

What is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) is comprised of several conditions that center around challenges with social skills, repetitive behaviours, speech and nonverbal communication. The exact cause of autism is unknown and while there are many subtypes of autism influenced by genetic and environmental factors, science has confirmed that **vaccines do not cause Autism**. In 2013, the American Psychiatric Association merged autistic disorder, childhood disintegrative disorder, pervasive developmental disorder- not otherwise specified (PDD-NOS), and Asperger syndrome under the umbrella of diagnosis of autism spectrum disorder (ASD).

As a spectrum disorder, individuals experience many differing strengths and challenges in areas such as the way one learns, thinks, and problem solves. Individuals support needs will also vary. It is also important to note that while individuals with ASD experience many challenges, they also experience positive outcomes such as outstanding achievements from specialized interests, original ideas as a result of viewing the world from a different perspective, and unique approaches to problem solving.

The development of ASD is influenced by several factors, and early intervention leads to positive outcomes later in life. Signs usually appear by age 2 or 3 with some developmental delays appearing as early as 18 months.

Individuals with ASD process information differently and as such may be hypo- or hypersensitive to sights, sounds, smells, touch and/or taste. Some individuals with ASD may also experience synaesthesia in which senses are mixed. For example, seeing colours when hearing sounds or 'tasting' musical notes.

ASD is often accompanied by sensory sensitivities and medical issues such as:

- Gastrointestinal disorders
- Sleep disorders
- Attention challenges
- Seizures
- Anxiety
- Depression

Signs of Autism and Diagnosis

Professional evaluation is critical in the diagnosis of ASD as the intensity of early signs and diagnosis age vary. Some individuals do not show all the signs and many individuals without autism may exhibit a few. Generally, referrals for a diagnostic assessment to achieve diagnosis are made by a family doctor, pediatrician, or psychiatrist. The assessments often include a multidisciplinary team that includes a specially trained physician, psychologist, speech language pathologist and occupational therapist.

Some indications of ASD are:

By 6 months: limited/ no eye contact, few/ no big smiles, or other warm, engaging and joyful expressions

By 9 months: little/ no back and forth sharing of sounds, smiles or other facial expressions

By 12 months: Little or no babbling, back and forth gestures, response to name

By 16 months: very few/ no words

By 24 months: very few/ no meaningful 2-word phrases (not including mimicking or repeating).

At any age:

- Loss of previous speech, babbling, social skills.
- Avoidance of eye contact.
- Persistent need to be alone.
- Difficulty understanding others' feelings.
- A delay in language development.
- Echolalia- repetition of words/ phrases
- Resistance to minor change in routine and surroundings.
- Restricted interests.
- Repetitive behaviours such as flapping, rocking, spinning etc.
- Unusual and intense reaction to sounds, smells, tastes, textures, lights, and/or colours.

Severity Levels for ASD

Severity Level	Social Communication	Restricted & Repetitive Behaviours
<p>Level 1- Requiring support</p>	<ul style="list-style-type: none"> • Noticeable impairment without supports. 	<ul style="list-style-type: none"> • Inflexibility of behaviour results in significant interference in functioning in one or more contexts. • Difficulty switching between activities. • Organization and planning challenges create a barrier to independence.
<p>Level 2- Requiring substantial support</p>	<ul style="list-style-type: none"> • Social impairments apparent even with supports in place. 	<ul style="list-style-type: none"> • Inflexibility of behaviour, difficulty coping with change or other restricted/repetitive behaviours are frequent enough to be noticed by casual observer and interfere with functioning in many contexts. • Distress/ difficulty changing focus or attention.
<p>Level 3 - Requiring very substantial support</p>	<ul style="list-style-type: none"> • Severe impairments in functioning caused by severe deficits in verbal and nonverbal communication skills. • Initiation of social interactions and response to the social efforts of others is very limited. 	<ul style="list-style-type: none"> • Inflexibility of behaviour • Extreme difficulty coping with change. • Repetitive and restricted behaviors interfere with functioning in all contexts. • Extreme distress/ difficulty changing focus or attention.



