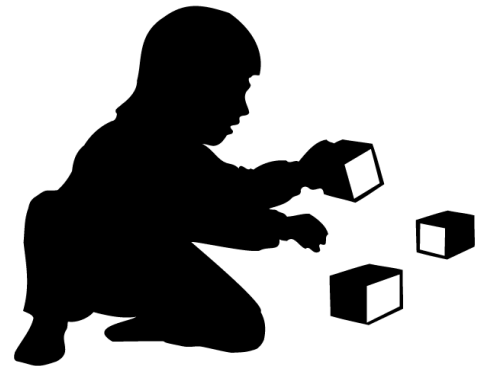


BRIEFING PAPER

A publication of the National Dissemination Center for Children with Disabilities

Pervasive Developmental Disorders

by Luke Y. Tsai, M.D.



Every year the National Dissemination Center for Children with Disabilities (NICHCY) receives thousands of requests for information about the diagnosis, educational programming, and special needs of children and youth with Pervasive Developmental Disorders (PDD). Over the past few years, PDD has become a subject of increased attention among parents, professionals, and policymakers across the country.

NICHCY developed this *Briefing Paper* in response to the growing concern about, and interest in, this disability. This publication is designed to answer some of the most commonly asked questions regarding PDD and to provide concerned individuals with other resources for information and support.

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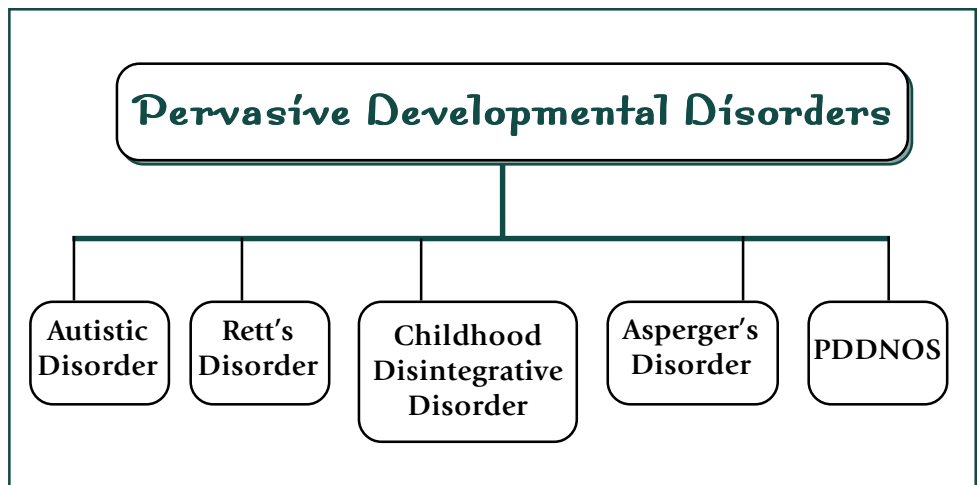


INTRODUCTION

The term Pervasive Developmental Disorders was first used in the 1980s to describe a class of disorders. This class of disorders has in common the following characteristics: impairments in social interaction, imaginative activity, verbal and nonverbal communication skills, and a limited number of interests and activities that tend to be repetitive.

The manual used by physicians and mental health professionals as a guide to diagnosing disorders is the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). The DSM was last revised in 1994. In this latest revision, known as the DSM-IV, five disorders are identified under the category of Pervasive Developmental Disorders (see chart at right): (1) Autistic Disorder, (2) Rett's Disorder, (3) Childhood Disintegrative Disorder, (4) Asperger's Disorder, and (5) Pervasive Developmental Disorder Not Otherwise Specified, or PDDNOS. (*Editor's note in 2003: The current version of the DSM is the DSM-IV-TR, published in 2000. The categorization of PDD that is described in this Briefing Paper has not changed.*)

Many of the questions parents and education professionals ask NICHCY have to do with children who have been diagnosed with "PDD." Doctors are divided on the use of the term PDD. Many professionals use the term PDD as a short way of saying PDDNOS. Some doctors, however, are hesitant to diagnose very young children with a specific type of PDD, such as Autistic Disorder, and therefore only use the general category label of PDD. This approach contributes to the confu-



sion about the term, because the term PDD actually refers to a *category* of disorders and is not a diagnostic label. The appropriate diagnostic label to be used is PDDNOS—Pervasive Developmental Disorder Not Otherwise Specified—not PDD (the umbrella category under which PDDNOS is found).

Accordingly, this *Briefing Paper* will use the term PDD to refer to the overall category of Pervasive Developmental Disorders and the term PDDNOS to refer to the specific disorder, Pervasive Developmental Disorder Not Otherwise Specified. The majority of this *Briefing Paper* will focus on PDDNOS.

All of the disorders that fall under the category of PDD share, to some extent, similar characteristics. To understand how the disorders differ and how they are alike, it's useful to look at the definition of each disorder. Therefore, before we begin our discussion of PDDNOS, let us look first at the definition of the general category PDD and its specific disorders.

THE PDD CATEGORY & ITS FIVE SPECIFIC DISORDERS

All types of PDD are neurological disorders that are usually evident by age 3. In general, children who have a type of PDD have difficulty in talking, playing with other children, and relating to others, including their family.

