

From the Asperger's Association of New England (AANE) website:

[http://www.aane.org/about\\_asperger\\_syndrome/what\\_is\\_asperger\\_syndrome.html](http://www.aane.org/about_asperger_syndrome/what_is_asperger_syndrome.html)

## What is Asperger Syndrome?

Asperger Syndrome (AS) is a neurological condition. People who have AS are born with it, and have it for life, although as they mature they may gain new skills, outgrow some of their AS traits, or use their strengths to compensate for their areas of disability. AS is generally considered a form of autism, an autism spectrum disorder (ASD). Other closely related autism spectrum disorders include HFA (High-Functioning Autism), PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified) and NLD or NVLD (Nonverbal Learning Disorder). The boundaries among these diagnoses—and whether in fact they are all on the same spectrum with each other and with profound, classical, or Kanner's autism—remain open to discussion.

Current research indicates that there is a genetic foundation for AS, involving a number of different genes. So it's not surprising that when a person gets an AS diagnosis, the family often realizes that many relatives also have AS or other forms of autism. At AANE we have met or talked with well over 6,000 families. We see that in many families where a child has AS, one or both biological parents will also have AS, or have AS traits to some degree. People also report that many relatives from previous generations (when AS was unknown) were eccentric or quirky, were diagnosed with a mental illness or hospitalized, lived a reclusive life, were chronically unemployed, or married and divorced multiple times. At the same time, many relatives may have shown high intelligence, superior memory, single-minded focus, original thinking, or unusual interest areas. Some may have achieved great success in engineering, math, writing, composing, philosophy, or other fields. These relatives, whether quirky, gifted, or both, may well have been people with undiagnosed AS.

No one really knows how prevalent AS is; perhaps one in every 250 people has AS—and maybe more. Dr. Tony Attwood estimates that as many as 50% of people with AS remain undiagnosed, in part because AS has only recently been publicly recognized on a broad scale. (It only became an official diagnosis in the United States in 1994.) Some people with AS continue to be misdiagnosed, while others “fly under the radar.” That is, they have traits that are mild enough so that they manage to adapt and function sufficiently well to be considered merely eccentric or quirky.

AS is a “pervasive developmental disability.” That is, people with AS may often appear or act younger than others of the same age. Children with AS often show delays in multiple areas of functioning, such as gross or fine motor coordination, social skills, or executive functioning (organization, prioritizing, and follow-through). However, they also continue to develop and mature—on their own time-table. Some people with AS may have specific gifts in mathematics, literature, or the arts. There is strong evidence that such superstars as Vincent Van Gogh, Emily Dickinson, Albert Einstein, code-breaker Alan Turing, and musician Glen Gould, among many others, all had Asperger Syndrome. Today, too, there are adults with AS who are successful as professors, lawyers, physicians, artists, authors, and educators. For this reason,

many people with AS, and professionals who know them, consider AS a difference rather than a disability. The brains of people with AS seem to process information and sensory stimuli differently than the brains of neurotypical (NT) people. This can be a source of difficulty, but it can also be a strength. For example, people with AS are often very good at noticing visual details or remembering facts, skills that are useful in many professions. On the other hand, the same people may be too perfectionistic, become too obsessed with details, or have so much trouble seeing the big picture that they cannot complete a project.

While respecting the abilities and humanity of people with AS, one should not underestimate their struggles and suffering. A society designed for and dominated by the neurotypical majority (i.e., people who do not have AS) can feel uncongenial and even overwhelming for a person with AS. In particular, living in the United States in the modern information age—in a crowded, complex, industrial society—can pose real challenges for people with AS. American children are generally expected to “play well with others” and grow up fast. Adults are expected to work 40–60 hour weeks under fluorescent lights, to attend meetings, work on teams, rapidly absorb oceans of information, and multi-task. Solitary pursuits such as hunting, farming, or tending a light house are less available today. On the other hand, some people with AS have found employment (and sometimes mates) in the computer industry and the global economy.

People with Asperger Syndrome usually experience:

- Difficulty knowing what to say or how to behave in social situations. Many have a tendency to say the “wrong thing.” They may appear awkward or rude, and unintentionally upset others.
- Trouble with “theory of mind,” that is, trouble perceiving the intentions or emotions of other people, due to a tendency to ignore or misinterpret such cues as facial expression, body language, and vocal intonation.
- Slower than average auditory, visual, or intellectual processing, which can contribute to difficulties keeping up in a range of social settings—a class, a soccer game, a party.
- Challenges with “executive functioning,” that is, organizing, initiating, analyzing, prioritizing, and completing tasks.
- A tendency to focus on the details of a given situation and miss the big picture.
- Intense, narrow, time-consuming personal interest(s) — sometimes eccentric in nature — that may result in social isolation, or interfere with the completion of everyday tasks. (On the other hand, some interests can lead to social connection and even careers. For example, there are children and adults with an encyclopedic knowledge of vacuum cleaners.)
- Inflexibility and resistance to change. Change may trigger anxiety, while familiar objects, settings, and routines offer reassurance. One result is difficulty transitioning from one activity to another: from one class to another, from work time to lunch, from talking to listening. Moving to a new school, new town, or new social role can be an enormous challenge.
- Feeling somehow different and disconnected from the rest of the world and not “fitting in”—sometimes called “wrong planet” syndrome.

- Extreme sensitivity—or relative insensitivity—to sights, sounds, smells, tastes, or textures. Many people outgrow these sensory issues at least to some extent as they mature.
- Vulnerability to stress, sometimes escalating to psychological or emotional problems including low self-esteem, depression, anxiety, and obsessive-compulsive behaviors.

AS affects people lifelong, but many can use their cognitive and intellectual abilities to compensate for some of the challenges they face, so as people grow, AS can be managed. At AANE, we have seen countless people with AS who, given the proper supports, have used their AS traits to their advantage to accomplish feats beyond what the “typical” mind could muster. Traits and talents from which individuals with AS often benefit include:

- Normal to very high intelligence
- Good verbal skills, including rich vocabularies
- Originality and creativity including a propensity for “thinking outside the box”
- Honesty and ingenuity
- Careful attention to details
- Strong work ethic, with particular attention to accuracy and quality of work
- Special interests that can be tailored toward productive work or hobbies; individuals with AS who have intensive knowledge in one or more specific areas can channel their expertise toward new discoveries and creations in their chosen field
- Keen senses allow some people with AS to see, hear or feel subtle changes in the environment that others do not, resulting in phenomenal powers of observation

The gap between intellectual ability and functional presentation complicates the AS experience. Friends and family members often see a highly intelligent, talented individual, and cannot comprehend why the person with AS struggles during routine social or organizational experiences.

One of the frustrations of an Asperger diagnosis is that because people with AS are often extremely bright, with excellent rote memories and verbal skills, overall expectations for these individuals are high. Those around them may be surprised to see how deeply people with AS struggle in certain areas, such as the social realm, and may not understand that such difficulties are valid and real. Many times, people with AS are blamed for behaviors they cannot control.

Dr. Stephen M. Shore says, “When you meet one person with AS—you’ve met one person with AS.” That is, it is very important to remember that people with AS can differ greatly from one other. Everyone with AS is affected by a common cluster of traits, but the intensity of each trait lies along a continuum. As a result, the extent to which AS shapes an individual’s life course and experiences is highly variable.

We hope this information helps your awareness of Asperger Syndrome. Knowledge is the first step toward positive change in the lives of you and your loved ones. Good luck on your journey to understanding the role AS has played in your life.