



Mental Health Literacy Guide for Autism

**Written by the Autism Mental Health Literacy
Project (AM-HeLP) Group**



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Foreword

It is my pleasure to provide a foreword to this *Mental Health Literacy Guide for Autism*. This guide developed out of a desire to increase awareness, knowledge and acceptance around issues relevant to the mental health of Autistic adults. It is meant to be read by everyone, especially by Autistic adults, by family members, by professionals and by policy-makers and leaders to increase their understanding about mental health within the context of autism.

Starting with some existing materials, our core team consulted with a large and diverse group of Autistic adults and family members of Autistic adults from many parts of Canada, getting input on the chapter content and format over a period of nearly two years. Advisers did not represent any specific organization or group. We wanted to learn from them about what they thought was needed to support mental health. The content of this guide does not necessarily represent any specific adviser's views or ideas.

Some advisers were also keen to provide their first-hand Autistic experiences in different sections, which we have kept as quotes, to bring a first-person account of the content we cover. These perspectives and opinions complement the broader content, acknowledging that there are different ways of doing things and that each person's experience is unique. I hope that as you read this, you generate more ideas around how to promote mental health and address mental health problems when they arise.

It became clear in consulting with advisers just how passionate they were in changing the way Autistic adults are treated in Canada and beyond. There is a sincere desire and recognition that for well-being to occur, our society must accept people for who they are, with all their diversity. There was a strong focus on the social contexts for mental health: that the current states of mental health for Autistic adults lie in their experiences in the world—and that solutions must be found in how to change these contexts for the better, moving beyond the traditional focus on the individual. I hope that all who read this document reflect on how autism is understood and how Autistic adults are supported.

It was also clear that many Autistic adults feel hurt, marginalized, stigmatized and disenfranchised by non-Autistic society at large. Many advisers described negative experiences that they have had, or that other Autistic people have had, with non-Autistic-led organizations, providers and advocacy groups. As well,

some advisers shared similar experiences that they have had with some Autistic-led organizations. There was a general concern that adviser contributions in this guide could end up serving goals and organizations that advisers did not support. I have elected to use a disclaimer section that follows this foreword to reflect some of these concerns. I ask readers to keep them in mind as they review the guide. I believe that these sentiments reflect the belief that for things to be better, systems of care need to improve, and for that to happen, these systems must learn from Autistic people.

This guide is meant to be used openly and freely to benefit the mental health of Autistic adults by increasing readers' awareness of mental health within the context of autism. Knowing more can empower us to do more.

Sincerely,

A handwritten signature in blue ink that reads "Jonathan Weiss". The signature is written in a cursive style with a long, sweeping horizontal line extending to the right from the end of the name.

Dr. Jonathan Weiss

DISCLAIMERS

Autistic advisers informed the development of this guide, but this process and the writing was not led by Autistic people. As was pointed out to us, there may continue to be some aspects that have a “neurotypical lens.”

The views expressed in this guide do not necessarily reflect the views of all contributing advisers or authors, and not all the ideas that emerged in consultations were included. Throughout, we did include unedited adviser quotes that reflect a variety of perspectives and opinions, to capture some of the diversity of what people experience and want. There is no single perspective that is endorsed.

The content of this guide focuses on mental health. As such, there is content that may be triggering to some readers.

The information provided in this guide is not meant to be a substitute for mental health care. Its purpose is to increase awareness and share knowledge, not to provide readers with skills in mental health care provision.

Some advisers do not support the notion of a national autism strategy in Canada and are concerned that this guide will be used by non–Autistic-run advocacy groups, who do not represent their views, for a national strategy. Some advisers expressly asked that this material “not benefit the Applied Behaviour Analysis industry in any way.”

This guide should be reviewed and taken in its entirety. There was concern shared that only portions of this guide would end up being considered to suit any one particular organization’s agenda.

The use of this guide does not mean an endorsement of any organization or movement.

Some sections were written expressly with the Canadian mental health context in mind, though much of it is not specific to the Canadian context.

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Introduction

Welcome to the *Mental Health Literacy Guide for Autism!* This guide is meant to provide information about the mental health needs of Autistic adults. The guide was developed in consultation with Autistic adults and parents and siblings of Autistic adults. Autistic adults shared their mental health experiences and provided ideas of what was needed to promote their well-being.^a

Who should read the guide?

The guide is for Autistic adults and the Autistic community, as well as for the autism community, such as families, caregivers, service providers, educators, institutions, organizations, agencies and policy-makers.

Purpose of the guide

The guide's main purpose is to improve mental health literacy in Autistic adults in Canada. This means sharing knowledge and combating myths about autism, Autistic experiences and the unique mental health needs of Autistic people.

Some of the goals for this guide are:

- to provide knowledge about mental health as it relates to Autistic adults
- to communicate this knowledge through the lens of lived Autistic experiences in order to provide the most relevant, useful and valid information
- to be a resource that Autistic people can use to help understand the mental health systems across Canada
- to be a resource for Autistic and autism communities, families, mental health practitioners and service providers
- to inform people about the mental health needs that may be experienced by Autistic adults.

What are the limitations of this guide?

Every effort has been made to produce a guide that is a helpful tool. However, this guide does not address the specific needs of everyone. It is meant to be a starting point. It is recommended that readers further investigate the topics by accessing other resources.

^a The authors acknowledge that the advisory group was made up of Autistic adults or parents who were all physically and verbally able to share and represent their lived experiences.

Terms within the guide

Identity-first language

There have been major changes in the last 30 years that have profoundly shaped the ways in which autism is discussed, defined and described. There are some recommendations for **identity-first language** (e.g., “Autistic person”) or for **person-first language** (e.g., “people with autism”).

Throughout the guide, the terms **Autistic person** or **Autistic people** will be used when communicating about autism.

While traditionally, person-first language was the recommended method for describing autism, many advocates and authors have highlighted the issues with this approach for the Autistic community.¹ There is relative consensus among disabled advocates in general and those in the Autistic community in particular, that identity-first language is the preferred way of talking about autism. Autism is seen as an inseparable part of who Autistic people are. At the same time, some family members, service providers and Autistic people themselves may still prefer person-first language or the use of a different term other than “Autistic.”

The use of **identity-first language is meant to recognize, affirm and validate the ownership of an identity as an Autistic person.** “Autistic” is not a derogatory term. It is seen as a source of pride. We discuss stigma and autism in **Section 1.**

Gendered and gender-neutral language

The term “**sex**” refers to the biological characteristics of being male, female or intersex, while the term “**gender**” refers to the psychological, social, behavioural and cultural attributes related to assigned gender and non-binary genders. “**Gender identity**” refers to the subjective experience of being a boy, a girl, a man, a woman, non-binary, transgender, agender, genderqueer or gender-neutral.²

Throughout the guide, we use gender-neutral and gender-inclusive language as much as possible.^b We talk more about gender and autism in **Section 3.**

Sex refers to the biological characteristics of being male, female or intersex.

Gender refers to the psychological, social, behavioural and cultural attributes related to one’s assigned gender and non-binary gender.

Gender identity refers to the subjective experience of being a boy, a girl, a man, a woman, non-binary, transgender, agender, genderqueer or gender-neutral.

Medical and non-medical references

Another common debate involves the language used when describing mental health. **Labels and diagnostic terms that are often used can be stigmatizing and overly pathologizing. They can imply something to be disapproved of, or as something “abnormal” or “unhealthy.”**

The stigma and negative perceptions with medical terms can cause emotional pain for Autistic people. It is important to acknowledge the limitations and potential consequences in using medicalized language.

Throughout the guide, we aim to use a minimal number of medicalized terms, unless required for the sake of clarity.

Throughout the guide, we try not to use medicalized terms (e.g., using the word “disorder”), unless it was felt to be required for clarity or to inform about common words used by professionals, or unless such terms were used by Autistic advisers when sharing their experiences. **Section 7** discusses the diagnostic process, including the advantages and disadvantages of using certain language.

Structure and layout of the guide

The structure and layout of the guide helps provide both depth and range. Each section starts with a snapshot (a quick summary) of what will be discussed, and parts of the guide use visual summaries. The first few chapters aim to present general information, including definitions for autism, mental health and more. The guide then becomes more specific, discussing common mental health triggers, strategies to promote mental health wellness and formal mental health systems in Canada. We end the guide with a List of Resources and a Glossary of Terms.

^bAccording to the United Nations, “gender-inclusive language means speaking and writing in a way that does not discriminate against a particular sex, social gender or gender identity, and does not perpetuate gender stereotypes.”³

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Mental Health Literacy

Snapshot

- Mental health literacy means knowing about mental health and having skills and support to apply that knowledge.
- Improving mental health literacy can decrease stigma and make it easier to find helpful supports.
- Acknowledging and understanding the different ways Autistic people experience mental health can be empowering.

This guide's primary goals are to promote and improve mental health literacy in Canada for Autistic adults. This section defines what mental health literacy is.

Defining mental health literacy



According to the Canadian Alliance on Mental Illness and Mental Health (2008), **mental health literacy** is defined as the “knowledge and skills that enable people to access, understand and apply information for mental health.”¹ It is thought that when we know more and have positive attitudes about mental health, we can notice our mental health and take steps to stay healthy or to help others.

Mental health literacy is the knowledge and skills that enable people to access, understand and apply information for mental health.

The four components of mental health literacy²



1. **Recognizing different mental health states** (such as distress, difficulties, trauma and well-being) that affect how a person behaves and interacts with others. In other words, knowing how to tell how people are feeling and what happens when people feel that way.
2. **Improving mental health knowledge and beliefs** about risks, causes of distress or mental health problems, and self-care and support. Learning more about what mental health means, what it means to have a problem and what people can do when there is a problem increases mental health literacy.
3. **Reducing the stigma of mental health difficulties.** Helping people to know they can have mental health problems and that this is okay—we should not think bad things about people when they are having a hard time. Mental health difficulties do not make people burdens. They deserve acceptance and support.

4. **Increasing mental health help-seeking abilities**, which means:

- Knowing **when** to get help—for example: knowing your triggers.
- Knowing where and how to get help.
- Having (or developing) the **skills** for self-care.
- Knowing **what to look for in supports** and **what good supports look like**.
- Increasing self-advocacy skills, which means being able to communicate your thoughts, feelings and what you need and want for your mental health. It also means knowing and being able to communicate about your rights and being able to make decisions that are important to you.

People may not seek support for their mental health because they do not notice the signs of distress. They may not know how or where to access supports that can help, or they may feel that not doing anything is (or seems like) their safest option. Improving mental health literacy means providing information to increase our understanding of resources and positive and helpful supports.

Using an Autistic lens to understand mental health literacy

Stigma

Stigma is a crucial factor why some people may not seek help.^{3,4} Stigma is when someone views you in a negative way because of a characteristic, trait or label. Autistic people may not seek help because of a fear of being stigmatized by other people, including by service providers. Learning about mental health can address the mental health stigma in youth and adults.⁵ Mental health literacy can empower a person to understand mental health in others and in themselves.

Stigma is when a person negatively views others because of a unique characteristic or personal trait that they think is a weakness.

Self-stigma

Self-stigma is when a person believes that they are inferior because of their condition, like believing they are less than someone else because of their mental health or because they are Autistic. They stigmatize themselves.

Self-stigma is when a person believes that their condition makes them inferior.

Mental health literacy can mean **understanding ways of finding inclusive spaces, enhancing a sense of belonging or connecting with a supportive community to reduce feelings of isolation.**

Internalized ableism

Ableism is when a person is seen and treated as “less than” because of their disability.

Internalized ableism is when a disabled person accepts that they are “less than” non-disabled people because of their disability.

One way that Autistic people can experience the world is by absorbing (i.e., internalizing and coming to believe and accept) what society says is “normal” and “acceptable,” and then judging themselves against these standards and feeling less than others (i.e., accepting that being Autistic makes them inferior). This may contribute to mental health problems or distress (like depression, anxiety, burnout), especially when Autistic people experience negative feelings about being Autistic. Mental health literacy can mean **acknowledging and understanding how internalized ableism can have a significant negative effect on Autistic mental health.**

For example, **internalized ableism** is accepting that being Autistic makes a person inferior.

“Autistic adults can often feel that we’re ‘bad people’ or failures or that we are always wrong and that those who are not Autistic are always right in what they do or say because we have internalized that our behaviour is wrong or incorrect—we were rude without knowing it, we didn’t see the whole picture like we were supposed to, we thought we did well in a situation and it turns out we didn’t . . . and so, that can lead to a distrust of the self; the idea that you know nothing or are somehow unreliable but others around you are correct or in the know or to be trusted.”

“Suicide is something I’ve thought about quite frequently. My life is a constant battle for survival against ableist assumptions that deny me basic necessities. I have no social life because ableist assumptions about friendship deny me friends. I have no financial stability because ableist assumptions about what constitutes a good employee deny me a job. Ableist assumptions about autism and lack of intelligence also deny me access to disability supports. Despite a growing number of Autistics with PhDs, there’s still a belief even among service providers that, if I have a PhD, then either I can’t be Autistic or I’m ‘not Autistic enough’ to need supports. So, the same ableist attitudes that cause me to think about suicide, on an irregular basis, also prevent access to supports that could help.”

Socialization and communication

Autistic people may act, socialize and communicate differently than what is expected by non-Autistic people. They can be stigmatized because they are outside the non-Autistic culture's idea of "normal." This stigma can affect mental health, access to essential services, employment, education and housing, and it can lead to dangerous misunderstandings with law enforcement. Within the Autistic community, different ways of socializing are the norm, and communication barriers are not experienced to the same degree as when interacting with the non-Autistic community.

Improved mental health literacy can mean **providing information to non-Autistic people to be more accepting of and to learn about social norms for Autistic people**. It also requires an understanding of the ways that Autistic people can communicate that may be different from non-Autistic expectations. Wellness comes from being accepting, being patient with and listening to people whose ways of being, behaviours, communication or socializing are different than the "norm."