According to the definition set forth in the DSM-IV (American Psychiatric Association, 1994), Pervasive Developmental Disorders are characterized by severe and pervasive impairment in several areas of development:

- social interaction skills;
- communication skills; or
- the presence of stereotyped behavior, interests, and activities. (p. 65)

The Five Types of PDD

(1) *Autistic Disorder*. Autistic Disorder, sometimes referred to as *early infantile autism* or *childhood autism*, is four times more common in boys than in girls. Children with Autistic Disorder have a moderate to severe range of communication, socialization, and behavior problems. Many children with autism also have mental

Diagnostic Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. (APA, 1994, pp. 70-71)

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Diagnostic Criteria for Rett's Disorder

A. All of the following:

(1) apparently normal prenatal and perinatal development

(2) apparently normal psychomotor development through the first 5 months after birth

(3) normal head circumference at birth

B. Onset of all of the following after the period of normal development

(1) deceleration of head growth between ages 5 and 48 months

(2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)

(3) loss of social engagement early in the course (although often social interaction develops later)

(4) appearance of poorly coordinated gait or trunk movements

(5) severely impaired expressive and receptive language development with severe psychomotor retardation. (APA, 1994, pp. 72-73)

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retardation. The DSM-IV criteria by which Autistic Disorder is diagnosed are presented on page 3.

(2) *Rett's Disorder*. Rett's Disorder, also known as Rett Syndrome, is diagnosed primarily in females. In children with Rett's Disorder, development proceeds in an apparently normal fashion over the first 6 to 18 months at which point parents notice a change in their child's behavior and some regression or loss of abilities, especially in gross motor skills such as walking and moving. This is followed by an obvious loss in

abilities such as speech, reasoning, and hand use. The repetition of certain meaningless gestures or movements is an important clue to diagnosing Rett's Disorder; these gestures typically consist of constant hand-wringing or hand-washing (Moeschler, Gibbs, & Graham 1990). The diagnostic criteria for Rett's Disorder as set forth in the DSM-IV appear in the second box on page 3.

(3) *Childhood Disintegrative Disorder*. Childhood Disintegrative Disorder, an extremely rare disorder, is a clearly apparent regression

in multiple areas of functioning (such as the ability to move, bladder and bowel control, and social and language skills) following a period of at least 2 years of apparently normal development. By definition, Childhood Disintegrative Disorder can *only* be diagnosed if the symptoms are preceded by *at least* 2 years of normal development and the onset of decline is prior to age 10 (American Psychiatric Association, 1994). DSM-IV criteria are presented below.

(4) *Asperger's Disorder*. Asperger's Disorder, also referred to as Asperger's or Asperger's Syndrome, is a developmental disorder characterized by a lack of social skills; difficulty with social relationships; poor coordination and poor concentration; and a restricted range of interests, but normal intelligence and adequate language skills in the areas of vocabulary and grammar. Asperger's Disorder appears to have a somewhat later onset than Autistic Disorder, or at least is recognized later. An individual with Asperger's Disorder does not possess a significant delay in language development; however, he or she may have difficulty understanding the subtleties used in conversation, such as irony and humor. Also, while many individuals with autism have mental retardation, a person with Asperger's possesses an average to above average intelligence (Autism Society of America, 1995). Asperger's is sometimes incorrectly referred to as "high-functioning autism." The diagnostic criteria for Asperger's Disorder as set forth in the DSM-IV are presented in the box on page 5.

(5) *Pervasive Developmental Disorder Not Otherwise Specified*. Children with PDDNOS either (a)

Diagnostic Criteria for Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

- (1) expressive or receptive language
- (2) social skills or adaptive behavior
- (3) bowel or bladder control
- (4) play
- (5) motor skills

C. Abnormalities of functioning in at least two of the following areas:

- (1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
- (2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
- (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia. (APA, 1994, pp. 74-75)

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do not fully meet the criteria of symptoms clinicians use to diagnose any of the four specific types of PDD above, and/or (b) do not have the *degree* of impairment described in any of the above four PDD specific types.

According to the DSM-IV, this category should be used “when there is a severe and pervasive impairment in the development of social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder” (American Psychiatric Association, 1994, pp. 77-78).

The Confusion of Diagnostic Labels

The intent behind the DSM-IV is that the diagnostic criteria not be used as a checklist but, rather, as guidelines for diagnosing pervasive developmental disorders. There are no clearly established guidelines for measuring the severity of a person’s symptoms. Therefore, the line between autism and PDDNOS is blurry (Boyle, 1995).

As discussed earlier, there is still some disagreement among professionals concerning the PDDNOS label. Some professionals consider “Autistic Disorder” appropriate only for those who show extreme symptoms in every one of several developmental areas related to autism. Other professionals are more comfortable with the term Autistic Disorder and use it to cover a broad range of symptoms connected with language and social dysfunction. Therefore, an individual may be diagnosed by one practitioner as having Autistic

Diagnostic Criteria for Asperger’s Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
- (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (4) lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
- (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single word used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder, or Schizophrenia. (APA, 1994, p. 77)

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Disorder and by another practitioner as having PDDNOS (or PDD, if the practitioner is abbreviating for PDDNOS).

