



About Autism

Many people within the school community who use this kit will be familiar with some aspects of autism, particularly as they relate to the school setting. This information is meant to provide a general overview for people who are new to autism and to fill in the gaps of information for people with experience. Be on the look out for information you didn't know and how it might apply to your future experiences supporting students with autism!

- What is Autism?
- More Information About Symptoms of Autism
- Physical and Medical Issues That May Accompany Autism
- Additional Challenges That May Accompany Autism
- Unique Abilities That May Accompany Autism
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What is Autism?

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. They include autistic disorder, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS) and Asperger syndrome. ASD can be associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances.

Each individual with autism is unique. Many of those on the autism spectrum have exceptional abilities in visual skills, music and academic skills. About 40 percent have average to above average intellectual abilities. Indeed, many persons on the spectrum take deserved pride in their distinctive abilities and “atypical” ways of viewing the world. Others with autism have significant disability and are unable to live independently. About 25 percent of individuals with ASD are nonverbal but can learn to communicate using other means.

How Common is Autism?

Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 88 American children as on the autism spectrum—a ten-fold increase in prevalence in 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 54 boys and 1 in 252 girls are diagnosed with autism in the United States.

By way of comparison, more children are diagnosed with autism each year than with juvenile diabetes, AIDS or cancer, combined.* ASD affects over 2 million individuals in the U.S. and tens of millions worldwide. Moreover, government autism statistics suggest that prevalence rates have increased 10 to 17 percent annually in recent years. There is no established explanation for this continuing increase, although improved diagnosis and environmental influences are two reasons often considered.

* Comparison based on the prevalence statistics of the Child & Adolescent Health Measurement Initiative

One in every 88 children is diagnosed with autism.





More Information About Symptoms of Autism

Symptoms of autism, and their severity, vary considerably in each individual on the autism spectrum. The functional areas of communication, social interaction, and repetitive behaviors are viewed as the ‘core’ symptoms of autism. One child may not have the same symptoms and may seem very different from another child with the same diagnosis. It is sometimes said that if you know one person with autism; you know one person with autism.

The characteristics of autism typically last throughout a person’s lifetime, but can change considerably over time and through interventions. A mildly affected person might seem merely quirky and lead a relatively typical life. A severely affected person might be unable to speak or care for himself. Early and intensive intervention can make extraordinary differences in a child’s development and outcome.

The descriptions of symptoms that follow are drawn from the [National Institute of Mental Health Website](#):

Social Symptoms

From the start, typically developing infants are social beings. Early in life, they gaze at people, turn toward voices, grasp a finger, and even smile. In contrast, most children with autism seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem indifferent to other people, and often seem to prefer being alone. They may resist attention or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to parents’ displays of anger or affection in a typical way. Research has suggested that although children with autism are attached to their parents, their expression of this attachment is often unusual and difficult to “read.” To parents, it may seem as if their child is not attached at all. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of the expected and typical attachment behavior.

Children with autism also are slower in learning to interpret what others are thinking and feeling. Subtle social cues—whether a smile, a wink, or a grimace—may have little meaning. To a child who misses these cues, “Come here” always means the same thing, whether the speaker is smiling and extending her arms for a hug or frowning and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering. To compound the problem, people with autism have difficulty seeing things from another person’s perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with autism may lack such understanding. This inability leaves them unable to predict or understand other people’s actions.

Although not universal, it is common for people with autism also to have difficulty regulating their emotions. This can take the form of “immature” behavior such as crying in class or verbal outbursts that seem inappropriate to those around them. The individual with autism might also be disruptive and physically aggressive at times, making social relationships still more difficult. They have a tendency to “lose control,” particularly when they’re





in a strange or overwhelming environment, or when angry and frustrated. They may at times break things, attack others, or hurt themselves. In their frustration, some bang their heads, pull their hair, or bite their arms.

Communication Difficulties

By age 3, most children have passed predictable milestones on the path to learning language; one of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it clear that the answer is “no.”

