



Yale Developmental Disabilities Clinic

[Home](#)
[Clinic Information](#)
[Research Studies](#)
[Fellowships](#)
[PDD Information](#)
[Resources](#)
[Publications](#)
[Conferences](#)
[Related Websites](#)
[Faculty & Staff](#)
[Contact Us](#)
[Supporting Research](#)

Information About Pervasive Developmental Disorders

- [Autism](#)
- [Asperger's Syndrome](#)
- [Childhood Disintegrative Disorder](#)
- [Multiplex Developmental Disorder](#)
- [Pervasive Developmental Disorder - Not Otherwise Specified](#)
- [Rett's Disorder](#)

*Cited in Mark H. V. Lemahieu,
No. 05-16236, archived on January 25, 2008*

Frequently Asked Questions About Pervasive Developmental Disorders

The answers provided below are necessarily general in nature. Each child is different and needs professional consultation to clarify the pertinent issues. We hope that parents and teachers would consult with the professionals involved in the child's care. Please send suggestions for additional questions to [Kathy Koenig](#).

- [How is the diagnosis of autism made? Are there any special tests my doctor can do to determine whether my child is autistic?](#)
- [Are there other conditions that can mimic autism?](#)
- [At what age can autism be diagnosed?](#)
- [If my young child does not talk by the time s/he is 2 or 3, does that mean s/he has autism?](#)
- [How can my child be assessed if he/she cannot talk?](#)
- [Should my nonspeaking child with autism use some other form of communication, like signs or pictures?](#)
- [What is the difference between autism and PDD or PDD-NOS?](#)
- [What is the best intervention for my child with autism/PDD? Can autism be cured?](#)
- [What about medication for my child with autism?](#)
- [If I have one child with autism, what are my chances of having another child with autism?](#)
- [What is the prognosis for my child with autism/PDD?](#)
- [What is the best intervention for my child with autism/PDD?](#)
- [What services are children with autism entitled to?](#)
- [I've heard about a treatment for autism called secretin. What is the Yale Child Study Center's policy on secretin?](#)

How is the diagnosis of autism made? Are there special tests my doctor can do to determine whether my child is autistic?

The diagnosis is made by a professional experienced in the evaluation of children with developmental disorders. A qualified professional may be a pediatrician, pediatric neurologist, child psychiatrist, or psychologist. The diagnosis is based on a history of the child's development provided by those who know the child well, as well as clinical interview/observation of the child. Some professionals may use behavior checklists or other standardized screening instruments to help with diagnosis. There are no blood tests or brain tests (EEG, CAT scan, MRI, PET scan) that conclusively identify the presence of autism. However, your doctor may recommend blood tests or brain tests/scans to rule out the presence of other conditions.

[Top](#)

Are there other conditions that can mimic autism?

There are several other conditions that can look similar to autism. Some of these fall within the PDD spectrum.

1. **Rett's Disorder** is a pervasive developmental disorder that follows a very specific progression. Children with this disorder seem to develop normally for the first six to eight months of life. Parents may notice excess levels of hand patting, waving, and involuntary movements of the fingers, wrists and arms. However, these signs are subtle and may go unnoticed. There is a slowing of normal development and a failure to reach developmental milestones on time. Particular problems occur with the acquisition of skills requiring balance such as walking. Head deceleration occurs (the head fails to grow larger at the proper rate.) Children undergo a rapid deterioration in behavior including loss of acquired speech, and purposeful use of hands. A lack of interest in social relationships occurs, and stereotyped behaviors may develop. The most prominent symptom in Rett's syndrome may be "hand washing" movements which develop after the ability to move hands purposefully is lost. These children are generally mentally retarded. Episodes of screaming or tantrums may occur. Sleep abnormalities and seizure disorder are present in over half of the children with this disorder. The lack of interest in social relationships, loss of expressive language and the development of stereotypes can cause this disorder to be confused with autism.