Generally, an individual is diagnosed as having PDDNOS if he or she has some behaviors that are seen in autism but does not meet the full DSM-IV criteria for

having Autistic Disorder. Despite the DSM-IV concept of Autistic Disorder and PDDNOS being two distinct types of PDD, there is clinical evidence suggesting that Autistic Disorder and PDDNOS are on a continuum (i.e., an individual with Autistic Disorder can improve and be rediagnosed as having PDDNOS, or a young child

can begin with PDDNOS, develop more autistic features, and be re-diagnosed as having Autistic Disorder).

To add to the list of labels that parents, teachers, and others may encounter, a new classification system was recently developed by ZERO TO THREE: National Center for Infants, Toddlers, and Families (1994). Under this system, called the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood*, the term Multisystem Developmental Disorder, or MSDD, is used to describe pervasive developmental disorders.

However, amidst all this confusion, it is very important to remember that, regardless of whether a child's diagnostic label is autism, PDDNOS, or MSDD, his or her treatment is similar.

THE CAUSE OF PDDNOS

Both behavioral and biological studies have generated sufficient evidence to suggest that PDDNOS is caused by a neurological abnormality—problems with the nervous system. However, no specific cause has been identified.

While studies have found various nervous-system problems, no single problem has been consistently found, and exact causes are far from clear. This may be due to the current approach of defining PDDNOS based on behaviors (as opposed to, say, genetic testing). Hence, it is possible that PDDNOS is the result of several different conditions. If this is the case, it is anticipated that future studies will identify a range of causes.

SYMPTOMS AND SIGNS OF PDDNOS

Generally, children are 3 to 4 years old before they exhibit enough symptoms for parents to seek a diagnosis. There is no set pattern of symptoms and signs in children with PDDNOS. It is important to realize that a very wide range of diversity is seen in children with PDDNOS. All the items of behavior described in this section are common in these children, but a single child *seldom* shows all the features at one time. In other words, all children with PDDNOS do not have the same degree or intensity of the disorder. PDDNOS can be mild, with the child exhibiting a few symptoms while in the school or neighborhood environment. Other children may have a more severe form of PDDNOS and have difficulties in all areas of their lives. Because of


the possibility that PDDNOS and Autistic Disorder are on a continuum, many clinical features described in the following section are very similar to those being described in the literature for Autistic Disorder.

Deficits in Social Behavior

Some infants with PDDNOS tend to avoid eye contact and demonstrate little interest in the human voice. They do not usually put up their arms to be picked up in the way that typical children do. They may seem indifferent to affection and seldom show facial responsiveness. As a result, parents often think the child is deaf. In children with fewer delays, lack of social responsiveness may not be obvious until well into the second or third year of life.

In early childhood, children with PDDNOS may continue to show a lack of eye contact, but they may enjoy a tickle or may passively accept physical contact. They do not develop typical attachment behavior, and there may seem to be a failure to bond. Generally, they do not follow their parents about the house. The majority do not show normal separation or stranger anxiety. These children may approach a stranger almost as readily as they do their parents. Many such children show a lack of interest in being with or playing with other children. They may even actively avoid other children.

In middle childhood, such children may develop a greater awareness or attachment to parents and other familiar adults. However, social difficulties continue. They still have problems with group games and forming peer relationships. Some of the



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children with less severe PDDNOS may become involved in other children's games.

As these children grow older, they may become affectionate and friendly with their parents and siblings. However, they still have difficulty understanding the complexity of social relationships. Some individuals with less severe impairments may have a desire for friendships. But a lack of response to other people's interests and emotions, as well as a lack of understanding of humor, often results in these youngsters saying or doing things that can slow the development of friendships.

Impairment in Nonverbal Communication

In early childhood, children with PDDNOS may develop the concrete gesture of pulling adults by the hand to the object that is wanted. They often do this without the typical accompanying facial expression. They seldom nod or shake their heads to substitute for or to accompany speech. Children with PDDNOS generally do not participate in games that involve imitation. They are less likely than typical children to copy their parents' activity.

In middle and late childhood, such children may not frequently use gestures, even when they understand other people's gestures fairly well. Some children do develop imitative play, but this tends to be repetitive.

Generally, children with PDDNOS are able to show joy, fear, or anger, but they may only show the extreme of emotions. They often do not use facial expressions that ordinarily show subtle emotion.

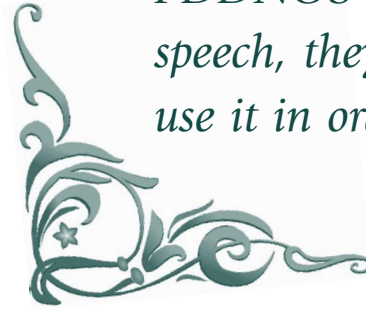
Impairment in Understanding Speech

Comprehension of speech in children with PDDNOS is impaired to varying degrees, depending on where the child is within the wide spectrum of PDDNOS. Individuals with PDDNOS who also have mental retardation may never develop more than a limited understanding of speech. Children who have less severe impairments may follow simple instructions if given in an immediate context or with the aid of gestures (e.g., telling the child to "put your glass on the counter," while pointing to the counter). When impairment is mild, only the comprehension of subtle or abstract meanings may be affected. Humor, sarcasm, and common sayings (e.g., "it's raining cats and dogs") can be confusing for individuals with the most mild PDDNOS.

