

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a complex, lifelong neurological disorder that affects the functioning of the brain. Symptoms of ASD typically appear during the first three years of life. ASD crosses all cultural, ethnic, geographic and socioeconomic boundaries.

Autism Spectrum Disorder is one of the most common developmental disabilities. Data from the Canadian National Autism Spectrum Disorder Surveillance System indicated that 1 in 66 children or youth (ages 5-17) are diagnosed with ASD (March 2018). The Centre for Disease Control and Prevention (CDC) in the USA reported a prevalence rate of 1 in 54 births in 2020. In Ontario, it is estimated that there are more than 135,000 individuals diagnosed with ASD. While most people now recognize the term “Autism” many people including many professionals in the medical, educational and vocational fields are still not clear how ASD affects people and how they can effectively support individuals with ASD.

As the term “spectrum” applies ASD represents a wide range severity and ability. The ways in which ASD affects individuals varies widely. While all share common challenges related to social communication and behavior, no two people with ASD present as exactly the same. “If you have met one person with ASD, you have met one person with ASD.” (Dr. Stephen Shore, Self-advocate).

Impact of ASD

ASD impacts the development of the brain in the areas of social interaction, communication skills and patterns of behaviour. Children and adults with ASD typically have difficulties in verbal and non-verbal communication, social interactions, leisure or play activities and flexible behaviour. They often have difficulty communicating with others and relating to the world around them. Repetitive and restricted patterns of behaviour are often present and, in some cases, aggressive and/or self-injurious behaviour may occur. People with ASD may exhibit repeated body movements (hand flapping, rocking), unusual responses to people, unusual attachments to objects and resistance to changes in routines. Individuals may also experience different responses to sensory input including sight, hearing, touch, smell and taste. Children within the ASD may appear to be developing typically until the age of 24-30 months when parents become concerned about delays in language, play or social interactions.

How is ASD Diagnosed?

Diagnostic evaluations are based on the presence of specific patterns of behaviour and impairments in social/communication indicated by observation and through parent consultation and should be made by an experienced, highly trained team.

Diagnostic Criteria

In North America, the diagnosis of Autism Spectrum Disorder is based on criteria identified in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

(DSM-V) published by the American Psychiatric Association in 2013. The diagnostic criteria identifies two categories of impairment; Social Communication and Restricted and Repetitive Behaviours, Interests or Activities) with specific characteristics in each category.

The first category requires persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

- Deficits in social-emotional reciprocity,
- Deficits in nonverbal communicative behaviours used for social interaction,
- Deficits in developing, maintaining, and understanding relationships.

The second category requires restricted, repetitive patterns of behaviour, interests, or activities as manifested by at least two of the following, currently or by history:

- Stereotyped or repetitive motor movements, use of objects or speech,
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour,
- Highly restricted, fixated interests that are abnormal in intensity or focus,
- Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

Additional Criteria

Additionally, the following criteria are identified:

- The symptoms must be present in the early developmental period
- Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning
- These disturbances are not better explained by intellectual disability or global developmental delay. Social communication should be below that expected for general developmental level

Diagnostic Specifiers

Diagnosis also includes the following specifiers:

- With or without accompanying intellectual and/or language impairment
- Association with a known medical, genetic condition, or environmental factor
- Association with another neurodevelopmental, mental, or behavior disorder or catatonia
- Severity of expression from Level 1 to Level 3

Severity Levels

Finally, there are three identified severity levels which address the degree to which the characteristics have an impact on daily life and the supports that an individual may

require and are rated separately for social communication difficulties and restricted, repetitive behaviours:

- Level 3 - Requiring very substantial support
- Level 2 - Requiring substantial support
- Level 1 - Requiring support

It is important to remember that there is no standard “type” or “typical” person with ASD. Although the formal diagnostic term is ASD, parents may hear different terms used to describe children within this spectrum, such as: autistic, autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, more-able or less-able ASD or Aspergers Disorder. Regardless of the label, all children with ASD can learn, show gains from appropriate education and treatment and lead functional, productive lives.

What Causes ASD?

Research occurring around the world is exploring different explanations for the various forms of ASD.