Some children diagnosed with autism remain mute throughout their lives. Some infants who later show signs of autism coo and babble during the first few months of life, but they soon stop. Others may be delayed, developing language as late as age 5 to 9. Some children may learn to use communication systems such as pictures or sign language.

Many of those who do speak often use language in unusual ways. They seem unable to combine words into meaningful sentences. Some speak only single words, while others repeat the same phrase over and over. Some children with autism parrot what they hear, a condition called echolalia. Although many typical children go through a stage where they repeat what they hear, it normally passes by the time they are 3.

Some children only mildly affected may exhibit slight delays in language, or even seem to have precocious language and unusually large vocabularies, but have great difficulty in sustaining a conversation. The “give and take” of normal conversation is hard for them, although they often carry on a monologue on a favorite subject, giving no one else an opportunity to comment. Another difficulty is often the inability to understand body language, tone of voice, or “phrases of speech.” They might interpret a sarcastic expression such as “Oh, that’s just great” as meaning it really IS great.

While it can be hard to understand what a child with autism is saying, their body language is also difficult to understand. Facial expressions, movements, and gestures rarely match what they are saying. Also, their tone of voice fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common. Some children with relatively good language skills speak like little adults, failing to pick up on the “kid-speak” that is common in their peers.

Without meaningful gestures or the language to ask for things, people with autism are at a loss to let others know what they need. As a result, they may simply scream or grab what they want. Until they are taught better ways to express their needs, children with autism do whatever they can to get through to others. As people with autism grow up, they can become increasingly aware of their difficulties in understanding others and in being understood. As a result they may become anxious or depressed.

Repetitive Behaviors

Although children with autism usually appear physically normal and many have good muscle control, odd repetitive motions may set them off from other children. These behaviors might be extreme and highly apparent or more subtle. Some children and older individuals spend a lot of time repeatedly flapping their arms or walking on their toes. Some suddenly freeze in position.





As children, they might spend hours lining up their cars and trains in a certain way, rather than using them for pretend play. If someone accidentally moves one of the toys, the child may be tremendously upset. Children with autism often need, and demand, absolute consistency in their environment. A slight change in any routine — in mealtimes, dressing, taking a bath, going to school at a certain time and by the same route — can be extremely disturbing. Perhaps order and sameness lend some stability in a world of confusion.

Repetitive behavior sometimes takes the form of a persistent, intense preoccupation. For example, the child might be obsessed with learning all about vacuum cleaners, train schedules, or lighthouses. Often there is great interest in numbers, symbols, or science topics.

Physical and Medical Issues That May Accompany Autism

Seizure Disorder (Epilepsy)

Over a third of people with autism develop seizures. These often start in early childhood or during adolescence. Seizures, caused by abnormal electrical activity in the brain, can produce a temporary loss of consciousness (a “blackout”), a body convulsion, unusual movements, or staring spells. Sometimes a contributing factor is a lack of sleep or a high fever. An electroencephalogram (EEG, a recording of the electric currents in the brain through electrodes applied to the scalp) can help confirm the presence of irregular electrical activity or seizures.

People with autism may experience more than one type of seizure activity. The easiest to recognize are large “grand mal” (or tonic-clonic) seizures. Others include “petit mal” (or absence) seizures and sub-clinical seizures, which may only be apparent in an EEG. Especially in the case of absence seizures, school staff may be the first to note that something is awry and it is important to alert the family and school team if seizures are suspected.

Recurrent seizure activity is called epilepsy, and treatment typically involves anticonvulsant medicines to reduce or eliminate occurrence. For a student with a seizure disorder, it is important for the school team to recognize seizure signs and to know the best way to manage the student and ensure his safety should a seizure occur. The team should be made aware of any side effects that might be caused by seizure medications.

Genetic Disorders

A small number of children with autism may also have a neuro-genetic condition such as Fragile X Syndrome, Angelman’s Syndrome, Tuberous Sclerosis, Chromosome 15 Duplication Syndrome or another chromosomal abnormality. It is important to know if a student has one of these syndromes because there may be accompanying medical issues.