While the DSM-IV does not list male sex in the exclusionary criteria, the existing literature on Rett's syndrome documents the condition primarily in girls. The DSM-IV field trial sample included only girls and a recent, very well executed epidemiological investigation documented a prevalence of 3.8 per 10,000 girls; boys were not included. Since the discovery of the MECP2 gene, responsible for Rett's, variants of the syndrome have been reported in males who have mutations of MECP2, with some overlap in the symptomatology observed in girls (Amir, Van de Veyver, Wan, Tran, Franke, & Zoghbi, 1999; Schwartzman, Zatz, Vasquez, Gomes, Koiffman, Fridman & Otto, 1999; Schanen, Kurczynski, Brunelle, Woodcock, Dure, & Percy 1998).

2. **Heller's syndrome**, also know as **Childhood Disintegrative Disorder (CDD)** is another pervasive developmental disorder. CDD occurs more frequently in boys, although both boys and girls can be affected. In CDD, children develop normally in language, social and other skills until between the ages of two and three. A marked period of regression occurs which may be insidious (over a period of months) or more rapid (over a period of weeks.) Previously developed skills are lost, such as bowel and bladder training, language skills and social skills. The child may become essentially mute, lose the ability to play purposefully and develop autistic-like stereotypies. Prior to this period of marked deterioration, the child may exhibit periods of agitation or dysphoria. A child with CDD is often indistinguishable from a child with autism. Diagnosis of CDD as distinct from autism is made based on history of the child's early development.
3. **Children who are deaf** may be mistakenly identified as autistic in the very early stage of diagnosis, when others have noticed their lack of responsiveness to the environment. However, deaf children who are developing typically will exhibit some non-verbal social behaviors that demonstrate a level of emotional and social contact with the world. A pediatrician or neurologist can recommend audiological evaluation if there is a question about whether a child can hear. If the child has difficulty cooperating with this kind of examination, another kind of non-invasive brain test can be done to clarify whether the child's hearing is intact.
4. **Children with Developmental Language disorder** or **Semantic-Pragmatic disorder** demonstrate difficulty in communication skills and pragmatics. Semantic-Pragmatic language disorder is a condition in which complex language is intact, but either the content of the communication or the functional purpose of the communication is not clear. Children diagnosed with Pervasive Developmental Disorder may also be diagnosed with a developmental language disorder.
5. **Landau-Kleffner Syndrome (LKS)**, which is also called **Acquired Aphasia with Epilepsy**, is a syndrome in which children loose the ability to speak and develop seizures. LKS is associated with a characteristic pattern of waves on EEG (electroencephalogram). These children usually continue to be interested in communicating using non-verbal modalities. Other non-verbal abilities are spared. Regression is confined to the area of language.

[Top](#)

At what age can autism be diagnosed?

Although some children show autistic patterns of social interaction almost from birth, it can be difficult to give a definitive diagnosis of autism before age three. This is because rates of development in infants and young children are widely variable. Also, autism is frequently accompanied by mental retardation (about 70% of the time.) Some behaviors associated with autism are also frequently found in children who are mentally retarded. This may make it difficult to discriminate between the two conditions, or determine that both conditions are present, in very young children. By the time a child is three or four, cognitive development can be more accurately assessed. At the same time, social development can be more clearly assessed for delay or deviance.

[Top](#)

If my young child does not talk by the time s/he is 2 or 3, does that mean s/he has autism?

Many young children are late to begin speaking. In fact, failure to begin talking is the most common presenting complaint for preschool children suspected of developmental disabilities. Although lack of speech at the expected time is typical of children with autism, there are many other developmental disabilities in which children are also late to start talking. In fact, 10-15% of otherwise normal children do not reach language milestones at the expected time. Not talking at the normal time, then, does not necessarily mean that a child has autism.

If there are other worrisome signs, however, such as failure to respond to the child's own name, lack of pointing and other gestures to indicate things to parents, difficulty making eye contact with others at appropriate times, or obsessive interest in unusual objects or activities, parents may suspect autism, even in a child under three years old.

When autism is suspected in a young child, parents should contact a local agency that serves children with disabilities from birth to three. The first step in dealing with the problem is to get a thorough evaluation of the child's communicative, cognitive, and sensory motor skills. Birth to three professionals are trained to make these evaluations and can help families determine whether autism is the appropriate diagnosis and can design a program to help address the child's disability.