At the same time, mental health literacy can mean **helping Autistic people to navigate the societal attitudes that currently exist**. Mental health literacy can also mean providing Autistic people with the social-communication skills they require to effectively communicate their intentions.

Lived experiences

Autistic people often report not being consulted or listened to about their lived experiences, and this can have a negative and lasting effect on their mental health. Mental health literacy can mean **increasing society's understanding and acceptance of autism and of the right of Autistic people to be heard**.

Mental health challenges

Like non-Autistic people, Autistic people can have a wide variety of mental health challenges. Autistic people may experience difficulties and distress in ways that may or may not be visible and that may be expressed in different ways. They may not express the distress in ways that non-Autistic people expect. Mental health challenges can affect how a person is able to describe their experience using spoken or alternative communication methods, or how they communicate

their mental state using body language, facial expressions and tone of voice. This can mean they may not appear, to a non-Autistic person, to seem anxious, depressed or in crisis, even when they are.

Service providers may not have training or an understanding of how mental health difficulties may look in Autistic people. This can worsen the experiences for Autistic people when seeking help. It creates barriers to accessing the mental health support they need. Autistic adults may feel invalidated and dismissed by professionals.

Mental health literacy can mean **understanding the importance of non-Autistic people to ask about, respect and listen to what Autistic people share about their mental health.** It also involves understanding that there are negative effects on health when Autistic people experience barriers to receiving correct diagnosis or access to appropriate supports, because their needs are not recognized by others.

Double empathy problem

The “**double empathy problem**” refers to when people with different perspectives and ways of communicating have a breakdown in understanding each other’s views.⁶ Traditionally, it was thought that Autistic people struggled to understand the views of non-Autistic people. Instead, the double empathy problem means that this difficulty goes both ways, since non-Autistic people are not able to understand the perspectives of Autistic people.⁷

Double empathy problem
involves people with different perspectives struggling to empathize or see each other’s views.

Mental health literacy can mean **understanding the “double empathy problem” that Autistic people experience with non-Autistic people, and the other way around.** It is knowing that non-Autistic people need to learn how Autistic people experience things. It allows both sides to see each perspective that makes way for supporting mental health and healing. Listening to Autistic people is where real change and understanding can flourish.

“Communicating with non-Autistics has always been a problem for me. I’m expected to communicate in non-Autistic ways, following a huge rule book of social rules. Rules about facial expressions, about tone of voice, about vocal inflections, about body language, about interpreting spoken language and subtext. I don’t have issues communicating with other Autistics because we, more or less, use the same rule book. But non-Autistics expect me to ‘speak their language’ rather than meeting me halfway. As a result, it can be difficult to talk to non-Autistics about my needs or, more accurately, meeting my needs. My needs aren’t any different than other peoples’ needs; they aren’t special. They just aren’t met because non-Autistics misunderstand me all the time because they try to understand me using their non-Autistic rule book. People think I’m being unfriendly because they have a non-Autistic idea of what ‘being friendly’ means. People think I’m being unempathetic when I’m just showing empathy in a different and ‘abnormal’ way. Communication is a two-way street — I can only go so far when others won’t make the effort to understand that, even if I’m speaking English, my language isn’t the same as yours.”

Autistic experiences with mental health literacy

“I walked into my bank with a large cheque a few weeks ago (just a little inheritance). I never have large cheques, and the cashier wanted to know where I got it. I was a little confused because I’ve never been questioned before about such a thing. Classically, the teller thought that I was getting agitated, which I am often accused of even though I am completely unaware of it. I was simply trying to understand why I needed to give them information about where I got the cheque. Instead of escalating the situation, the teller said, ‘Sir, I can see that you are getting agitated with me.’

With my new-found self-diagnosis, it suddenly dawned on me to let her know that I’m not agitated but that, because I am Autistic, people often think I’m angry. She immediately put me at ease by saying, ‘Well, then there is no problem, I understand!’ I was shocked in a very good way to have this happen, and it made me realize the power in asking the right questions and being aware that there are different ways that people communicate. This awareness was as good for me to realize about myself as it was for the teller to have openly communicated her feeling about our conversation.”

“There’s been plenty of times that I’ve felt I was ‘broken’ or ‘defective.’ It seems to be a common experience for Autistics. It still happens even though I understand that I’m just different. Being treated like I’m ‘defective’ or ‘unwanted’ by so many usually well-meaning people can have a strong effect on your feelings about yourself even when you know the treatment isn’t justified or that it often comes from ignorance. Most people have no idea that they treat us in problematic ways that negatively affect our mental health. They’re just behaving ‘normally,’ ignorant of the fact that ‘normal’ is defined by those in power and it doesn’t work for everyone. Talking to someone about it can sometimes make a difference, but many people get defensive and move into explicitly stating there’s something wrong with me. This is what medicalizing and pathologizing neurological differences does. It gives us a negative and harmful self-image that is constantly reinforced by the idea that anything the medical community calls a disability is inherently bad. I’m not broken. I’m not defective. There’s nothing wrong with me. Yet, I’m disabled.”

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Understanding Mental Health

Snapshot

- Mental health is the ability to feel, think and act in ways that help us enjoy life and deal with difficulties.
- Mental health problems can occur when a person experiences a lot of distress.
- There are many reasons why a person can experience mental distress. Often, it is related to events in their environment and/or how the person understands them.
- Understanding is unique and can affect well-being.
- A person can experience the positive and negative sides to mental health at the same time.

Just like everyone has various states of physical health throughout their lives, everyone also experiences different mental health states. **Mental health, just like physical health, has positive and negative aspects.** People can have good mental health in some ways and at the same time struggle with certain aspects.

There are many words used to describe mental health. Some words can be more hurtful than others. Terms like “mental disorders,” “mental illness,” “mental health difficulties” and “mental health problems,” are historically stigmatizing and can be pathologizing, suggesting the experiences are “abnormal.” These terms, when used on their own, may not really show the full range of what mental health means or reflect mental health as part of the human experience. In this section, we try to describe a broad way of defining mental health and its different aspects, to reflect lived experience.

It is also important to understand the effect of context on a person’s mental health, and to debunk myths that surround it. Context means the environments and situations people find themselves in. It is a myth that everything about mental health has to do only with the person experiencing that mental health state; that a person’s state of mental health is because of something only within them. **Mental health is also about the interactions between a person and their many environments** (such as sensory inputs, family, school, workplace, support systems, etc.).

The state of a person’s mental health often depends on the resources they can access outside of themselves, such as services, safe housing, social support, healthy food, literature about mental health, or meaningful activities. These help people grow and be healthy and enables them to be confident to reach out. Everyone also has strengths that come from inside themselves (e.g., their emotions, thoughts, attitude, perspective and behaviours) that can contribute to good mental health.

A person’s mental health may vary day to day, as mental health is not a fixed state and is not “all or nothing”—it is dimensional. A person may feel better or worse one day to the next. It depends on what is going on in their life.

Mental health depends on the person, their contexts and their response to their contexts.

Defining mental health

There are many definitions of mental health. The Public Health Agency of Canada (2006)¹ takes a broad definition of **mental health** as “the capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity.”

Mental health is the capacity of each and all of us to feel, think and act in ways that enhance our ability to enjoy life and deal with the challenges we face.

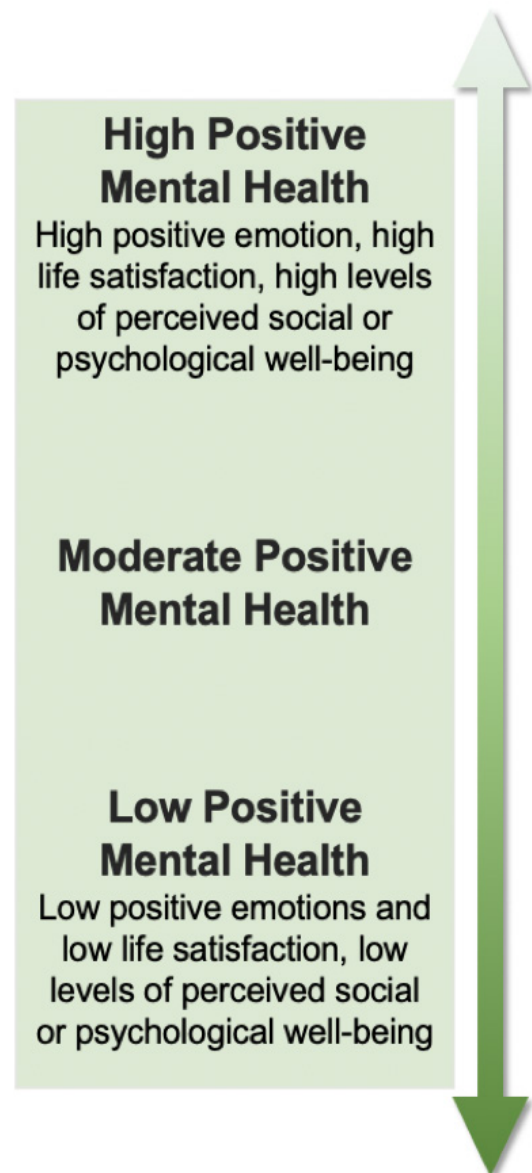
Positive mental health: from low to high

Mental health has positive parts to it. Mental health is not just about the absence of problems. **Positive mental health** is often described as spanning a continuum from low positive mental health (sometimes described as “languishing”) to high positive mental health (sometimes described as “flourishing”).² This is illustrated in the diagram on the next page.

High positive mental health involves:

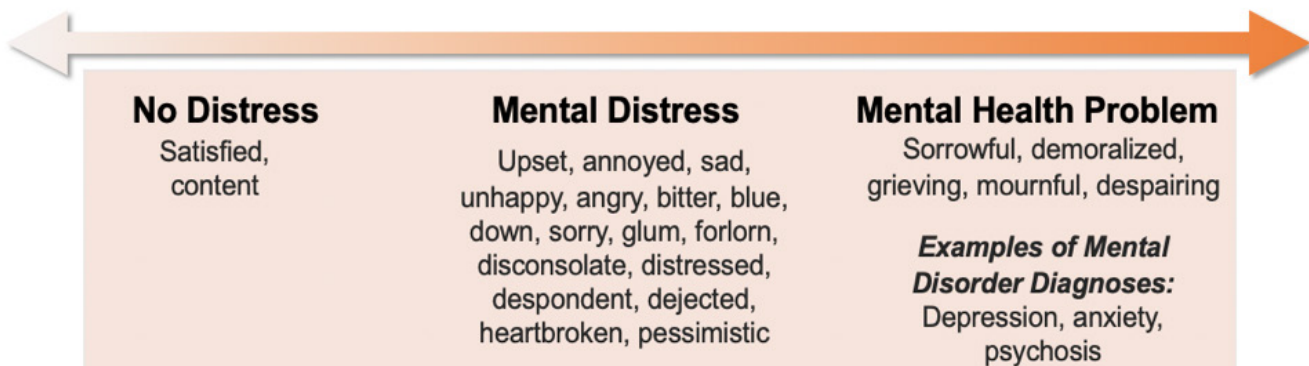
- Regularly feeling positive emotions
 - Examples: in good spirits, happy, cheerful, calm and peaceful
- Being generally satisfied with life
- Experiencing psychological well-being
 - Examples: growing as a person, feeling a sense of purpose, accepting oneself
- Experiencing social well-being
 - Examples: feeling included by others, feeling accepted by others and society.

On the other end, **low positive mental health** means rarely experiencing positive emotions and life satisfaction, and not regularly experiencing psychological and social well-being. **Just because a person has low positive mental health does not mean they have lots of distress.** It just means that they are not experiencing a positive state very often. Many people experience what is defined as moderate levels of mental health.



Negative mental health: from no distress to mental health problems

Mental health can also span from having no distress to serious mental health problems. This is illustrated in the diagram below:



What is mental distress?

When a person's situation becomes challenging (e.g., due to being excluded, writing a test, going to a job interview, speaking to a new person), a person can experience an inner signal of stress—a “stress response.” This stress is also known as **mental distress**.

Mental distress isn't necessarily a bad thing.

It can get a person ready to do something. For example, it can help prompt a person to access resources—the supports that can help a person deal with challenges. Mental distress can also prompt a person to engage in certain behaviours or actions that may help to lower the stress.

Mental distress is an experience of negative feelings that is often a signal of stress.

Distress can have many positive and negative components, including:

- feelings (e.g., energized, motivated versus drained, frustrated)
- thoughts (e.g., positive thoughts: “This is new, but I will try,” versus negative thoughts: “What will they think of me?”)
- body responses (e.g., stomach or muscle aches, fast heart rate, shaking)
- behaviours (e.g., accessing supports or creating a plan, versus avoiding or yelling).

Mental distress is part of mental health, and people experience it in many ways. **Distress can be a part of good mental health.** The feelings that come in times of distress (e.g., feeling sad, annoyed, panicked, or angry) are often very appropriate responses to life's challenges. They are ways that a person's body and mind tell them that something hard or upsetting is happening in their lives. Just because a person may feel stressed or overwhelmed sometimes does not mean that they do not have positive mental health. Noticing when you are stressed, and experiencing it in a way that does not lead to more distress, is important for good mental health.

When people experience mental distress, they are not “sick” or “disordered.” Patience and support are needed. People should have the chance to develop skills and experience distress in a healthy way. It could also be that the environment needs to adapt, not the person.

What are mental health problems?

When the causes of distress are intense for a person or do not go away, and these stresses outweigh resources, the person's mental distress can become a **mental health problem**. Mental health problems can have combinations of internal (e.g., physical conditions, genetics) and external causes (e.g., environment, traumatizing events).

Mental health problems happen when the causes of distress outweigh a person's resources.

According to the *Australian Mental Health First Aid Intellectual Disability Guidelines*³: “A mental health problem is when there is a major change in a person's normal way of thinking, feeling or behaving. It affects the person's ability to get on with life. It does not go away quickly or lasts longer than normal emotions or reactions would be expected to. It might involve a diagnosed mental illness, a worsening of mental health or an undiagnosed problem, or a drug or alcohol problem.”