Impairment in Speech Development

Many infants with PDDNOS do not babble, or may begin to babble in their first year but then stop. When the child develops speech, he or she often exhibits abnormalities. Echolalia (seemingly meaningless repetition of words or phrases) may be the only kind of speech some children acquire. Though echolalic speech might be produced quite accurately, the child may have limited comprehension of the meaning. In the past, it was thought that echolalia had no real function. More recent studies have found that echolalia can serve several functions, such as self-stimulation (when a child says

When children with PDDNOS develop speech, they may not use it in ordinary ways.



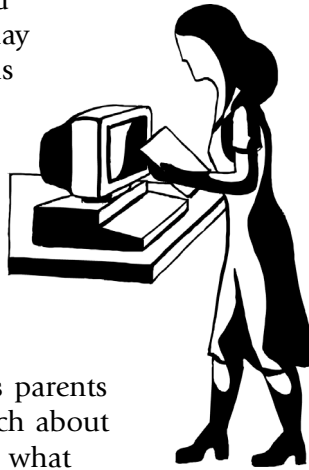
words or phrases repeatedly without a communicative purpose—just because it feels good); as a step between a child being nonverbal and verbal; or as a way to communicate (Prizant & Rydell, 1993). Other children develop the appropriate use of phrases copied from others. This is often accompanied by pronoun reversal in the early stages of language development. For instance, when the child is asked "How are you?" he or she may answer "You are fine."

The actual production of speech may be impaired. The child's speech may be like that of a robot, characterized by a monotonous, flat delivery with little change in pitch, change of emphasis, or emotional expression.

Problems of pronunciation are common in young children with PDDNOS, but these often diminish as the child gets older. There may be a striking contrast between clearly enunciated echolalic speech and poorly pronounced spontaneous speech. Some children have a chanting or singsong speech, with odd prolongation of sounds, syllables, and words. A question-like intonation may be used for statements. Odd breathing rhythms may produce staccato speech in some children.

Beginning the Search for Information

Sam was an active and busy child. But his parents were worried about him. Compared with the other 3-year-olds they knew, Sam was different—he wasn't talking, and he didn't seem to want or try to play with his sister. At day care Sam wouldn't join in with the other kids, but he really enjoyed playing with water. He would splash and play at the sink for hours, with a big smile on his face. After a year of expressing concern to their pediatrician, Sam's parents finally obtained a referral to a developmental psychologist who diagnosed Sam as having PDDNOS. The pediatrician also suggested that they get the school to test Sam. The school tested him and said he had autism. No one seemed to know anything about PDDNOS, and although Sam's parents had heard of autism, they didn't know much about it. They began to search for information on what PDDNOS was and what autism was.



Abnormal grammar is frequently present in the spontaneous speech of verbal children with PDDNOS. As a result:

- phrases may be telegraphic (brief and monotone) and distorted;
- words of similar sound or related meaning may be muddled;
- some objects may be labeled by their use;
- new words may be coined; and
- prepositions, conjunctions, and pronouns may be dropped from phrases or used incorrectly.

When children with PDDNOS do develop functional speech, they may not use it in ordinary ways. Such children tend to rely on repetitive phrases. Their speech does not usually convey imagination, abstraction, or subtle emotion. They generally have difficulty talking about anything outside of

the immediate context. They may talk excessively about their special interests, and they may talk about the same pieces of information whenever the same subject is raised. The most able persons can exchange concrete pieces of information that interest them, but once the conversation departs from this level, they can become lost and may withdraw from social contact. Ordinary to-and-fro conversational chatter is lacking. Thus, they give the impression of talking "at" someone, rather than "with" someone.

Unusual Patterns of Behavior

The unusual responses of children with PDDNOS to the environment take several forms.

Resistance to change. Many children are upset by changes in the familiar environment. Even a minor change of everyday routine may lead to tantrums. Some children line up toys or objects

and become very distressed if these are disturbed. Efforts to teach new activities may be resisted.

Ritualistic or compulsive behaviors. Ritualistic or compulsive behaviors usually involve rigid routines (e.g., insistence on eating particular foods) or repetitive acts, such as hand flapping or finger mannerisms (e.g., twisting, flicking movements of hands and fingers carried out near the face). Some children develop preoccupations; they may spend a great deal of time memorizing weather information, state capitals, or birth dates of family members.

Abnormal attachments and behaviors. Some children develop intense attachments to odd objects, such as pipe cleaners, batteries, or film canisters. Some children may have a preoccupation with certain features of favored objects, such as their texture, taste, smell, or shape.

Unusual responses to sensory experiences. Many children may seem underresponsive or overresponsive to sensory stimuli. Thus, they may be suspected of being deaf or visually impaired. It is common for such young children to be referred for hearing and vision tests. Some children avoid gentle physical contact, yet react with pleasure to rough-and-tumble games. Some children carry food preferences to extremes, with favored foods eaten to excess. Some children limit their diet to a small selection, while others are hearty eaters who do not seem to know when they are full.

Disturbance of Movement

The typical motor milestones (e.g., throwing, catching, kicking) may be delayed but are often within the normal range. Young

children with PDDNOS usually have difficulty with imitation skills, such as clapping hands. Many such children are very overactive, yet tend to become less overactive in adolescence. Children with PDDNOS may exhibit characteristics such as grimacing, hand flapping or twisting, toe walking, lunging, jumping, darting or pacing, body rocking and swaying, or head rolling or banging. In some cases the behaviors appear only from time to time; in other cases they are present continuously.

