



Your child has normal cognitive abilities and has experienced normal language development, but has been diagnosed with Asperger Syndrome or High Functioning Autism, and you have asked for help. This is an important turning point in your journey. For some families, this may be the point when, after a long search for answers, you now have a name for something you didn't know what to call, but you knew existed. Many families report mixed feelings of sadness and relief when their child is diagnosed. You may feel completely overwhelmed. You may also feel relieved to know that the concerns you had for your child are valid. Whatever you feel, you should know that thousands of parents share this journey. You are not alone. There is help and reason to hope.

Now that you have the diagnosis, the question is: Where do you go from here? This handbook, part of Autism Speaks™ 100 Day Kit, focuses specifically on Asperger Syndrome (AS) and High Functioning Autism (HFA). It was created to help you make the best possible use of the next 100 days in the life of your child. It contains information and advice collected from trusted and respected experts on Asperger Syndrome /HFA and parents just like you.

Contact Us...

Ask for Help! Contact the Autism Response Team (ART). Our ART team members are specially trained to help families with the day-to-day challenges of living with Asperger Syndrome or High Functioning Autism. Contact ART for resources, support and information.

Call us at 888-AUTISM 2 (288-4762) or email familyservices@autismspeaks.org.

More information... There is a wealth of information on the Autism Speaks web site. Visit www.AutismSpeaks.org

Share your comments. To share your comments on the kit – What was helpful? What additional information could be included? etc. – please email them to 100daykit@AutismSpeaks.org, with the word “feedback” in the subject line.

What is Asperger Syndrome/HFA?

 The National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institute of Health, defines Asperger Syndrome as:

A developmental disorder that is characterized by:

- repetitive routines or rituals,
- peculiarities in speech and language, such as speaking in an overly formal manner or in a monotone, or taking figures of speech literally,
- socially and emotionally inappropriate behavior and the inability to interact successfully with peers,
- problems with non-verbal communication, including the restricted use of gestures, limited or inappropriate facial expressions or a peculiar, stiff gaze,
- clumsiness and uncoordinated motor movements.


Below is the NINDS history of Asperger Syndrome, which we hope will help you to understand more about the disorder and what the diagnosis means for your child and your family:

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.

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" syndrome. Wing's writings were widely published and popularized. AS became a distinct condition 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 fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*, the American Psychiatric Association's diagnostic reference book.

Individuals who are diagnosed with autism or autism spectrum disorder who have normal cognitive abilities, and experienced no significant delay in acquiring language skills, are very similar to individuals with Asperger Syndrome. High Functioning Autism Spectrum Disorder (HFA) and Asperger Syndrome share similar symptoms and are helped by similar treatment approaches.

What are the Symptoms of Asperger Syndrome/HFA?

 Oftentimes, Asperger Syndrome is not diagnosed until a child is school age. Unlike autism, AS can generally only be determined based on a child's social interactions. Children with Asperger Syndrome show typical language development and often an above average vocabulary. However, you may have noticed that when your child interacts with others, he or she might use language skills inappropriately or awkwardly. Because of regularly developing language skills, in the early stages, symptoms of AS may be hard to differentiate from those of other behavioral issues like attention deficit



hyperactivity disorder (ADHD). As a result, your child may have first been diagnosed with disorders such as ADHD, until the issues appear to be caused by more of an inability to socialize than an inability to focus.

The following is a list of symptoms that may present themselves in children with Asperger Syndrome:

- improper or very few social interactions
- "robotic" or repetitive speech
- average or below average nonverbal communication skills, yet average or above average verbal communication skills
- tendency to discuss self rather than others
- inability to understand issues or phrases that are considered "common sense"
- lack of eye contact or reciprocal conversation
- obsession with specific unique topics
- one-sided conversations
- awkward movements and/or mannerisms

A very obvious and distinct indicator of Asperger Syndrome is preoccupation with one particular issue, from simple things like refrigerators or weather, to complex topics like President Franklin D. Roosevelt during the Great Depression. They become so attentive to these topics that they strive to learn every possible fact and detail, and as a result become incredible experts. Children with AS might initiate one-way conversations with others by speaking only about the facts related to their particular topic of interest. They may not like the idea of discussing anything else, or may be unable to listen to and understand the responses of others. Your child may not be aware that his or her audience may no longer be listening, or may not be in the topic of discussion.

Another symptom of Asperger Syndrome is an inability to understand the actions, words or behaviors of other people. Individuals with AS very often don't understand humor or the implications of particular phrases or actions of other people. Subtle gestures or expressions such as a smile, a frown or a "come here" motion may not phase children with AS because they are unable to see the relationship between these nonverbal communication methods, and verbal methods like speech and language. Because they are often incapable of understanding these nonverbal cues, the social world can seem very confusing and overwhelming to these individuals. To compound the problem, people with Asperger Syndrome have difficulty seeing things from another person's perspective. This inability leaves them unable to predict or understand other people's actions. Although not universal, it is common for people with AS to have difficulty regulating their emotions.

Individuals with Asperger Syndrome may have an awkward or peculiar way of speaking. They might speak extremely loudly, constantly in a monotone, or with a particular accent. These individuals lack understanding of social interactions, and as a result, are unaware that their topics of discussion or method of speaking might be inappropriate or awkward, particularly in specific situations. For example, children who speak very loudly might enter a church and not understand that they can no longer speak at the same volume.



Another typical sign of Asperger Syndrome may be awkward movements, or a delay in motor skills. They may have an abnormal walk or a poor sense of coordination. Though these individuals might be very intelligent and might display expert language skills, they may not be able to catch a ball or understand how to bounce on a trampoline, despite the many attempts of others to teach them.

It is important to note that not all individuals with Asperger Syndrome display each of these symptoms, and that the presence and severity of each symptom is likely to vary between individuals with the same diagnosis. While displaying some or all of these symptoms, each child with autism also possesses many unique gifts.

What Causes Asperger Syndrome/HFA?

■ It is important to keep in mind that autism spectrum disorders are not one disorder with one cause. Rather, the term represents a group of related disorders with many different causes. In most instances, AS/HFA is caused by a combination of genetic risk factors that may interact with environmental risk factors. Many genes likely contribute to Asperger Syndrome/HFA. These genes are believed to interact with environmental factors. A great deal of research is currently focused on identifying how both genetic and environmental risk factors contribute to autism.

There may be some common misconceptions about people with Asperger Syndrome/HFA. AS/HFA cannot be caused by the way a person was brought up, bad parenting, or emotional issues a child may have experienced at some point early on. Asperger Syndrome/HFA is a neurobiological disorder, and not the result of issues stemming from the child's life experiences.