A mental health problem can mean that a person may need support beyond the strategies and resources that they already have access to. **Mental distress and mental health problems can happen at the same time**. Mental health problems can affect a person's employment, academic experiences and achievement of personal and relationship goals. This state may make them feel unwell and make it difficult to perform well in different parts of their lives that are important to them.

A person with mental health problems may experience:

- emotional suffering
- loss of control over emotions
- immense sadness and/or anger
- exhaustion
- isolation
- consistent negative social interactions
- inconsistent cognitive function (e.g., poor concentration; memory lapse)
- suicidal thoughts.

Traditionally, mental health literacy guides make a distinction between a mental health problem and a mental disorder/illness. The term “mental disorder/illness” is often used to reflect “a diagnosable illness that affects a person’s thinking, emotional state and behaviour, and disrupts the person’s ability to work and carry out other daily activities and engage in satisfying personal relationships.”⁴

“**Diagnosable**” means that a person’s patterns of thoughts, feelings and behaviours fit with a description found in a classification system, and that this pattern is having a negative effect in that person’s life. Because diagnoses are part of the medical disease model, they can be very stigmatizing and shaming and can make mental health problems worse for some people. That said, other people feel that there is value in a mental health problem diagnosis, as it can provide a common label and the language to help explain experiences, or it may help getting supports (e.g., health and social service systems may need a diagnosis to access resources). Some classification systems that you may come across are the ***Diagnostic and Statistical Manual of Mental Disorders*** published by the American Psychiatric Association or the ***International Statistical Classification of Diseases and Related Health Problems*** published by the World Health Organization.

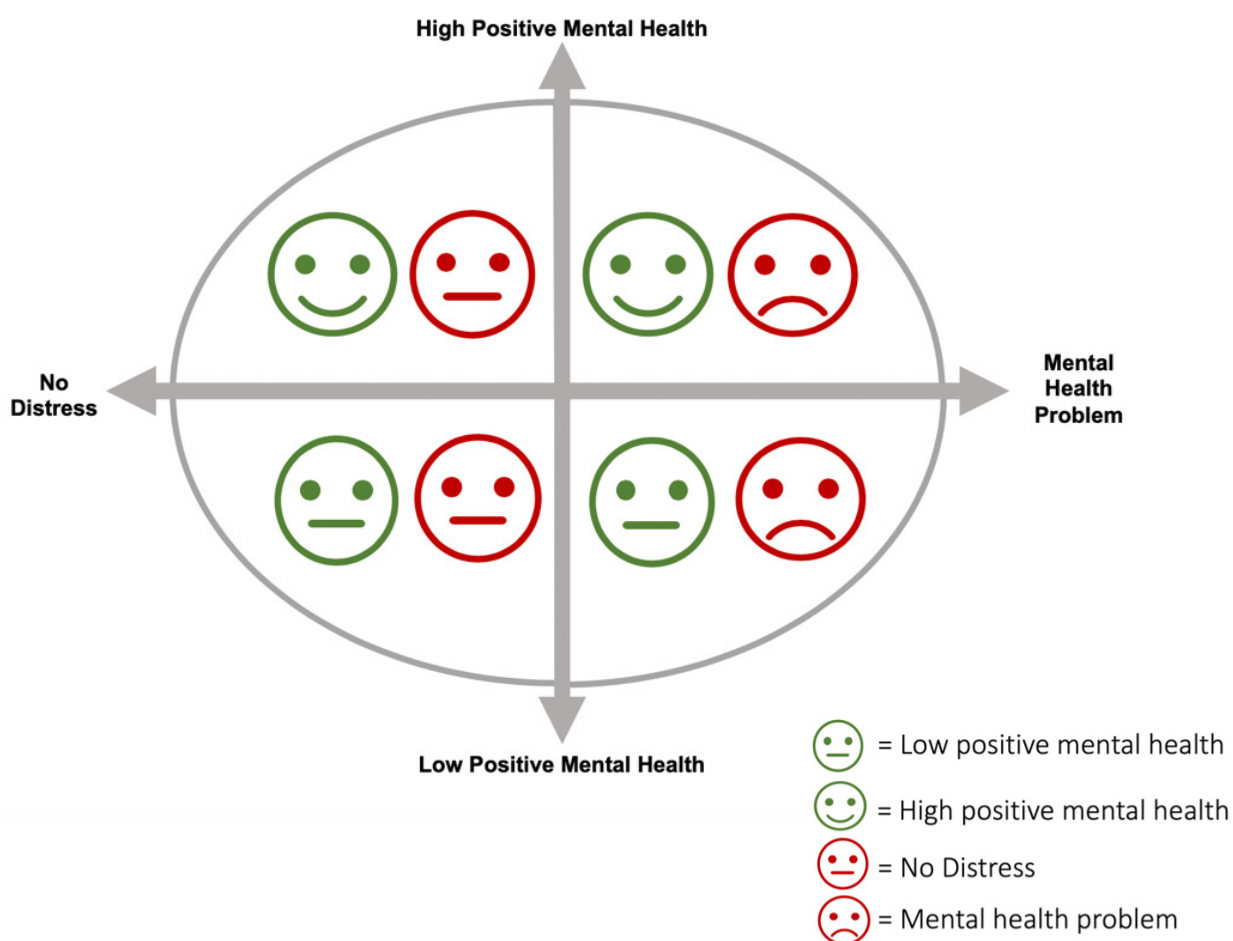
Diagnosable means:

1. a person’s patterns of thoughts, feelings and behaviours fit with a description found in a classification system
2. the pattern is having a negative effect in the person’s life.

These labels are based on a person’s (usually a clinician’s) judgment and may not always be completely accurate. In some cases, gender bias and racism can affect diagnosis. Some mental health services may turn away Autistic people because they have an autism diagnosis. It is possible that professionals may not notice or see difficulties as mental health problems when a person has an autism label, or they may not listen to what Autistic people are telling them. This can greatly affect mental health.

Mental health along two dimensions

These two dimensions (the positive mental health continuum and the mental distress continuum) are related, but not the same thing.⁵ **A person can find themselves in different combinations of distress and positive mental health.** For instance, people can have states of positive mental health and experience mental distress. They can experience low positive mental health but not experience lots of mental distress. Others can have low positive mental health and have mental health problems. This is displayed in the diagram below.



The important take-home message here is that a person’s state of mental health can be positive and negative. When a person thinks about being “mentally healthy,” it can mean thinking about what needs to happen so they can experience positive mental health and less negative mental health. If an Autistic person is experiencing a lot of mental distress, or mental health problems, they may want more support. **Section 6** and **Section 7** of this guide are about different kinds of supports.

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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.”

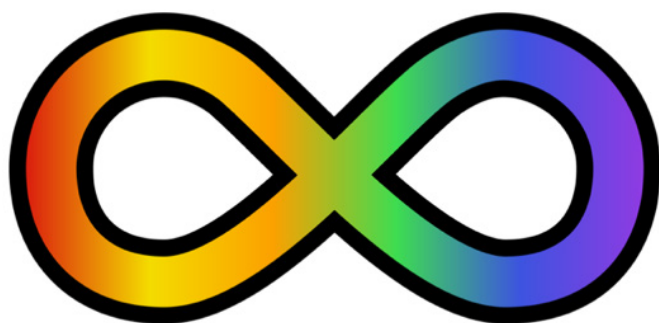
“I always knew I was different, even before my first day of school. But things were mostly okay until I started school. That’s when, day after day, my difference made me stand out in lots of negative ways. It took until I was 42 years old and after many different diagnoses to find out that I’m Autistic.

“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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Understanding Mental Health within the Context of Autism

Snapshot

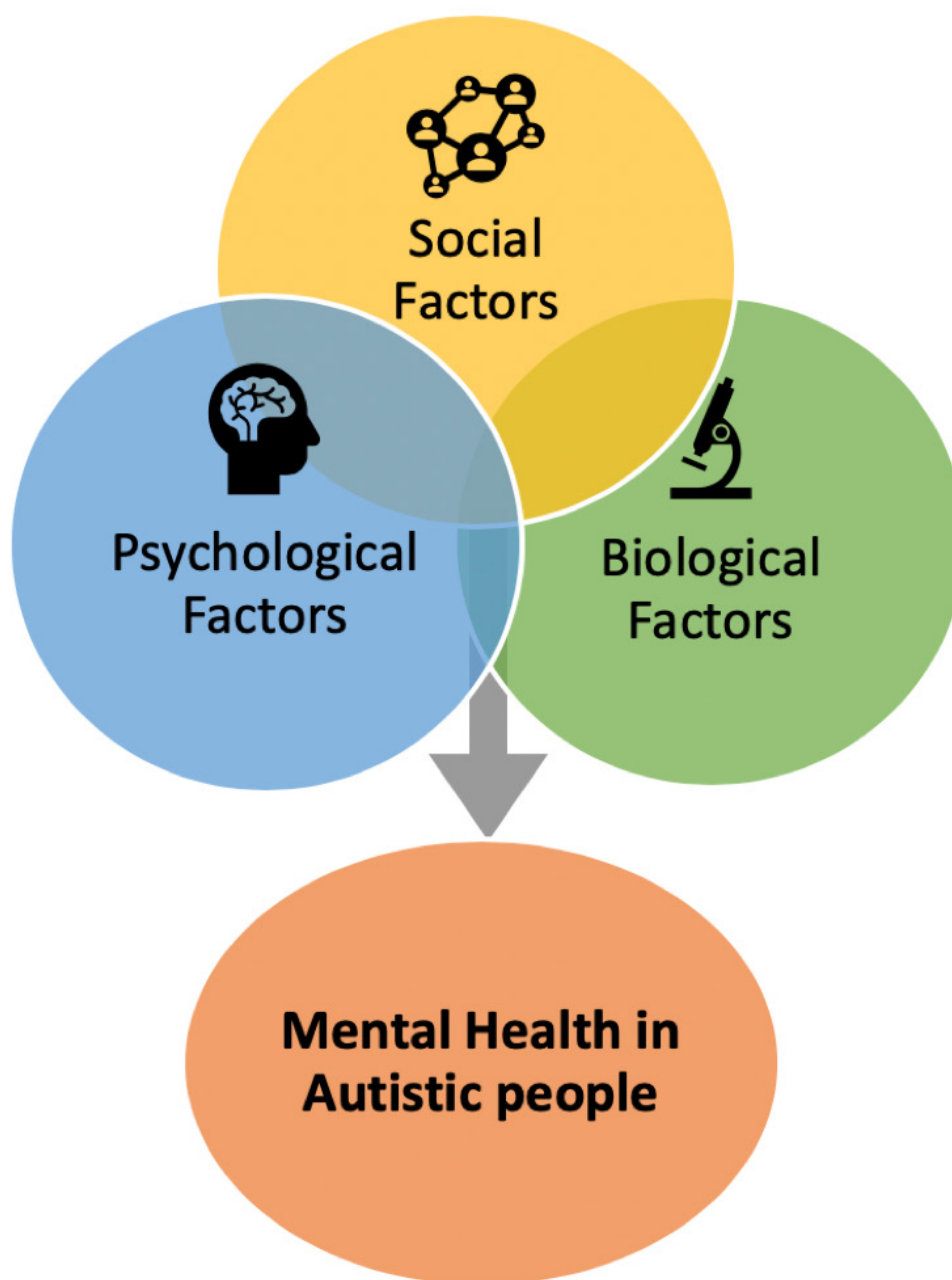
- Mental health problems can look different in Autistic people.
- Growing up in a society that is not understanding, accepting or supportive can affect how Autistic people see themselves, others and their lives.
- Providing the wrong kind of support can affect how Autistic people feel about themselves 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.¹ 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.¹

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.¹ 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,² 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 (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,² by pretending to be non-Autistic.

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.

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.”

“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.”

“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.”

“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.”

“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.”

“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!’”

“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.³ 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,⁴ and this struggle can lead to mental health problems.⁵

Schools need to supply a supportive environment to address these challenges. They may give services offering support for academic success,⁶ 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.”

“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.”

“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.”

“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.”

“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.⁷

“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.⁸ 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 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 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.”

“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.”

“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.⁹ 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,¹⁰ 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.”

“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.”

“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.¹¹

- 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,”¹² 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.”

“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.”

“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.”

“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.¹² 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.”

“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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Identifying Mental Health Problems in Autistic People

Snapshot

- This section describes common mental health problems experienced by Autistic people.
- We identify common "body", "doing" and "thinking" signs of mental health problems.
- For Autistic people, the combination of stressors and mental health problems can lead to meltdowns, shutdowns, or burnout.

It is important to note that this is not a diagnostic manual. There are many mental health problems that are not discussed here, as this guide's goal was to touch on some of the more common mental health problems Autistic adults may experience. Noticing the signs may help people to seek help or support. A lot of the signs can occur in more than one mental health problem (e.g., weight loss or gain can be a physical sign of eating problems or of substance misuse).

Content warning: Parts of this section talk about identifying physical experiences, behaviours and feelings that Autistic people may experience. The content described here does not reflect all Autistic people's experiences.

There is content in the Autistic experiences boxes that may contain topics including medication, trauma, abuse, suicide or assault. It could be triggering for some people.

The visuals and texts are not meant to suggest that an Autistic person has any of, many of or all of these issues; rather, these are the kinds of mental health problems that can be seen when Autistic people seek help for their mental health.

Knowing your own “usual”^a (knowing you)

Understanding your own “usual” is just as important as knowing what good mental health means and what it looks and feels like. **Someone’s “usual” (also known as “baseline”) is how they are on a typical day.** This includes their usual preferences, feelings, social interactions and activities.

Your “usual” (or baseline) is how you are on a regular day. It is different for everyone.

It can be helpful to know your own usual and let others know what your usual is. Otherwise, people may think there is something wrong when, in fact, there isn’t.