[Top](#)

How can my child be assessed if he/she cannot talk?

Many children with autism do not talk, but assessment can be carried out by evaluating nonverbal behavior, through observational methods, and by using parent report and interview information. Several assessment instruments have been developed to get information from parents about their child's skills. One example is the Vineland Adaptive Behavior Scales, which collects information on children's communication, social, daily living and motor skills, and compares it to that gathered from children with typical development, as well as with various kinds of disabilities. Because there are groups with which to compare a child's performance, these kinds of instruments allow a standardized score to be assigned. These standardized scores are helpful in determining eligibility to special services and in planning intervention programs.

A licensed psychologist can administer cognitive tests that are specially designed to look at a child's problem solving skills without language. These tests ask children to match pictures, sort by category, remember series of pictures, duplicate designs with blocks, and so on. A psychologist is trained to interpret these findings to help understand the child's cognitive ability, even when speech is not present.

In addition, much communication can go on in the absence of speech. Babies under a year old communicate frequently before they start talking, using gaze, gestures, and vocalizations to get other's attention and get messages across. A certified speech-language pathologist (SLP) can evaluate a child's ability to use these kinds of nonverbal communication. SLPs engage nonverbal children in play activities and observe whether the children initiate communication by looking, pointing, gesturing, or making sounds. In assessing children with autism, SLPs often "tempt" children to communicate by, for example, blowing bubbles and stopping, to see if they can get the child to

indicate with gestures and sounds that s/he wants more. The communication temptations are used by SLPs evaluating nonverbal children to find out what kinds of communicative strategies the child has available, and what activities are most likely to elicit communication in an intervention program. Some SLPs do this assessment informally. Others use formal measures, such as the Communication and Symbolic Behavior Scales to accomplish this assessment.

[Top](#)

Should my nonspeaking child with autism use some other form of communication, like signs or pictures?

Since 40-50% of children with autism do not talk, an alternative form of communication is often considered in order to give the child some means to communicate. Research has demonstrated that the use of an alternative mode of communication does NOT inhibit the development of speech. In fact, some research suggests that once the child "gets the idea" of what communication is about from the alternative modality, s/he may be more likely to begin using speech. Many clinicians believe that using an alternative modality reduces frustration and serves as a good starting point for a communication program for children with autism. Because visual symbols, like signs, pictures, or written words, are more stable (last longer) than speech, they may be easier for children with autism to learn.

The bottom line is: alternative modes of communication may help nonspeaking children with autism get started with communication. If speech is going to emerge, an alternative modality will not inhibit it. If speech does begin after an alternative modality has been introduced, communication therapy can switch to a speech mode. If it does not, the alternative modality will continue to provide some form of communication that will help the child with autism make wants and needs known to others.

Some alternative modalities that have been used with nonspeaking children with autism include:

- Signs from American Sign Language of the Deaf
- Picture Exchange Communication System (PECS)
- Communication boards, using for example, Mayer-Johnson picture symbols, or Blissymbols to which children point to indicate communication
- Voice Output Communication Devices (VOCAs); computerized switches or other devices programmed to emit recorded speech when activated
- Written words

[Top](#)

What is the difference between autism and PDD or PDD-NOS?

Pervasive Developmental Disorder (PDD) is a category designated by the American Psychiatric Association to indicate children with delay or deviance in their social/language/motor and/or cognitive development. A child may have delays in social development and delays in one or more of the other categories. The profiles of children with a PDD can vary tremendously. PDD is not one disorder but a category that encompasses a wide range of delays of different magnitude in different domains. Autism is the most severe of the pervasive developmental disorders. Autism indicates a primary disturbance in the individual's ability to relate to others. Language delay and cognitive delays are also common.

PDD-NOS represents Pervasive Developmental Disorder-Not Otherwise Specified. This is a diagnosis given to a child who exhibits impairment in the development of reciprocal social interaction, verbal and non-verbal communication, or when stereotyped behavior or activities are present. However, the child does not meet the criteria for any specific pervasive developmental disorder.