Communication Devices and Strategies

Speech Language Pathologists (SLP) will perform augmentative and alternative communication interventions (AAC) evaluations to help determine the best communication options for the individual. These options may include:

1. Sign Language- often Signing Exact English (SEE) is the form of sign language most often used by individuals with autism. This option is practical and functional as it requires no props and is recognized globally. Individuals who are visual or tactile learners will adapt easier to learning sign language than auditory learners.
2. Gestures- can be used as an alternative to sign language. However, as some individuals may have challenges connecting specific gestures to phrases or needs, the caregivers and parents must be aware of each gesture's meaning.
3. Visual boards- help with expression of emotions, preferences, rules and schedules. The boards consist of pictures often attached by Velcro or other adhesives that can be pointed to or arranged in order. The array of images grows along with the individual's skill level.
4. Picture exchange communication system (PECS)- broken into 6 progressive phases that can teach functional communication and in some cases develop speech.

6 Phases of PECS are:

1. How to communicate
 2. Distance and persistence
 3. Picture discrimination
 4. Sentence structure
 5. Responsive requesting
 6. Commenting
5. Low technology AAC interventions- are used most often as aids to already developed language skills and are often parts of a whole system such as the Velcro in a visual board or an adaptive writing tool.
 6. High technology interventions- help to vocalize speech for those able to type or identify pictures. There are currently apps readily available as an alternative to the more complex and sometimes expensive devices. This method of communication may take several months or years for the child to learn to use at a high level.

Wandering

The occurrence of an individual to wander off is common for children with ASD. It is also dangerous and incredibly stressful for families.

6 tips to help prevent wandering:

1. Secure your home with key locks on both sides of a doorway, an alarm system, inexpensive battery-operated alarms on doors, or hook and eye locks above reach. Fencing around your yard, along with printable stop signs on doors, windows, and other exits, are also helpful.
2. Consider a radio or GPS tracking device worn on the wrist or ankle such as Project Lifesaver or LoJak SafetyNet services. Information is available through local law enforcement.
3. A Medical ID bracelet including name, telephone number and other important information such as that the child has ASD and if they are nonverbal. A temporary tattoo if the child will not wear a necklace or bracelet is also an alternative.
4. Swimming lessons that include a final lesson with the child's clothes on can be invaluable. Lessons can be available at many YMCA locations.
5. Meet with your neighbours to introduce the child or provide a photo and explain there may be instances of wandering.
6. Provide first responders, caregivers, neighbours, friends, and coworkers with handouts that contain key information before an incident of wandering occurs.

Recreation

Recreational activities are important for individuals with ASD as it provides opportunities to practice social skills, physical aptitude, and motivation - all of which increase self-confidence and help individuals develop general skills that can be applied in a variety of settings, such as work or school.

Benefits include:

- The promotion of inclusion and quality of life through opportunities to make friends and become involved in the community.
- Increased confidence, self-esteem, satisfaction, enjoyment, independence, and increased opportunities to make their own choices.
- Reduces the reliance on parents and other adults.
- Improved physical and mental health.

Examples of recreational activities include:

1. Hobbies

- Stamp collecting
- Playing cards/board games
- Drawing
- Photography

2. Individual Sports

- Track
- Skiing
- Hiking
- Golf
- Cycling
- Cross country

3. Team Sports

- Hockey
- Baseball
- Soccer
- Football
- Scouts

Recreation Therapists or Therapeutic Recreation Specialists use a variety of techniques to provide treatment services and recreational activities that will improve and maintain mental, physical, and emotional well-being, reduce stress and anxiety, build confidence and learn effective socialization to support independence and community integration. These activities include:

- Arts and crafts
- Games
- Music
- Animals
- Dance and movement
- Community outings
- Sports
- Drama

Travel

Changes in routine, crowds, new noises, sights, and smells can make travel challenging for individuals with ASD and their families.