Allergies, Gastrointestinal Disorders, and Pain

Due to the frequent inability to verbally communicate, pain in a child with autism is sometimes recognized only because of patterns or changes in his behavior, such as an increase in self soothing behaviors (e.g., rocking)





or outbursts of aggression or self-injury. This may be true of treatable physical pain, such as a toothache, injury or gastrointestinal distress.

Many parents report gastrointestinal (GI) problems in their children with autism and the medical community is starting to recognize this as a real, and treatable, co-occurring condition. The exact number of children with gastrointestinal issues such as gastritis, chronic constipation, colitis, celiac disease and esophagitis is unknown, but surveys have suggested that the majority of young children with autism have problems such as chronic constipation or diarrhea. In addition to the associated discomfort, these issues, coupled with communication, disorganization and sensory difficulties, can result in challenges surrounding toileting for many children with autism. Food and/or environmental allergies are also common in people with autism.

Some students may be under the care of a GI specialist or allergist who recommends specific protocols the team will need to follow, while other families might choose to employ specific nutritional protocols or a popular dietary intervention used in autism - eliminating dairy and gluten containing foods. It is often necessary for the school team to assist in the effective delivery of dietary interventions and it is important to communicate well with the family and be knowledgeable to implement these interventions effectively.

Perhaps because of gastrointestinal concerns, sensory issues, oral motor delays, or learned behaviors, many people with autism experience significant food aversions and eating challenges. This may result in highly restrictive food choices and concerns about nutritional health.

For more information on this topic see [Take a Bite](#) in the resources.

Sleep Dysfunction

Sleep problems are common in children and adolescents with autism. Many children have trouble falling asleep, experience night waking, or seem to function on considerably less sleep than is usually considered normal. Lack of sleep can affect attention and learning and the student's ability to benefit from therapeutic interventions.

Medical issues such as obstructive sleep apnea or gastro esophageal reflux may cause sleep issues. Addressing the medical issues may solve the problem. In other cases, when there is no medical cause, sleep issues may be managed with behavioral interventions including "sleep-hygiene" measures such as limiting the amount of sleep during the day, and establishing regular bedtime routines. Experienced school behaviorists may be able to provide the family with strategies that will improve sleep and function for all involved, and in doing so increase the student's ability benefit from educational efforts.

Pica

Pica is an eating disorder involving eating things that are not food. Children between 18 and 24 months old often eat non-food items, but this is typically a normal part of development. Some children with autism and other developmental disabilities persist beyond the developmentally typical time frame and continue to eat items such as dirt, clay, chalk or paint chips.





Additional Challenges That May Accompany Autism

Sensory Processing

Many people with autism have unusual responses to sensory input (also called stimuli). These responses are due to difficulties in processing and integrating sensory information. Vision, hearing, touch, smell, taste, the sense of movement (vestibular system) and the sense of position (proprioception) can all be affected. This means that while information may be sensed normally, it may be perceived much differently.

The process of the brain organizing and interpreting sensory information is called sensory integration. Children with sensory dysfunction can experience stimuli that seem “normal” to others as painful, unpleasant or confusing. For some, the inability to process sensory information normally might be described using a clinical term such as Sensory Integration Dysfunction, Sensory Processing Disorder or Sensory Integration Disorder. Even for those who do not receive a formal classification, it is important to recognize that a student may have significant sensory issues as an isolated issue, or accompanying a variety of learning and neurological disorders such as autism, dyslexia, dyspraxia, multiple sclerosis, and speech delay.

A student’s sensory challenges can involve hypersensitivity (over reactivity), also known as sensory defensiveness, or hyposensitivity (under reactivity). Many people with autism are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothing touching their skin almost unbearable, or might be distracted by the buzz of an airplane or a bee long before anyone else is aware of its presence. Hyposensitivity might be apparent in an increased tolerance of pain or a constant need for sensory stimulation. Some people with autism are oblivious to extreme cold or heat (dangerous in icy conditions or when working near a stove). A child with autism may fall and break an arm, yet never cry. Responses to sensory overload can range from shutting down and “checking out” of the environment, to preoccupation or distraction, or negative behaviors such as aggression or running away. Sensitivities can change or improve over time.

