

# Understanding Mental Health within the Context of Autism

## Snapshot

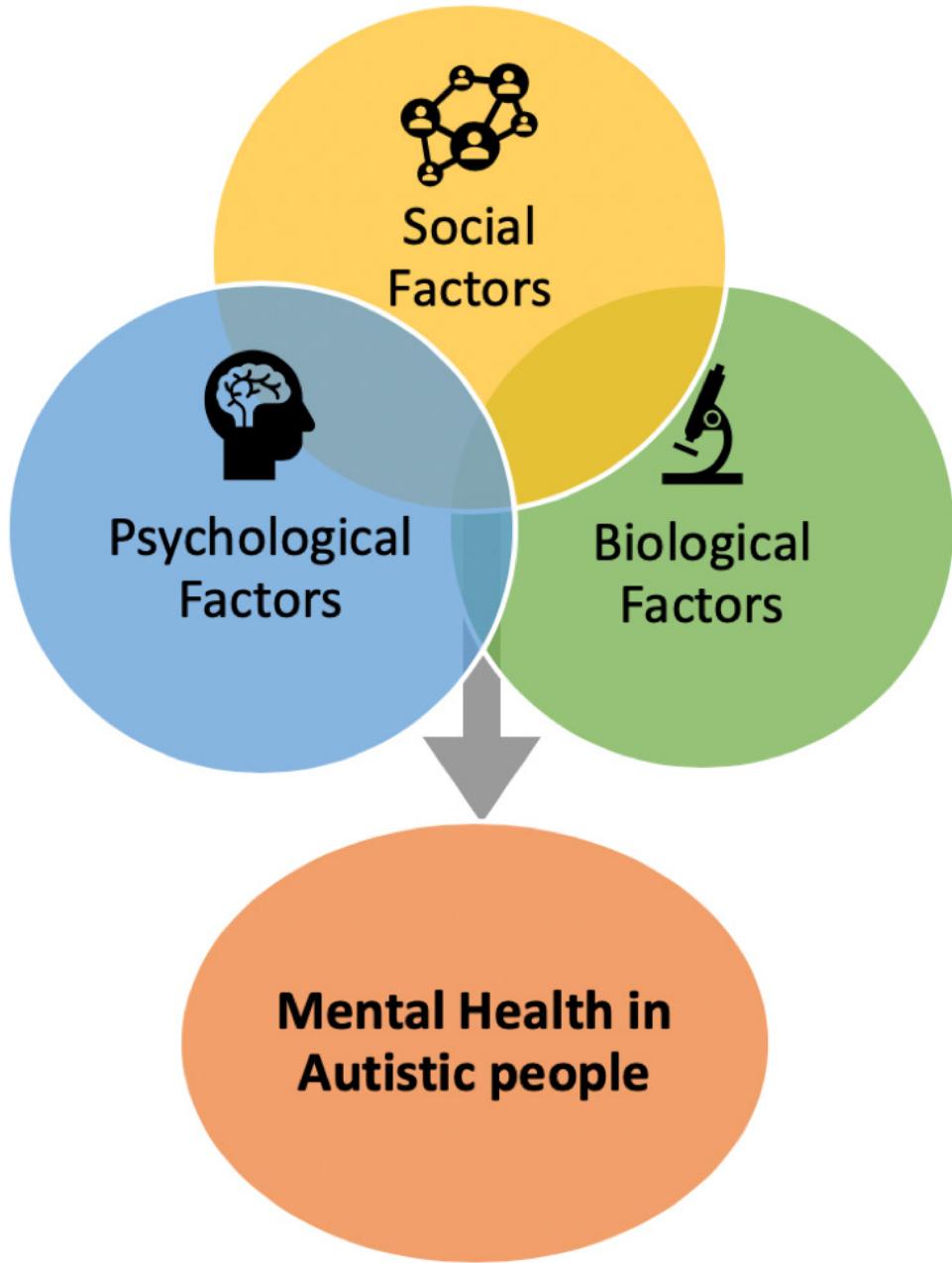
- Mental health problems can look different in Autistic people.
- Growing up in a society that is not understanding, accepting or supportive can affect how Autistic people see themselves, others and their lives.
- Providing the wrong kind of support can affect how Autistic people feel about themselves and can contribute to mental health challenges.
- Autistic people experience positive mental health.
- Social, psychological and biological factors play an important role in mental health.

**Content warning:** This section includes a discussion of difficulties that Autistic people can experience, including trauma, and that can be triggering for some people.

## Specific factors that can contribute to mental health

Challenges with mental health are very common, including for non-Autistic people. One in five people are estimated to experience a mental health problem at some point in their life.

There are many possible reasons why people develop mental health problems. Mental health is influenced by social (one's relationships or environments), psychological (one's mind) and biological (one's body) factors. These factors can also interact with each other.



Social factors

### The big picture: growing up Autistic in a non-Autistic society

**Growing up in a non-Autistic society can lead Autistic people to feel isolated, misunderstood and rejected because of who they are.<sup>1</sup>** They may even have trauma from negative experiences of being bullied, excluded from society, misunderstood or left out by their peers, families and services providers.<sup>1</sup>

Autistic people may differ from non-Autistic people in the way they relate to or communicate with others, in their interests and in how they prefer to spend their social time.<sup>1</sup> The difficulties that can happen in interactions between an Autistic person and another person are relationship difficulties—they are difficulties that involve both people. It is not just because of the Autistic person's traits.

But sometimes, social pressures can influence Autistic people to change their behaviour and act in a way to satisfy the non-Autistic people that are around them. Some Autistic people refer to this as “masking,” or “camouflaging.”

**Masking**, or **camouflaging**, means that an Autistic person hides or does not show their preferences and sense of self, because of the needs of other people. They may not trust their instincts and may change how they act because of what is expected by non-Autistic society.

