



About Autism Spectrum Disorder

About this section

Understanding Autism Spectrum Disorder can be complex and overwhelming. In this section, we will outline how ASD is defined, characteristics, prevalence, statistics and general information to help better understand the disorder. Autism is considered to be a “spectrum” disorder because there is vast variability in how autism presents in every individual. As well, there are many commonly associated health issues that an individual may experience. While the information in this section provides general information, it is important to remember that every individual with ASD is unique and different. Due to this, support for every individual will be different based on their abilities and areas of need. Customized plans of care are critical for individuals and families to get the proper supports.

Receiving an autism diagnosis can result in variety of challenges for families including family stress, significant financial challenges, and mental health issues. It can also result in a number of emotions including confusion, anxiety and fear. This tool kit was developed to provide information to help with these challenges and emotions.

What is Autism Spectrum Disorder (ASD)?

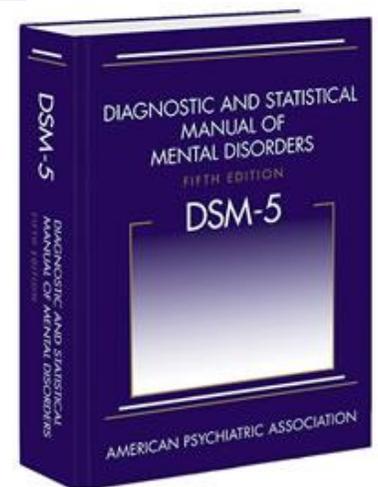
Autism Spectrum Disorder (ASD), generally referred to as autism, is a neurodevelopmental disorder characterized by challenges, in varying degrees, in social interaction, language and communication and repetitive and restrictive behaviours (DSM-5, 2013). Autism is a lifelong disorder and is currently diagnosed in 1 in 66 children and youth between the ages of 5-17 years in Canada (PHAC, 2018) making it *the fastest growing and most commonly diagnosed neurodevelopmental disorder today*.

Parents are usually the first to notice early signs of autism in their child. You may have noticed your child was developing differently from his or her peers. These differences may have been subtle or quite obvious. Sometimes these differences are noticeable from birth and other times they may have become more noticeable later on. You may have wondered if it is important for your child to receive a diagnosis. A thorough and detailed diagnosis provides important information about your child's development and behaviour. It can also create a roadmap for treatment by identifying your child's strengths and challenges and providing useful information about which needs and skills should be targeted for effective treatment. A diagnosis is often required to access autism-specific services through early intervention programs or your local school district. This tool kit will cover some useful information primarily focused on children. For additional resources related to adults with autism and additional information, please see our additional 41 tool kits available for free download at www.autismspeaks.ca.

HOW IS AUTISM DIAGNOSED?

Signs of ASD are typically detected in early childhood and a diagnosis can reliably be made by the age of two. A formal diagnosis is made from a series of observations and screening measures. There is currently no blood test or medical test that can detect autism. In Canada, a medical doctor such as a general practitioner, pediatrician, psychiatrist as well as psychologists are permitted to give a formal diagnosis. Other professionals such as social workers, occupational therapists and speech-language pathologists may support a diagnosis by providing their professional opinion about the individual. A variety of screening tools are available to use for a diagnosis.

In Canada, the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used to evaluate autism spectrum disorder. In 2013, the DSM-5 merged all autism disorders into one umbrella diagnosis of Autism Spectrum Disorder (ASD). Under the DSM-5, the diagnosis of autism requires that at least six developmental and behavioural characteristics are observed, that concerns are present before the age of three and that there is no evidence of certain other conditions that are similar (DSM-5, 2013).



There are two domains where people with ASD must show persistent deficits:

- (i) social communication and social interaction
- (ii) restricted and repetitive patterns of behaviour

Figure 1.1 outlines the Diagnostic Criteria as outlined in the DSM-5:

Figure 1.1

Autism Spectrum Disorder 299.00 (F84.0)

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) **(Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2: Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and- fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

(DSM-5, 2013).