Sensory imbalances can also occur in a seemingly incongruous combination in a single person, for example one who might crave deep pressure (such as a hug) but cannot tolerate the sensation of light touch (such as a kiss on the cheek.) Shirt labels or seams on socks can annoy a child to distraction, while the hum of a vacuum can be terrifying, or the flicker of a fluorescent light completely disorienting. Many young children with autism seem particularly upset by the ‘Happy Birthday’ song (or the clapping that follows), so it is helpful to be aware that this might be distressing as it is likely to come up many times over the course of a school year. Indoor lunch, recess, physical education classes and assemblies are also times where the lack of structure, large numbers of students, unpredictability and excessive noise can become overwhelming.





Some Signs of Sensory Dysfunction

- Overly sensitive to touch, to movement, sights or sounds
- Under-reactive to touch, movement, sights or sounds
- Easily distracted
- Social and/or emotional problems
- Activity level that is unusually high or unusually low
- Physical clumsiness or apparent carelessness
- Impulsive, lacking in self-control
- Difficulty making transitions from one situation to another
- Inability to unwind or calm self
- Poor self-concept
- Delays in speech, language or motor skills
- Delays in academic achievement

Organization and Attention

Students with autism are overwhelmingly challenged by difficulties with organization, both in terms of their own selves, and in their interactions with the world around. While a student with autism might craft an elaborate scheme of associations to aid in structuring his view of the world (i.e. A=red, B=yellow, C=black, etc.), many of these ritualistic patterns do not follow the organizational modes that most of society employs.

In addition, focusing or sustaining attention to subjects that others find interesting or important can be extremely difficult, while at the same time the ability to attend to something motivating to the individual with autism can maintain considerable intensity. Many autism specific interventions view building this shared focus, or ‘joint attention’ as a component of instruction. The ability to appropriately shift attention, and the speed with which this occurs, is also a noted deficit in autism. This can have profound effects on communication, learning and social ability.

Many of the tasks of ‘executive function’ are notably disordered in autism, as in ADHD, Alzheimer’s and individuals who have sustained injuries to the frontal lobe of the brain. Just as sensory issues are often related to challenges in making sense of the whole, executive function skills are instrumental for proper coordination of cognitive resources: planning and organization, flexible and abstract thinking, short term and working memory, initiating appropriate actions and inhibiting inappropriate actions. Executive function deficits can have broad effects on a learner (for example, if it is impossible to recall the question a teacher just asked, then it becomes equally impossible to answer it). For many higher functioning individuals this deficit is especially problematic, as these organizational skills are not usually taught directly (for example, a student might be able to compose sentences, but not create a journal entry on a specified topic because of the challenges with organizing thoughts and putting these in an understandable sequence on paper).





People with autism may also have difficulty with respect to ‘theory of mind’, or the ability to recognize various mental states (beliefs, intentions, knowledge, etc.) in themselves and others, and to understand that others might have beliefs, desires and intentions that differ from their own. While understanding the role of theory of mind is still an evolving area of science, it is worth noting that perspective taking is often an area of great challenge to individuals with all forms of autism, socially, emotionally and even linguistically (e.g. ‘when is I you and you me?’).

Cognitive Impairment

While average or above average intelligence is intrinsic to the definition of Asperger Syndrome and usually recognized in individuals characterized as having High Functioning Autism, according to most research, some degree of cognitive impairment has been shown in a majority of individuals with classic autism. Formal testing often shows significant variability, with some areas at normal levels and others weak. For example, a student with autism may do well on the parts of an intelligence test that measure visual and problem solving skills, but earn low scores on the language subtests. Significantly language-disordered students who are assessed using non-verbal tests often show markedly higher intelligence scores than when a verbally based test is used.