Although a single specific cause of ASD has not been identified, current research links ASD to biological or neurological differences in the brain. At this time, no single gene has been directly linked to ASD. Research suggests that ASD develops from a combination of genetic and environmental influences which increase the risk that a child will develop ASD. The genetic basis is believed by researchers to be highly complex, probably involving several genes in combination.

Research shows that ASD tends to run in families. Changes in specific genes increase the risk that a child will develop ASD. If a parent has one or more of these gene changes, they may get passed on to the child even if the parent does not have ASD. At other times, the gene changes may occur spontaneously in either the sperm or egg or early in embryonic development. Research also shows that certain environmental influences may further increase the risk for those with a genetic predisposition.

Other key facts related to the cause of ASD include:

- ASD is not a mental illness and is not caused by trauma
- Children with ASD are not just badly behaved children
- ASD is not caused by bad parenting

What are Some Common Characteristics of People with ASD?

The following are some examples of some characteristics commonly seen in individuals with ASD. Individuals will demonstrate some, not all, of these characteristics and will present with their own unique profile. Every person with ASD is an individual and there are vast differences among people with ASD.

- Communication: language develops slowly or not at all; uses words without attaching the usual meaning to them; struggles to communicate with gestures

instead of words; short attention span; difficulty using and understanding non-verbal communication; difficulty initiating and/or maintaining a conversation;

- Social Interaction: spends time alone rather than with others; shows little interest in making friends; less responsive to social cues such as eye contact or smiles
- Sensory Processing Difficulties: may process sensory information differently; may be more or less sensitive in the areas of sight, hearing, touch, smell, and taste
- Play: lack of spontaneous or imaginative play; may not imitate others' actions, may not initiate pretend games, uses toys and objects in a repetitive, rigid fashion
- Behaviour: may be overactive or very passive; may throw tantrums for no apparent reason, may show an obsessive interest in a single item, idea, activity or person; apparent lack of common sense; may show aggression to others or self; often has difficulty with changes in routine.
- Anxiety: may experienced generalized anxiety or specific anxieties or phobias; may be apparent in childhood or appear during adolescence; may be severe enough to impact functioning

Other Disorders Which May Co-Occur

Some individuals with ASD may also have other disorders which affect the functioning of the brain such as: Epilepsy or Down Syndrome or genetic disorders such as Fragile X syndrome, Landau-Kleffner Syndrome, William's Syndrome or Tourette's Syndrome. Many of those diagnosed with ASD will also test in the range of developmental disability. Approximately 25-30 percent of individuals diagnosed with ASD may develop a seizure pattern at some time during their life.

Contrary to popular understanding, many people with ASD may make eye contact, show affection, smile and laugh and demonstrate a variety of other emotions, although in varying degrees. Like other people, they respond to their environment in both positive and negative ways. ASD may affect their range of responses and make it more difficult to control how their bodies and minds react.

Sometimes visual, motor and/or processing problems make it difficult to maintain eye contact with others. Some individuals with ASD may use peripheral vision rather than looking directly at others. Sometimes the touch or closeness of others may be painful to a person with ASD resulting in withdrawal even from family members. Anxiety, fear and confusion may result from being unable to "make sense" of the world in a routine way.

What Does the Future Hold for People with ASD?

Individuals with ASD can learn when educators and other service providers consider information about their unique patterns of learning strengths and difficulties when developing and implementing their programs. The abilities of an individual with ASD may fluctuate from day to day due to difficulties in concentration, processing or anxiety. The person may show evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning. They may have average or above average verbal,

memory or spatial skills but find it difficult to be imaginative or join in activities with others. Individuals with more severe challenges may require intensive support to manage the basic tasks and needs of living day to day.

Changes Over Time

With appropriate treatment some behaviours associated with ASD may change or diminish over time. The communication and social deficits can persist and often require daily effort on the part of the individual to mediate these challenges throughout life. Difficulties in other areas may fade or change with age, education, or level of stress. Often, the person begins to use skills in natural situations and to participate in a broader range of interests and activities. Many individuals with ASD enjoy their lives and contribute to their community in a meaningful way. People with ASD can learn to compensate for and cope with their disability, often quite well.

