

ASPERGER'S SYNDROME

What is Asperger Syndrome?

Okay, so you're thinking that your child is "a little different than the other kids". He's like a walking dictionary and he's so so smart, but something is off. Next, you're Googling and you have just YouTube'd Asperger Syndrome...and there they are...other children just like yours, or are they? Asperger's Syndrome or (AS) is a developmental disorder that is characterized by: ¹

- limited interests or an unusual preoccupation with a particular subject to the exclusion of other activities.
- repetitive routines or rituals are demanded
- peculiarities in speech and language, such as speaking in an overly formal manner or monotone, or taking figures of speech literally
- socially and emotionally inappropriate behavior and the inability to interact successfully with kids his/her same age. Gets along better with adults.
- problems with non-verbal communication, including the restricted use of gestures, limited or inappropriate facial expressions, or a peculiar, stiff gaze
- clumsy and uncoordinated motor movements

Wikipedia will inform you that AS is an autism spectrum disorder (ASD), one of a distinct group of neurological conditions characterized by a greater or lesser degree of impairment in language and communication skills, as well as repetitive or restrictive patterns of thought and behavior. Other ASDs include: classic autism, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).

Parents usually sense there is something unusual about a child with AS by the time of his or her third birthday, and some children may exhibit symptoms as early as infancy. Unlike children with Autism, children with AS retain their early language skills. They speak single words and begin sentences by a year old, but their communication style seems different. They may not make eye contact or they may not point to objects with interest. Typically, language is not a problem so AS is overlooked. Motor development delays – crawling or walking late, clumsiness – are sometimes the first indicator of the disorder.

The incidence of AS is not well established, but experts in population studies conservatively estimate that two out of every 10,000 children have the disorder. Boys are three to four times more likely than girls to have AS.

¹Adapted from the *Diagnostic and Statistical Manual of Mental Disorders IV* and the *International Classification of Diseases - 10*

Studies of children with AS suggest that their problems with socialization and communication continue into adulthood. Some of these children develop additional psychiatric symptoms and disorders in adolescence and adulthood. Although diagnosed mainly in children, AS is being increasingly diagnosed in adults who seek medical help for mental health conditions such as depression, obsessive-compulsive disorder (OCD), and attention deficit hyperactivity disorder (ADHD). No studies have yet been conducted to determine the incidence of AS in adult populations.

Why is it called Asperger's Syndrome?

In 1944, an Austrian pediatrician named Hans Asperger observed four children in his practice who had difficulty integrating socially. Although their intelligence appeared normal, the children lacked nonverbal communication skills, failed to demonstrate empathy with their peers, and were physically clumsy. Their way of speaking was either disjointed or overly formal, and their all-absorbing interest in a single topic dominated their conversations. Dr. Asperger called the condition "autistic psychopathy" and described it as a personality disorder primarily marked by social isolation.

Asperger's observations, published in German, were not widely known until 1981, when an English doctor named Lorna Wing published a series of case studies of children showing similar symptoms, which she called "Asperger's" syndrome. Dr. Wing's writings were widely published and popularized. AS became a distinct disease and diagnosis in 1992, when it was included in the tenth published edition of the World Health Organization's diagnostic manual, *International Classification of Diseases (ICD-10)*, and in 1994 it was added to the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, the American Psychiatric Association's diagnostic reference book. The DSM-V, due out in 2010, is considering removing the diagnosis Asperger's and integrating those afflicted with the symptoms under Autism with modifiers to describe the variance in level of functioning. The counseling community is divided in this action but in agreement that children with Asperger's have a wide range of capability.

What do children with Asperger's Syndrome look like?

The most distinguishing symptom of AS is a child's obsessive interest in a single object or topic to the exclusion of any other. Some children with AS have become experts on vacuum cleaners, makes and models of cars, even objects as odd as deep fat fryers. Children with AS want to know everything about their topic of interest and their conversations with others will be about little else. Their expertise, high level of vocabulary, and formal speech patterns make them seem like little professors or "walking dictionaries".

Children with AS will gather enormous amounts of factual information about their favorite subject and will talk incessantly about it, but the conversation may seem like a random collection of facts or statistics, with no point or conclusion.

Their speech may be marked by a lack of rhythm, an odd inflection, or a monotone pitch. Children with AS often lack the ability to modulate the volume of their voice to match their

surrounding. For example, they will have to be reminded to talk softly every time they enter a library or a movie theatre.

Unlike the severe withdrawal from the rest of the world that is characteristic of Autism, children with AS are isolated because of their poor social skills and narrow interests. In fact, they may approach other people, but make normal conversation impossible by inappropriate or eccentric behavior, or by wanting only to talk about their singular interest.

Children with AS usually have a history of developmental delays in motor skills such as pedaling a bike, catching a ball, or climbing outdoor play equipment. They are often awkward and poorly coordinated with a walk that can appear either stilted or bouncy.

Many children with AS are highly active in early childhood, and then develop anxiety or depression in young adulthood. Other conditions that often co-exist with AS include ADHD, tic disorder, depression, anxiety disorder and obsessive compulsive disorder.

What causes AS? Is it genetic?

Current research points to brain abnormalities as the cause of AS. Using advanced brain imaging techniques, scientists have revealed structural and functional differences in specific regions of the brains of normal versus AS children. These defects are most likely caused by the abnormal migration of embryonic cells during fetal development that affects brain structure and “wiring” and then goes on to affect the neural circuits that control thought and behavior.

For example, one study found a reduction of brain activity in the frontal lobe of AS children when they were asked to respond to tasks that required them to use their judgment. Another study found differences in activity when children were asked to respond to facial expressions. Another study investigated brain function in adults with AS revealed abnormal levels of specific proteins which correlated with obsessive and repetitive behaviors.

