

# WHAT IS SO SPECIAL ABOUT THEM? SHORT REVIEW OF ASPERGER'S SYNDROME

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## **Abstract**

Often considered a “genius disability”, Asperger’s syndrome is a condition that, as all those found under the umbrella of what is generically referred to as “pervasive developmental disorders”, still raises many questions to specialists.

**Key words:** Asperger’s syndrome, autism, pervasive developmental disorders, therapy.

## **Characteristics of persons with Asperger’s Syndrome**

The terms “Asperger’s syndrome” were introduced by Lorna Wing (Happe, 1995) and were utilized to illustrate what Hans Asperger was first describing as an “autistic psychopathy”(Klin, Volkmar, and Sparrow, 2000). Asperger, a Viennese pediatrician interested in uncovering ways to treat children with emotional and learning problems, published his work in 1944 (Siegel, 1996). In the same period, in America, without being aware of Asperger’s studies, Leo Kanner was talking, about the “early infantile autism” (Kanner, 1973). Although Kanner’s work was well known in Europe, it was only in 1891, when Wing, a British child psychiatrist, brought Asperger’s work into the English-language literature (Siegel, 1996).

Asperger’s work was motivated by a group of four boys, ages 6 to 11 who, in fact, it is believed that were actually part of a much larger sample. These children, despite possessing what appeared to be cognitive and language abilities, were described as having major social interactions difficulties (Klin et al., 2000). Based on Asperger’s work, Wing listed six

major aspects that one should take into consideration when referring to Asperger's syndrome. These features are: speech, non-verbal communication, social interactions, resistance to change, motor coordination, and skills and interests (Happe, 1995). According to Kluth (2003), who is citing the American Psychology Association, the definition of AS includes:

- A. Qualitative impairment in social interaction (...)
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (...)
- C. The disturbance causes significant impairment in social, occupational, or other important areas or functioning.
- D. There is no clinically significant general delay in language (e.g., single words 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 Pervasive Developmental Disorder or Schizophrenia

For a better understanding of what Asperger's syndrome implies, a comparison between autism and Asperger's may be useful. The onset of the syndrome is, according to Asperger, the main point of differentiating autism from Asperger's: children with autism are almost always seen of having problems before they are 3 years-old, while early development of the cases studied by him was apparently normal (Klin et al., 2000)

Lorna Wing (Siegel, 1996) distinguishes between "autistic disorder (autism)" and "non-autistic pervasive developmental disorders" (PDDs), which include: Asperger's Syndrome, Pervasive Developmental Disorder, Not Otherwise Specified (NOS), Fragile X Syndrome, Rett's Syndrome, and Childhood Disintegrative Disorder. Considered to be falling within the autism spectrum (Kluth, 2003), Asperger's syndrome can be characterized, as Happe (1995) suggests, as "autism without the language and cognitive impairments." The distinction between children with autism and those with Asperger's is, according to the author

mentioned above, that children with autism “act as if others did not exist, while children with Asperger’s syndrome wade other people, of whom they are aware” (Happe, 1995). Some researchers challenge the considering of Asperger’s as a “mild” form of autism insisting on the fact that the categorization of “mild” is too broad and may exclude very important characteristics of people who have this disability ( Kluth, 2003). Kalen Molton, a person diagnosed with Asperger’s syndrome, describes the way others perceive her disability affects her:

No matter how high functioning we are, a great deal of effort is going into coping. Some people have called Asperger syndrome “nerd disorder” as a way of minimizing it. There is a fine line between “normal but odd” and “very high functioning autistic.” My personal opinion is that the line is where the traits become disabling. I have a good “guest mode” where I can appear quite normal; however, being forced to sustain guest mode for an extended period can, and has, led to a serious breakdown. My ability to behave near normally at times has led others to believe that I can do it all the time and if I don’t then I am lazy, unmotivated, manipulative, and deliberately annoying. No one expects a tightrope walker to do it all the time. (Kluth, 2003)

What one might take into consideration when diagnosing Asperger’s (Happe, 1995) is Wing’s suggestion that this disability is, in fact, constituted by a triad of handicaps in imagination, socialization, and communication.

However, no matter how many attempts of understanding the etiology and the challenges of Asperger’s syndrome we do, we will never be able to comprehend it better than Royal, who was diagnosed with Asperger’s, and who writes:

“One foot in and one foot out  
is what Asperger’s is all about  
Sometimes I think why me;  
other times I think it’s the best way to be  
A little different from the rest

makes you think you're the second best  
Nobody quite understanding  
a hard life which is very demanding.  
I look like no other child  
but little things just make me wild". ( Kluth, 2003, p.3)

### **Etiology of Asperger's Syndrome**

Given the similarities between autism and Asperger's, in discussing the etiology of Asperger's syndrome one could take into consideration the main conditions that seem to be responsible for autism. One of the most discredited explanations of autism is the psychogenic one, or the "refrigerator mother" theory, as named by Bettelheim. This theory states that "children become autistic as a maladaptive response to a threatening and unloving environment" (Happe, 1995, p.27). Cohen and Donnellan (1987) believe that the etiology of autism is a heterogeneous one that holds both genetic and environmental explanations.