Early Childhood Milestone Map

Each child develops at his/her own pace, so it may be difficult to tell exactly when yours will learn a given skill. These developmental milestones are designed to give you a general idea of the changes you can expect as your child grows.

By 3 to 4 Months

- Watches faces with interest and follows moving objects
- Recognizes familiar objects and people; smiles at the sound of your voice
- Begins to develop a social smile
- Turns head toward sounds



By 7 Months

- Responds to other people's emotions
- Enjoys face-to-face play; can find partially hidden objects
- Explores with hands and mouth; struggles for out of reach objects
- Uses voice to express joy and displeasure; babbles chains of sounds

By 2 Years

- Imitates behavior of others; is excited about company of other children
- Understands several words
- Finds deeply hidden objects; points to named pictures and objects
- Begins to sort by shapes and colors; begins simple make-believe play
- Recognizes names of familiar people and objects; follows simple instructions
- Combines 2 words to communicate with others, such as "more cookie?"

By 4 Years

- Cooperates with other children; is increasingly inventive in fantasy play
- Names some colors; understands counting
- Speaks in sentences of 5 to 6 words
- Tells stories; speaks clearly enough for strangers to understand
- Follows 3-part commands; understands "same" and "different"



By 12 Months (1 Year)

- Enjoys imitating people; tries to imitate sounds
- Enjoys simple social games, such as "gonna get you!"
- Explores objects; finds hidden objects
- Responds to "no"; uses simple gestures, such as pointing to an object
- Babbles with changes in tone; may use single words ("dada," "mama," "Uh-oh!")
- Turns to person speaking when his/her name is called

By 3 Years

- Expresses affection openly and has a wide range of emotions
- Makes mechanical toys work; plays make-believe
- Sorts objects by shape and color; matches objects to pictures
- Follows a 2- or 3-part command; uses simple phrases to communicate with others, such as "go outside, swing?"
- Uses pronouns (I, you, me) and some plurals (cars, dogs)



By 5 years

- Wants to be like his/her friends; likes to sing, dance, and act
- Is able to distinguish fantasy from reality
- Shows increased independence
- Can count 10 or more objects and correctly name at least 4 colors
- Speaks in sentences of more than 5 words; tells longer stories



Individuals with autism must demonstrate (either in the past or presently) deficits in social-emotional reciprocity, deficits in non-verbal communicative behaviours used for social interactions and deficits in developing, maintaining, and understanding relationships. In addition, individuals must show at least two types of repetitive patterns of behaviour, including stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests, hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history. The DSM-5 also added an additional category called Social Communication Disorder (SCD). This allows for a diagnosis of disabilities in social communication without the presence of repetitive behaviour.

Autism is a spectrum disorder meaning that it has many forms that affect people in a variety of ways and in varying degrees. Each person's experience with autism presents unique challenges, as well as strengths, which define the type of support needed to lead a fulfilling life.

Once you have received a diagnosis, it is important that you also receive a report that includes the diagnosis in writing and recommendations for treatment.

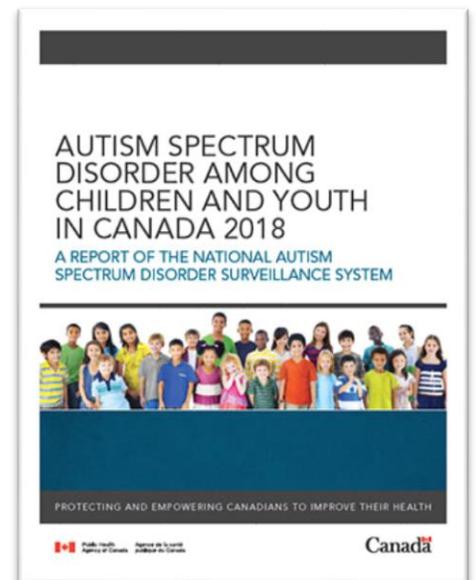
HOW COMMON IS AUTISM?