Masking is a very common experience for Autistic people trying to fit in to non-Autistic society. When Autistic people mask, they find ways to “pass” as non-Autistic in everyday social interactions. Autistic people can do it to try to prevent others from seeing social differences,<sup>2</sup> by pretending to be non-Autistic. In masking, an Autistic person tries tremendously hard to make things easier for non-Autistic people, so they can be understood, be accepted or not stand out. For instance, some Autistic people may actively stop their stimming when they are out in public.

**Masking means that Autistic people end up accommodating non-Autistic people.** Since this takes a lot of effort, it can greatly affect their mental health. Masking is associated with anxiety, depression, perfectionism and poor self-image. It can be exhausting to mask, and people can even lose their identity because they are trying to be someone they are not. Many Autistic people find that they have been masking so hard and for so long that they have no idea who they are underneath. Other times, Autistic people might not realize how much they are masking, especially if they are not diagnosed until much later in life.

**Masking** (also known as **camouflaging**) means to hide aspects of oneself from others, to find ways to “pass” as typical in everyday social interactions in a way that prevents others from seeing social differences,<sup>2</sup> by pretending to be non-Autistic.

## Autistic experiences with masking

"I feel really worn out and exhausted from masking and being social at work, to the point where I get home and just pass out. I get frustrated because I don't really work that many hours and yet I'm so tired afterwards. It often means the rest of my night is spent recuperating/sleeping off the workday, and I don't have the energy to do other things. Or I stay up very late trying to make up for that recuperation."

"I can get short-tempered, irritable and snap at people or cry easy after a long day—especially if my parents then want to go out for dinner or something. I'm completely burned out, and even just having to process other sounds hurts. And I hate myself for being horrible to others when I get like that; they didn't do anything really wrong."

"Sometimes I'm not sure I know how to turn off the masking. I've been doing it for so long . . . I rely on scripts and what I know people want me to say in a social situation. Sometimes I don't even understand the phrases or sentences I'm saying, I'm just parroting back bits and pieces of what I've heard others say in small talk or whatever."

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"I've never consciously tried to mask. Yet the pressure to act 'normal' has caused me to mask out of habit. My mask is a part of me. But masking is harmful. No one should be robbed of the opportunity to forge their own identity because the social pressure to fit in is so great that it unknowingly shapes who you are. I have no idea who I'd be in the absence of ableism, and that's both a common and serious problem."

**The need to mask or camouflage may lead an Autistic person to believe that their achievements are not authentic and that they are an imposter.** This may be because others are seeing achievements or skills that happened when the Autistic person was acting in a way that they thought people wanted them to act.

"How can I not be able to do *normal* things? Yet, at other times be able to do things, achieve some success, leave my house (*normal* things), so I must really be faking, and nothing is wrong with me."

Autistic people may accept that anything less than typical, or usual, is "less than." This internal battle can be distressing.

## There are many social factors that are linked to mental health:

- Appropriate and inappropriate environments

An “environment” means the places that a person lives, works or engages with their community. Being in healthy environments can help with positive mental health. Environments need to be a good fit for us, and this fit is unique to each of us. Some environments may be too isolating for a person, or an Autistic person may be treated unfairly or taken advantage of. Some environments do not give a person enough choice or control over their life. Some environments may provide too little or too much activity or stimulation.

- Social networks

Some Autistic people can thrive when they are connected with healthy social groups, such as having access to a network of Autistic peers who are supportive and help them feel like they matter and belong (e.g., advocacy groups or online communities). It can be very helpful in reaching goals and in finding community.

Autistic people may struggle to access this kind of social network. Some Autistic people may be involved in abusive relationships (e.g., bullying) or become involved with inappropriate peers to fit in with social networks. Online networks can be a very useful way to connect. But, similar to in-person environments, interactions can be helpful or harmful.

### Autistic experiences with social networks

“When I interact with most people, I am acutely aware of how I am different from them. I often have to create elaborately constructed roles and personalities to even communicate on the most basic of levels with another individual. This leads to feelings of loneliness, even when I am among friends. Unless someone is neurodivergent or Autistic like me, we simply do not speak the same language.”

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“I have always been a very social extroverted person—an ‘extreme networker,’ I call it. Many people on the spectrum have problems and get overwhelmed in large crowds. Sometimes my anxiety will rise if I am in a crowd and I want to meet a lot of people I don’t know.”

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"I also often feel overwhelmed by travel, so events in many places are frequently hard for me to attend. Additionally, many sorts of events are inherently difficult for Autistic people to go to. For me, I like to attend games nights, but a lot of these are held in noisy pubs, which can be a problem; even if I do go, I might leave early because of the noise. Rock concerts are right out . . . I believe I have never attended a rock concert without incident (such as covering my ears or fleeing in panic). There are many events, in any given year, that I intended to go to but am not ready to go to at the same time."

- Family and friends

Family members and friends can be an important source of positive mental health. These relationships can support, help, connect and bring joy to the Autistic person. They can also be a source of stress and distress. Sometimes family members or friends can be hostile, overprotective or have too many demands, and they may not provide enough understanding and support or the right kind of help.

What can be helpful at one point in time can be distressing at another. Autistic people may not feel safe enough to unmask around family members. It can be helpful to communicate about the kinds of support that is most useful. It is also helpful to have a good understanding of one another.

### **Autistic experiences with family and friends**

"I find that family members can be intolerant of requests related to my autism. For example, a recent get-together was arranged with adult children and my many grandchildren. There was a suggestion to take the children to a large indoor arcade—a place I know I could not tolerate because of the crowds, the noise, the lights and social demands of interacting with all my children, in-law children and grandkids. I said that I did not do well with crowded, noisy environments and asked if we could go to a fun family restaurant. I was told this was about the kids, not about me, and that I would be just fine for a couple of hours. I did my best but was on the verge of tears for the entire time. I held it together until I got home, but it was extremely difficult and not at all enjoyable. It makes me associate family gatherings with feelings of anxiety."