Because its symptoms were often visible in early childhood, in his initial description, Kanner suggested that autism was the effect of an "inborn defect." "Early infantile autism is a total psychobiological disorder. What is needed is a comprehensive study of the dysfunction at each level of integration: biological, psychological, and social" (Kanner, 1973, p.100).

When regarding Asperger's as related to autism, one may also pay attention to take Cohen and Donnellan's belief (1987) that there are four basic types of evidence that can link genetic aspects to autism. According to them, the first proof is the higher incidence of autism in those families where parents have autism, even when the affected children have been raised in adoptive homes. The second evidence is the higher incidence among monozygotic twins than among dizygotic ones. The third type of attestation can be the hereditary locus on a precise chromosome, while the fourth one is the important "aggregation of the illness within families."

One aspect that appears to support the idea that "the genetic component in autism is weighty" is the fact that autism is considered more than twice as common in boys as girls, and this ratio seems to increase at the high-ability end of the autism spectrum (Happe, 1995). Klin suggests that:

When counseling parents who have an autistic child however, it may be appropriate to say that over and above the 6-8% recurrence risk for autism, there may be an additional risk for a milder autism-related phenotype, such as AS, in the range of 4-5% (Klin et al., 2000, p.168)

One should also be aware of the viewpoint that affirms that women who develop certain viral infections (like rubella or cytomegalovirus) during their first late trimester of pregnancy are at a higher risk of having a child with autism (Siegel, 1996). Moreover, lack of oxygen during labor could be a potential factor for the child to develop autism. However, it is considered that in about thirty to forty percent of cases of autism the cause is neither genetic, nor attributed to pregnancy difficulties (Siegel, 1996).

Cohen and Donnellan (1987) imply that autism can develop after an “environmental insult,” though there is still not enough data to support this affirmation.

Happe (1995) mentions a study by Steffenburg who found that approximately 90% of a sample of 52 children (35 with autism and 17 with autism-like symptoms) illustrates evidence of “brain damage or dysfunction.” Starting in the late 1990s, researchers from the University of California, San Diego, tried to find out “whether there was a connection between autism and a newly discovered class of nerve cells in the brain called mirror neurons” (Vilayanur et al., 2006). These neurons seemed to be involved in abilities such as empathy and the perception of another individual's intentions, so it appeared “logical to hypothesize that a dysfunction of the mirror neuron system could result in some of the symptoms of autism” (Ramachandran and Oberman, 2006). Even though, over the past years, several studies have provided evidence for this theory, further investigations of mirror neurons are needed.

### **Assessment of Asperger's Syndrome**

Dr. Ann LeCouteur and colleagues developed the Autism Diagnostic Interview (ADI). Although this scale is appreciated as “the most detailed rating system (...) which contains hundreds of questions about past and present behavior” (Siegel, 1996, p.94), due to its

complexity, it is not usually used. One of the most widely used autism rating scale is the one developed by Dr. Eric Schopler and colleagues, named the Childhood Autism Rating Scale (CARS). Another frequently used scale is the Autism Behavior Checklist (ABC) which works in a way similar to CARS (Siegel, 1996). The most widely used test of adaptive behavior is the Vineland Adaptive Behavior Scales (VAIS).

Intelligence testing is another very important component in determining whether one has autism or not. These tests are used to measure the Verbal Intelligence Quotient (VIQ), the Performance Intelligence Quotient (PIQ). Among them, one could mention: Kanner's Islets of Intact Ability, Bayley Scales of Infant Development, Gesell Scales, Mullen Scales of Early Learning, Merrill-Palmer Scales of Mental Development, Weschler Preschool and Primary Scales of Intelligence-Revised (WPPSI-R), Kauffman ABC (K-ABC), the Stanford-Binet III (SBI-III), Weschler Intelligence Scale for Children-III (WISC-III), and Weschler Adult Intelligence Scale-Revised (WAIS-R).

Intelligence testing is still very disputable and many parents of children with autism question the fact that intelligence testing will actually show their child's "true intelligence" (Siegel, 1996). In addition, some authors insist that there is another aspect that one should always keep in mind when testing children with autism, which is the fact that, due to their "lack of self-reflectiveness," the information they provide is frequently considered unreliable (Klin et al., 2000).

### **What is the prognosis for persons with Asperger's?**

Kanner (1973) affirms that only 2 of the 11 children with autism that participated in one of his studies, "no differing essentially from than the others in their initial symptoms, had in their childhood attained a modus vivendi which allowed them to function gainfully in society". According to Siegel (1996), persons with Asperger's seem to have a better prognosis than those with autism. With the right type of motivation, more can live separately and be able to accomplish economic independence. Among the downsides of Asperger's, one should take into consideration its susceptibility to poor vocational and post-school outcomes (Marks and Schrader, 2003), and its openness to a diversity of

psychiatric disorders, “caused mainly by their pushing too hard, and not protected enough” (Siegel, 1996, p.119).