In March 2018, the Public Health Agency of Canada released its first report of the National Autism Spectrum Disorder Surveillance System indicating that 1 in 66 children and youth between the ages of 5-17 years has autism spectrum disorder. Boys are four times more frequently diagnosed with 1 in 42 males and 1 in 165 females being diagnosed with ASD. The report indicates that 56% of children and youth had received their diagnoses by age 6 and more than 90% of children and youth were diagnosed by age 12 (PHAC, 2018). Through the prevalence reports conducted through the Centre for Disease Control and Prevention in the U.S., there has been a 10-17% increase annually in recent years. As of April 2018, the current U.S. prevalence rate for autism is 1 in 59 children (CDC, 2018).

While IQ, physical and verbal abilities are not within the diagnostic criteria, approximately one third of people with autism are non-verbal, one third of have an intellectual disability and there are many medical and mental health issues which frequently accompany autism, including gastrointestinal (GI) disorders, seizures, sleep disturbances, attention deficit and hyperactivity disorder (ADHD), anxiety and phobias.

WHAT CAUSES AUTISM?

We now know that there is not one autism but many types, caused by different combinations of genetic and environmental influences. As there is no one type of autism, there is also no one cause of autism. Research has identified genetic links related to ASD. In about 15% of cases, a specific genetic cause of an individual's autism can be identified. However, in most cases a combination of genetic and environmental factors are involved in an individual being on the autism spectrum.



1 in 42 males
were diagnosed with ASD

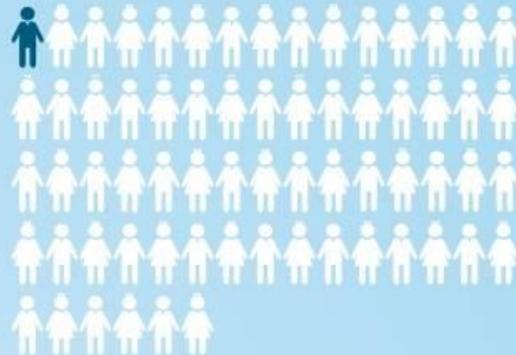
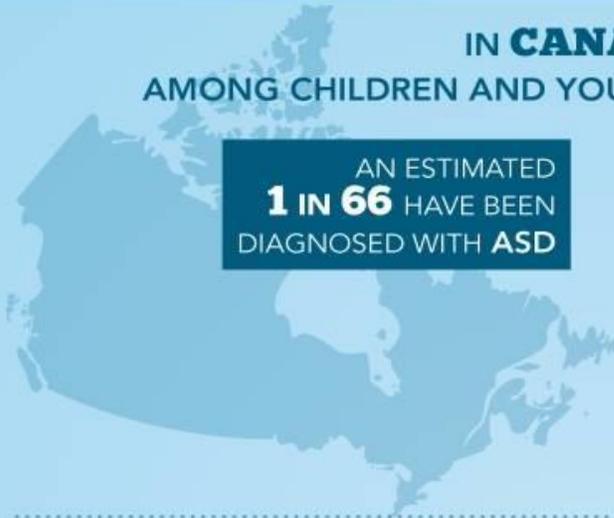


1 in 165 females
were diagnosed with ASD

AUTISM PREVALENCE AMONG CHILDREN AND YOUTH IN CANADA

2018 Report of the National Autism Spectrum
Disorder (ASD) Surveillance System*

IN CANADA,
AMONG CHILDREN AND YOUTH 5–17 YEARS OF AGE:



MALES WERE
IDENTIFIED WITH ASD **4X**
MORE FREQUENTLY
THAN FEMALES



1 IN 42
MALES
WERE DIAGNOSED WITH
ASD



MORE THAN HALF
OF CHILDREN AND
YOUTH HAD RECEIVED
THEIR DIAGNOSIS
BY AGE **6** **56%**



AND MORE THAN
90% OF CHILDREN
AND YOUTH WERE
DIAGNOSED BY AGE **12** **90%**



1 IN 165
FEMALES
WERE DIAGNOSED WITH
ASD

* Report findings are based on 2015 health, education and social services data collected from seven participating provincial and territorial governments (Newfoundland and Labrador, Nova Scotia, Prince Edward Island, New Brunswick, Quebec, British Columbia and the Yukon Territory), representing 40% of children and youth in Canada.

