

Understanding Autism

Snapshot

- Autism is not a mental health problem.
- Not all Autistic people are the same.
- Autistic people have a wide range of abilities and differences.
- Gender, racial, cultural and socioeconomic identities of Autistic people affect their experiences and their life course.
- This diversity needs to be factored into care and support.

Autism is not a mental health problem. It is described as “neurodevelopmental,” because it is a difference that people are born with and it involves the brain and nervous system. It is not something that can be “cured.” Autism is a way of being.

Autism is a **social-communication difference**. Autistic people may interact with others in different ways, as they experience the social world differently than non-Autistic people. Initiating, maintaining and nurturing social relationships can be confusing or difficult. Autistic people may not intuitively understand the hidden expectations of social situations.

People who are non-Autistic can expect social interaction and communication to be a certain way and can find it difficult to understand and interact with people who do not meet these expectations. If non-Autistic people cannot take the perspective of the Autistic person, it can make it difficult for the non-Autistic person to empathize with the needs, desires and feelings of Autistic people.

Autistic people may have difficulty communicating their needs, desires and feelings in ways that non-Autistic people can understand, in the same way that non-Autistic people can have trouble understanding Autistic communication.

What are some things that autism **IS**?

- Autism **IS** diverse
- Autism **IS** cognitive differences
- Autism **IS** sensory differences that impact a person's ability to function
- Autism **IS** communication differences
- Autism **IS** processing and perceiving differences
- Autism **IS** another way of being human

Even though it can be commonly be experienced by Autistic people, what are some things that autism **IS NOT**?

- Autism **IS NOT** a mental illness
- Autism **IS NOT** specific to one gender, culture, country or ethnic group
- Autism **IS NOT** the same as an intellectual disability
- Autism **IS NOT** a writing or physical co-ordination difficulty
- Autism **IS NOT** defined by meltdowns, or self-injurious behaviours or "problem behaviours"
- Autism **IS NOT** non-verbal or pre-verbal states
- Autism **IS NOT** seizures and epilepsy

"As an adult with autism, there is tremendous pressure to fit in—to not be Autistic. It may be internalized ableism, but it is painfully difficult—impossible, even—to recognize that I need help and to then ask for help when needed. I cannot do it.

"I am pretty blessed: I am financially stable, I have a large and supportive family, I am aware of the services in my community and know how to access them. Nevertheless, I am Autistic. Although I speak up for others to earn my living, I cannot speak up to improve my own life. While it can be argued that we have woefully inadequate mental health supports for adult Autistics, that is not my barrier for improving mental health and well-being—communicating my needs and being able to share my inner life is. If we are to improve the mental health outcomes for people on the spectrum, we have to find a way to address this. How do we destigmatize the act of seeking answers outside of ourselves?"

“As a senior Autistic adult, parent of an Autistic adult and someone who works in the autism field, I help other people to get what they need. I advocate for them — strongly and effectively. When it comes to taking care of myself, to setting limits and asking for help—that is a different story and has been a lifelong challenge. The communication skills that can turn challenges around for other people escape me when it comes to my own needs. Perhaps my awareness of the stigma around mental health in general, and the Autistic community specifically, has made it very difficult to ever reach out for help. I know it is irrational, but here we are. The words simply do not come.”

Autism involves some degree of difference in interacting with others, expressing emotions and experiencing the physical and sensory world. Autistic people often experience the world in very different ways than non-Autistic people. Many Autistic people can experience and feel the world quite intensely. This intensity can look like being very interested in certain topics or loving certain things so much that repeating them can be extremely satisfying and soothing (e.g., body movements, sounds, words). It can include how they experience their own emotions or the emotions of others.

Some Autistic people have positive experiences with different kinds of sensory input (e.g., deep pressure hugs, heavy blankets, certain scents) that help them feel soothed and calm. On the other hand, some Autistic people experience intense negative experiences (even painful experiences) because of some sensory input, including too much noise, bright or fluorescent lights, touch or other forms of overstimulation. These experiences may change throughout a lifetime.

Autistic experiences with autism

“My autism experience is my military models, built from scratch. I build tanks, rifles, aircraft, etc. All from scratch. My mind works like a 3-D printer.”