### **Treatment and intervention guidelines**

Klin insists that the assessment of children and adolescents with Asperger’s syndrome should be conducted by interdisciplinary teams who should be aware of the intervention resources that can be made available to individuals with this disability. Some of these resources are “social skill training programs, behavioral management approaches, family support techniques, and assistive technology” (Klin et al., 2000, p.334).

Attending to the social skills of students with Asperger’s syndrome is a difficult and challenging endeavor, though the implications of the deficits in this specific area need to be taken into consideration.

In this context, Siegel (1996) stresses “the sooner the better” philosophy, while he describes several major reasons why the early intervention is very important for children with PDD and autism. The most significant explanation for early intervention seems to be the one based on the neurological origin of developing skills:” the training of a new skill is easier to do than undoing an old skill and then retraining the new skill to replace it” (Siegel, 1996, p.199).

One recent approach for social skills training is the social story, which is the work of Gray and colleagues and is mainly a form of teaching social skills by making use of “ visual and written materials and techniques based on situations from a child ‘s actual experience” (Klin et al., 2000, p.353).

Some researchers also take into discussion the training of the social and communication skills of children with Asperger’s. Although they admit that this approach is not supported by too much research data, Klin and Volkmar (2000) bring out some of the most important aspects that the current “prepackaged social skills programs” have to offer. One of these features, considered very important in working with children with Asperger’s syndrome, is the use of strategies for improving communication. Educators can support their students by understanding their communication needs and by “helping them to build on and enhance the strategies and approaches they already employ successfully” (Kluth, 2003, p.110).

Some children with autism and related disorders can use speech unflinching, as long as others, although able to recite all of the words of a poem are not capable to “ask for a drink of water when they need one.” Klin and Volkmar (2000) describe the central strategies that are frequently included in social and communication skills training. They insist on teaching the child to be aware of conversation rules and ways of making topic transfers for different people and on training him/her correct “reading” of social signs and self-monitoring in conversation. They persist on the fact that a child with autism needs to be taught that different people have different communicational expectations and attitudes, and they need to adjust to the “social demands” of their interlocutors. Moreover, the child should learn to be aware of his voice’s tone and volume in different environments. Among the suggestions that the current research (Marks et al., 1999) offers for supporting the social skills development, one could take into consideration teaching coping strategies, providing ample social opportunities, and create a safe and accepting environment.

One very interesting attempt of teaching children with Asperger’s social skills is the one that helps them understand “underlying social cognitive principles necessary to infer the mental states of others (e.g., beliefs intentions, and feelings)” (Klin et al., 2000, p.353). This approach is called “teaching theory of mind” and is based on the belief that the etiology of autism might be a lack of a discrete capability or of the “ability to think about thoughts” (Happe, 1995). The explanation of this theory is the belief that children with Asperger’s syndrome, probably after a significant delay in early childhood and due to internal or external factors, as Happe (1995) notes, develop a theory of mind different from the one of normal children. A study conducted by the above-mentioned researcher shows the existence of a subgroup of subjects with autism, “the talented minority” who passed theory of mind tests. Although the results of this test seem very encouraging, her conclusion is that:

Asperger’s syndrome people (...) will still show characteristics (if milder) autistic social impairments in everyday life, despite “real” success on theory of mind tests. They will, however, have a better prognosis, and the type of skills they need to be taught will be meaningfully different

from those of other people with autism who lack theory of mind (Happé, 1995, p. 82)

One should also take into consideration the pharmacologic intervention, keeping in mind that there are significant age-related variations in the type and frequency of the medication prescribed to people with Asperger's syndrome. Martin, Patzer, and Volkmar (Klin, 2000) did a survey in order to "address the prevalence and patterns of psychotropic drug use among subjects with AS and HFA" (added, higher functioning autism). The outcome of the survey shows that approximately "70% of the subjects had received psychotropics at one point in their lives, and over half of those currently on medication took two or more agent simultaneously" (Klin et al, 2000, p.217). These results show that "individuals diagnosed with HFPDDs are overall a heavily medicated clinical population," when compared with outcomes of a larger-scale survey on subjects with autism, which demonstrated that only 30.5% percent of the subjects were taking psychotropic (Klin et. al., 2000).

As this discussion has shown, Asperger's is a very complex syndrome and needs to be researched even more. I believe that what actually matters when working with a child with Asperger's is not the amount of testing that diagnosing such a disability requires, its possible definitions, or its etiologies which are, very often, contradictory. What is important is to recognize that this child is an individual who has all the rights to be "different" and to be accepted and loved the way he is and for what he has to offer.

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