"I've always been wary of talking about autism with my family or people I know. Most non-Autistics I know treat it as a burden to have to put effort into understanding me or effort into changing ableist behaviour—it's always my responsibility to fit in. When we talk about assimilation with respect to other communities, such as Black or Indigenous communities, we recognize it as discriminatory. Expecting Black or Indigenous people to fit in with white culture is racist. But expecting Autistics to fit in is not only viewed as unproblematic, the dominant 'treatment' for autism is behaviour modification. It's also very segregationist insofar as 'experts' say that as much as 30-plus hours a week should be spent on these 'treatments.' I need my family and friends to accept me and to be willing to put in the work to make that acceptance more than just superficial, not tell me that I need to assimilate."

- Lateral aggression

Lateral aggression (also known as "lateral violence") refers to harmful behaviours that happen within minority groups in society. For example, when an Autistic person experiences aggression or exclusion from others within the Autistic community. These aggressions can be verbal, social, emotional or physical and negatively affect mental health.

**Lateral aggression** (also known as "lateral violence") refers to the harmful behaviours that happen within minority groups.

Lateral aggression occurs in interactions where there are disagreements and different perspectives. In some Autistic groups, social and communication challenges can make dealing with these types of interactions hard. Social communication challenges? can make some people more vulnerable to these aggressions.

### Autistic experience with lateral violence

"[Lateral violence] is certainly something that occurs among Autistics (lateral harassment, lateral ableism). One thing that gives me a lot of trouble interacting with non-Autistics is all the social rules about subtext and hidden meaning that are used in interpreting communication. They use various social rules about 'hidden meanings' to interpret things. As an Autistic who tends to be very literal, it can lead to a lot of problems.

“But I have the same problem with many Autistics as well. I see plenty of Autistics in various groups doing the same thing. Being Autistic doesn’t mean that we don’t pick up any allistic [non-Autistic] social norms at all. There are other ableist social norms that some Autistics pick up (and I expect I’ve picked up some as well). This is just one of the ones I often see, likely because it’s one of the ones that affect me.”

- Negative life events

Autistic people can be exposed to abuse, trauma, loss, rejection, bullying, harassment and exploitation in different environments (e.g., school, employment, health care or in public spaces). Just as positive life events can contribute to positive mental health, these harmful kinds of events can be a major cause of mental health problems. Discrimination can leave Autistic people stigmatized and affect their mental health.

- Economic and legal disadvantage

Autistic people often experience financial and social disadvantages, such as high rates of unemployment, job insecurity, food insecurity, homelessness and poverty. These disadvantages increase the chance of mental distress and mental health problems. **Many Autistic people live at or below the poverty line.**

Some Autistic people may not be aware of their rights or may be denied their rights, making them more vulnerable. Autistic people may also not be taken seriously when they advocate for themselves.

The ability to speak up for oneself and the things that are important is called **self-advocacy**. This can be hard to do, and many Autistic people are not taught personal and community self-advocacy skills (see **Section 6**). They may have to rely on others to be advocates for them. Sometimes even asking for help can be difficult, and relying on other people can be distressing, as other people may not be willing to help.

**Self-advocacy** is the ability to speak-up for oneself and the things that are important to them.

## Autistic experiences with legal rights

“Unfortunately, I was not yet aware of my legal rights within the Ontario Employment Standards Act and, as such, did not request ‘reasonable accommodations’ nor disclose that my challenges were a result of an ‘invisible’ disability. Moreover, I was often misunderstood as having a bad attitude, being lazy or even using my learning disability as ‘an excuse’ upon trying to account for certain struggles which inconvenienced a team member. Worse yet, I was even humiliated by a fellow server while working at a diner, who right in front of me actually told a customer: ‘He’s been working here for two weeks and still doesn’t know what he’s doing!’ Being stunned, I regrettably said nothing, but looking back, I sure wish I told her off or got her fired!

“The turning point toward obtaining a sense of more empowerment in the workforce emerged during my early 30s upon writing my master’s thesis on the subject of autism and *rewarding* employment. Besides being more informed on employment legislation outlined in the Ontario Human Rights Code on ‘reasonable accommodation,’ I sought job coaching and also made accommodation requests, leading to improved outcomes! I later discovered that official accommodations do not address all aspects of workplace hardships and that having a positive attitude and working relationships is also crucial for employment satisfaction. For instance, during the four years working at [autism services agency] as an autism consultant, I informed my co-workers that I was on the spectrum, which was overwhelmingly received positively and, in turn, increased their ability to more effectively approach concerns. There were nonetheless times when I encountered personal conflicts and *really* felt like quitting; however, I believe my overall experience within this role was positive as a result of these proactive steps.”

- **Housing**

When housing is inadequate, noisy, overcrowded or unavailable, maintaining one’s well-being is more difficult. Having basic needs met—shelter, food and clothing—is needed for good physical health and positive mental health. Proper, accessible and affordable housing is important for physical and emotional well-being. Feeling safe helps to reduce stress and can lead to improved sleep and diet. Affordable independent housing is to a large degree not possible for many Autistic people because of the cost.

- Transitions

There are many kinds of transitions. There are transitions that occur within a day or across situations. For example, school changes, going from one living situation to another or from one kind of activity to another can be big transitions. Transitions and changes can be highly stressful and can bring feelings of surprise and confusion. **Changes are more easily handled when there are no surprises.**

"I find transitions really difficult because I don't know what is happening next and it makes me very confused."

Distress can happen when the transition between supports is poorly managed. For example, when there is poor communication and planning, or when Autistic people feel they have little control over what happens to them during transitions. Because many Autistic people can feel anxious when there is uncertainty, poor planning and preparing for transitions can negatively affect mental health.

- Disclosure: telling others about being Autistic or about mental health

The decision to tell other people about personal information can sometimes be a positive experience, and sometimes it can be stressful or harmful. At times, these decisions can affect relationships, academics, employment, communities or opportunities. **When an Autistic person decides to share information about being Autistic or about their mental health, it could be a positive or stressful experience.** This can depend on when and how they disclose and who they disclose to.