Intelligence and Cognitive Deficits

Generally, children with PDDNOS do very well on tests requiring manipulative or visual skills or immediate memory, while they do poorly on tasks demanding symbolic or abstract thought and sequential logic. The process of learning and thinking in these children is impaired, most particularly in the capacity for imitation, comprehension of spoken words and gestures, flexibility, inventiveness, learning and applying rules, and using acquired information. Yet, a small number of children with PDDNOS show excellent rote memories and special skills in music, mechanics, mathematics, and reading.

Because many children with PDDNOS are either without functional speech or otherwise untestable, some people question the validity of testing their intelligence. Moreover, it has been observed that a number of these children show major improvements in other developmental areas during the follow-up period without a change in their tested IQ. Follow-up studies have also shown that retardation present at the time of initial diagnosis tends

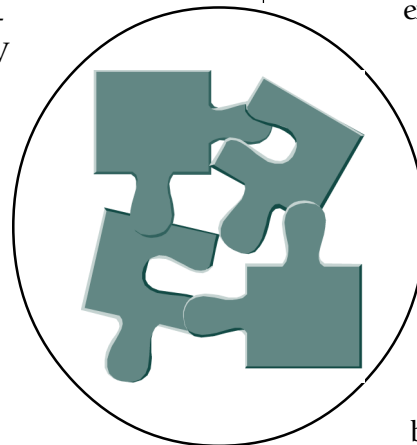
to persist. Those children with a low IQ show more severely impaired social development. They are more likely to display unusual social responses, such as touching or smelling people, ritualistic behavior, or self-injury.

Associated Features

The emotional expression of some children with PDDNOS may be flattened, excessive, or inappropriate to the situation. For no obvious reason, they may scream or sob inconsolably one time, yet giggle and laugh hysterically another time. Real dangers, such as moving vehicles or heights, may be ignored, yet the same child might seem frightened of a harmless object, such as a particular stuffed animal.

DIAGNOSING PDDNOS

The DSM-IV suggests that the diagnostic label of PDDNOS be used when there is a severe and pervasive impairment in the development of reciprocal social interaction, verbal and nonverbal communication skills, or the development of seemingly meaningless repetitive behavior, interests, and activities, but when the criteria are not completely met for a specific disorder within the category PDD (e.g., Autistic Disorder, Rett's Disorder, Asperger's Disorder). However, the DSM-IV framework has not offered specific techniques or criteria for diagnosing PDDNOS.



No Specific Test Available

Currently, no objective biological test, such as a blood test or an X-ray examination, can confirm a child's PDDNOS diagnosis. Diagnosing PDDNOS is complicated and much like putting together a jigsaw puzzle that does not have a clear border and picture. Therefore, it is reasonable to say that, when a PDDNOS diagnosis is made, it reflects the clinician's best guess. Obtaining an accurate diagnosis requires an assessment conducted by a well-trained professional who specializes in developmental disorders, usually a child psychiatrist, developmental pediatrician, pediatric neurologist, developmental pediatrician, child psychologist, developmental psychologist, or neuropsychologist.

PDDNOS Assessment

The purpose of PDDNOS assessment is twofold: to gather information to formulate an accurate diagnosis and to provide information that will form the basis of an appropriate intervention plan for the individual child and family. Assessment of PDDNOS usually includes the following elements:

Medical assessment. The medical evaluation should include a thorough birth, developmental, medical, and family history, and a full physical and neurological examination. Not all children with PDDNOS require laboratory tests such as a chromosome study, including a test for Fragile X, an EEG (which measures the brain's electrical activity), or a brain scan such as MRI (an X-ray that gives a picture of the brain's anatomy). The

primary care physician determines if these are needed. Although the cause of PDDNOS is generally unknown, the physician may discuss some medical conditions that do not cause PDDNOS but tend to be found in such children—for example, seizure disorder. Associated conditions can cause or worsen a child's problems.

Interviews with the parents, child, and child's teacher. A child with PDDNOS may exhibit different abilities and behaviors in different settings or situations. Parents and teachers can provide information about behaviors not observed during the formal testing sessions.

Behavior rating scales. Checklists of possible problems should be completed by parents or caretakers familiar with the child. Many diagnosticians use the checklist for autism. However, no scale has yet been developed *specifically* to determine the diagnosis of PDDNOS.

Direct behavioral observations. The child's behavior is recorded as it happens, and assessment results are often graphed to aid interpretation. This type of assessment can be carried out either in an artificial situation (e.g., a child taking an intelligence test) or in a natural situation (e.g., a child's home or classroom).

Psychological assessment. The psychologist uses standardized instruments to evaluate the child's cognitive, social, emotional, behavioral, and adaptive functioning. Parents learn in which areas of development their child exhibits delays.

Educational assessment. Both formal assessment (such as the use of standardized tests) and informal assessment (such as

direct observation and interviewing the parents) should be used to evaluate the child on the following points:

- preacademic skills (e.g., shape and letter naming),
- academic skills (e.g., reading and arithmetic),
- daily living skills (e.g., toileting, dressing, eating), and
- learning style and problem-solving approaches.

Communication assessment. Formal testing, observational assessment, and interviewing the child's parents are all useful strategies for assessing communication skills. It is important to assess a range of communication skills, including the child's interest in communication, why (for what purpose) the child communicates, the content and context of the communication, how the child communicates (including facial expression, posture, gestures, etc.), and how well the child understands when others communicate with him or her. Assessment results should be used when designing a communication program for the child. This may incorporate one or more alternative forms to spoken



communication, such as sign language and/or using a communication board (i.e., pointing to pictures to express oneself).

