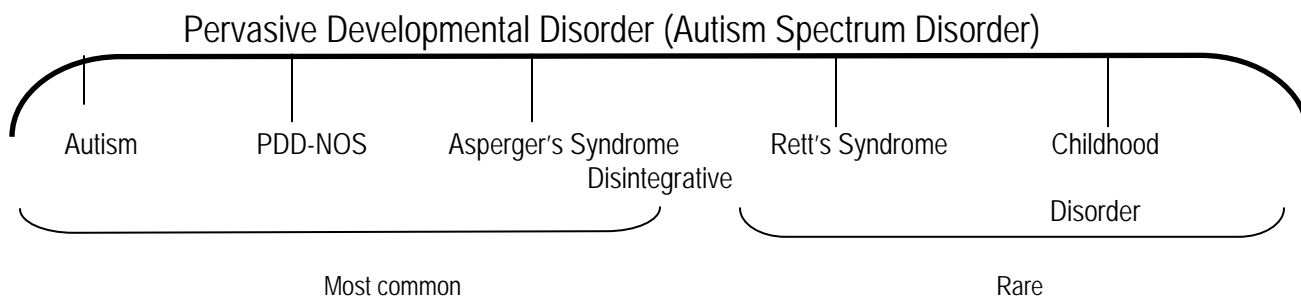


# Autism and Pervasive Developmental Disorders

Pervasive Developmental disorders are also known as “autism spectrum disorders”. This family of disorders is very complex, because they affect an individual in many ways. While it is important to understand as much as possible about these disorders if you have a loved one with an autism spectrum disorder, we emphasize that it can be overwhelming to try to digest a great deal of information right at the outset. You may feel pressure to “hurry up and learn” everything you need to know before losing valuable time. Emotions run high when a new diagnosis is given, and family members also need time to adjust, to grieve, and to begin the process of understanding how to help their loved one. Please remember that it is a process, and that no one learns all they need to know as quickly as they would wish. Gather the information you need methodically and consistently, but at your own pace to avoid adding even more stress to your lives. Too much stress in the household can affect the individual on the autism spectrum and add to the difficulties that already exist. It can also strain other relationships in the family as members try to deal with the changes to all of their lives. This is a complex disorder, and no one has all the right answers even after many years’ experience. We all make mistakes, and that’s okay. Please remember that family members of typically developing children make mistakes too. Keep moving forward, and your child will benefit from your love and dedication.

## What is a Pervasive developmental disorder?



“Pervasive developmental disorder” (PDD) is the umbrella-like term used to describe a group of developmental disorders that fall under it. That group includes autism, PDD-NOS (pervasive developmental disorder not otherwise specified), Asperger’s syndrome, Rett’s Syndrome and childhood disintegrative disorder. Rett’s syndrome and childhood disintegrative disorder are very rare conditions, and so will not be described here, the focus will be on autism, PDD-NOS, and Asperger’s syndrome. The specific requirements to diagnose an individual with any pervasive developmental disorder are listed in a book titled

the *Diagnostic and Statistical Manual IV* (DSM-IV), and the descriptions of autism, PDD-NOS and Asperger's syndrome appear in the *State of CT Autism Spectrum Resource Guide*. This group of disorders is also commonly known as the "autism spectrum", or ASD. The term "spectrum" is used because there is so much deviation in the types and level of severity of each symptom that it brings to mind a 'spectrum' of symptoms and level of function. Additionally, medical professionals have not yet been able to draw clear lines between the different diagnoses. This makes it particularly difficult to give parents an accurate picture of their child, especially if the child is very young. This is very frustrating to family members, who are so concerned about what the diagnosis will mean in all of their lives. Unfortunately, there is no single diagnostic 'test' that can be given to determine if someone has an ASD. The only way to determine if an individual has an ASD is an evaluation by an experienced professional of irregularities in development that are common to the various diagnoses under the autism spectrum umbrella. It is only through expert observation of behaviors, learning patterns, family histories, and other information from a variety of sources that a diagnosis can be made.

## **Similarities in autism spectrum disorders**

Research has begun to show us that autism spectrum disorders are, at least in part, genetic though this is not to say that there is one 'autism gene'. It is believed to be a complex issue of the contribution of a number of genes and how they interact together. It is known that more boys than girls are affected (4:1), though the reason this is true is unclear. There is also the possibility that environmental triggers (i.e. pollution, chemicals, etc. not natural to the body) alter the usual patterns in genes, and this adds to the complexity of the research scenario.