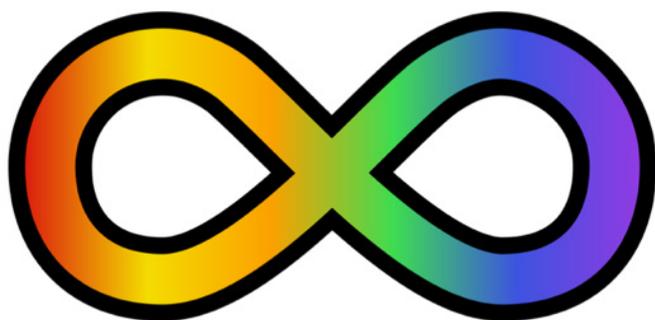
“I always knew I was different, even before my first day of school. But things were mostly okay until I started school. That’s when, day after day, my difference made me stand out in lots of negative ways. It took until I was 42 years old and after many different diagnoses to find out that I’m Autistic.

“Knowing what makes me feel so different saved my life, but decades of abuse and accumulated trauma have left my mental health in tatters. Autistic people need support throughout our entire lifespan, but there’s so little in the way of support. Unlike non-Autistic people who can think and dream and plan for retirement — we tend to not think in these ways. We think about things like suicide. This has to change.”

“Finding a community of people like me has been an absolute lifesaver. I’ve experienced no communication deficits with other Autistic people, and I’ve found out that virtually all of us have experienced great hardship and discrimination for what was actually our Autistic traits. One of the most freeing things that someone said to me early in my diagnosis journey was that ‘I am perfectly normal for someone like me.’ I’ve held that close to my heart, and I’ve found so many people who are exactly like me along the way.”

The spectrum

Autism is understood to be a **spectrum** of experiences. Using the term “spectrum” emphasizes how unique each Autistic person is; no two Autistic people experience the world in the same way. Autism is complex and multidimensional; it is not linear. The degree and types of support an Autistic person might need varies greatly depending on the person, their experiences and their contexts, and it can change throughout a person’s lifetime.



The **rainbow colour** represents the “spectrum,” as each Autistic individual is different and has a variety of strengths and challenges.

The **infinity symbol** represents the inclusiveness and integration of Autistic people in society.

The rainbow infinity symbol (image above) stands for the diversity of the autism spectrum and the neurodiversity movement. This includes people with attention-deficit/hyperactivity disorder, learning disabilities, cerebral palsy or people labelled with mental health diagnoses. The **rainbow colour** stands for the “spectrum,” as each Autistic person is different and has many strengths and challenges. The **infinity symbol** stands for the inclusiveness and integration of Autistic people in society.

The puzzle piece that is commonly seen in the media is not used here because it can be very upsetting to many Autistic people. The puzzle piece is very childlike and focuses on negative attitudes toward autism, and it implies that autism needs to be completed, solved or fixed. Instead, the infinity symbol focuses on the spectrum of Autistic experiences.

Diversity of autism

The Autistic population is extremely diverse. For example, autism occurs across cultures, ethnicities and income levels. The experiences of Autistic people from different groups in society need a voice. Each part of an Autistic person’s identity is affected in different ways at different times in their life. Many identities cut across cognitive and emotional experiences. The following are just a few of these important aspects to consider.

Autistic women

Many Autistic women were overlooked when they were children, even though they may have had some signs of struggle and felt they were different. Females are often identified as Autistic later in life than are males (i.e., they are diagnosed in adolescence or in adulthood). For example, in early childhood, the ratio that is often reported is 3:1; that is for every three boys, one girl is diagnosed.¹ By adulthood, the ratio is found to be around 1.8:1; that is, for every 1.8 Autistic men, one Autistic woman is diagnosed.²

Many Autistic women who were overlooked and not diagnosed in childhood often report being labelled with other terms, and many are negative. Some Autistic women

“I am a 47-year-old woman. I was diagnosed at 40 years old, years after both my children were diagnosed Autistic. Many people still do not believe that women can be Autistic, and that makes it hard to ask for even the slightest accommodation. I often hear ‘You don’t look Autistic’ or ‘Everyone’s a little Autistic.’ Both remarks are highly dismissive and devaluing. This impacts my mental health.”

also end up with an inaccurate list of diagnoses (e.g., one adviser was diagnosed with bipolar disorder instead of autism when she was 16 years of age). This may be because traditional tools that were used to identify autism were developed almost entirely by considering how autism can look in Autistic boys and men.

If Autistic girls and women express their autism differently than Autistic boys or men, this can be missed. For example, from an early age, there are social pressures that teach and enforce gender roles, which set higher expectations for women and girls to be social, and Autistic women can learn early how to show these characteristics in socially acceptable ways.

Autistic women may often imitate the behaviours and mannerisms of others, mask their own difficulties, have interests that are like non-Autistic peers or have traits that are considered to be socially acceptable feminine. These all contribute to misdiagnosis and missed diagnosis in Autistic girls and women.