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Read: Autism Spectrum Disorder among Children and Youth in Canada 2018: A Report of the National Autism Spectrum Disorder Surveillance System
www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html

• ASD Data Blog <https://infobase.phac-aspc.gc.ca/datalab/autism-blog-en.html>

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LEARN MORE ABOUT ASD IN CANADA

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Canada

Symptoms of Autism

Autism affects the way an individual perceives the world and makes certain aspects of communication and social interaction challenging. ASD is characterized by social-interaction difficulties, communication challenges and a tendency to engage in repetitive behaviours. However, symptoms and their severity vary widely across these core areas. While autism is usually a lifelong condition, all individuals benefit from proper support that increase skills, abilities and quality of life. Although it is best to begin intervention as soon as possible, the benefits of therapy can continue throughout life and long-term outcomes are highly variable. Many individuals with autism have normal cognitive skills, despite challenges in social and language abilities. As well, many individuals with autism develop speech and learn to communicate with others. Early intervention can make extraordinary differences in your child's development. How your child is functioning now may be very different from how he or she will function later on in life. The following is information on the social symptoms, communication disorders and repetitive behaviours associated with autism.

Social Symptoms

Typically developing infants are social by nature. They gaze at faces, turn toward voices, grasp a finger and even smile by 2 to 3 months of age. By contrast, most children who develop autism have difficulty engaging in the give-and-take of everyday human interactions. By 8 to 10 months of age, many infants who go on to develop autism are showing some symptoms such as failure to respond to their names, reduced interest in people and delayed babbling. By toddlerhood, many children with autism have difficulty playing social games, don't imitate the actions of others and prefer to play alone. They may fail to seek comfort or respond to parents' displays of anger or affection in typical ways. Research suggests that children with autism are attached to their parents. However, the way they express this attachment can be unusual. To parents, it may seem as if their child is disconnected. Both children and adults with autism also tend to have difficulty interpreting what others are thinking and feeling. Subtle social cues such as a smile, wave or grimace may convey little meaning. To a person who misses these social cues, a statement like "Come here!" may mean the same thing, regardless of 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 can seem bewildering. Many people with autism have similar difficulty seeing things from another person's perspective. Most five-year-olds understand that other people have different thoughts, feelings and goals than they have. A person with autism may lack such understanding. This, in turn, can interfere with the ability to predict or understand another person's actions. It is common – but not universal – for those with autism to have difficulty regulating emotions. This can take the form of seemingly "immature" behaviour such as crying or having outbursts in inappropriate situations. It can also lead to disruptive behaviour. The tendency to "lose control" may be particularly pronounced in unfamiliar, overwhelming or frustrating situations. Frustration can also result in self-injurious behaviours such as head banging, hair pulling or self-biting. Fortunately, children with autism can be taught how to socially interact, use gestures and recognize facial expressions. Also, there are many strategies that can be used to help the child with autism deal with frustration so that he or she doesn't have to resort to challenging behaviours.

Communication Difficulties

Young children with autism tend to be delayed in babbling, speaking and learning to use gestures. Some infants who later develop autism ‘coo’ and ‘babble’ during the first few months of life before losing these communicative behaviours. Others experience significant language delays and don’t begin to speak until much later. With therapy, however, most people with autism can learn to communicate. Many nonverbal or nearly nonverbal children and adults learn to use communication systems such as pictures, sign language, electronic word processors or speech-generating devices.