The specific developmental areas that can be affected by any of the diagnoses within the PDD family can include: speech and/or language, social skills, motor skills, sensory differences, repetitive behaviors, impaired relationship building, and inappropriate emotional reactions. It is important to know that *not all* individuals will be affected in *all* of these areas. The degree of affectedness differs for each individual, varying from mildly affected to severely affected within each area, and no two individuals will have the same profile. In other words, a person who is very severely affected socially, can have extremely good cognitive (learning) skills, and the reverse could be true for another individual with the very same diagnosis. It is therefore impossible to compare two persons with autism spectrum disorders or to predict their patterns of progress.

That being said, there are many areas in which individuals on the autism spectrum do appear to have commonalities. It is, for instance, quite common for individuals with any of the above disorders to have 'splinter skills', in other words, they are often exceptionally good at some skills, and yet may be exceptionally poor at others. For instance, some children on the autism spectrum will learn to read quite early (even at age 2), which is known as hyperlexia. However, their

comprehension of what they read can be significantly below their actual reading level. Unfortunately, this unusual profile of splintered skill levels can lead to misunderstanding by others, who may believe that the individual is more capable in all areas than he/she really is.

Because language deficits are an integral part of an autism-related disability, it is to be expected that some level of difficulty would exist for anyone with such a diagnosis. There are several types of language skills, and deficits in some types will be more apparent to the general populace than deficits in other types of language. Structural language (the use of grammar and sentence formation), for instance, is what we typically think of when we talk about language as a skill, and this may or may not be intact. However there are many other types, including social or pragmatic language (the ability to use language in an everyday, social context by using certain skills like inference, recognizing sarcasm, recognizing double meanings, etc.), and this may or may not be as obvious to the casual observer. However, for most individuals with an autism spectrum disorder, this is an area with which they struggle tremendously. Social language includes the non-verbal forms of communication, body language, facial expression, gestures, etc. and individuals with autism spectrum disorders have difficulty picking up the meaning of these cues. Unfortunately, it is known that about 80% of all human communication is nonverbal in nature, so this puts people who have an autism spectrum disorder at a great disadvantage. The lack of a command of social language can seriously affect the ability to understand the world around us, and how effectively we relate to others.

While sensory differences are not currently a characteristic that identifies an individual as having a pervasive developmental disorder, there are a great number of individuals who report this as an area of profound difficulty for them. There may be mild to moderate delays in gross motor (large muscles like those used for running, etc.) and/or fine motor (small muscles, used in writing, eating, etc.) development, or there may be repetitive motor movements such as rocking or arm flapping. Clumsiness, poor motor planning (working through a series of movements, like climbing stairs) and unusual body language (unusual posturing of hands, uneven gait, etc.) are somewhat more common in those with Asperger's syndrome. But while many individuals with autism spectrum disorders may have motor deficiencies, some might, conversely, be extraordinarily agile. They may have activity levels that would be considered over-active or under-active as compared to individuals with typical development. Hyper (over) and/or hypo (under) sensitivity to input from the senses (hearing, touch, smell, etc.) are also common, and the same individual can have both hyper-and hypo- sensitivity that can change by circumstance. These abnormalities can involve any or all of the five senses, but also commonly involve two less-known senses, the vestibular (sense of balance) and proprioceptive (input from joints and muscles that direct action) systems.

The ability to relate to others can vary greatly from person to person. Some infants may fail to cuddle and can be rigid in their posture; others may be excessively affectionate. Lack of eye contact is quite common, but one cannot rule out the diagnosis simply because a child can 'look at people'. Individuals with autism often prefer inanimate objects to people and avoid social interaction, while those with Asperger's syndrome generally want to interact – but they may not have the skills to do so successfully. Lack of understanding about feelings and motivations, understanding of social 'norms' and appropriate social behavior, as well as an inability to read facial expressions and body language are also shared across the spectrum. Inappropriate play in children (such as lining up objects rather than playing with them as they were intended) is likely to occur, and strict adherence to routines can be mild to extreme.

Anxiety affects many individuals with pervasive developmental disorders, and can be expressed in different ways – for instance, a child who tantrums and cries and another child who hides in a corner and appears not to hear his name called, may both be responding to their inner level of anxiety, it just appears different from person to person or situation to situation.