In some cases, sharing about being Autistic or about a mental health diagnosis may help others understand them better. It may lead to them receiving better support, having fewer misunderstandings and getting help more easily.

If it is not received well, a person can be stigmatized. Stigma can happen if people have limited knowledge about autism. They may not believe or accept information about autism or mental health, or they may judge or place stereotypes. It is hard not knowing how people will respond to disclosures or what they will understand, and this can cause a lot of anxiety and doubt.

## Autistic experiences with disclosure

“I find the phrase ‘But you don’t look Autistic’ to be incredibly demeaning and gaslighting. It is often said as a compliment. It is also used as a weapon to divide me from my fellow Autistics—a dig by implying I’m ‘high-functioning.’ Usually said in response to my disclosure to an acquaintance or friend, this dismissal of my experience makes me more cautious about disclosing. It puts me further in the Autistic closet.”

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“Even though I’m very much an open book about my mental health, I have reservations about disclosing my autism to others. For instance, in school, if I have to explain myself, I am more inclined to tell teachers or other students I have anxiety rather than disclosing that I have autism. I fear the reaction, and it’s a lot easier to explain away something as common as anxiety than to broadcast something as stigmatized as autism, or something that people have their own preconceived notions about. Disclosure feels like coming out. It feels too big.”

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“Disclosure of autism is often met by disbelief and criticism because people don’t understand what a social communication disorder is, or looks like, in an adult. I think differently than neurotypical people, and that informs all aspects of my life experience. Most people don’t know anyone who is an Autistic adult, and gaslighting continues with: ‘You’re nothing like my cousin’s best friend’s four-year-old son with severe autism!’”

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“Despite having a diagnosis since age 15, I only shared my autism label with family and service providers, due to deep shame of being different, a perspective I now believe was shaped by prior experiences of bullying and ostracization. In addition to not disclosing this fundamental aspect of me with close friends and women I dated seriously, I even hid my diagnosis from co-workers for eight years while working in the autism services field, due to fear of differential treatment. Surprisingly, the reactions of those I disclosed to were predominantly positive, although varied. Among the most noteworthy were ‘Suspected you had Asperger’s,’ ‘Never suspected anything different’ and even ‘I don’t think you have it!’ exclaimed by an ex-girlfriend of mine who appeared convinced I was ‘normal,’ which I interpreted somewhat complementary!”

"My outlook on being different changed during my late 20s after reading about and meeting highly accomplished autism self-advocates, including Temple Grandin and Stephen Shore, whom for me shed a light on the many *positive* aspects of autism. As a result of this change in mindset, I embraced autism through joining advisory committees, attending conferences, completing a master's thesis on barriers to rewarding employment, and delivery of presentations on my lived experiences. More recently, I discovered the concept of neurodiversity and have launched my own autism self-advocacy coaching practice specializing in employment and post-secondary support—an achievement I'm incredibly proud of!"

- Education

School settings are a major source of stress and have a long-lasting effect on many Autistic people. **Bullying and discrimination are big issues in elementary, high school and post-secondary education. A person's school experience can be full of isolation and social confusion.** At times, Autistic people may have other conditions (such as learning or physical disabilities) and economic factors that add to the stress of education and their mental health.

There are a lot of demands placed on students when they go through elementary school to high school and from high school to post-secondary education.<sup>3</sup> For example, when students transition from one school situation to another, there are often demands for socially interacting, being independent, learning new material and planning. Some students may be excited about the change in environment or meeting new people but may also struggle with new situations, people and expectations at the same time. There can be a possible "let down" when reality is quite different from what people expect the changes to be like. Many Autistic people will struggle to graduate,<sup>4</sup> and this struggle can lead to mental health problems.<sup>5</sup>

**Schools need to supply a supportive environment to address these challenges.** They may give services offering support for academic success,<sup>6</sup> such as accommodations for learning and testing; however, it is not the same as having supports for mental health or for the non-academic parts of education (e.g., when students are distressed or in crisis).

"Providing needed academic accommodations on paper but not teaching an Autistic person how to access them demonstrates a lack of understanding autism."

Many universities and colleges have invested in mental health services and supports on campus, but often the demand is much higher than what they can serve. Depending on the institution, disability services may not provide sufficient supports when the disability is mental health related.

Educational supports that are developed without Autistic students in mind, or without consulting with Autistic students who will use them, may not address Autistic students' needs. This means the supports can fall short.

Autistic students may need one-on-one support for their executive functioning needs (this will be discussed more under "Psychological factors" later in this section). They may need to be shown how to access services or need help understanding why or how supports can be useful. When there is no support available or the past experience in education has been damaging, some Autistic people may choose not to pursue post-secondary education—there can be a stigma to this.

### Autistic experiences with education

"I would have wanted more information and tools for how to politely stand up for myself amongst other peers. I feel like I wouldn't have to do the catching up in the former category that I am doing right now, if there was a better balance of that and I was taught about being open to other fun and safe activities, sudden changes or road routes to get to the same place. Also, I would have wanted more information as to how mainstream social dynamics change in high school. Having a good locker space, attending all classes, doing one or two extracurricular activities, wearing clean clothes and maintaining good personal hygiene does not mean that you are immune from being on the receiving end of peer pressure. Such as mean teasing or hearing slang words of private body areas that either seem silly or strange."

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"When I was in Grade 9, my autism was very overlooked by a lot of teachers and was not understood by many, including the bullying and the OCD. It took my mom and family a while to straighten things out. The transition to high school was very tough, certainly in the first half of Grade 9."

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"For me, co-occurring conditions such as dyslexia and dyspraxia, as well as economic factors and physical disability (Ehlers-Danlos, scoliosis, and IBS), played major roles in adding to my stress and mental health. Without proper or late diagnosis, I had no support and was blamed for my perceived failures and weaknesses."