Occupational assessment. An occupational therapist may evaluate the child to determine the nature of his or her sensory integrative functioning: how the child's different senses—hearing, sight, taste, smell, touch—work together. Standardized tools are used to assess fine motor skills (such as using fingers to pick up small objects), gross motor skills (such as running and jumping), whether the child is right or left handed, and various visual skills (such as depth perception).

Evaluation summary. The professional evaluating a child will use all the information collected through these varying techniques to decide whether that child has a disability that falls under the category of PDD. Assessment and evaluation can be done through the child's local public school or a private practitioner.

SPECIAL EDUCATION AND PDDNOS

By law, schools must make special services available to eligible children with disabilities. These services are called *special education and related services* (discussed more below). The law that requires this is the Individuals with Disabilities Education Act, or IDEA. Under the IDEA, school-aged children who are thought to have a disability must be evaluated by the public schools at no cost to parents. Based on the evaluation, a determination is made as to their eligibility for services.

IDEA defines categories of disability under which a child is considered eligible for services. These categories are: autism, deaf-

blindness, hearing impairments including deafness, mental retardation, other health impairments, orthopedic impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, visual impairments including blindness, or multiple disabilities. If permitted by the state and the local educational agency, a school may also provide services to a student, from age 3 through age 9, under the separate category of "developmental delay." Parents should check with their state department of special education to find out what guidelines their state uses.

It's important to realize that a child may have a disability and still not be eligible for special education and related services. For a child to be determined to be eligible, the child's disability must adversely affect his or her educational performance.

Special education is instruction that is specially designed to meet a child's unique educational needs. Related services can include a range of services that are provided to help the student benefit from his or her special education. Related services include (but are not limited to) such services as occupational therapy, speech therapy, or physical therapy. Both special education and related services must be provided at no cost to the parents; both can be extremely beneficial for children with PDDNOS.

Services to very young children are also covered under the IDEA. Through the Program for Infants and Toddlers with Disabilities, states make *early intervention services* available to eligible infants and toddlers (birth through two years). Not all services are free; some may

A Mother's Story

Ryan, always in a whirl of activity, has had many labels. He was diagnosed with PDDNOS at age three and a half. When he went to preschool, his label was "developmentally delayed." Now he's 8 years old, and his label is "autistic."

He spends most of his time in a 2nd grade class. He's doing great, but he still needs lots of extra help—speech therapy, occupational therapy, and physical therapy. He loves playing soccer with kids in his class. His disability is only one part of who he is; he also has lots of strengths and talents. Every day still has its challenges, but we love him. He's not a label—he's Ryan.



be provided on a sliding-scale basis (in other words, according to the parents' ability to pay).

Early intervention services are designed to meet the developmental needs of the infant or toddler in areas such as their physical development, cognitive development, communication development, social or emotional development, or adaptive development. Services include (but are not limited to) such services as: family training and home visits, special instruction, speech-language pathology, vision services, and occupational therapy. To the maximum extent appropriate, early intervention services are to be provided in natural environments, including the home and community settings in which children without disabilities participate.

The IFSP and the IEP

The majority of school-aged children with PDDNOS will need some special education services, just as those who are younger will need early intervention services. If a school-aged child is found eligible for services, the parents

and the school will develop an Individualized Education Program (IEP). This is a document that lists, among other things, the child's strengths and weaknesses, and what special education and related services the school will provide to address those needs. If the child is less than 3 years old, he or she will have an Individualized Family Service Plan, (IFSP). Parents can contact their state parent training and information center (PTI) or NICHCY for helpful information about IEP or IFSP development and the special education process.

TREATMENT OF PDDNOS

On the whole, children with PDDNOS share the social and communicative disabilities found in children with Autistic Disorder. They often need services or treatments similar to those provided to children with autism.

Traditional Methods

No one therapy or method will work for all individuals with Autistic Disorder or PDDNOS. Many professionals and families

will use a range of treatments simultaneously, including behavior modification, structured educational approaches, medications, speech therapy, occupational therapy, and counseling. These treatments promote more typical social and communication behavior and minimize negative behaviors (e.g., hyperactivity, meaningless, repetitive behavior, self-injury, aggressiveness) that interfere with the child's functioning and learning. There has been an increasing focus on treating preschool children with PDDNOS by working closely with family members to help the children cope with the problems encountered at home before they enter school. Many times, the earlier these children begin treatment, the better the outcome.

Addressing behavior issues. As children with PDDNOS struggle to make sense of the many things that are confusing to them, they do best in an organized environment where rules and expectations are clear and consistent. The child's environment needs to be very structured and predictable.

Many times a behavior problem indicates that the child is trying to communicate something—confusion, frustration or

fear. Think of the child's behavior problem as a message to be decoded. Try to determine the possible cause of the behavior. Has the child's routine or schedule changed recently? Has something new been introduced that may be distressing or confusing the child? When a child's communication skills improve, behavior problems often diminish—the child now has a means of expressing what is bothering him or her, without resorting to negative behavior.