Differences in development in any or all of the above areas can result in odd or disruptive behaviors, and it is the behavioral patterns that often best identify a child as having an autism spectrum disorder. Behaviors can result from a lack of understanding language, social deficits (such as misinterpretation of social cues), anxiety, sensory difficulties (i.e. inability to handle loud noises), or a need for strict adherence to structure. It is important to learn how to analyze these behaviors to determine their purpose (i.e. to get out of a too-difficult task, or to add structure to a situation where there is none), so that more appropriate behaviors can be taught.

People who have an autism spectrum disorder have many strengths that should not be overlooked, since they will be important in making life decisions like developing educational programs or in choosing a career. Some common strengths:

- An exceptionally good visual memory
- Ability to learn rote material easily
- Exceptionally good long-term memory
- Visual thinking
- Taking in chunks of information quickly
- Ability to perform highly precise tasks
- Perfectionism
- Reliability in adherence to rules or schedules
- Honesty and integrity

# Differences in autism, Asperger's syndrome, and PDD-NOS

Differences among the disorders are as unique as the similarities, and can vary across the spectrum. The drawn lines between them are simply not that clear at this point in time, so generalizations can only be made loosely.

## Autism

Children with 'classic' or 'Kanner's' autism are the most severely affected, and about 80% also have a condition known as mental retardation. Only about 20% of children on the autism spectrum have classic autism, however, and the rest fall in the milder range of symptoms. Symptoms are usually apparent before the age of 3. Improvement of symptoms can happen through early intervention, intensive education and therapy, but children progress in different patterns and to varying degrees, and it is therefore very difficult to predict how much progress a child with autism will make. We do know, however, that they can make far more progress than had long been believed, and this is certainly welcome news.

Communication skills in individuals with classic autism will likely be affected in many areas. Spoken language may be delayed in the child's development and some individuals in fact remain non-verbal (which does not necessarily mean he/she is unable to communicate). Individuals may develop unusual rhythms of speech (such as a monotone), have a limited understanding of conceptual ideas, use words without attached meaning, use echolalia (repeating phrases) and/or irrelevant verbalizations, become "stuck" on one topic, lack "useful" language for the purpose of communicating ideas, and lack an understanding of pragmatic language.

## Asperger's Syndrome

Asperger's Syndrome (AS) is the most recent addition to the diagnostic category of PDD's, and individuals with AS were misunderstood for many, many years because of the general lack of awareness. Individuals with Asperger's syndrome and PDD-NOS (about 80% of the spectrum) are most often in the average to above average intelligence range. Symptoms may not become evident until the child is involved in a play group or preschool environment that involves regular social interaction. Unfortunately, this can prevent them from accessing early intervention options such as (in Connecticut) state funded Birth to Three services.

People with Asperger's syndrome are often quite adept at spoken language (some have even used the term 'little professor syndrome', though this does not necessarily describe everyone with AS). Even though these individuals can use language in sometimes sophisticated ways, they often use it in a different manner than what would be considered 'typical', and their comprehension of language may not be as sophisticated as their structured use of words. They can have a 'special interest' that consumes all of their time, and

while they are very conversant on the subject of their interest, may have difficulty talking about, or remaining on, other topics. Many people can be mistaken in their belief that Asperger's is a 'mild' disorder, because it is not as visible a disability as classic autism or even other developmental disabilities such as mental retardation. It must be understood however, because the disability affects many areas that involve the understanding of communication and the social world around them, that this also is a disability requiring intensive intervention. The inherent anxiety can be accompanied by depression, especially in older individuals that are higher-functioning and who seek out relationships, in part because they are able to understand how their disability interferes with their success at friendships and perhaps even their ability to live and work independently.

### **PDD-NOS**

PDD-NOS (PDD Not Otherwise Specified) is a controversial category that describes children who do not fit neatly into the 'box' of autism or Asperger's, even though they seem to exhibit many of the traits found in this group of disorders. These individuals were once referred to as having 'atypical autism'. People with PDD-NOS may have symptoms that are 'autistic-like' yet may not meet the specific criteria required to obtain the autism diagnosis (such as onset of symptoms by the age of 3). What is clear is that their grasp of social skills, language competence, and unusual behaviors fit the category of a pervasive developmental disorder, and that they are individuals who require intervention in order to make the progress to function independently in the social world.

Science has begun to invest the time and interest in researching the various components of these disorders, including genetics, environmental contributors, brain structure differences, brain functioning, medication possibilities, etc. Hopefully, it will not be long before we have a better understanding about these complex disorders, as well as how to maximize intervention success. The individuals who have autism spectrum disorders deserve our support, but also our respect, for they add such color and joy to the lives of those who take the time to get to know them.