10 Tips for Travel:

1. Use teaching stories and if possible, a 'dress rehearsal' to aid the individual in becoming prepared and comfortable with the new experiences (sounds, sights, smells) that may cause anxiety during travel.
2. Contact guest services at the airports, train stations, hotels etc. before the trip to arrange assistance such as advanced boarding, special meals, rental equipment, or service animals.
3. Providing choices can help the individual maintain a feeling of control. An example may be allowing them to pack their own travel pack with items that comfort them and provide stress/ boredom relief during 'wait' times.
4. Prepare for sensory concerns by providing earplugs or noise cancelling headphones for unfamiliar noises. Early or late boarding can also aid with wait times and crowds. Seats in the front of a plane, bus or train can reduce the feeling of being cramped or crowded.
5. Employ wandering safety plans and protection measures.
6. Prepare the environment ahead of time by requesting a quiet room that has all the equipment for an individual's needs. An example may be a refrigerator if there are specific dietary needs. Ask about safety precautions such as door alarms, pool access etc.
7. Organize a family watch system whereby a rotation of persons will take turns to provide one to one supervision of the individual with ASD. This reduces stress and anxiety and provides peace of mind.
8. Provide rewards and positive reinforcement for good behaviours such as wearing a seatbelt or sitting quietly.
9. While on the trip keep to a routine as much as possible and make sure to include any items that can be packed to support the routine are brought along on the trip.
10. Create a schedule to facilitate a routine while on the trip such as scheduled mealtimes, times for sightseeing or travel etc.

Eating Out

Mealtime is a critical aspect of routine for those with ASD. Preparation is key to reducing anxiety caused by the disruption of a routine when eating in a restaurant. Take into consideration before going out the choice of restaurant aspects such as:

- Is it an over-stimulating environment?
- Is it a new place?
- What is on the menu? Are favorite/familiar foods available?
- Wait times.
- Reservation options.
- Time of day.

There are several areas of skill one can work on to make eating out a less stressful experience. Each individual's needs must be taken into consideration when building these skills and may include:

- **Waiting-** to order, for food arrival, for others to finish eating.
- **Ordering-** food/ meal choice, speaking at appropriate volume with appropriate language.
- **Sitting appropriately-** upright, hands down in absence of non-contextual vocalizations and without inappropriate movements.
- **Table manners-** pace, utensil, and napkin use, chewing with mouth closed.
- **Social skills-** conversation, use of "please," "thank you," and "excuse me." Commenting on food choice and acceptance if food choice is unavailable.
- **Other skills-** use of public restrooms.



Social Communication

Often individuals with ASD also have delays in language skills and may have difficulty expressing themselves properly. This can include articulating what they want from you as well as understanding what you want from them.

- Speech is different (tone articulation, volume).
- Challenges with eye contact.
- Challenges understanding others' emotions and interpreting social cues.
- Intense interests in specific topics may cause an individual with ASD to steer a conversation to areas that interest them and may result in the conversation extending too long as the person does not immediately recognize a social cue for boredom or uninterest.
- Absolute honesty is often displayed.

Key Approaches to Navigation

- When available, understand the degree of ASD, as it varies for each individual.
- Accept their behaviours and language patterns.
- Presume competence – an individual that cannot speak may still have comprehension.
- Ensure the individual has communication options available.
- Listen carefully to how the individual is speaking and be cognizant of key words and phrases.
- Adjust your language level as needed.
- Speak slower, give time to process and respond.
- Use simple concrete language- no metaphors or abstract concepts.
- Be patient and give the individual space.
- Avoid quick movements, loud noises, and touching unless necessary.
- Be alert to signs of frustration and eliminate the source, if possible, to avoid an escalation in behaviours.

Restricted Behaviours

Understand that routine and rules are comforting for an individual with ASD. Specific rituals or schedules are often needed, and unknown and unexpected situations might cause the person to become confused, overwhelmed or upset and may cause them to shut down. One can help someone with ASD prepare in advance for these situations by providing them with details such as things they may encounter and what they should expect. Visuals such as pictures or a 'dress rehearsal' or 'run through' may also be helpful in reducing stress and anxiety that may result from a change in routine or a new experience.

Repetitive Behaviours

Are used as a calming mechanism and are often referred to as self-stimulation or 'stimming.' It is important to understand these behaviours and accept them instead of becoming upset with the individual or trying to stop them.

Repetitive behaviours may include:

- Flapping
- Lining up objects
- Carrying familiar items
- Bouncing of the leg(s)
- Clapping
- Rocking
- Excessive or hard blinking
- Pacing
- Head banging
- Repeating noises or words
- Snapping fingers
- Spinning objects