The use of positive behavioral support strategies for these children has proved effective. It is important to remember that:

1. Programs should be designed on an individual basis, because children vary greatly in their disabilities and abilities. Treatment approaches that work in certain cases may not work in others.

2. Children with PDDNOS have difficulty generalizing from one situation to another. The skills they have learned in school tend not to be transferred to the home or other settings. It is very important to be consistent in the treatment of a problem across all areas of the child's life—school, community, and home. This encourages generalization of behavior changes.

3. A home-community-based approach, which trains parents and special education teachers to carry out positive behavioral support strategies, can be instrumental in achieving maximum results.

Appropriate educational program. Education is the primary tool for

treating PDDNOS. Many children with PDDNOS experience the greatest difficulty in school, where demands for attention and impulse control are virtual requirements for success. Behavioral difficulties can prevent some children from adapting to the classroom. However, with appropriate educational help, a child with PDDNOS can succeed in school.

The most essential ingredient of a quality educational program is a knowledgeable teacher. Other elements of a quality educational program include:

- structured, consistent, predictable classes with schedules and assignments posted and clearly explained;
- information presented visually as well as verbally;
- opportunities to interact with nondisabled peers who model appropriate language, social, and behavioral skills;
- a focus on improving a child's communications skills using tools such as communication devices;
- reduced class size and an appropriate seating arrangement to help the child with PDDNOS avoid distraction;
- modified curriculum based on the particular child's strengths and weaknesses;
- using a combination of positive behavioral supports and other educational interventions; and
- frequent and adequate communication among teachers, parents, and the primary care clinician.



Medical treatment. The primary aim of medical treatment of children with PDDNOS is to ensure physical and psychological health. A good preventive health care program should include regular physical checkups to monitor growth, vision, hearing, and blood pressure; immunization according to schedule; regular visits to the dentist; and attention to diet and hygiene.

An effective medical treatment begins with a thorough medical assessment. The pretreatment assessment is essential for detecting existing medical conditions, such as a seizure disorder.

There is no one specific medication that helps all children with PDDNOS. Some medications have been found to be helpful, but for many children with autism or PDDNOS, medication levels need to be experimented with until the optimal combination and dosage are found. Since this differs with each child, there is no set medical treatment for children with PDDNOS but, rather, an individual medication regimen for each. Because of these complexities, in the eyes of many, medication therapy is viewed as a treatment to be used only when other types of treatment have been unsuccessful. It is important to note that medication can be effective and necessary for conditions that may coexist in children with PDDNOS, such as attention deficit disorder or obsessive compulsive disorder.

Parents' final decision on whether to use medication as part of their child's therapy is a personal one and should be respected and supported. Medication should *always* be used in conjunction with other therapies, and its effects should be monitored through



Children with PDDNOS are not the only ones who need extra help and support. Parenting a child with special needs is a demanding task.

feedback from the child, parents, and teachers.

Psychological treatment. Counseling may be helpful to families to help them adjust to raising a child with a disability. If the child is already attending a school program, both parents and teachers need to be told of the symptoms of PDDNOS and how those symptoms may affect the child's ability to function at home, in the neighborhood, in school, and in social situations. Psychologists can also provide ongoing assessments, school consultation, case management, and behavior training. Some children also benefit from counseling from an experienced practitioner who knows about PDDNOS. Family teamwork can ease the burden on the primary home caregiver, who needs a support system.

Other Therapies and Treatments

While exploring the treatment options available to help children with PDDNOS, parents and others may come across several therapies that can be used in conjunction with traditional ones. When considering one of these other therapies for a child, ask questions

and carefully assess the program. It's important to ask for a written description of the program, including its length, the frequency of sessions, cost, and the rationale, philosophy, or purpose underlying the program. It's also important to investigate the credentials of the program director and staff and whether evidence exists to prove the effectiveness of the program, as well as the possible negative side effects. Here are some alternative programs available:

Facilitated communication. This is a method of encouraging people with communication impairments to express themselves. By providing physical assistance, a person, called a facilitator, helps the individual to spell words using a keyboard of a typewriter or computer or other letter display. Facilitation may involve hand-over-hand support or a simple touch on the shoulder. The individual with the impairment initiates the movement while the facilitator offers physical support.

Successful anecdotes of Facilitated Communication therapy have been reported and published over the past few years. They have also provoked considerable

controversy, because generally they have not been supported by empirical research. It appears that Facilitated Communication has the potential for becoming a useful technique for some children with PDDNOS, particularly those who are precocious readers and good with other forms of communication such as computer and signs, but who also are severely impaired in verbal expression skills.

Auditory integration therapy (AIT). AIT uses a device that randomly selects low and high frequencies from a music source (a cassette or CD player) and then sends these sounds through headphones to the child.

There are anecdotes about the positive effects from AIT. Some of the results that have been reported include diminished sensitivity to sounds, more spontaneous speech, more complex language development, answering questions on topic, more interaction with peers, and more appropriate social behavior. However, significant results from a well-designed treatment study have not been available. It is still unclear how AIT works and whether people benefit from it.

Sensory integration therapy. Sensory integration is the nervous system's process of organizing sensory information for functional use. It refers to a normally occurring process in the brain that allows people to put sights, sounds, touch, taste, smells, and movements together to understand and interact with the world around them (Mailloux & Lacroix, 1992).