Adult Life

While no one can predict the future for any one individual some adults with ASD successfully live and work independently in the community (drive a car, earn a college degree, get married, have children.) Others may need significant support from family and professionals. Adults with ASD can benefit from vocational training to provide them with the skills needed for obtaining jobs, in addition to social and recreational programs. Adults with ASD may live in a variety of residential settings ranging from an independent home or apartment to group homes, supervised apartment settings, living with other family members or more structured residential care.

Self-Advocacy

An increasing number of support groups for adults with ASD are emerging around the country. Many self-advocates are forming networks to share information, support each other and speak for themselves in the public arena. More frequently, people with ASD are attending and/or speaking at conferences and workshops on autism. Individuals with autism are providing valuable insight into the challenges of this disability publishing articles and books and appearing in television specials about themselves and their disabilities.

What are the Most Effective Approaches?

Evidence shows that early intervention results in dramatically positive outcomes for young children with ASD. While various pre-school models emphasize different program components, all share an emphasis on early, appropriate and intensive education interventions for young children.

Common Factors in Effective Intervention

Common factors that contribute to the effectiveness of any intervention are: an emphasis on communication skills, some degree of inclusion, interventions based on applied

behaviour analysis, programs that build on the interests of the child, extensive use of visuals to accompany instructions, highly structured and predictable schedules of activities, parent and staff training, transition planning and follow-up.

Types of Therapies

The spectrum nature of ASD and the many behaviour combinations which can occur means that no one approach is effective in alleviating symptoms of ASD in all cases. Various types of therapies are available including (but not limited to) applied behaviour analysis, auditory integration training, dietary interventions, discrete trial teaching, medications, music therapy, occupational therapy, PECS, physical therapy, sensory integration, speech/language therapy, communication and social skills training and TEACCH.

Common Elements of Effective Therapies

Studies show that individuals with ASD respond well to a highly structured, specialized education program tailored to their individual needs. A well designed intervention approach may include some elements of communications therapy, social skill development, sensory integration therapy and applied behaviour analysis delivered by trained professionals in a consistent, comprehensive and coordinated manner.

To be effective, any approach should be flexible in nature, rely on positive reinforcement, be re-evaluated on a regular basis and provide a smooth transition from home to school to community environments. A good program will also incorporate training and support systems for parents and caregivers to ensure consistency and help with generalization of skills to all settings.

Education Approaches

The more severe challenges of some children with ASD may be best addressed by a structured education and behaviour program, which contains a one-on-one teacher to student ratio or small group environment. However, many other children with ASD may be successful in a fully inclusive general education environment with appropriate support.

In addition to appropriate educational supports in the area of academics, students with ASD should have training in functional living skills at the earliest possible age. Learning to cross a street safely, to make a simple purchase or to ask for assistance when needed are critical skills, and may be difficult, even for those with average intelligence levels and good communication skills. Tasks that enhance the person's independence and give more opportunity for personal choice and freedom in the community are important.

Long-Term Outlook

Generations ago, the vast majority of the people with ASD were eventually placed in institutions. Professionals were much less educated about ASD than they are today. Supports and services specifically for people with ASD were largely non-existent. Today,

the picture is brighter. Most families are able to support their child at home with appropriate services, training and information and there are more options for out of home support. Programs, supports and services designed for people with ASD provide the opportunity for individuals to be taught skills and allow them to reach their fullest potential.

Impact on Families

The families of people with ASD can experience high levels of stress. Families often have difficulty participating in typical community activities due to a variety of factors including the challenging behaviours of their children, the demands of relationships with service providers, difficulties securing appropriate services, resulting financial hardships and/or very busy schedules,. This often results in isolation and difficulty in developing needed community supports.

Is There a Cure for ASD?

Our understanding of ASD has grown tremendously since it was first described by Dr. Leo Kanner in 1943. To cure means “to restore to health, soundness, or normality.” So, in the medical sense, there is no cure for the differences in the brain as a result of ASD. However, better understanding of the disorder has led to the development of better coping mechanisms and strategies for the various manifestations of the disability. Some symptoms may lessen as the child ages; others may disappear altogether. Many of the associated skills deficits and behaviours can be positively changed with appropriate intervention. In some cases, the person may appear to the untrained person to no longer have ASD. The majority of children and adults will, however, continue to manage some manifestations of ASD to some degree throughout their entire lives.