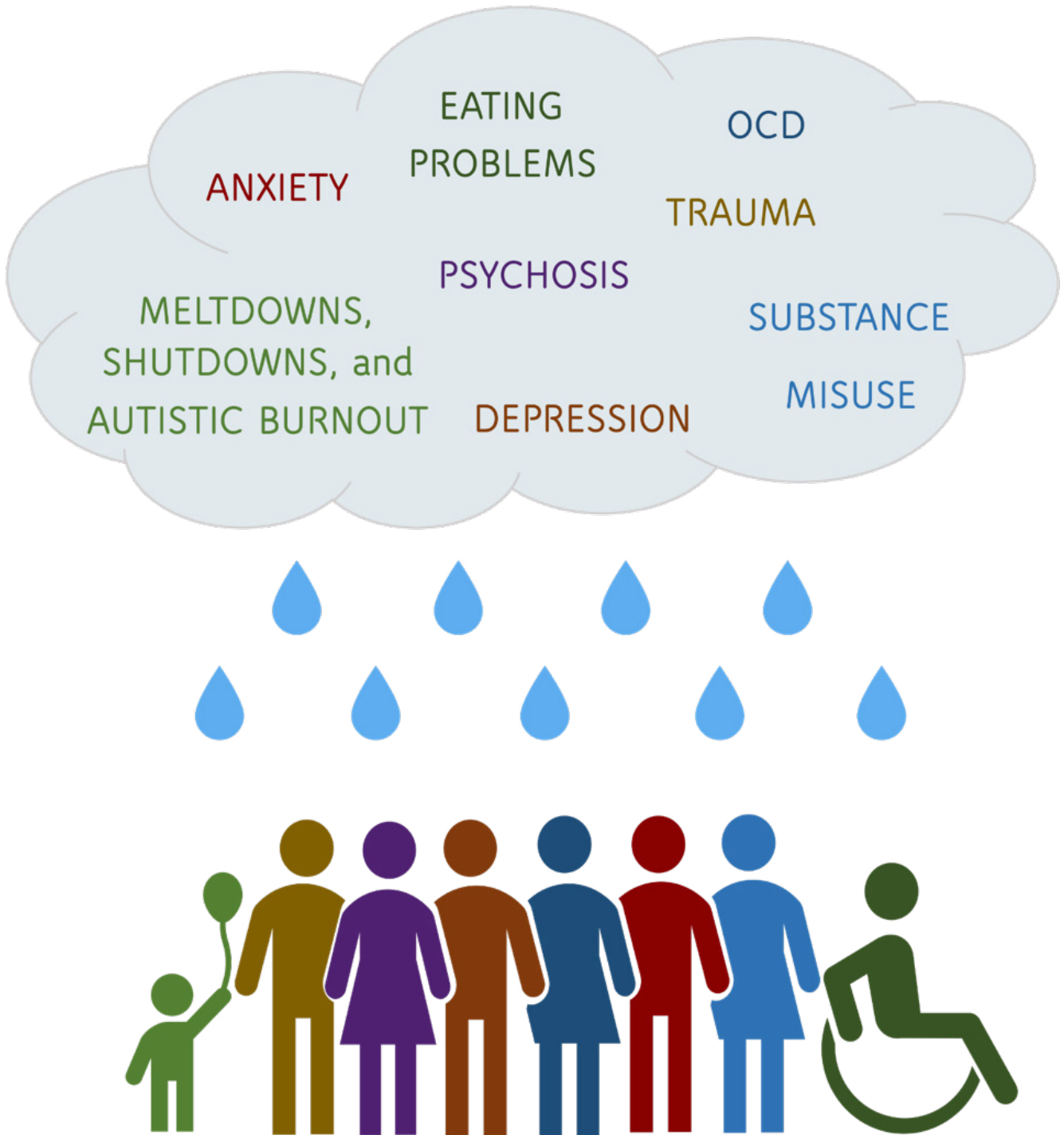
Usual is different for every person. One Autistic person’s own usual is different than another Autistic or non-Autistic person’s usual. A person may notice that their feelings, social interactions, activities and preferences change when they are experiencing poor mental health. Mental health problems change what is usual. In some cases, because of mental health challenges, trauma and long-term bad circumstances, “usual” may not always mean good mental health.

Knowing your baseline is very valuable in terms of mental health. When a person first notices changes in their usual self, it can signal them to check in about their mental and physical health. In doing so, they can notice if things are going well or not. This may prompt a person to take steps to help themselves or reach out for help if they determine their behaviours and responses are outside of what is usual for them.

It can be helpful to understand what usual is for other people, along with knowing your own. Again, **everyone is different, and that is okay!**

^a The concept of “Knowing your own usual (knowing you)” was inspired by the *Know Your Normal Toolkit* created by Ambitious about Autism (2019).

What are some mental health problems Autistic people can have?



Anxiety

Every person feels nervous, scared and anxious about things from time to time. Everyone experiences anxiety—both helpful and unhelpful kinds. **It can be useful to have fears and be nervous**; it can help people to be aware of and avoid danger and stay safe. Anxiety is an emotion that is especially useful when needing to notice dangers in the world (e.g., “Watch out for that car!”)—this is **useful anxiety**. For most people, when the trigger of the anxiety is no longer there, the anxiety ends, too. They no longer feel the uncomfortable symptoms that can go with anxiety, such as a sense of danger, rapid breathing and pounding heart. Autistic people are often marginalized, vulnerable and sensitive to their environments, and their anxiety is often triggered for valid reasons. It is important that people do not invalidate an Autistic person’s anxiety.

People can also have unhelpful anxiety, which includes anxiety that does not end even when the causes of it are no longer there or anxiety that does not help a person figure out what is dangerous or stressful about their environment or situation.

Anxiety can be unhelpful if it leads a person to avoid things that the person would like to do. Unhelpful anxiety can stop people from being at their best, whether it be at work, in relationships or in managing their daily activities. Anxiety can be a problem when feelings of fear, worry and even panic **become overwhelming**, and if a person feels that the feelings are **out of their control**.

Unhelpful anxiety can:

- continue even when the cause has stopped
- be unhelpful in identifying what is dangerous or stressful
- make you avoid things you like to do
- stop you from being able to do your best
- make you feel overwhelmed and out of control

People can have anxiety about many different things. Some people have anxiety when they think about scary things that may happen in the future. Others may be anxious specifically about being in social situations, open spaces and crowds, or about the thought of a panic attack. They may have anxiety and fears about specific topics (such as animals, harsh weather or their personal health) or situations (such as getting a needle). Autistic people may have more reasons to feel anxious or be more at risk for anxiety because of their lived experiences.

What does anxiety typically look like?

There are lots of potential signs of anxiety. Remember, just because a person can experience some of these signs does not make them bad, negative or wrong. They are just some possible signs that a person is feeling anxious.

Some Autistic people may be anxious and still not show these signs or may show only one or two of them. It is important to know that these same signs may not be anxiety and could be mistaken for anxiety (e.g., a person may be hungry or may have had too much coffee). But when a person feels anxious, they often show some of these signs. So, “knowing your own usual/baseline” (and others knowing it, too) is important.

Signs of anxiety¹

Following are some of the common signs of anxiety that people can experience. It is not only Autistic people who experience these signs—everyone who experiences anxiety can have different “body,” “doing” and “thinking” signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> • Heart racing fast • Chest pains • Breathing heavily or shortness of breath • Dizziness/light-headedness • Having a lot of energy • Hands shaking • Knees feel shaky or weak • Dry mouth • Sweating even if it's not hot • Having “butterflies” in stomach • Sweaty hands • Sweaty armpits • Feeling nauseous or sick • Gastrointestinal issues (diarrhea, heartburn, etc.) • Neck and shoulder stiffness • Acid reflux, belching or burping 	<ul style="list-style-type: none"> • Meltdowns and shutdowns • Insisting upon certain routines to avoid bad things from happening, when they are unlikely to happen • Stimming to help calm when feeling anxious: body rocking or flapping, etc. • Leaving anxiety-producing situations • Arguing • Pacing • Physical self-harm, such as skin picking, nail biting, hair pulling or head banging • Being less social, asking others for space or wanting to talk about a problem • Cancelling plans with family or friends that the person typically attends • Wanting to go to the bathroom • Over-talking • Information seeking • Appearing vacant • Going rigid • Becoming very still and quiet • Acting out toward others or their environment 	<ul style="list-style-type: none"> • Getting stuck in thinking over and over again (also known as “ruminating”) that something distressing will happen • Only seeing the negatives when there are also positives • Trying to plan for every possible outcome of a situation • Thinking may become overwhelming or out of control • Feeling scared without a reason to be scared • Slowing down of productive focusing • Having trouble focusing • Feeling agitated

What are some common triggers of anxiety for Autistic people?

- **Uncertainty**

Not knowing what is going to happen next or how others will act or how one is supposed to act can be challenging and upsetting. For Autistic people, this uncertainty may be threatening, especially when there are no clear plans or explanations of what will happen next. Many Autistic people prefer to know what to expect and what is expected of them. When they have uncertainty instead of predictability, it can contribute to or trigger anxiety.

- **Changes**

Changes or transitions in day-to-day life are disruptive, and for some people, these changes are incredibly stressful and hard to manage. Changes in schedules, routines or the environment, especially when unplanned, can contribute to or trigger anxiety.

- **Sensory experiences**

The majority of Autistic people have sensory and motor processing differences. Some people are very affected by these experiences, and others are less affected.

Sometimes, the experience of the environment triggers anxiety when the sensory demands are not well-matched to sensory needs. Sensory experiences that are understimulating or overwhelming can happen anytime or anywhere, and it can be stressful and increase anxiety.

For example, some Autistic adults have described the following as anxiety triggering:

- **Visual** – bright lights (e.g., florescent lights)
- **Sounds** – a baby crying, certain people's voices, white noises (ambient sounds), crowds at a mall, a revving engine, hand driers, traffic, chatter at a party or people talking really loudly
- **Smells** – new packaging smell, new carpeting at the office releasing odour, perfume or cologne, hair product, washrooms or food may be strongly aversive. Or a person might be triggered by smelling people, food or other things in their environment.

- **Touch** – food textures, an unexpected hug or kiss on the cheek, being tapped on the shoulder, certain fabrics and textures of clothing, getting water on the skin such as when it rains, getting a massage, or massaging shampoo into the scalp.
 - **Taste** – strong tastes, either soft or hard textures
 - **Interoception** – feeling any difference in heart rate, unexpected rises in their beats per minute, awareness of appetite or thirst or bowels or bladder
- **Social situations and expectations**

When expectations are not clearly communicated or do not fit with an Autistic person's way of understanding, they may feel anxious. Some Autistic people may feel anxious about their performance or how they appear to others or about being forced to behave or mask their personality. This can be especially triggering in social situations where a person does not feel accepted, where they are being judged or where they are expected to communicate in ways that are not comfortable or well-suited to them.

Some Autistic adults may not always understand the hidden expectations of dating, the workplace or social opportunities. In these situations, an Autistic person could be shamed by those around them, which can naturally lead to being anxious about those situations. For example, if they act in a way that others see as “weird”, “rude”, or “self-centred”, and react to them in negative ways rather than supporting them. When expectations do not match the skill level, anxiety can increase.

- **Specific fears**

Specific fears (also called phobias) are common and can make everyday life more difficult. These fears may stop a person from doing what they would like to do or would usually do, because a person may be afraid that they might have to interact with the source of the anxiety.

People can have unique fears that other people may not typically be afraid of. Fears may include dogs, needles, public speaking, heights, planes, vacuum cleaners, balloons, public bathrooms, meeting new people or meeting groups, but there is no limit to the kinds of fears that people can have.

Autistic experiences with anxiety

“When I was a senior in high school, I’d become so fearful of committing more faux pas with my classmates and getting unwanted attention from guys that my school days consisted of going to class, being there for that class period and then leaving the class immediately.

“As I’ve mentioned before, I also felt deep down in the pit of my stomach that if I was to try to explain my side of the story and Asperger syndrome, [it] would not have been taken seriously by my classmates and things might end up worse for me if I did. That fed into my spending time in the class only as long as I needed to and not sticking around, which had become my self-imposed strategy to minimize, if not eliminate, my chances of committing more social faux pas with my classmates and getting unwanted attention.”

“My panic attacks started when I was nine, and they really forced me to get to know myself, my baseline, my triggers and my emotional awareness. While I really identify with my autism, I really don’t identify with my panic disorder. Autism gave back to me in skills and strengths, but panic disorder really hurt and made it hard to enjoy things I typically liked or wanted to do. Panic disorder didn’t make me strong; I got strong because no one else was going to handle my panic attacks for me, and because I wanted my life back.”

“There are difficulties of keeping on the mask in order to not be crucified, but I’m finding the older I get, the more difficult it is to play the NT [neurologically typical] role. When I was young, masking my differences was a huge source of anxiety. Masking my struggles with verbal direction . . . waiting for other children to follow the directions and watching them before mimicking them and faking it until I could figure it out. So many gym class games were so difficult. All verbal rules directed in an echoing gymnasium with bright-white linoleum floors and the anxiety of being seen as ‘dumb’ or ‘stupid.’ I faked it. I faked it hard.”

“It wasn’t until about Grade 5 or 6 that I finally figured out all the rules to the games they played in gym class . . . basketball, dodgeball, soccer, etc. It took years of inventory and careful study of observing others’ behaviours in these games to get it. So, the anxiety started very early—right from kindergarten, always faking, always masking. That anxiety was very early on my ‘usual.’ So, ‘knowing my usual’ is not really what should be my ‘normal.’”

“My biggest triggers for anxiety are (1) expecting to have to deal with certain kinds of ableism and (2) unclear instructions. Both of these are very much related to anxiety about uncertainty and change. I often get anxious about uncertainty or change, but it’s not the uncertainty or change that’s the primary source of the anxiety. It’s that I don’t know the ‘appropriate’ social rules and have to worry about the consequences for doing something ‘wrong.’