Autism, gender and sexuality

Gender identities and sexualities are important aspects of people's experiences. Autistic people can be disbelieved about their gender identity and sexuality. There is a myth that because a person is Autistic, they cannot understand what gender and sexual orientation means or that it is not important.

Autistic adults sometimes report a gender identity that is different than their assigned gender. Compared to adults who are non-Autistic, **Autistic adults are more likely to be trans-gender, non-binary, transgender gender fluid or agender (or another gender identity not listed here).** Many Autistic people are a part of the LGBTQIA2S+ community.³ When it comes to sexuality, **Autistic people tend to be more open to identifying with non-heterosexuality than are non-Autistic people.**⁴

“I would have wanted people to attend to issues other than my autism. It was a big focus of my childhood, but I had other things going on. For instance, I've always been trans—there were signs, but I think these were dismissed as weird Autistic behaviour, and lukewarm or negative reactions pushed me into the closet.”

Autism and race

Autism can be experienced differently because of race, religion and culture. These factors can affect how autism is diagnosed and how supports are accessed. In many societies, racialized groups are often diagnosed later than their white peers.⁵

Racialized groups are also more likely to receive mental health diagnoses before an autism diagnosis.⁶ Language barriers also add to the challenges and can delay diagnoses and supports.⁶ Children from racialized groups with lower socioeconomic background can wait longer and get less services compared to white peers, even those who have similar socioeconomic backgrounds.^{7,8}

Socioeconomic status refers to a person or a group's position in society, and involves:

- education
- occupation
- income
- wealth.

There are also cultural norms that become barriers within racialized communities, where stigma, lack of knowledge and acceptance of autism make it hard to disclose and find appropriate supports for autism. For example, in some Asian and South Asian communities, autism is thought to be caused by familial mistakes or karma from a past life.⁹ These norms may lead to being excluded and holding stigma toward autism. Family caregivers may hesitate to reach out for help because of the stigma.

The Indigenous Autistic community is very much underrepresented and often forgotten.

The oppression and discrimination consistently experienced by Indigenous groups makes it hard to reach out and find the best support for their mental health needs. Many tools lack cultural sensitivity.¹⁰ There is often poor access to health care, supports and culturally sensitive supports or service providers, especially for Indigenous Autistic people who live in remote residential areas of Canada.¹¹ There is a significant need for fair access to supports for Indigenous Autistic people, but there is often a lack of resources, research and funding.

“Invisible disability and the barriers our society creates for people like me are unseen and not validated or appreciated by general society. People who identify as or are perceived by others as racialized/visible minority, visually identifiable disability, etc. have even more difficulty than I.”

Autism and socioeconomic status

Socioeconomic status can affect how autism is identified and supported. Socioeconomic status refers to a person or group's position in society and involves factors such as education, occupation, income and wealth. **People with lower socioeconomic status and who live in disadvantaged and remote neighbourhoods are less likely to receive an autism diagnosis in a timely manner and access supports.**^{8,12,13} Many times, immigrant and racialized communities are more likely to experience these economic barriers.

“I’ve always found it virtually impossible to find a job. No matter what the actual skill set needed for a given job, there’s always a social skills test. It starts right from the beginning, with expectations for resumés and cover letters and [it] just gets worse with the interview. Some employers that have made genuine attempts to include Autistics in their workforce don’t even use interviews with Autistic candidates. But such employers are still extremely rare. Around 96 per cent of employable Autistics are unemployed, including 85 per cent of those with a college education. The problem is ableist attitudes and expectations rather than any lack of skills on our part.

“I spend a lot of time thinking about suicide or the possibility of homelessness and wondering which one would come first if things don’t improve. There are employment assistance programs aimed at those with disabilities, but they seem to focus mostly on ‘helping us fit in.’ Not only does this approach not work for everyone, it’s about assimilation rather than acceptance. My experience with looking for employment and using employment services has taught me that (1) no one is really attempting to address the actual problem underlying those abysmal unemployment numbers and that (2) the reason has a lot to do with the all-too-common ableist view that including those with disabilities is a responsibility—or, more accurately, burden—that no one (neither employers nor governments) wants.”

Myths and facts about autism

Below are some myths and facts that are often seen and heard in society.

- **Myth:** Vaccines cause autism.
Fact: They do not. People are born Autistic, not made Autistic.
- **Myth:** There is an autism epidemic.
Fact: There’s been an increase in the ability to diagnose autism. It is thought that changing numbers are partly due to improved accuracy and evolving definitions of diagnoses and partly due to increased referrals for diagnosis, with professionals who gain more awareness of autism and recognition of contributions from different identity aspects such as culture, gender and so on.