[Top](#)

What is the best intervention for my child with autism/PDD? Can autism be cured?

There is no cure for autism at present. There are many kinds of intervention suggested by people and professionals with different degrees of experience with autistic people. Be wary of any intervention

that promises a cure or that suggests that the particular method advocated is the only effective approach. There are data to indicate that the best intervention for autism/PDD is early intensive intervention that utilizes behavioral methods and speech and language therapy to remediate specific deficits.

[Top](#)

What about medication for my child with autism?

There is no medication that can cure autism, and no one medication that is recommended for individuals with autism. Medications can be recommended to help with very specific target symptoms that are associated with autism. Some of these symptoms might be extreme difficulty attending to the pertinent aspects of the environment or aggression towards self or others.

[Top](#)

If I have one child with autism, what are my chances of having another child with autism?

Current data suggest that the likelihood of having a child with autism if the biological parents already have one child with autism is at least 1/20. This rate may be an underestimate, given that many families with one autistic child will stop having children due to stress or the fear of having another child with the disorder.

[Top](#)

What is the prognosis for my child with autism/PDD?

Clearly it is impossible to make a generalization about how any individual child will grow and progress. All children continue to develop, despite delays or the presence of deviant behaviors. Information that we have currently about the progress of adults with autism is based on the treatments these individuals received twenty or thirty years ago. Our knowledge base about what educational strategies are most effective with these children has increased tremendously over the last ten to twenty years. A child diagnosed with autism will receive much different intervention beginning at an earlier age than was possible many years ago. This means each child's chances for remediating behavior are greater today than years ago.

[Top](#)

What is the best intervention for my child with autism/PDD?

Although it has no cure, autism does respond to behavioral and educational treatment. Research suggests that early intervention is especially effective in achieving growth in cognitive and communication skills. There are a variety of intervention programs that have been designed specifically to work with children with autism. Parents may hear that one or another of these (such as "Floor Time," "FastForWord," "ABA," "Auditory Integration Training," or "Social Stories") is THE intervention that a child must have to make progress. Unfortunately, there is little evidence to support the claim that any one intervention program will guarantee progress for all children with autism. Like children everywhere, children with autism differ from each other. Like all children, they differ in terms of their IQs, their interests, their strengths, and their educational needs. An intervention program must be individually designed, with the help of experienced professionals, so that it is tailored to the strengths, interests and needs of each child with autism. In general, operant behavioral programs, such as ABA, are often helpful in initiating behaviors the child does not show spontaneously. But operant programs will need to be supplemented by more naturalistic approaches that encourage the child to use newly learned behaviors in real life situations. Successful intervention programs usually involve a mix of highly structured and more naturalistic activities and have the following properties:

- Individualized
- Specialized curriculum for children with autism
- Strong communication component
- Family involvement

- Systematic, structured teaching
- Intensity of engagement (at least 20 hours/week)
- Developmentally appropriate practice
- Some contact with typical peers

Parents should be wary of any intervention that promises a cure or suggests that its method is the only effective approach. Parents should also suspect any program that requires parents to personally pay high fees. Children with autism are entitled to public educational services and legitimate services should be provided by public agencies. Parents should not be obligated to pay for educational services themselves.

[Top](#)

What services are children with autism entitled to?

The Individuals with Disabilities Education Act (IDEA), reauthorized in 1997, provides that every child with a disability under the age of 21 is entitled to a free appropriate public education (FAPE). Depending on the child's age, the educational program is outlined in an Individualized Family Service Plan (IFSP; for children under 3) or an Individualized Educational Program (IEP; for students 3-21). These describe the special educational and related services specifically designed to meet the needs of the child with a disability. These programs are developed, following an assessment of the child's current functioning, at a series of meetings that include the child's family, the special education and/or medical professionals involved in the child's care, and the regular education teachers who may be including the child in a mainstream educational program. IDEA mandates that all children should receive their education in the least restrictive environment (LRE) that is appropriate for the child. Although the law encourages placement in neighborhood schools and interaction with typical peers, it is the child's needs that are the primary determiner of placement. Services for children under 3 are usually home-based, with professionals visiting periodically to evaluate progress, provide direct teaching, and recommend activities to parents. Children from 3-5 may be served in special programs, or in typical preschools with supportive services. School aged children are usually served within the local school district. If the team agrees that an out-of-district placement will best serve the child's needs, however, that placement will be part of the IEP, and will be financed by the local school district.