“Of course, uncertainty and change by themselves can be primary sources of anxiety for some Autistics. But sometimes it’s ultimately the uncertainty regarding figuring out how to conform to ableist expectations and social rules in uncertain or changing environments that are the root of the anxiety.”

“One trigger I have for anxiety is when co-workers are looking at me and whispering to each other or laughing and staring at me, or when people suddenly get quiet when I come into a room, or when someone makes a veiled threat to my livelihood or my character reputation—then my anxiety spikes very high. Also, during almost all social interactions I invariably sweat a lot, so I try to wear clothes that conceal underarm sweat.”

Depression

Everyone gets sad and down sometimes, especially as a reaction to challenging situations in life. **But sometimes people experience a kind of sadness that is not simply a reaction to specific situations but rather, it goes on and on,** growing into a long-lasting feeling of sadness and hopelessness (which means having or feeling no hope). Hopelessness can lead to someone giving up on life, leading to suicidal thoughts, which can then lead to suicidal plans and actions. These feelings and thoughts can cause problems in life and take away from the person’s potential to thrive.

Depression is a mental health problem that is commonly experienced by Autistic people.² It's important to note that any signs of depression should be compared to a person's own sense of their usual mood and behaviours. For example, if someone in their usual state does not have a big appetite, then a loss of appetite needs to be compared to their usual state.

Depression can occur when a person gets stuck focusing on negative things that happened in the past—what should have been or could have been, and what used to be (this is called rumination). Some Autistic people may ruminate or “loop” on social mistakes or on times they were excluded, teased or bullied or

Hopelessness is a key part of depression.

did not receive a job offer or promotion. They might be dissatisfied with their lack of social connections or disappointed in not finding or keeping a relationship or employment. Over time, these life experiences can build up.

Grief is not the same thing as depression. Grief is a part of life, and everyone grieves in their own unique ways. Grief is a feeling that comes when we lose something. It is complex, and any loss can cause grief. Some people may react to grief with a lot of emotions, and others may not. Some people experience grief right after a loss, or it may begin weeks, months or years after the loss.

Autistic people also grieve but may not always express it the same way as non-Autistic people do. Some Autistic people's grief may look more like Autistic traits (such as higher sensory sensitivity or intense focus on a topic) or they may have no reaction. They may also want more alone time to process the loss, instead of talking about it, and it may last for longer than others expect. These reactions can affect mental health, as it can worsen their experiences of anxiety, trauma or depression. But grief is not a mental health problem. It is a natural reaction to loss. Everyone deserves support when they are grieving.

Signs of depression²

Depression and anxiety are two states that often happen together. It is sometimes hard to notice whether someone is depressed without asking questions or looking for specific signs. Following are some potential signs:

Body Signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> • Weight loss or gain • Scars from self-injury/self-harm • Changes in sleep: Increase in the need to sleep, or feeling like sleeping much less than is usual • Always feeling tired or having aches and pains • Changes in appetite: Being hungrier than usual or not as hungry as usual 	<ul style="list-style-type: none"> • Eating less due to loss of appetite • Overeating due to increased appetite • Increase in social withdrawal or isolation: <ul style="list-style-type: none"> →Cancelling plans with family or friends that the person typically connects with → Staying alone in the room or apartment for days when this is not usual for the person • Avoiding social situations that the person usually feels able to take part in • Being overly irritable or aggressive for reasons that are not usual for that person • Lower productivity • More, or less, stimming than is usual • Sleeping a lot more or less than usual • Extreme increases in disorganization from lack of motivation for everyday responsibilities, including basic tidying (e.g., clothes all over the floor) 	<ul style="list-style-type: none"> • Loss of interest in things that are usually pleasurable • Loss of motivation to do things that the person usually does • Feelings of sadness and being overall down and 'blue' that do not go away • Feelings of hopelessness: <ul style="list-style-type: none"> → "Nothing will ever change"; "It will always be this way." • Feelings of exhaustion for no physical reason • An increase in being focused on certain topics and not being able to shift off of them the way the person usually could • Inability to feel joy and other positive emotions; unable to look forward to anything • Increased obsessive thoughts or suicidal ideation • Suicidal thoughts

Autistic experiences with depression

"Many of my stims are pleasure/feel-good stims to mitigate tough situations or when I'm feeling overwhelmed by stimuli. One of my big signs of depression is that I don't do any of these things to help me self-regulate because I can't be bothered and it's too much effort/energy. The loss of stims is a huge sign that I'm depressed."

“In some ways I saw myself as a survivor; getting through depression and anxiety wasn’t always pretty or convenient, and at times I scraped and crawled and fought dirty, but I made it.”

“When I was 13, my GP tried to put me on an antidepressant, but for whatever reason it didn’t seem to be working in my opinion, so I threw them out. I was too young to figure out what to do on my own, and there were no adults who knew how to help me at that time. A decade later, things got bad enough again that I asked about medication for depression. After trying all the classes of typical antidepressants and finding that none of them worked and often had awful side-effects, I happened to try that first atypical medication again but in a lower dose, and it worked, so I stayed on it for a few years before feeling confident enough to taper off and function without it.”

“I find I cannot pull things together. Like, my brain doesn’t work as well. Same with anxiety. I just cannot get anything mobilized. My executive function is out the window, when it already struggles from sensory issues.”

Trauma

Trauma is “an event that damages or harms the individual even though the severity, longevity and permanency of that harm may vary widely.”³ Things that distress or traumatize an Autistic person can be very different from what may be distressing or traumatic for many non-Autistic people.

Trauma is an event that hurts someone. How severe, long or permanent that harm is can be different for each person.

Being Autistic can make it more likely that a person will experience stressful events, which can increase the chance of trauma. Stressful social events, like being bullied, attacked, rejected or segregated, can lead to harm. Changes to schedules, hard transitions, being stopped from doing behaviours that are pleasurable or calming, or being prevented from engaging in preferred interests, can also be traumatic, especially when it happens regularly.

Service providers may receive very little training to work with Autistic people around mental health and trauma. Signs of **trauma may be overlooked in services that are designed to support an Autistic person, which can make the support services unintentionally traumatizing themselves.** There can be trauma when a person is not listened to or repeatedly told that there is nothing wrong, when they know that there is. As one adviser said: “There must be a way to support Autistic people without sending them to the emergency department, only to be revictimized there.”

“It can also be dangerous for Autistics to seek health care, especially mental health care, if they cannot be certain that Autistic- and trauma-informed allies will receive them.”

What are some common responses to trauma?

Some common experiences and responses to trauma include⁴:

- **Emotional**

Emotional reactions to trauma vary greatly and are influenced by a person’s background. The most common reactions are anger, fear, sadness and shame. People can also experience the emotions very intensely (and be overwhelmed by it) or be unable to experience any emotion (and so may feel numb). Some people may have difficulty noticing, labelling or dealing with these feelings.

- **Physical**

Trauma can lead to negative physical experiences like sleep problems, muscle pain, breathing pain, gut and stomach issues or skin picking (leading to skin conditions). Physical experiences may become chronic if they are not addressed.

- **Psychological**

Traumatic experiences can change the way a person thinks about and sees themselves, the world around them and their future. Some people who experience trauma may see themselves as helpless or incapable. They may think that the world is unsafe, people are dangerous or there is no meaning to life.

- Behavioural

Responses to trauma are very different for each person. Many times, people will do things to avoid or cope with the intense emotions that come with trauma. Some people may self-medicate by using drugs or alcohol. They may engage in risky behaviours, overdo activities that feel good or are part of their usual routine or turn to harming themselves as a way of coping with their distress.

- Social/Interpersonal

Trauma also affects relationships. Some people may want to reach out for support, and others may isolate themselves from their friends, families or support systems. They may do so because that is how they manage trauma, and if others don't understand their coping approach, this can affect their relationships. Sometimes, reaching out for support can cause more harm, especially when the person is misunderstood.

What is posttraumatic stress?

Autistic people experience trauma significantly more than non-Autistic people. This can lead to stress that lasts long after the trauma, or **posttraumatic stress**. There are three types of posttraumatic conditions that are reported to be commonly experienced among Autistic adults, though not everyone has access to a formal diagnosis:

1. posttraumatic stress disorder
2. complex posttraumatic stress disorder
3. developmental trauma.

Sometimes trauma can happen because of a single event. Other times it develops over time.

What is posttraumatic stress disorder (PTSD)?

Posttraumatic stress disorder refers to ongoing negative emotional and psychological reactions that are caused by specific events in a person's past.

Posttraumatic stress is stress that lasts long after a harmful or traumatic event.

It is triggered by witnessing or experiencing a frightening or life-threatening event, such as a catastrophic car accident, a natural disaster or a physical assault. A main feature of PTSD is that the traumatized person psychologically re-experiences the traumatic events.

Posttraumatic stress disorder

is the most well-known post-traumatic stress condition. It is caused by specific events in a person's past and a main feature is **flashbacks**—reliving the events.

Signs of PTSD⁴

Following are just a few of the common signs of PTSD that people can experience. It is not only Autistic people who experience these—everyone who experiences PTSD may have a variety of the different body, doing and thinking signs.

Body Signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> • Aches and pains: <ul style="list-style-type: none"> →Migraines (headaches) →Chest pain like a heart attack →Back aches →Stomach aches • Acid reflux • When reliving what happened, the person may feel nauseous, sweaty or shaking, or their heart may beat fast • Becoming numb (person stops receiving bodily cues) • Not feeling in touch or connected with bodily sensations 	<ul style="list-style-type: none"> • Being easily irritated or aggressive • Avoiding people, places and activities that remind the person of the event • Having sleep problems • Using alcohol or drugs to feel something • Needing to always feel busy • Having difficulty concentrating on daily activities • Participating in risky activities or putting one's self in dangerous situations • Not expressing a lot of affection • Expressing less interest in things the person enjoys 	<ul style="list-style-type: none"> • Feeling very alert, jumpy or on the edge • Feeling very distressed and confused • Feelings of anger, shame, sadness or guilt about the event or about themselves • Feeling disconnected from what the person is really feeling • Feeling alone • Difficulty believing what has happened <ul style="list-style-type: none"> →Feeling betrayed and unsafe →Having a hard time remembering details • Intense flashbacks to what happened <ul style="list-style-type: none"> →Experiencing nightmares replaying the event →Being triggered by specific memories that remind the person of the place, the sights or sounds from the event • Having blackouts (no memory of the day or period of time the traumatic event occurred)

What is complex posttraumatic stress disorder (C-PTSD)?

Complex posttraumatic stress disorder

is when a person experiences multiple, repeated and long-term trauma (like ongoing bullying, verbal, physical or sexual abuse). The *ICD-10*^b included a diagnostic category called Enduring Personality Change after Catastrophic Events to describe this experience. The main difference from the PTSD signs described above is that with complex posttraumatic stress, **a person may also change in their personality in an ongoing way**, beyond things that remind them of the harm they experienced. It affects how they see themselves and how they manage stressful events. Autistic people can experience PTSD and C-PTSD at the same time.

Complex posttraumatic stress is caused by long-term trauma, like ongoing abuse, and can result in personality change and dissociation.

C-PTSD is also associated with repeated social injury over time, where the victim feels they have no chance to escape. For Autistic people, they may be forced to go to schools or supports where the sensory and social demands are overwhelming; where they are teased, bullied, rejected and shamed—and they are forced to do this regularly over a period of years.

Sometimes people with C-PTSD may feel permanently worthless and that nobody can understand what happened, or they may regularly have suicidal feelings. Because of the ongoing causes of trauma, they may experience what is called “**dissociation**”—where they become “disconnected from the here and now.” People describe the sensation or experience in different ways, such as feeling disconnected from the environment they are in or from their own body. Some may “zone out,” “space out” or have no memory of what just happened.

Though people can at times experience some disconnection in this way, people who experience extreme anxiety or stress may be at greater risk for these symptoms. When they occur frequently, it may cause distress for the person. The experience happens without warning or sometimes without a person being aware that it is happening.

^b *ICD-10* refers to the *International Classification of Diseases*, 10th Edition, which is published by the World Health Organization.

What is developmental trauma?

Developmental trauma is a term that is less widely used. It refers to how early experiences in childhood can lead to trauma in adulthood. Experiencing abuse as a child, like physical, sexual and/or emotional abuse, can last with a person into adulthood. Autistic people are at greater risk of interpersonal victimization—of experiencing sexual victimization, physical abuse and emotional abuse compared to non-Autistic people.

Developmental trauma refers to how early experiences in childhood can lead to trauma in adulthood.

Autistic adults have written about being traumatized by others' behaviour toward them, such as being bullied, teased, berated and devalued.

Invalidation happens when a child regularly learns from their environment that their feelings and experiences are disapproved of, are perceived as wrong and are misunderstood, or they learn that they do not matter to others. As this child ages, they can have stronger and stronger beliefs of being worthless which can lead to many mental health problems. Some Autistic people have described how they experienced harm as a result of their interactions with the school system, and that it has led to trauma.

Invalidation, childhood abuse and harmful autism interventions can cause developmental trauma.

Early experiences of treatment in childhood or adulthood may also be traumatizing for an Autistic person. For example, some Autistic adults have written about how their early experiences with Applied Behaviour Analysis have traumatized them and have led to mental health problems as adults. Others have noted the negative effects of psychotherapy or medications, as well as the harm caused by being unable to consent to treatments and interventions. Interventions that require someone to change who they are, or how they behave, can change how a person sees themselves, how they interact with others and how they navigate their future.

Other Autistic adults have written about the trauma they experienced as a result of going to the emergency department or being hospitalized, or as a result of their interactions with police. The trauma often stems from the lack of understanding and mischaracterization of Autistic people's experiences.

Content warning: Some of the experiences shared here may contain traumatic experiences related to medical errors, abuse, school and sexual assault.