“With respect to influencing attitudes toward Autistics, I believe it’s incredibly important to address the misconception that ‘vaccines cause autism.’ Despite being widely debunked by high-ranking researchers, many people continue to believe this myth, which in turn reinforces the offensive ideology around the term the ‘autism epidemic’ view, (especially in mainstream media), which serves as fearmongering. The media continuously make reference to ‘rates of autism’ and that ‘rates’ are increasing, while failing to acknowledge that the increase may also be due to improved diagnosis. As an aspiring writer, speaker and self-advocacy coach working tirelessly to influence a more positive outlook of being on the spectrum, such misconceptions actually *drive* my passion to deliver the *truth* to wider and wider audiences, which I hope will inspire other self-advocates to do the same!”

- **Myth:** The autism spectrum goes from “severe” or “low-functioning” to “high-functioning.”

Fact: Autism does not go from low to high. It is multidimensional. The traditional “spectrum,” with two extreme ends, is inaccurate and is hurtful and stigmatizing. A person’s functioning is often linked to the amount of stress being experienced by the person. The same person can be “low-functioning” one day and “high-functioning” the next. So, fixed labels like these are not accurate definitions of an Autistic person’s experience. These labels aren’t merely inaccurate, they’re also harmful.

“What I would like to see is that autism is no longer conflated with its co-occurring conditions. The only thing universal to Autistic people is that they are Autistic. When people are presumed to be ‘low-functioning’ because they are non-speaking because they have something like apraxia of speech, for instance, this is not the autism itself. I happen to have Ehlers-Danlos syndrome, which more research is finding is a frequent co-occurring condition, but I would never presume that all Autistic people are physically disabled or that I’m somehow higher or less functional than others because I have it. We are often denied agency based on our co-occurring conditions or lack thereof, when in reality we are all Autistic.”

- **Myth:** You should try to stop an Autistic person’s repetitive behaviours.

Fact: These behaviours usually have a purpose, and that purpose usually contributes to positive mental health (e.g., helping maintain focus or handle stress).

- **Myth:** Only men can be Autistic.
Fact: Women can be Autistic as well. But autism can look different and be experienced differently between men and women and is more likely to be missed in women.
- **Myth:** Only children can be Autistic.
Fact: People don't outgrow autism. Autistic children grow up to be Autistic adults.
- **Myth:** Autistic people are all non-verbal or don't understand language.
Fact: While some Autistic people don't speak, many of them can understand language and use many different ways to communicate, including using sign language and technology.
- **Myth:** Autistic people can't work.
Fact: Autistic people can and do want to work—most are out of work not by choice but because they are passed over in favour of non-Autistic applicants.
- **Myth:** All Autistic people have special interests, talents or savant skills.
Fact: Some Autistic people may have savant skills, just as some non-Autistic people do. Most Autistic people do not have savant skills, just like most non-Autistic people.
- **Myth:** If you make eye contact or have friendships with others, you can't be Autistic.
Fact: Many Autistic people learn to mask or camouflage and follow social rules of other people. This does not mean they are not Autistic.
- **Myth:** Autistic people don't like to socialize.
Fact: Many Autistic people want to socialize and are good at doing so, especially when other people understand their Autistic ways of interacting. Non-Autistic people can assume that Autistic people lack interest in socializing because Autistic people may communicate their social interests in different ways.
- **Myth:** Autistic people do not have the ability to empathise.
Fact: Autistic people feel emotions just as much, and sometimes more, than others. They may not communicate those emotions in the same way as non-Autistic people. There are different kinds and expressions of empathy. Different ways of communicating can mean that Autistic and non-Autistic people can misunderstand each other's empathy.

- **Myth:** Autism can be cured with special diets or special vitamins or with bleach-based solutions, etc.
Fact: Autism is a neurological difference. Autism isn't something that needs to be cured. Eating or drinking something isn't going to change Autistic neurology.
- **Myth:** Everyone who is Autistic wants to be labelled as Autistic.
Fact: Some do, but not all. It is up to each person how they want to identify.
- **Myth:** Autistic people are violent.
Fact: Autistic people are diverse. Being Autistic **does not** mean being violent or having aggressive tendencies. Behaviour problems in children or adults can come out because of frustration and a lack of understanding from others. The media can push stories of violence in Autistic children or adults that can make it seem like this is common, but these are exceptions. Sensational stories create more harm than good when it comes to Autistic people.
- **Myth:** Autistic people cannot parent.
Fact: Autistic parents are just like non-Autistic parents in that there are parts of parenting that can be hard and some that are easier.
- **Myth:** An Autistic person looks/appears a certain way.
Fact: There is no one way that an Autistic person may look and appear, just like non-Autistic people may not look or appear in a certain way.

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