When language begins to develop, people with autism may use speech in different ways that can seem unusual. Some have difficulty combining words into meaningful sentences. They may speak only single words or repeat the same phrase over and over. Some go through a stage where they repeat what they hear verbatim (echolalia). Many people assume that difficulties expressing language automatically means a child isn’t able to understand the language of others, but this is not always the case. It is important to distinguish between *expressive language* and *receptive language*. Children with difficulties in expressive language are often unable to express what they are thinking through language, whereas children with difficulties in receptive language are often unable to understand what others are saying. Therefore, the fact that a child may seem unable to express him or herself through language does not necessarily mean he or she is unable to comprehend the language of others. Be sure to talk to your doctor or look for signs that your child is able to interpret language, as this important distinction will affect the way you communicate with him or her. It is important to understand the importance of pragmatics when looking to improve and expand upon your child’s communication skills. *Pragmatics* are social rules for using language in a meaningful context or conversation. While it is important that your child learns how to communicate through words or sentences, it is also key to emphasize both when and where the specific message should be conveyed. Challenges in pragmatics are a common feature of spoken language difficulties in children with autism. These challenges may become more apparent as your child gets older. Some children exhibit only slight delays in language or even develop precocious language and unusually large vocabularies – yet have difficulty sustaining a conversation. Some children and adults with autism tend to carry on monologues on a favorite subject, giving others little chance to comment. In other words, the ordinary “give-and-take” of conversation proves difficult. Some children with ASD with superior language skills tend to speak like little professors, failing to pick up on the “kid-speak” that’s common among their peers.

Another common difficulty is the inability to understand body language, tone of voice and expressions that aren’t meant to be taken literally. For example, someone with autism might interpret a sarcastic “Oh, that’s just great!” as meaning it really is great. Conversely, individuals with autism may not exhibit typical body language. Facial expressions, movements and gestures may not match what they are saying. Their tone of voice may fail to reflect their feelings. Some use a high-pitched sing-song or a flat, robot-like voice. This can make it difficult for others to know what they want and need. This failed communication, in turn, can lead to frustration and inappropriate behaviour (such as screaming or grabbing) on the part of the person with autism. Fortunately, there are proven methods for helping children and adults with autism learn better

ways to express their needs. As the person with autism learns to communicate what he or she wants, challenging behaviours often subside. Children with autism often have difficulty letting others know what they want or need until they are taught how to communicate through speech, gestures or other means.

Repetitive Behaviours

Unusual repetitive behaviours and/or a tendency to engage in a restricted range of activities are another core symptom of autism. Common repetitive behaviours include hand-flapping, rocking, jumping and twirling, arranging and rearranging objects and repeating sounds, words or phrases. Sometimes the repetitive behaviour is self-stimulating, such as wiggling fingers in front of the eyes. The tendency to engage in a restricted range of activities can be seen in the way that many children with autism play with toys. Some spend hours lining up toys in a specific way instead of using them for pretend play. Similarly, some adults are preoccupied with having household or other objects in a fixed order or place. It can prove extremely upsetting if someone or something disrupts the order. Along these lines, many children and adults with autism require extreme consistency in their environment and daily routine. Slight changes can be extremely stressful and lead to outbursts. Repetitive behaviours can take the form of intense preoccupations or obsessions. These extreme interests can prove all the more unusual for their content (e.g. fans, vacuum cleaners or toilets) or depth of knowledge (e.g. knowing and repeating astonishingly detailed information about Thomas the Tank Engine or astronomy). Older children and adults with autism may develop tremendous interest in numbers, symbols, dates or science topics. Many children with autism need and demand consistency in their environment.

Unique Abilities that May Accompany Autism

Along with the challenges that autism involves, individuals with autism also exhibit considerable areas of strength. It is not uncommon for individuals with autism to have exceptional skills in math, music, art and reading, among others. These areas of expertise can provide great satisfaction and pride for the individual with autism. If possible, incorporate their areas of expertise into his or her everyday activities and use them whenever possible as a way for them to learn and excel.