Autistic experiences with trauma

“My experiences with trauma go through elementary school to high school and beyond. One major event I had trouble with is being threatened with the ‘time out’ room, where there was no handle on the inside of the door, just a steel pad. I would have been left alone. The room was carpet-padded up to six feet in height. With an opposite window to an adjacent hallway. I was too young and small at the time to see anybody out of it. That was one main event in elementary school that was traumatic. I had a big fear of being left alone at the time.”

“Autistic people, particularly Autistic non-binary people and women, are at higher risk of sexual abuse and child sexual abuse. We really need people to believe us and to be on the lookout for us.

“When I disclosed to my therapist as a teenager that a family member was sexually abusing me, her first words were to ask me if I somehow ‘provoked’ him. She never believed me or trusted me. She is now the director of the mental health centre where she works. The male police officer that my school reported the incident to also asked me if I encouraged my family member. I wonder if the fact that I had documented mental illness, that since my therapist’s notes said I ‘struggled socially,’ they thought I must have welcomed or instigated the abuse somehow.

“In many ways, the adults in my life I reached out to for help caused me more trauma than the actual sexual abuse itself. To this day, I have immense distrust of most mental health professionals and law enforcement authorities. They have let me down as a victim and survivor over and over again. Thankfully, I do see a therapist that is actually trauma-informed, after many years of searching. It helps that this therapist has lived experiences that mirror mine. But these kinds of mental health professionals are far and few between.”

“I have experienced two separate traumas in my life related to medical errors. As a result, I am terrified of doctors and it is very difficult to attend a medical appointment. It has definitely shaped my life. I used to live in fear of getting sick or being in an accident—not because of the illness or accident, but these would mean that I would have to experience the fear of being in a hospital. I was also assaulted. I was in my 20s and had my baby with me. I could not get help for my trauma. It always seemed far too frightening to engage in anything that would make me talk about the events. I could not tolerate the intensity of that emotion. Fear and trauma have made my life smaller than it could have been. I wish I had the courage and capacity to find help and free myself when I was younger.”

“I believe Autistic people are the true heroes. If it is hard to deal with Autistic trauma and meltdowns—imagine living through them. We are resilient, creative, interdependent and brilliant in more ways than what can ever be shown through a clickbait inspiration-porn news article or blog post. We survive abuse, invalidation, discrimination and systemic barriers day after day.

“For parents, professionals and allies, my advice is to assume that the Autistic person in your life has a degree of trauma. All Autistic people go through traumatizing life events because of how invalidating and unaccommodating the world is to us. We also have a higher risk of being abused and bullied by the people and institutions we interact with. Start trauma-informed, and go from there.”

Meltdowns, shutdowns and Autistic burnout

Some Autistic people may experience meltdowns, shutdowns or burnout because of stress. While these experiences are not diagnosable mental health problems in themselves, they can contribute to them or worsen existing mental health difficulties. Many stressors and mental health problems can lead to meltdowns, shutdowns or burnout. It depends on each person, their experiences and their triggers.

What are meltdowns?

Meltdowns are described as bursts of overwhelming emotion, which can take the form of anger, crying, screaming, self-harm or harming others, and sometimes environmental aggression (e.g., throwing or breaking objects). They can also be silent, where the person withdraws and may become inactive, slower to respond and unable to attend to anything going on around them. These behaviours are not panic attacks. Meltdowns are intensely distressing, and an Autistic person may have very little control during these times.

Meltdowns are bursts of overwhelming emotion and are hard for an Autistic person to control.

Meltdowns are an emotional response to an accumulated or immediate experience in the environment. Too much sensory or social demands that exceed the person's capacity to cope can lead to overload.

Meltdowns can be caused by several factors, including environmental triggers, sensory overstimulation, stress, uncertainty, transitions and rapid change. It is important to note that meltdowns can change over time, not all Autistic people have meltdowns and most meltdowns in adulthood can look like a release of emotion (e.g., crying, sometimes a raised voice).

Educating others in what a meltdown can mean for the Autistic person is essential. Every human is unique in how they like to be supported through a difficult moment. Some need reassurance, some need space, and most people benefit from a calm, non-judgmental approach. Some Autistic people may not want anyone to touch them when they are experiencing a difficult moment. It is important to know how the person wants others to respond if they have a meltdown. It can be helpful for the Autistic person to tell people how they want to be supported if they are having a meltdown.

What are shutdowns?

Shutdowns are sometimes described as “silent meltdowns.” At times, shutdowns can be a short escape from the situation or task. It often involves a person becoming very reserved, caught-up, tired or zoned-out, and less aware of what is going on around them. They may need to go to a less stimulating place, such as a quiet room. Some people may have trouble moving—when they shut down, their movements slow down, and they can become inactive and may need physical

guidance or prompting to move. Others may find it challenging to communicate. Those who communicate in non-traditional ways may be unable to share what they are feeling or what they need. Those who are able to communicate by spoken word may not be able to speak at all.

When a person has a shutdown, it does not mean they are purposely giving the “silent treatment” to others. Too often, verbal Autistic people are accused of being rude or ignoring others when they don’t speak due to a shutdown.

If a person struggles with spoken language during shutdowns or meltdowns, they may need to use other methods to communicate, such as through augmentative and alternative communication devices. Though shutdowns may look less extreme than meltdowns from the outside, they can be just as distressing.

What is Autistic burnout?

Autistic burnout is a broader experience, which might follow a stressful or very exhausting period of time in an Autistic person’s life⁶. This may result from a constant state of camouflaging or being overwhelmed. It is like a “shutting down of the mind and body” and it can take quite some time to recover fully—for some people, it may take months or years. It can lead a person to greatly struggle with ordinary activities such as hobbies, work, self-care or socializing.

Further to this burnout experience, some Autistic adults experience Autistic regression. **Autistic regression**⁶ involves the loss of previously gained skills (such as language or maintaining personal hygiene) or social-emotional maturity regresses, sometimes to the extent that the person may act in a childlike way. As one adviser said: “When I am

Shutdowns or “silent meltdowns” may involve:

- zoning out
- being less aware of the environment
- needing to leave for a less stimulating environment
- difficulty moving
- difficulty speaking or communicating.

Autistic burnout is a shutting down of the mind and body after a long period of stress and being overwhelmed. It results in more difficulty with usual activities and takes a long time to recover from.

Autistic regression involves a loss of previously gained skills after a period of burnout. These two terms are often used interchangeably.

under severe emotional stress due to major internal changes (a new brain therapy, for example), I become temporarily functionally regressed in my skills of daily living. I'm not burnt-out, I'm not depressed . . . I may feel like a kid again and vulnerable and 'regress.' Even the quality of my crying is different, more childlike.”

When an Autistic person is under pressure or is experiencing a negative mental health state, they are more prone to experiencing meltdowns, shutdowns, burnouts and regression. Understanding what the mental health problems are, and knowing what to do about them, can help a person to access the help or support they need. In **Section 6**, strategies to promote well-being and how to access support will be described.

If someone is experiencing meltdowns or burnout, it's important that they take the time to heal and recover and that they are connected to people who have the knowledge, patience and support needed to help them do so. When experienced long-term, this can also feed into depression or anxiety and contribute to physical health problems.

Autistic experiences with burnout

“Often the feeling of burnout is something that can happen with me when I deal with difficult people. Intrusive thoughts—worrying thoughts—about scenarios that probably will never happen, but the compulsions to check on things, for example, is high (autism and OCD). But when things are good, I will feel refreshed.”

“Dealing with and thinking about the people that have made me stressed or have anxiety about makes me feel more burnt-out.”

Eating problems

Some Autistic people may have a limited diet; in other words, there is a narrow range of foods that they can enjoy or tolerate. The reasons for this vary from person to person. Some people with limited diets may have sensitive stomachs that make digestion uncomfortable or may have sensory sensitivities related to smells, textures and tastes of certain food. Sometimes Autistic people can find comfort in eating the same meal all the time—this does not mean it's an eating disorder. If a person has a limited diet, this is not the same thing as an eating problem or disorder, but it can sometimes develop into one. Most eating problems that develop (see below) do not necessarily begin with a limited diet.

What is anorexia?

Anorexia is a severe eating disorder that affects all genders and usually does not start until adolescence. Autistic women may be at particular risk for anorexia.⁷ The symptoms of anorexia include⁸:

1. Limited food or calorie intake, which leads to very low body weight, especially if it's much lower than what would be expected for the person's age and height. People with anorexia generally lose weight by not eating enough calories.
2. Intense fear of gaining weight or becoming "fat" even when the person is underweight.
3. Troublesome experience with one's body shape or weight. A person's weight may be a part of how they see their self-worth, or they may deny their body's fragile state.

Anorexia involves restricting calories by not eating, while **bulimia** involves purging of food after eating.

What is bulimia?⁹

Bulimia involves purging food after intense periods of eating (i.e., eating way too much). Purging means that the person gets rid of the food. Purging often happens by forced vomiting after eating, taking laxatives to have bowel movements when it is not needed or exercising too much to lose the calories that were eaten, especially after a period of binge eating. While vomiting or taking laxatives are more obvious, excessive exercise is more accepted in society, and it is harder to see as being harmful.

What is binge eating?

Binge eating involves eating large quantities of food in short periods of time and feeling that the overeating is uncontrollable. It is usually done in secret and even when a person is not hungry. People with binge-eating problems are not always overweight; their weight may fluctuate, and they may not engage in purging behaviours. Feeling embarrassed and guilty is common.

What is avoidant/restrictive food intake disorder (ARFID)?

Avoidant/restrictive food intake disorder is sometimes described as "extreme picky eating," as it is characterized by highly selective eating patterns. This diagnosis was added to the most recent version of the *DSM-5*.¹⁰

ARFID may come from traumatic avoidance related to food (e.g., choking, force feeding, negative experiences with interventions involving food). People with ARFID may be unable to eat certain foods—they may develop an aversion to the smell, taste, temperature or texture of food. People with ARFID tend to eat a limited variety of foods, which can cause low energy, malnutrition and weight loss. It may sometimes be misdiagnosed as anorexia.

Binge eating involves consuming large quantities of food in relatively short periods of time and feeling that the overeating is uncontrollable.

ARFID involves a highly selective eating pattern.

Signs of eating problems⁷⁻¹⁰

Following are just a few of the common signs that people with eating problems may experience. Depending on the type of eating problem, some or none of the below may apply. It is not only Autistic people who experience these — everyone who experiences eating problems may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> • Very noticeable weight loss or gain • Dry skin and brittle nails • Weak muscles • Tooth problems, like discoloured teeth or sensitivity • Thinning hair • Stomach issues (like cramps, acid reflux, constipation) • Irregular menstruation (missing periods) • Dizziness 	<ul style="list-style-type: none"> • Eating in secret, or eating very small or large portions • Eating very fast • Avoiding or refusing to eat certain foods • Lying about whether they have eaten or what they have eaten • Dressing in bulky clothes • Hoarding or hiding food • Withdrawing from social activities (especially if food is involved) • Excessive exercising 	<ul style="list-style-type: none"> • Feeling very anxious about body image, or feeling “fat” • Having a negative self-image • Feeling fearful of gaining weight and worried about eating in front of others • Always thinking about weight, food, calories or dieting • Having difficulty concentrating • Having a strong need for control about food/eating habits; very rigid • Having sensory problems with food • Difficulty feeling hunger • Feeling embarrassed or guilty about eating habits • Feeling a sense of being in control of food and eating habits when everything else seems to be out of one’s control

Autistic experiences with eating problems

“Food textures and eating, especially during anxiety, can be a huge problem. I began limiting my food during puberty. The change my body was going through was more than I could handle, and I didn’t have any adults talk to me about it or help me understand what was going on. I didn’t like the change this was doing to my body; I wanted my body to stay the same as how I’d always known it and felt comfortable with it for so many years.

“Controlling my food intake was my way of trying to stop my body from changing and also remove the textural and taste triggers, as well as helped me find a way to gain a bit of control in my life. I struggled with food intake from about 12 years of age until I was approximately 23 years old. Then I was up and down until now. I still struggle with eating when overanxious. Food is just too yucky, and all of my sensitivities increase to make things even less palatable. Now I tend to seek out new tastes a lot more than I ever have before, and in my mid-40s my super-taste and super-smell is starting to reduce a bit, opening up my palette a bit more.”

“As a former anorexic, a very hyposensitive sense of interoception compounded the problem, as hunger was (and still is) rarely felt. Unfortunately, seeking help for this eating disorder was met with group therapy that wasn’t adapted to Autistic people.”

“Until professionals learn how to modify treatment for the Autistic person, professionals are going to continue to struggle to help Autistic people to recover from anorexia. I was hospitalized as a teen with an eating disorder, and nothing they said made any difference—until one person happened to say the right thing. It was logical, made sense, and I immediately (and I mean, that day) stopped being anorexic. This is just another example of why we must have only autism-informed and educated professionals helping us when we reach out.”

Substance misuse and addiction

In Canadian society, many people tend to use substances that have an effect on how they feel or think. Some common examples of these substances include caffeine and sugar that people may consume to get a boost of energy or to become alert. Then there are substances that people take that can change a person's feelings, thoughts and behaviours in a more extreme way. Examples of these sorts of substances include alcohol, nicotine, cannabis, cocaine, stimulants (e.g., amphetamines), opioids (e.g., oxycontin), hallucinogens and other forms of drugs, including prescription drugs, either the person's own or taken from a family member without their knowledge.

The terms “**substance abuse**” and “**substance misuse**” refer to when a person uses these sorts of mind- and mood-changing substances regularly to feel better. **Addiction** means a person may feel that they need to keep taking the substance, even when they do not want to take it (they have cravings for it), and they may need to take more and more of it for the craving to go away.

Substance abuse/misuse is when a person uses harmful mind- and mood-changing substances regularly to feel better.

Addiction is when a person feels like they cannot stop taking the substance, even if they want to.