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"While the teachers, EAs and other staff members are trained, students are not, and as a result there is a knowledge disconnect, even though Autistic people interact with both [students and school staff] during their time at school.

"The biggest source of isolation during my time in high school was sensing that my peers would not understand if I tried to explain Asperger's to them when I committed a social faux pas (e.g., when a classmate flipped the hood of my sweater over my head playfully, I angrily turned around and said 'Geez, what was that for?!' when I had never been taught that people may do things like that because they are playfully teasing). Also, I looked able-bodied (still do), so I felt that disclosing would have resulted in them thinking, 'What is this girl talking about?' if not worse. So, I withdrew further and further into myself in high school and was constantly hoping that I would get by and not get attention from any more accidental faux pas.

"One time I asked a class how many of the students had heard about autism and Asperger's, and only one out of 30 raised their hand. That is a microcosm of the knowledge disconnect that I've mentioned earlier. So, in this case, not being able to explain or disclose to my peers and be sure that I would get a positive reaction if I did so was the biggest social factor that I faced during high school."

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"The college I went to had a 'Calm Down' room they were very proud of, but it was only accessible if you were registered with the Disability Office and wasn't largely known outside said office. The room was small, quiet, had a box of tissues, a stuffed toy and dim lighting. Mostly it was for students in emotional distress—though I used it one day when I was overstimulated from walking in the noisy halls. One day an Autistic classmate had an emotional outburst and went to sit in the hall. I followed him after a minute to sit quietly with him. I asked if he wanted to use the Calm Down room. He didn't even know it existed."

“Starting at the age of five, I received a learning disability (LD) label and was subsequently sent to a range of ‘special’ classes, with mixed outcomes and levels of comfort for me. As a result of society’s failure to adequately *educate* the masses on ways to respond and *listen* to people with unique challenges, I experienced teasing, bullying and even very harsh responses from mean-spirited teachers! Such experiences impacted my self-esteem and, consequently, I became ‘selectively mute’ between the ages of eight and ten, [during] which I only spoke to immediate family. I was sent to another ‘special’ school and after a year ‘started talking,’ as everyone including my teacher and peers exclaimed enthusiastically on April 12, 1989—a date forever locked into my soul! I later attended high school and once again was bullied, teased, excluded and even deliberately humiliated in front of peers I mistakenly thought were my friends. I nonetheless received sufficient academic support and was on the honour roll!

“Despite my earlier struggles in educational institutions, I was determined to attend post-secondary education and persevered with flying colours! Not only was there virtually no bullying, but my years in college starting in the year 2000 was a very empowering experience for me. I registered with the necessary centres for students with disabilities and received a range of accommodations including extra time, tutoring and access to adaptive technologies. I went on to complete my Bachelor of Arts with honours, followed by attending teachers’ college for two months, which simply put, was not the right fit for me. I returned three years later for a Master’s in critical disability studies, and completed four years later with a straight ‘A’ average!”

- Employment

Many adults find employment to be important for their lives: for money, social connection and meaning. Having the right employment is linked to **financial independence, self-esteem, and autonomy** (Autonomy means a person’s ability to speak and act on their own.) Many Autistic people are unemployed or underemployed.<sup>7</sup>

“Employment means I have somewhere to be during the day. I can take pride in my work. I can get out of the house and be . . . outside.”

Employment may not always be associated with improved mental health for Autistic people. Autistic adults in the workforce can experience poor mental health and low job satisfaction.<sup>8</sup> Though some workplaces may be accessible and supportive, other workplaces may not be accepting of, or accommodating to, Autistic people. For instance, they may not give accommodations that could reduce or prevent stress, such as by creating and defining routines, allowing for flexibility, being aware of sensory needs or finding ways to communicate effectively with Autistic employees.

**Workplace bullying and complex social dynamics can be a barrier when it comes to employment.** Autistic people have a higher risk of workplace bullying or not being recognized by their co-workers for their contributions. These factors can play a role in how Autistic people experience work-related distress. Due to discriminatory hiring practices, Autistic people often mask to get a job. Continuing to mask once hired can be a health risk and not sustainable.

**Some disabled people cannot work, and this is okay, too.** There should not be any shame about being on disability benefits. As a society, there needs to be support for disabled people who cannot work to live full lives, and support provided to create opportunities for disabled people who can and do want to work, to do so.

### Autistic experiences with employment

“I’ve had some very understanding employers, and I’ve also had some that were not understanding as much. One employer I had that was not [understanding] was focused on her own issues and not the issues of her employees but her own self, as well as putting the management of the business at risk.”

“As I’ve gotten older, the need to feel safe and in control of my environment has become more pronounced. I have learned from hard experience, time and time again. I have had probably 20 different jobs, and every single one has taught me that I cannot rely on my employer or co-workers to help me or to understand. I know now that working from home is the only long-term employment option where I will be safe. My stress response is heightened, and that leads to adrenal depletion and the cascade of poor physical and mental health that eventually leads to.”

"Within employment there's always the extra push to mask and do even more than my best: Never ever complain. Only use positive language. Don't slouch. Smile. Never give your employer a reason to regret hiring you. The job you have is likely the *only* job you have, and with the unemployment rates so high, it's not like you can just walk out and get a new one tomorrow. You have to show them that hiring an Autistic person wasn't a mistake."

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"I can't provide employers with the documentation that they can ask for if I make an accommodation request. I'm treated differently than Autistics with documentation when I seek employment services. People make inferences about the level of support that might be useful or necessary based on whether you have documentation or not."

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"Even though I work in a social services agency, human resource personnel are most often not autism-informed and lack true understanding. I have had a couple of unpleasant experiences in spite of finding the strength to advocate for my needs at work. I say 'strength' because it definitely feels like a risk to ask for accommodations.