Many individuals with autism learn at a rate slower than those of their peers, but the specific percentage of those with mental retardation is poorly understood. Intelligence is extremely difficult to assess due to challenges in communication and attention. In addition, while true intelligence is believed to be static (IQ should not change as a person ages and is educated), significant changes in IQ in young children with autism who have received intensive interventions indicates that testing at a particular point in time might not be a true representation of long-term potential. In a particular child, functional, adaptive or problem solving skills can greatly exceed those measured on a test, and more educators are experiencing the intelligence (and language) trapped within nonverbal children once they are given alternative modes of communication and access.

From an intervention standpoint, it is always best to assume intellect and know that every individual deserves the opportunity to learn and reach his fullest potential.

Motor Challenges

Many people with autism experience challenges with muscle tone and/or coordination that can affect their ability to function at age appropriate levels. In some, the difficulty is in motor planning and execution. This can extend from speech to gross motor activities.

Impairments in the ability to coordinate and perform purposeful movements in the absence of motor or sensory impairments are termed dyspraxia (disordered ability) or apraxia (absence of this ability). If a child has apraxic or dyspraxic speech, the brain’s ability to plan the movement of the lips, jaw, and tongue may make intelligible speech incredibly difficult, even if he has intact language and knows what he wants to say.

In others, muscle tone might be intact, but he may have challenges in timing and the ability to attend. Sports can be difficult, and fine motor tasks (buttoning, handwriting, using utensils and tools) often require intervention and support using occupational therapy techniques. Some children have difficulty in understanding where their body is in





space (a sensation that comes automatically to the rest of us), which is extremely disconcerting when moving throughout the environment, navigating stairs, balancing on a bicycle, or even walking down a hallway without ‘checking in’ with the location of the wall. The communicative, social and behavioral implications of imprecise timing and motor abilities are worth considering when planning for and interacting with a student. There may be specific strategies recommended by the speech pathologist or occupational therapist supporting the team in addressing these issues.

Emotional Issues, including Anxiety & Stress

Imagine being in another country with a different language and markedly different cultural conventions. If the world were swirling all around and language, gestures, schedules and signs made no sense, anxiety would likely result. With no one to tell and no way to ask for help, that anxiety might increase.

Anxiety and stress are very real byproducts of the challenges of autism. Understanding this while interacting with and supporting students will be helpful. Many of the strategies suggested in this tool kit are helpful in reducing these feelings in learners with autism. Recognizing that many of the ‘behaviors’ of autism may also be signs of stress or anxiety (pacing, distractibility, acting out, nail biting, repetitive actions, etc.) may help in determining the supports needed for an individual student.

The same biochemical differences that might cause anxiety in the general population can be present in individuals with autism. Autism spectrum disorders can co-occur with other behavioral, mood and anxiety disorders, which are more likely to be diagnosed separately as a student ages and reaches adolescence. Co-occurring conditions may respond to therapies or may present additional considerations for the team.





Unique Abilities That May Accompany Autism

Some individuals with autism possess unusual skills and exceptional abilities. While true savants (savant syndrome describes a person with a mental deficit who has one or more genius level abilities) are rare, many individuals with autism have strengths that may make them unique or interesting.

Some of the strengths some people with autism possess are outlined here. While it is important to never assume that any individual student has any or all of these strengths, awareness that a student has a skill such as one described here might create an opportunity to form a connection, to motivate or reward attention to more difficult challenges, or to use that strength in overcoming other areas of deficit.

Some of the strengths you may see in people with autism – Adapted from *A Parent's Guide to Asperger's Syndrome and High Functioning Autism* by Sally Ozonoff, Geraldine Dawson, and James McPartland:

- Strong visual skills
- Ability to understand and retain concrete concepts, rules, sequences and patterns
- Good memory of details or rote facts (math facts, train schedules, baseball statistics)
- Long-term memory
- Computer and technology skills
- Musical ability or interest
- Intense concentration or focus, especially on a preferred activity
- Artistic ability
- Mathematical ability
- Ability to decode written language (read) at an early age (but not necessarily comprehend)
- Strong encoding (spelling)
- Honesty
- Problem solving ability (when you cannot ask for something you want, you can get pretty creative about getting your hands on it yourself.)