Autistic people are at greater risk of developing substance misuse and becoming addicted to substances compared to non-Autistic people.¹¹ Substance misuse and addictions are more common among people who have experienced trauma and/or have problems with meaningful relationships, employment and financial security. Autistic people often experience these kinds of problems. These things can affect a person's mental health, making them more vulnerable to substances that give relief from the emotional pain they experience.

Using substances can be a way to feel better or remove negative feelings, such as anger or sadness. Some people say they use these substances in order to numb their feelings so that they don't feel anything. Doing this is called **self-medicating**. Self-medicating with alcohol or drugs can make situations worse in the long run, even though it feels helpful in the short term.

What are the signs of substance misuse and addiction?

When trying to understand if someone is using a substance in an unhealthy or dangerous way, there may be some clues in their appearance or behaviours.

But a lot of the time, people hide that they misuse substances. This may be because the substance they are using is illegal or they do not want to get into trouble, or they feel ashamed or bad about using it. Other times, people may not yet realize that they are abusing or are addicted to a substance. For some Autistic people, especially those on a limited income, difficulty or inability to meet financial obligations may be another clue of substance abuse. They may be spending their limited income on their substance of choice.

Quick questions to identify substance misuse:

- **How often?**

Think about how regularly they use the substance. Is it once a week, a few times a week or every day? Do they look for more opportunities to drink or use substances?

- **How much?**

Think about how much they consume: how many drinks they consume daily or how often they use drugs.

- **How negative are the consequences?**

Think about what is affected when they use the substance. Has their physical appearance, behaviours or relationships changed? Are they able to do their work and/or keep up with their responsibilities?

- **Do they continue using despite negative consequences?**

Think about how they are continuing to use these substances. Do they continue even when they feel sick or start to have health problems? Do they experience more cravings or urges to drink or to use drugs, or do they stop?

- **Do they consume more and more of the substance as time goes on?**

Think about when they are drinking or using substances. Are the amounts getting larger or smaller? Do they try different substances? Are they trying to cope with anxiety or trying to fit in?

Signs of substance misuse

Following are just a few of the common signs that people with substance misuse can experience. It is not only Autistic people who experience these—everyone who experiences substance misuse may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> • Sleeping too much or too little • Physical appearance changes: <ul style="list-style-type: none"> →Weight loss or gain →Body shakes and tremors →Bad breath and/or body odour • Speech changes: <ul style="list-style-type: none"> →Rapid or rambling speech →May have slurred/slow speech • Feeling sick when not on substances (stomach aches, headaches) • Low coordination 	<ul style="list-style-type: none"> • Aggressive behaviours • Not meeting responsibilities at home, school or work • Engaging in more dangerous or risky activities: <ul style="list-style-type: none"> →Stealing items (such as drugs or alcohol) • Continuously taking the substance even though it creates problems • Being secretive • Never focused 	<ul style="list-style-type: none"> • Feeling confident when using the substance in ways/situations the person typically does not feel confident • Feeling confused about situations or not feeling in control of situations • Feeling irritable more than usual • Losing interest in things and activities once enjoyed • Lack of motivation • High anxiety or paranoid thinking

Autistic experiences with substance misuse

“I used alcohol in my teens to cope with sensory overload and social environments. My home life was bleak, and I was not at all understood. To escape this, I would go out and party, but could only do so if I drank, because it dulled my senses a lot. This was my coping mechanism and it worked but was not very healthy and would exhaust me.”

“During my early to mid-20s, I commonly drank alcohol in excess while with peers at nightclubs or parties, not merely to enhance excitement but, rather, to assist in feeling more comfortable and confident approaching women I hoped to flirt with—an area of socializing that did not come naturally to me when sober. Despite feeling much more confident in such situations, there were several instances in which I later regretted the way I had acted as a result of having way too much to drink, which included making a fool of myself in front of my friends, vomiting, or displaying anger toward others. Fortunately, my tendencies of drinking in excess were infrequent, confined to large social gatherings and didn’t lead to an addiction. I later learned to limit my drinking in similar social situations, such as to have a ‘buzz’ but not make a fool of myself, which I now view as a happy medium.”

Obsessive-compulsive problems

It's common to go and check if the door is locked, or the stove is off, or to worry about getting sick. **Obsessive-compulsive disorder (OCD)** is when these kinds of thoughts and behaviours change in ways that interfere with daily life.¹² Although many behaviours that can be found in OCD, such as anxiety, repetitive behaviours and social problems, are also common in autism, these are not necessarily the same as an OCD.

Obsessions are distressing and distracting thoughts or images that repeatedly occur.

Compulsions are behaviours or rituals that people feel forced to do repeatedly to stop the obsessive thoughts.

Obsessive-compulsive difficulties feel uncontrollable, unwanted and forced. **Obsessions** are repeated thoughts or images that occur in a person's mind that they can't stop, and most of the time these thoughts are distressing and distracting. **Compulsions** are behaviours or rituals that people feel forced to do again and again to get rid of the obsessive thoughts.

Some Autistic people may have obsessive thinking in ways that can cause distress. They may have difficulty stopping thoughts about social situations—times they have they felt shamed, excluded, rejected, treated unjustly or unkindly. For example, even years later, they may be unable to stop thinking about a time someone was late and ruined the evening or put them down for being late for work.

What are common types of OCD?¹³

- **Checking**

Compulsion: the need to check on something (e.g., checking locks, windows, taps or ovens); **Obsession:** to prevent danger (e.g., fire, harm).

- **Contamination**

Compulsion: the need to wash, clean or avoid; **Obsession:** worry of being dirty and contaminated or of contracting a contagious virus or disease through, for example, shaking hands, using telephones or using public washrooms.

- **Symmetry and ordering**

Compulsion: the need to have everything lined up; **Obsession:** to ensure everything is in the right spot to feel comfortable and sometimes prevent harm. For example, neatening surroundings or aligning items.

- **Ruminations/intrusive thoughts**

Compulsion: repetitive thoughts; **Obsession:** thoughts about a subject or question that is aimless, uncontrollable and distressing. For example, having supernatural-themed thoughts.

- **Hoarding**

Compulsion: inability to let go of specific possessions; **Obsession:** emotional attachment to an item. For example, a person may hoard newspapers, letters, household supplies or other things that seem to have no personal value to others.

Signs of OCD¹²⁻¹³

Following are just a few of the common signs. Depending on the type of OCD, some or none of the below may apply. It is not only Autistic people who experience these—everyone who experiences OCD may have a variety of different body, doing and thinking signs.

Body signs	Doing signs	Thinking signs
<ul style="list-style-type: none"> • Scars on the face and skin from repetitive body-focused behaviours (nibbling, picking) • Recurring open wounds <ul style="list-style-type: none"> →Skin is raw or broken from overwashing, picking or scratching →Some areas of the body may be infected • Noticeable hair loss due to hair pulling (also known as trichotillomania) <ul style="list-style-type: none"> →Thinned or bald areas on the body →Missing eyelashes or eyebrows • Hiding scars by putting on makeup and getting tattoos • Damaged nail cuticles from nail biting • Raw or bleeding inner cheeks or lips from lip and cheek biting • When unable to perform the repetitive behaviour, the person feel may feel nauseous, sweaty or shaky, or their heart beats faster 	<ul style="list-style-type: none"> • Checking things like locked doors, appliances and lights over and over • Checking on loved ones over and over to make sure they are safe • Counting, tapping or repeating certain words to lower anxiety • A lot of time spent on washing or cleaning, to a point that it is a problem for the person and/or disturbs their daily life • Avoiding touching objects or others (like shaking hands) • Constant arranging or organizing things • Performing in unwanted rituals • Keeping items or finding it hard to throw away items that may not have a special meaning • Asking the same questions over and over • Needing to record obsessive activities 	<ul style="list-style-type: none"> • Fearful of getting sick, getting in contact with germs • Feeling afraid of losing control and hurting oneself or others • Unwanted constant thoughts of making sure everything is perfect or “just right” • Feeling like they don’t have everything they need • Having disturbing or inappropriate thoughts that can’t seem to stop (also known as “intrusive thoughts”) • Believing in supernatural influence on what happens in daily life (superstitions) to maintain good luck or avoid bad luck—unrelated to spiritual, cultural beliefs • Thinking of intrusive scenarios in one’s mind that may never happen

Autistic experiences with OCD

“I was diagnosed with OCD at the age of 12. Intrusive thoughts and scenarios kept going through my head. I am a checker, so checking a certain area thoroughly might be enough or it might not. I also take medication for OCD. Alongside autism, OCD has been significant in shaping my life as well as fuelling my perfectionist behaviour with my military models and neighbourhood-watch operations.”

“For me, my OCD really picks up when I’m anxious, and so it becomes a sort of barometer for my emotional climate. If my OCD is picking up or I’m having more trouble ignoring it, then I know something’s up and my anxiety is on the rise. It’s tiring. Some ticks are harmless, and I allow them—I walk around the manholes in our street in a certain way and certain order, and that I let slide. But there’s other ticks that I need to stop cold, and that hurts.”

“It can be hard to differentiate between autism and OCD sometimes—similar to how autism and ADHD can be hard to differentiate. Certainly, there is a lot of overlap all around. For me, the difference between OCD and autism is that with OCD, I’m always asking ‘What if?’ If I don’t check each question I fill out in an exam or a form three times, what if I get it wrong and something bad happens? If I don’t wash my hands for a certain amount of time, what if there are still pathogens on my hands and I get sick? Catastrophizing plays a big role.

“In contrast, things that are anxiety-provoking to my Autistic mind-body are distressing in and of themselves and often interact with my disability and the environment to create barriers. For example, rushed transitions and unexpected surprises are overwhelming, period. Same goes for loud noises and bright lights. What I get is an immediate visceral reaction—literal physical pain. Things that are comforting to my Autistic mind-body, such as eating familiar foods or carrying stim toys and comfort items around, are soothing on their own in their repetition and familiarity.

“To me, autism is a much more embodied experience. It is a part of my mind and body, a part of me. OCD only happened to me later. This is why I say I am Autistic, but I have OCD.”

“I kept pillow cases, I kept torn pieces of wallpaper, I kept an old sundress my mom used to wear—because they were a part of my life, and throwing them away, discarding them, was like taking a part of my home, my life, and just throwing it out, like it meant nothing. I hate change. I hate the word ‘goodbye.’ I hate loss. Even the wallpaper—because it was there through all our Christmases, all our birthdays and rainy days and times together. So, I kept it until I was ready to throw it away.”

“I’ve had trichotillomania since I was about nine years old. I’ve come to a place of acceptance about it now, but it’s greatly impacted my life, my confidence and my relationships in the past. I’ve had to shave my head and wear wigs in the past. Trich is also a manual and oral stim for me. Despite countless attempts to curb this behaviour, I’ve been unsuccessful, which is why I now live in acceptance of it. The guilt and shame associated with it was just too much to bear, especially since it alters my appearance so drastically and I’m already at risk for bullying and ostracization.”

Psychosis

Psychosis is a state where a person experiences hallucination and/or delusions.

People experiencing **hallucinations** may hear, see, smell or feel things that are not real or present, such as¹⁴:

- hearing voices
- strange sensations or feelings
- seeing objects, people or creatures that are not there.

Delusions are strong beliefs that may not be true or unreasonable to others. During delusions, people might have repeated unwanted thoughts and feelings that are not based in reality, such as¹⁴:

- believing outside forces control their thoughts, feelings and behaviours
- believing that simple comments, events or objects have personal meaning
- thinking they have powers, are on a special mission or that they are the chosen one or God.

Most of these experiences can be frightening and confusing for the person experiencing them. Episodes of psychosis may occur because the person is living with a mental health problem such as schizophrenia, bipolar disorder or severe depression. Certain substances (e.g., drugs) can also bring about hallucinations and delusions.

Psychosis makes it difficult for a person to take care of themselves and others (e.g., having a job, keeping family relationships and friendships). For example, people with **schizophrenia** will experience hallucinations and delusions, have fast and disorganized speech and can have difficulty coordinating their motor movements. They also can experience social withdrawal, have a harder time with self-care, have sleep problems or have muted emotional responses (sometimes called the “negative traits”).

Most Autistic people will not experience periods of psychosis, though it can occur more frequently than for non-Autistic people. It is relatively rare compared to the other conditions we describe in this section.¹⁵ If Autistic people do experience periods of psychosis, PTSD, C-PTSD or dissociative disorders may be contributing factors. Noticing periods of psychosis or schizophrenia in Autistic people can be difficult and can be missed because people may misinterpret the signs of psychosis as part of a person’s autism. This is why knowing a person’s usual self is important.

Signs of psychosis¹⁴⁻¹⁵

Following are just a few of the common signs that people can experience. Depending on the type of psychosis, some or none of the below may apply. It is not only Autistic people who experience these — everyone who experiences psychosis may have a variety of different body, doing and thinking signs.

Psychosis is when a person experiences:

- **hallucinations** (seeing, hearing, smelling, feeling things that are not there) and/or
- **delusions** (believing in things that are not consistent with the person’s values and that may not be true or reasonable to others).

Psychosis can happen in people with schizophrenia, bipolar disorder and some cases of depression.

Body signs	Doing Signs	Thinking Signs
<ul style="list-style-type: none"> • Decreased self-care or personal hygiene • Sleep problems • May appear to be in a trance-like state (catatonic, motionless or in a daze) • Overactive and uncoordinated movements • Verbalizations do not make sense (slurred speech, irrational sentences) 	<ul style="list-style-type: none"> • Wanting to be alone • Seemingly agitated • Disengaged with others • Talking to self or yelling at voices • Rigid behaviours • May be aggressive • Impulsive thoughts and decisions • Setting unrealistic goals • Disorganized and dangerous behaviours • Engaging in dangerous activities • Unaware of their own surroundings 	<ul style="list-style-type: none"> • Experiencing hallucinations or delusions • Being suspicious or having feelings of unease with others • High anxiety about people and the world around them • Having very strong and inappropriate emotions, or having numbed emotions • Having trouble thinking clearly or concentrating • Periods of depression • Disinterested in things or people • Elevated moods, or rapid changes in mood

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Strategies to Promote Well-Being

Snapshot

- Well-being has many different aspects and is influenced by internal, external and social factors.
- Self-care means making it a priority to do things that a person loves to do that make them feel better.
- Community care involves taking care of the needs of each other.
- We can learn self-care strategies to help us when we are feeling stressed or worn down by demands.
- Self-care planning involves building physical and emotional strategies into daily living to help deal with life challenges.