"One example: I was considering applying for a new position that opened up—a position where the successful candidate would be primarily responsible for educating the public about autism. My role already involved delivering workshops, and I did well with them. Community agencies and outside professionals were calling in to request me specifically for presentations.

"I made some inquiries to HR before applying, though it made me feel very vulnerable to do so. I did not want to change their perception of me or for them to feel that I was 'too much work' or 'high maintenance.' Since I had been with my employer for many years, and my skill as a presenter was already known, I asked if could I be considered based on my performance reviews, workshop feedback from years of presenting, or by providing a demonstration task instead of going through a lengthy panel-interview process that assessed my ability to communicate under tremendous stress. Demonstration tasks are a reasonable and relevant way to assess suitability of Autistic employees. The answer was: 'No.' All candidates had to go through the interview process."

“During my mid to late teens, I obtained restaurant roles in food preparation as well as CIT and camp counsellor jobs during summers. Despite facing significant challenges with aspects of camp facilitation and getting fired for being ‘too slow,’ in the food prep role, I remained determined to persevere. Besides roles within my fields of study, including autism support, during my early 20s I simultaneously held server and table-bussing roles in restaurants due to my enjoyment of such lively and high-paced atmospheres. However, I struggled with many aspects and was terminated for making ‘too many mistakes.’”

- Access to supports and services

Autistic people often report difficulties when accessing supports. **Effective and autism-informed mental health supports may not exist or may be rare and hard to come by.** If they do exist, they may be difficult to get because of barriers to finding them, barriers to affording them or lengthy wait-lists.<sup>9</sup> There can also be stress in trying to access supports. The time and effort related to finding, applying to and coordinating supports can add up, making accessing supports feel overwhelming.

**Most supports require phone contact or in-person appointments, both of which can be hard to access for some Autistic people.** Without other ways to connect, they often go without them. The need to secure appointments require people to have social-communication skills, the ability to resolve conflict and the ability to respond appropriately to the unexpected. These may be areas of relative weakness for an Autistic adult, leaving them at a disadvantage to connect with relevant, autism-informed supports.

Autism is, at its core, a social-communication difference. This can mean an Autistic person may not be able to speak up and ask for help or even recognize that they need help. They may not have learned how to advocate for themselves or how to respond to service providers who misunderstand their needs.

It may be challenging to find Autistic-friendly and trauma-informed services that take an Autistic person’s needs into account. Services may not have the right kind of experiences, training and skills for working with Autistic people,<sup>10</sup> and may not be willing to listen to Autistic people or may be dismissive.

Negative or traumatic experiences with past services can prevent or discourage Autistic adults from finding or seeking services in fear of the same experience happening again.

For some Autistic adults, difficulty getting a diagnosis can be a huge barrier in accessing services and supports. At the same time, unfair policies may exist whereby services exclude people with an autism diagnosis from accessing care, claiming it is outside their clinical scope.

## Autistic experiences with accessing mental health supports

“My new doctor helped my children and I (all of us are Autistic) get through the onerous paperwork. As a result, all of us were provided access to support. Having a doctor that believes you and supports you is a total game changer. And it really helps your mental health to know that you are heard and supported.”

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“Being denied augmentative and alternative communication (AAC) access is one of the worst feelings in the world. It means that the person does not want to listen to you. It means they would rather have you miscommunicate or be silenced. It’s deeply traumatizing to have your voice taken away from you. People who do not accommodate AAC are enacting a form of control over partially and non-speaking Autistic people. They are saying: ‘Listen to me, and I do not care about what you say.’

“My worst memories of mental health care wards are being expected to discuss my care without any method of reliable communication available to me. The psychiatrists demanded me to only talk with my mouthparts, which triggered more stress and caused more trauma. It happens in schools, it happens in ABA [Applied Behaviour Analysis] clinics (ACC access has been used as rewards), it happens in hospitals. Similarly, deaf people have told me that they have had their American Sign Language interpreters asked to leave in hospitals.”

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“As I got older—and perhaps this has changed over the years—it was hard to find people who would support me from a psych perspective because they didn’t ‘do’ autism. Like, I’d be coming in asking for help for my panic disorder and anxiety, but because autism was on my file, they’d turn me away and say, ‘Well, we don’t do autism supports’—despite that not really being what I was there for. Sure, autism will factor in no matter what, but what I was really there for was anxiety.”

“When I have sought help for my mental illnesses, virtually all of the programs that I have been referred to have been designed for non-Autistic people and involve things like group therapy and meditation, both of which are distressing to me. Even if I give them a try and find them unsuitable, I am often labelled as ‘non-compliant’ and there are no alternatives made available to me. Even though I recognize that I am mentally ill and I am asking for help, there simply isn’t any help available for someone like me, and this has had devastating effects on my mental health.”

“I have had the good side of being able to access certain services while living at home as I am now. But certain services, such as regular mental health services, are said [by service providers] to be unavailable to Autistic people.”

- Stigma

Stigma can have a major impact on a person’s mental health. Stigma is when someone views you in a negative way because of a characteristic, trait or label. Many Autistic people experience this regularly. For instance, people may have negative attitudes or beliefs about Autistic people, such as the myth that Autistic people do not care for others or that they are burdens. This stigma affects Autistic well-being and can increase stress.

If not challenged, stigma can lead to discrimination. **Discrimination** is the act of treating someone negatively because of one’s identity (e.g., gender, ethnicity or disability). Many Autistic people report that a lack of understanding and acceptance contributes to their isolation and anxiety.<sup>11</sup>

- Gaslighting

One social factor that can affect Autistic adults’ mental health is gaslighting. **Gaslighting** means making someone doubt their own experiences. It is a form of psychological or emotional abuse aimed at making those who are vulnerable seem or feel wrong or “insane,”<sup>12</sup> or doubt their own reality.