On the basis of assessment results, an occupational therapist who has been trained in sensory integration therapy guides an

individual through activities that challenge his or her ability to respond appropriately to sensory stimulation. This type of therapy is directed toward improving how an individual's senses process stimulation and work together to respond appropriately. As with other therapies, no conclusive research demonstrates clear progress made through sensory integration therapy, but it is used in many areas.

The Lovaas method. This method (which is a type of Applied Behavior Analysis [ABA]), developed by psychologist Ivar Lovaas at UCLA, is an intensive intervention program originally designed for pre-school-aged children with autism. It uses behavioral techniques—molding and rewarding desired behavior, and ignoring or discouraging undesirable actions—to achieve its goals. Generally, this method consists of 30 to 40 hours a week of basic language skills, behavior, and academic training. Therapy usually consists of 4 to 6 hours per day of one-on-one training, 5 to 7 days a week. Some research has shown remarkable progress in about 50% of the children receiving this therapy. The Lovaas Method is getting wide attention, but, as with other therapies, it needs more study.

Vitamin therapy. Some anecdotal evidence has shown that Vitamin B6 and magnesium help children with autism and PDDNOS. The rationale for this is that Vitamin B6 helps the formation of neurotransmitters, which are thought to malfunction in such children (Dalldorf, 1995).

Dietary intervention. Some individuals with PDDNOS have been found to have food sensitivities or food allergies. Some parents choose to have their children evaluated by allergists and, based on the testing results, may eliminate or decrease foods to which their child shows the most sensitivity. For example, some foods seem to increase hyperactivity and autistic-like behavior. Eliminating these from the child's diet has been found to help decrease negative behaviors.

Anti-yeast therapy. Often the progression of autism and PDDNOS involves unusual behaviors and communication problems arising around the toddler stage, when many children are treated with antibiotics for problems such as middle ear infections. Antibiotics can upset the intestinal flora and possibly cause "yeast overgrowth." However, the existence of higher yeast levels in children with autism and PDDNOS could very well be coincidence (Dalldorf, 1995). Some parents have found that giving their child an anti-yeast medication decreases some negative behaviors. Some preliminary study findings support this type of treatment; however, the results are not conclusive.

Summary. Since well-designed studies of these therapies have not been conducted, their effectiveness in treating PDDNOS is unclear.

Helping Children at Home

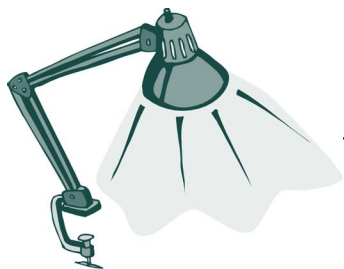
Parents can use many techniques and treatments to help their young child with PDDNOS at home.



These techniques should be discussed with other family members and the professionals who are working with the child, so that the individuals close to the child may employ the same methods. This will help the child generalize skills learned at home to other settings, such as at school and in the community. Parents can work at improving communication skills and social skills. See the "NICHCY Resources...on Autism and PDD" that accompanies this *Briefing Paper* for publications on techniques to use with children with PDDNOS.

FINDING A PARENT SUPPORT GROUP

Children with PDDNOS are not the only ones who need extra help and support. Parenting a child with special needs is a demanding task. Learning and accepting that a child has a disability is a very emotional process. Initially, parents may feel alone and



ORGANIZATIONS

Asperger Syndrome Coalition of the United States, Inc. (ASC-U.S.), 2020 Pennsylvania Ave., NW, Box 771, Washington, DC 20006. Telephone: 1-866-427-7747. Web: www.asperger.org

Autism Society of America, 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: 1-800-328-8476. Web: www.autism-society.org

International Rett Syndrome Association, 9121 Piscataway Road, Clinton, MD 20735. Telephone: 1-800-818-RETT; (301) 856-3334. Web: www.rettsyndrome.org

not know where to begin their search for information, assistance, and support. Parent groups offer parents and families a place to share information, give and receive emotional and practical support, and work as a team to address common goals.

Autism parent support groups are located throughout the country. Families whose child has PDDNOS can benefit from joining these support groups. See "Organizations" listed below.

CONCLUSION

Children with PDDNOS happen to have a unique disorder that will make certain parts of life more challenging. For a wealth of information, contact the organizations below and visit the Web sites we've listed. We also offer a separate "NICHCY Resources...on Autism and PDD," which lists books, articles, videos, and parent materials on this disability.

Learning more about the special needs of children with PDDNOS can be of enormous

emotional and practical help to those who are involved with, and who care about, these special children.

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And try these Web Sites!

Autism Coalition
www.autismcoalition.com/

Autism Patient Center
www.patientcenters.com/autism/

Autism-PDD Resources Network
www.autism-pdd.net/

Division TEACCH: www.teacch.com/

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

National Institute of Child Health and Human Development
www.nichd.nih.gov/publications/pubskey.cfm

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Director Suzanne Ripley
Assistant Director Donna Waghorn
Editor Mary Kate Gutiérrez
Author Luke Y. Tsai, M.D.
Professor of Psychiatry and Pediatrics
Director, Developmental Disorders Clinic
University of Michigan Medical Center

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**National Dissemination Center
for Children with Disabilities**

P.O. Box 1492
Washington, DC 20013
(800) 695-0285 (V/TTY)
(202) 884-8200 (V/TTY)
E-mail: nichcy@aed.org
Web: www.nichcy.org



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