Scientists have always known that there had to be a genetic component to AS and the other Autism Spectrum Disorders because of their tendency to run in families. Additional evidence for the link between inherited genetic mutations and AS was observed in the higher incidence of family members who have behavioral symptoms similar to AS but in a more limited form. For example, they had slight difficulties with social interaction, language, or reading.

A specific gene for AS, however, has never been identified. Instead, the most recent research indicates that there are most likely a common group of genes whose variations or deletions make an individual vulnerable to developing AS. This combination of genetic variations or deletions will determine the severity and symptoms for each individual with AS.

How is it diagnosed?

The diagnosis of AS is complicated by the lack of a standardized diagnostic screen or schedule. In fact, because there are several screening instruments in current use, each with different criteria, the same child could receive different diagnoses, depending on the screening tool the doctor uses.

To further complicate the issue, some clinicians now believe that AS is not a separate and distinct disorder. Instead, they call it high-functioning Autism (HFA), and view it as being on the mild end of the ASD spectrum with symptoms that differ -- only in degree -- from classic Autism. Some clinicians use the two diagnoses, AS or HFA, interchangeably. This makes gathering data about the incidence of AS difficult, since some children will be diagnosed with HFA instead of AS, and vice versa.

To be conclusive about the diagnosis, it should involve a two-stage process. The first stage begins with a developmental screening during a "well-child" check-up with a family doctor or pediatrician. Most doctors rely on the presence of a core group of behaviors to alert them to the possibility of a diagnosis of AS. These behaviors are:

- abnormal eye contact
- aloofness
- the failure to turn when called by name
- the failure to use gestures to point or show
- a lack of interactive play
- a lack of interest in same age peers

Some of these behaviors may be apparent in the first few months of a child's life, or they may appear later. Problems in at least one of the areas of communication and socialization or repetitive, restricted behavior must be present before the age of 3.

The second stage of the diagnostic process includes a comprehensive team evaluation to either rule in or rule out AS. This team generally includes a psychologist, neurologist, psychiatrist, speech therapist, counselors and additional professionals who have expertise in diagnosing children with AS.

The comprehensive evaluation includes neurologic and genetic assessment, with in-depth cognitive and language testing to establish IQ and evaluate psychomotor function, verbal and non-verbal strengths and weaknesses, style of learning, and independent living skills. An assessment of communication strengths and weaknesses includes evaluating non-verbal forms of communication (gaze and gestures); the use of non-literal language (metaphor, irony, absurdities, and humor); patterns of inflection, stress and volume modulation; pragmatics (turn-taking and sensitivity to verbal cues); and the content, clarity, and coherence of conversation. The physician will look at the testing results and combine them with the child's developmental history and current symptoms to make a diagnosis.

Are there treatments available?

The ideal treatment for AS coordinates therapies that address the three core symptoms of the disorder: poor communication skills, obsessive or repetitive routines, and physical clumsiness. There is no single best treatment package for all children with AS, but most professionals agree that the earlier the intervention, the better.

An effective treatment program builds on the child's interests, offers a predictable schedule, teaches tasks as a series of simple steps, actively engages the child's attention in highly structured activities, and provides regular reinforcement of behavior. This kind of program generally includes:

- social skills training, a form of therapy that teaches children with AS the skills they need to interact more successfully with other children
- cognitive behavioral therapy, a type of "talk" therapy that can help the more explosive or anxious children to manage their emotions better and cut back on obsessive interests and repetitive routines
- medication, for co-existing conditions such as depression and anxiety
- occupational or physical therapy, for children with sensory integration problems or poor motor coordination
- specialized speech/language therapy, to help children who have trouble with the pragmatics of speech – the give and take of normal conversation
- parent training and support, to teach parents behavioral techniques to use at home

What research is being done?

The National Institute of Neurological Disorders and Stroke (NINDS) is one of the federal government's leading supporters of biomedical research on brain and nervous system disorders. The NINDS conducts research in its laboratories at the National Institutes of Health (NIH) in Bethesda, Maryland and awards grants to support research at universities and other facilities. Many of the Institutes at the NIH, including the NINDS, are sponsoring research to understand what causes AS and how it can be effectively treated.

One study is using functional magnetic resonance imaging (fMRI) to show how abnormalities in particular areas of the brain cause changes in brain function that result in the symptoms of AS and other ASDs. Another large-scale study is comparing neuropsychological and psychiatric assessments of children with possible diagnoses of AS or HFA to those of their parents and siblings to see if there are patterns of symptoms that link AS and HFA to specific neuropsychological profiles.

NINDS is also supporting a long-range international study that brings together investigators to collect and analyze DNA samples from children with AS and HFA, as well as their families, to identify associated genes and how they interact. Called the Autism Genome Project, it's a consortium of scientists from universities, academic centers, and

institutions around the world that functions as a repository for genetic data so that researchers can look for the genetic “building blocks” of AS and the other ASDs.

Since there are so many different forms of ASD, understanding the genetic basis of each opens the door to opportunities for more precise diagnosis and treatment. Knowing the genetic profile of a particular disorder could mean early identification of those at risk, and early intervention when treatments and therapies are likely to be the most successful.

Do children with AS get better? What happens when they become adults?

With effective treatment, children with AS can learn to cope with their disabilities, but they may still find social situations and personal relationships challenging. Many adults with AS are able to work successfully in mainstream jobs, although they may continue to need encouragement and moral support to maintain an independent life. The important thing to focus on is the uniqueness of your child and the contributions that he or she makes as an individual, as a family member and ultimately as a citizen. There is typically no “lying” in the child with AS. They may learn how to manipulate the truth as an attempt to navigate society but they are black and white/right and wrong thinkers...simple, yet profound.

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