**Gaslighting** involves making someone doubt their own experiences.

One adviser provided the following example: “For the non-Autistics, sensory difficulties may not be a big deal. They may ridicule, minimize and disregard Autistic people’s sensory needs and force them into environments (like rooms with bright lights or crowded spaces) that could be distressing. Then, they blame the Autistic individual for not responding well. They may say, ‘It’s all in your head!’, ‘It’s just you, no one else feels this way’; ‘Everyone has trouble with \_\_\_\_\_ from time to time, you’re overreacting/you’re a drama queen’; or ‘It’s not that bad!’” There can be a misunderstanding in communication and the Autistic person could be blamed because they do not communicate in a way that is expected by the non-Autistic person.

An Autistic person may take on being gaslighted as part of who they are as a person and how they see themselves in society, doubting their own experiences and beliefs. They may take on the negative views that other people have of them and form a negative self-image.

Building trust within society and oneself can be a long process. **Greenlighting** is an approach to heal relationships and help with building trust. It involves showing compassion and acceptance of people’s lived experiences. For example, someone saying, “Yes, tell me more about that.”

**Greenlighting** involves expressing compassion and acceptance of one’s own or another person’s lived experiences.

## Psychological factors

### There are many psychological factors that are linked to mental health:

- Self-worth and self-image

How a person feels about themselves matters. When a person sees themselves in positive ways—appreciated for their strengths and uniqueness, kind and accepting of themselves—they can have a positive way of seeing who they are. When a person negatively judges themselves, they can be ashamed, distressed and more likely to have negative mental health.

Sometimes a person can develop a negative self-image because of how other people judge and treat them. When Autistic people do not have opportunities to achieve and feel success, they may have negative self-talk and can develop low expectations of themselves. Many times, Autistic people’s gender, racial, cultural and sexual identities may not be recognized, and this also can affect how they see themselves and those around them.

## Autistic experiences with self-worth and self-image

"As a result of the social isolation, my self-worth and image were at its lowest point in high school. However, it has increased steadily since then. It's still sometimes a learning curve for me to remember that not everything that went wrong in [an] interaction was my fault. However, as I said, my self-esteem and image has increased steadily within the past nine years, much more than it did in the first 18 years of my life."

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"I know that being around open and proactive and accepting people helps my mental health. I have been a victim of a lot of gaslighting and attempted forced masking of who I am for a few years with an organization. Some of the forms of attack come from mental abuse, bullying, the pressure to mask, and I have been working to improve and build up my self-esteem since then."

- Planning and organizing

It can feel good to have predictability, be organized and plan ways to have needs met. When a person can plan, solve problems and access support, they are more likely to have positive mental health and low levels of emotional distress. This can reduce stress and contribute to a good mental state. If a person finds it difficult to organize their thoughts and actions, then this can add stress to their daily lives. There can be a constant fear of "messing up" or missing something important.

Planning, remembering or focusing on a series of tasks can be challenging for some Autistic people. These kinds of skills are what is sometimes called "**executive functioning**". For some Autistic people, using executive functioning skills use up a lot of energy and stamina. If someone finds it hard or tiring to use their executive functions, it does not mean that a person is lazy or not motivated, although others may think this of them.

**Executive functioning skills**  
involve planning, remembering  
or focusing on a series of tasks.

It is important to note that emotional distress can make executive functioning difficulties worse. Executive function can also be affected in multiple ways

through social, psychological or biological factors. When a person is experiencing high levels of anxiety or other negative emotion, it can affect a person's executive functioning skills. Reducing anxiety may improve executive functioning skills.

"Sometimes I mistake myself for thinking I'm lazy, when I'm just processing things."

## Autistic experiences with planning and organizing

"I find when my routine is thrown off, my executive function gets worse. For instance, if my therapy appointments are always Fridays at 10:00 a.m. and then we suddenly switch them up and now I don't know when they are, my brain tries to default to Fridays at 10:00 a.m."

"As I have gotten older, I notice that my executive function is getting worse. Maybe because I have . . . more adult expectations now? Like a six-year-old doesn't have to worry about when their therapist appointment is or when to reorder their meds—their parents deal with those things. I'm scared about getting into my senior years and what my low executive function will mean."

- Monitoring and expressing emotions

When a person has emotional distress, it can be helpful to communicate about the source of the distress and what the distress feels like. This can help to address the cause of the distress or just help the person to be better understood.

Some Autistic people might find it difficult to identify, distinguish or feel emotions. For example, an Autistic person may experience feelings as body sensations but not make the connection between the two. Some Autistic people may struggle to understand the connection between their emotional states and what they are experiencing in their body. They may not be aware of how the body feels different when "fine" (i.e., body is relaxed, breathing is even and regular) versus a "crisis" state (i.e., muscles are tense, heart is racing, breathing is quickened). In the absence of this awareness, they may not take steps that could help them to cope with any distress they are feeling. At the same time, it is important to note that many Autistic people are extremely aware of their emotions and feel their

emotions intensely. Some Autistic people may show their emotions differently than most people and therefore others may not recognize how an Autistic person is feeling. They may find it difficult to express their emotions or thoughts, and it can be hard for them to manage their feelings or find support.

- **Areas of focus and interest (passions)**

Many Autistic people can focus very intently on specific passions, and this can be a source of joy and positive mental health. This strong focus means that Autistic people can be very passionate about their interest. The same may be said for non-Autistic people; however, while society calls their interests “hobbies” or “expertise,” interests can be pathologized in autism. Autistic people’s interests have been called “fixations” and “obsessions.” Interests can be very fulfilling and, at times, extremely productive. Interests can provide a relief from the demands of society. Communicating with other Autistic adults and sharing interests can be a very validating experience.

An Autistic person’s interests can also cause conflict with other people or within themselves. At times, it can be difficult for some Autistic people to stop and switch over to other topics. An Autistic person may benefit from accommodation for when they transition out of their preferred interest, and this accommodation may not always be given. An intense focus can also look like constant thinking about worries or uncertainties. It may be difficult to let go of a situation that happened or a worry or concern. Some Autistic people describe a feeling of not being able to “turn their thoughts off,” which can make it hard to relax and sleep. When these thoughts are negative or worrying, they can be very distressing and can lead to sadness or anxiety.