Often the unique talents of people with autism are a reflection of the focus they place on a particular area, and how much it interests them. If sorting out the days on a calendar helps provide structure and predictability to an otherwise confusing world, then it might make sense that an individual would be able to memorize incredible amounts of information and be able to tell the day of the week on which a person was born, when provided the date. Inherent to the development of these exceptional skills is the individual's understanding of the processes and patterns involved, and the motivation to focus on them - absolutely critical features to keep in mind when undertaking the task of teaching something new. Breaking down tasks into understandable components, and providing motivational support (remembering that what motivates a child with autism may be different from what motivates a typical child) will help expand a student's set of skills and strengths.





Specific Features of Asperger's Syndrome

Asperger's Syndrome is a neurological disorder on the autism spectrum named after the Austrian pediatrician Hans Asperger, who first described a group of children who had a similar set of behavioral features. People with Asperger's Syndrome have difficulties with social interaction and restrictive or repetitive behaviors, but in contrast to those with classic autism, they do not have delays in language development or evident cognitive delays. Most achieve their early developmental milestones and academic targets on time. Many having IQs in the superior range. As a result of this more subtle presentation, people with Asperger's Syndrome are usually diagnosed later than those with autism, sometimes even in adolescence or adulthood. Asperger's Syndrome is diagnosed in boys approximately ten times more often than in girls.

People with Asperger's Syndrome find it challenging to connect with others, often having difficulty maintaining eye contact, reading other people's facial expressions or body language and taking another's perspective. While they develop language in a typical timeframe and their vocabulary might actually be advanced, they have difficulty understanding the subtle aspects of communication - reading gestures, understanding idioms, recognizing and expressing emotions, and flowing with the social back and forth of communication. Language is usually interpreted very literally, so idioms and sarcasm can be very confusing. Many learn to read easily and early, but decoding skills often obscure significant challenges with comprehension and contextual understanding. Students with Asperger's are usually highly verbal, saying things others have learned to keep to themselves (thereby appearing rude) or producing lengthy dissertations on favored topics (e.g. New York City's train schedules) without the realization that the information is of no interest to those around him. These traits make students with Asperger's particularly vulnerable to bullying.

Sensory processing differences and motor difficulties - issues with attention and timing, clumsiness and low muscle tone - are often present, making social connections through play and sports even more challenging. Organization and attention are often disordered, and most students with Asperger's Syndrome experience ever-present anxiety. Extreme adherence to rules, routines and favored activities or topics often make transitions, changes and flexibility (such as playing a game according to another child's method) extremely difficult and distressing.

Since the challenges presented vary considerably from those of classic autism, the needs of students with Asperger's Syndrome often go unaddressed, leading to increasing isolation and anxiety. Skill deficits with organization and attention - especially in an intellectually gifted child - are often misinterpreted as lack of effort or interest and the student is often penalized, rather than taught the isolated skills. Without failing grades, fine motor issues related to shoe tying or penmanship might not be addressed with occupational therapy and the intricacies of conversational reciprocity might not be addressed in speech therapy sessions. In fact, because of frequent success with typical standards of evaluation (learning factual information, processes and academics), the needs of students with Asperger's Syndrome are often overlooked and inappropriately supported.

As students age and become aware of their differences, anxiety often increases and depression might develop. Again, bullying is common, as naïve students without self-advocacy skills or desperate for friendships become victims. Educating peers and fostering emotional literacy, self awareness and development of the skills required to develop peer relationships can go a long way in helping to create a successful student.

For more information on Asperger's Syndrome, see the [Organization for Autism Research's Steps to Success](#).