Parents have a broad range of rights under IDEA. These include:

- The right to be informed about any evaluation activities that will be conducted with their child
- The right to attend the IEP meeting and have input into the formulation of the IEP
- The right to contest an IEP recommended by their local district if they do not feel it meets their child's needs
- The right to a hearing and to mediation to resolve such conflicts.
- As a last resort, they have the right to take the school district to court to resolve their differences

Parents should understand, though, that an appropriate educational program does not necessarily mean the most intensive or most innovative program that money can buy. It is possible that a school district may refuse, for example, to pay for 40 hours/week of ABA training, even though the parents feel this is what they want for their child. If the school can, using available evidence from educational research, convince a hearing officer or a judge that a less intensive program is nonetheless an appropriate form of education, the school's view may prevail.

Generally, it is advantageous to the child and the family to maintain cordial relations with their school district and to avoid antagonisms that may increase the stress in their lives. Autism will not be cured by ANY school program; but most children with autism will benefit from the mixture of highly structured and more naturalistic activities that constitute typical programs in most schools that serve these students. Most benefit from some interaction with peers, but will also need some specialized, focused intervention that addresses their individual needs. There is no magic procedure or amount of intervention that is "right" for children with autism. And all children, even those with autism, need some "down time" just to do what they enjoy doing, even if it is snapping rubber bands, or lining up alphabet blocks. We encourage parents of children with autism to keep these facts in mind as they develop programs for their children with local educational agencies.

To learn more about IDEA and your child's right to education, or to link up with other parents of

children with disabilities, you may want to visit the following web sites:

- <http://www.bbbautism.com>
- <http://www.ed.gov/about/offices/list/osers/osep/index.html>
- http://www.education-world.com/special_ed/iep
- <http://www.ideallives.com>
- <http://www.ldonline.org>
- <http://www.pacer.org>
- <http://www.parentsunitedtogether.com>

[Top](#)

I've heard about a treatment for autism called secretin. What is the Yale Child Study Center's policy on secretin?

We at the Yale Child Study Center Autism Research Group watched the "Dateline NBC" program about secretin on 10/7/98 with interest. Immediately after the program was aired, we were receiving requests for information about the efficacy of this drug for treating autism.

Now, literature has begun to appear detailing the results of controlled clinical trials of secretin. Currently, researchers at the University of Chicago, University of Utah and University of California-Irvine are conducting a multi-site trial to determine its efficacy. There are also related trials being conducted at the University of Colorado and University of Washington. The first results from the multi-site study have been published by Thomas Owley, MD, Elisa Steele, MS, Christina Corsello, MA, Susan Risi, PhD, Kathryn McKaig, MS, Catherine Lord, PhD, Bennett L. Leventhal, MD, and Edwin H. Cook Jr, MD, and you can view them on [Medscape](#). Using a double-blind, placebo-controlled design, they found no significant difference in improvement between the children who received secretin and those who received just saline. Because of the study's small sample size (20 subjects) and relatively short duration (4 weeks of secretin and 4 weeks of the saline placebo), further research is necessary to determine the effects of secretin. We do not advocate the use of this medication at this time, but we will be waiting for the results of the other studies that are in progress. As new information becomes available, we will try to update this page.

Our position on non-proven treatments in autism is that such treatments can be considered:

1. If it is clear that the treatment is not harmful or dangerous,
2. If the treatment is not prohibitively expensive, and
3. If the treatment does not interfere with the child's participation in regular daily educational, language, and behavioral interventions (all of which have been proven to be of benefit).

[Top](#)

FAQ References

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[Top](#)

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