It can be very upsetting or painful when an Autistic person is prevented from engaging in their interest or using their focus, or when an Autistic person who is focused on a task is suddenly interrupted. It can also be distressing when the object of intense focus or interest is taken away, or if a person is told what they can or cannot do. Autistic people can also be judged because others do not share that same interest, or if they do share interests, the intensity is mismatched. This can be upsetting and can affect mental health and well-being.

## Autistic experiences with passions

“Our daughter danced for 20-plus hours a week. It was her obsession but also her source of physical activity—her ‘safe’ place, where the work that she put in was equivalent to what she got out. It was a world that she understood and loved. Unfortunately, dance also caused her tremendous physical pain. She was diagnosed with Ehlers-Danlos syndrome and was forced to cut down on the frequency and intensity of her dancing.

“Our daughter is 150 per cent or nothing, and so she stopped dancing. Her grief was unbearable and continues to this day (four years later). Anything related to dance is a trigger. While she struggled with intense worry and rumination while she was dancing, it mostly provided her with a productive passion and goal. When that was gone, she was left with nothing. The forceful removal of an intense focus can send one’s mental health plummeting.”

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“As for intense focus and interests, having multiple interests and realizing how they supplement each other was encouraged in the Montessori-based therapy that I had. As a result, switching is generally easier for me. I can have several conversations with someone ranging from Disney princesses to autism to Norval Morrisseau to the latest book by Philippa Gregory, just to name a few examples.”

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“My super interest in the military and military history is at the forefront, but I also have other interests: working out, politics, martial arts, woodworking.”

### Biological factors

#### There are many biological factors that are linked to mental health:

- Genetics

Some mental health problems seem to be genetic or to run in families—not just families with Autistic people. People can have a biological tendency to develop mental health problems such as depression, anxiety or psychosis. However, it does not mean that such problems will happen.

**It means that if certain factors come together, a person has a higher chance of developing a problem and a higher chance of the problem being disruptive to their daily life.** Understanding family medical history may motivate a person to learn about mental health and seek out support early.

- Sensory differences

**Many Autistic people tend to have different sensory profiles,** and sensory differences may contribute to certain behaviours or emotional states.<sup>12</sup> Not getting enough sensory input, or getting too much, can add to stress and distress, which can lead to mental health problems. When an Autistic person gets the right kinds of sensory input (information from seeing, hearing, tasting, smelling or feeling, sensing), they can feel good. It can be calming or enjoyable. For example, some Autistic people stim, and this is often a calming tool used or a mode of expression. They may either seek sensations or avoid them. Difficulties with sensing body cues (called interoception) and body position, movement or placement (called proprioception) can also lead to difficulties with sensing injury, illness or distress and seeking help.

### **Autistic experiences with sensory differences**

“Sensory sensitivities and anxious rumination make it very difficult for me to sleep. It is very hard to fall asleep when the slightest noise keeps you awake, the texture of bedclothes is all wrong, the room temperature is too high or too low, the light coming from the window is too bright, and so on. While I am stewing in this physical discomfort, my mind likes to play a highlight reel of all my anxieties. It is a miracle for me to fall asleep and to stay asleep. Many Autistic people have sleep issues. Lack of sleep is incredibly detrimental to mood and overall health.”

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“From a young age, me and my sisters had soymilk, rice pasta and wheat-free bread as part of our diet, as per Mom and Dad following the advice of their nutritionist. I’m glad that healthy alternatives to certain products (e.g., almond milk) has expanded in the over 20 years I’ve been alive. Having almond milk in particular has felt very grounding for me, and I’ve had the least amount of small momentary blackouts in years. I can certainly affirm that healthy food impacts mental health. When I had Montessori-based therapy sessions, I would go on outings with my therapist which would gradually acclimate my bodily senses, so I wasn’t overwhelmed all the time. That was also helped by art and music therapy sessions, too.”

“I experience sensory overload on a daily basis. Being an adult means that I have a lot more control over my environment than I did as a child, but that doesn’t mean that I am free of this issue.

“Anytime I leave my home (where I have total control over sensory input), I run the risk of overload. That could trigger a meltdown or shutdown in public, something that can be acutely embarrassing, especially with the stigma attached to such ‘behaviours.’ Our society judges a parent harshly when their child has a meltdown in public; it is far worse for adults when we meltdown/shutdown. We are judged for ‘lack of self-control,’ and we can be profiled as ‘dangerously disturbed’ and be arrested, be assaulted or be committed. It’s very stressful to walk outside my own front door and try to engage in everyday, normal activities, because society doesn’t understand and is so judgmental.

“I hate seasonal displays in malls because of overstimulation. I am subjected to noises and smells, bright lights and crowds, beyond my control. Online shopping is so very attractive. It’s quiet and I can have a cup of tea at home while shopping.”

- **Physical health problems**

When a person is able to exercise, have good nutrition and be in generally good physical health, they are also more likely to be in good mental health. If they have physical health problems or poor physical health, like chronic pain, digestion issues, irritable bowel syndrome or problems sleeping, this can affect mental health. It is important that these problems are recognized and treated. Treatments for physical health problems may have some side-effects or may be stressful, and sometimes seeking help for physical health problems can be distressing. One adviser shared that going to a walk-in clinic is not accessible when someone has a long list of health problems, and it made them feel “complicated, annoying or burdensome.”

## **Autistic experiences with physical health**

“I keep very fit—work out four times a week or more. It helps physical health, but also mental health as well and anxiety.”

“I have a condition called Ehlers-Danlos syndrome, which many Autistic people have. I do not receive adequate care or treatment for this, which causes me pain virtually all of the time. This has devastating effects on my mental health, as pain makes all of my sensory issues so much worse.”

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