Well-being

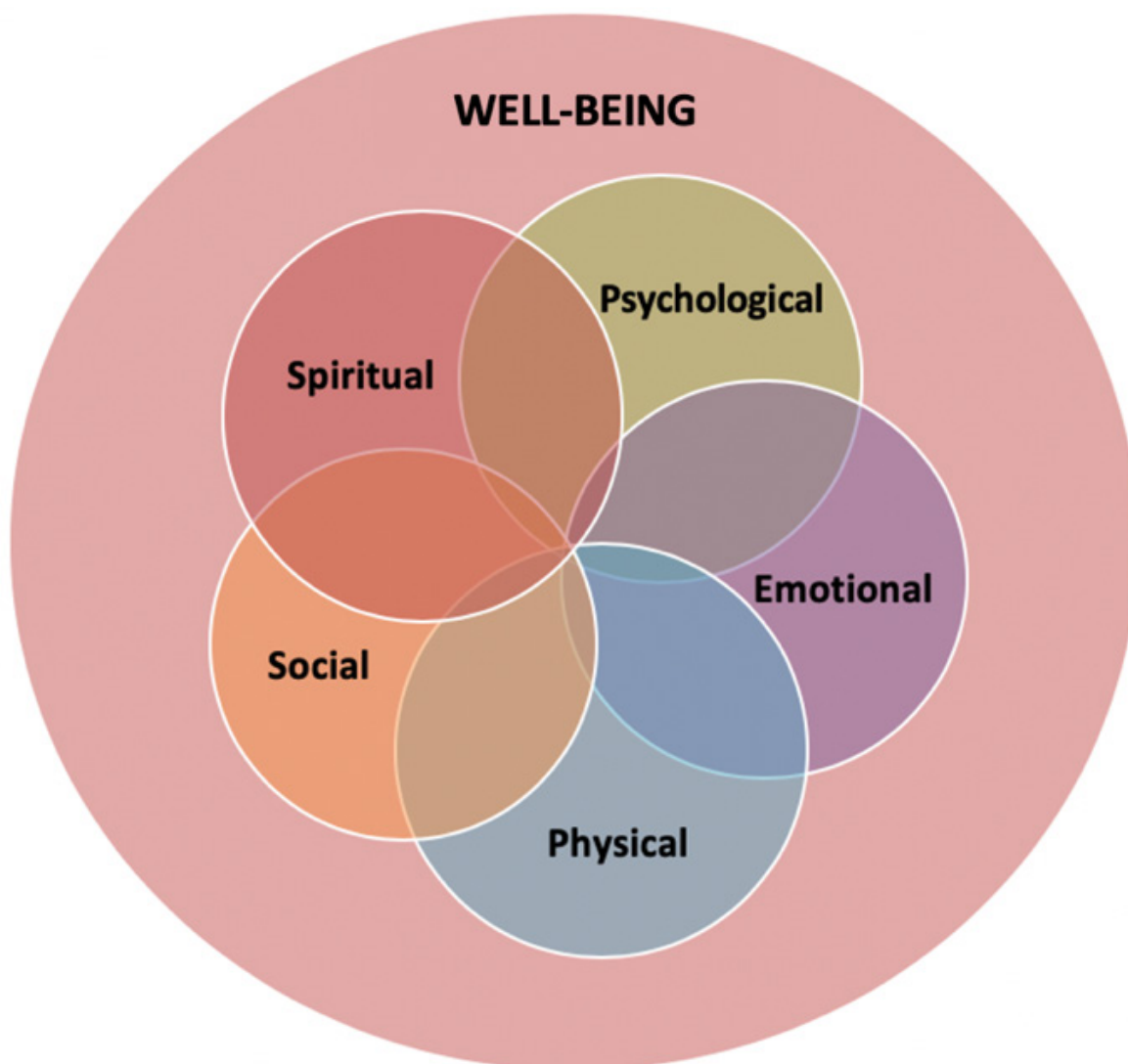
Well-being is a broad concept and has many different meanings. Well-being has been described as including “the presence of positive emotions and moods (e.g., contentment, happiness), the absence of negative emotions (e.g., depression, anxiety), satisfaction with life, fulfilment and positive functioning.”¹

Well-being can be understood as how people feel and how they function, on both a personal and a social level, and how they make sense of their lives. There are different aspects of well-being, many of which may look like:

Well-being is based on how people feel and function, on both a personal and social level, and how they evaluate their lives. There are different aspects of well-being:

- psychological
- emotional
- physical
- social
- spiritual.

- **Psychological well-being²**
 - Self-acceptance (positive attitude about oneself)
 - Feeling of control over one's life
 - Ability to meet demands
 - Personal growth (knowledge about oneself or maturing; moving toward one's potential)
 - Sense of security in relationships with others
 - Confidence in one's skills
- **Emotional well-being³**
 - Being able to manage emotions
 - Being aware of emotions and understanding why they appear
 - Coping or adapting to stressors or problems
 - Managing stress and anxiety
- **Physical well-being⁴**
 - Feeling comfortable in one's own body
 - Being able to physically complete tasks (even if helped by aids)
 - Knowing the importance of, and doing, physical activity
 - Maintaining nutrition
 - Doing a variety of physical activities
 - Knowing when emotional stresses affect the body
- **Social well-being⁵**
 - Being connected to a community
 - Understanding how society works
 - Ability to make and keep friends
 - Having a personal network of support
 - Contributing to society
 - Feeling accepted in one's community
 - Seeing how society is going forward and how we can improve it
- **Spiritual well-being⁶**
 - Having a sense of purpose in the world (feeling that life has meaning)
 - Believing in something greater than oneself (e.g., nature or higher power)
 - Feelings of hope, faith or social connection



Well-being is a key element of a person's overall quality of life. Well-being is something people strive toward—and it is very personal. **Well-being is different for each person day to day, and many factors can influence it.** External factors (such as community care, accessibility, housing, income and social connections) as well as internal resources (such as optimism, coping strategies or self-esteem) can affect well-being.

Autistic people, like everyone else, need friendship, support and opportunities to work and play in order to have a fulfilling life and to experience well-being. However, much of the time, these needs may not be met or be within reach.

Autistic experiences of well-being

“Autistic folks do have fun, we do build coping skills, we do have enjoyable things that make our lives worthwhile. Our lives are treated by society as being the worst-case scenario—like my birth was nothing to be celebrated. But that’s not true. I have fun; I have favourite toys/games, I like to draw and read, I look forward to comic book conventions, I love Christmas and Halloween . . . I have a full life. Not a tragedy.”

“No one else has reason to care about my well-being as much as myself. I'm a woman in my 40s who looks neurotypical but doesn't behave that way. I don't tend to get a positive response when asking for help or accommodation or asking a lot of questions unless I tell them my diagnosis of ASD. For some reason, the gender role expectations of a woman in her 40s these days is that I should be able to ‘handle it’ all by myself while juggling the demands of others, kids, a spouse and a full-time job, all while sleep-deprived.

“It is ridiculous what women are expected to manage every day inside and outside the home. I used to try to meet societal and role expectations and was very cruel to myself in the process. After my health reached a dangerous low, I was forced to stop trying to be ‘successful.’ I knew that if I was going to survive, I had to put myself first. I have learned that prioritizing self-care, self-compassion, non-comparison and developing an identity of my own that doesn't hinge on being something to someone else, are all ways that have helped me cope and find peace. Taking time to figure out ‘who is this person and what and how does she want to feel in this life and how can she best go about that?’”

Disclaimer: Some of these tips may not be relatable or accessible for all Autistic people, especially marginalized Autistic people, such as Autistic people of colour, Indigenous Autistic communities or the Autistic LGBTQIA2S+ community.

Knowing when to use self-care strategies

The “self” in ‘self-care’ reflects a focus on considering what we can do to help ourselves. It does *not* mean that a person excludes other people when caring for themselves. Self-care looks different for everyone and is not something that is always done in isolation. For some, self-care may mean connecting with others; that is, getting and giving support. For others, it may mean taking a break from connecting with others.

People may do self-care from time to time. **Self-care** is the many ways people can attend to their own needs, to keep themselves feeling as well as possible. Self-care can be important to maintain positive mental health, and to help when we are in distress or crisis.

Self-care are the ways people can attend to their own needs, to keep themselves feeling well.

Knowing you

An important part of self-care is knowing what a person’s **usual (or baseline)** is on a typical day (see **Section 5**). In thinking about what “usual” looks like for you, take note of how you are feeling in times when you are at your best self.

When a person understands their usual self and what is important to them in their day-to-day life, they are more likely to know when something is not right. This is a time when some self-care may help. It is also a time when a person can share about what they need with other people.

There are ways to help a person figure out their own usual. The national U.K. charity Ambitious about Autism created a toolkit for Autistic people to define their usual experiences, and record habits and feelings.⁸ It can be filled out any time

and can be used as a reference when sharing with others (such as family members, friends, teachers, co-workers/supervisors, service providers, etc.).

It describes brief baseline information about the individual completing the page with regard to the following (see Activity 6.1):

- An introduction to the person (e.g., name, age, a description or picture)
- Sleep routine—their usual waking and sleeping routine
- Relationships—how, when and with whom they usually spend their social time
- Interests and hobbies—their preferred leisure activities
- Staying Healthy—their preferred foods and physical activities
- Ways of looking after oneself—their usual hygiene routine
- Attitude and mood—their usual mood and feelings toward people and activities

Activity 6.1 – Knowing Your Own Usual^a

Follow this link to access Ambitious about Autism's "Know Your Normal" toolkit:

www.ambitiousaboutautism.org.uk/sites/default/files/toolkits/know-your-normal-toolkit-ambitious-about-autism.pdf

The toolkit explains how to fill it out and provides an example of a completed one for people to follow.

It can also be helpful to rate stress levels. One straightforward way to do this may be through the **Brief Distress Scale** (see Activity 6.2). This scale can quickly help a person understand where their stress levels are at or whether they are in crisis.⁹ This scale is like a distress thermometer. As a person's distress level goes up, that could be a good time to start self-care.

^a Please note the terminology change in the activity title from “normal” to “usual” as the AM-HeLP Group preferred less stigmatizing terms.

Activity 6.2 – Brief Distress Scale

On a scale from 1 to 10, rate where you are right now in terms of stress and crisis by picking one of the following statements:

Brief Distress Scale Adapted from the Brief Family Distress Scale ⁹
1 – Everything is fine, I am not in crisis at all.
2 – Everything is fine, but sometimes I have my difficulties.
3 – Things are sometimes stressful, but I can deal with problems if they arise.
4 – Things are often stressful, but I am managing to deal with problems when they arise.
5 – Things are very stressful, but I am getting by with a lot of effort.
6 – I have to work extremely hard every moment of every day to avoid having a crisis.
7 – I won't be able to handle things; If one more thing goes wrong – I will be in crisis.
8 – I am currently in crisis, but I am dealing with it myself.
9 – I am currently in crisis, and have asked for help from crisis services (community crisis supports, hospital, emergency room, etc.)
10 – I am currently in crisis, and it could not get any worse.

Autistic experiences with self-care

“Self-care was—and is—always important for me. The realization that no one was going to come and take care of things for me meant that I had to start doing what was best for me anxiety-wise from a young age. The teacher in our class isn't going to hold my hand when a panic attack rolls through—that's not their job. The professor isn't going to sit with me while my meds kick in. The principal isn't going to fight this anxiety attack for me—not only because they physically can't, but also because they don't care to. So, if I get up and leave the class, that's what I need to do for me. If I need to go for a walk, if I need to decide I can't come in to the lesson today, that's what's happening. And if the professor or the principal or whoever doesn't like it, they have two choices: I can have this episode in their class and it will be uncomfortable for everyone involved, or I can quietly get up, go for a walk and maybe come back when I've come down from it. They are not my priority. My first loyalty is to myself.”

“I find it exceptionally hard to know I need help or ask for help when I need it. Like many Autistics, I am supremely sensitive to judgments and negative feedback and have the irrational notion that asking for help will diminish my stature in the eyes of family and work colleagues. As well, when I try to do self-care, a family member is inevitably asking for my help. I cannot get that quiet ‘alone’ time to read a book, have a bubble bath or browse antique markets. Families can be great; they can also talk the talk but not walk the walk. It’s like, ‘I know you’re Autistic—now don’t be, because I need you to babysit all weekend.’ Self-care is a self-indulgent concept in my life, one that is not necessarily well-tolerated. I love my family, so it seems a small price to pay for peace.”

“When dealing with a highly stressful situation or problem, the last thing on my mind is self-care. When I am going through hell, the only way out is to keep going. I need to solve the dilemma, come up with a plan and figure it out. The planning and problem-solving, for me, improve my well-being.”

“I choose to find value in crafting, sewing, gardening and home improvements—all activities that are home-based. And I only shop locally, a short walk from home . . . I prioritize family and friends and have people over for tea in the garden or BBQs in good weather. Music and art, reading and learning are all positive activities that can be fulfilled over the internet. I enjoy teaching and offer sewing and crafting on a one-to-one basis. My life is balanced and fulfilling.”

“I try not to be too hard on myself. I allow myself to hear and respond to things the way my mind naturally wants to. If I’m in the middle of a conversation and I’m focused on what another person is saying, I may look away as a butterfly moves past or a bird comes into focus on a nearby tree. Having a partner who accepts this is important for me and for our relationship. I’ve always been very easily distracted. I’ve constructed my world so that there are no other people around me most of the time, and a lot of space (no houses or any neighbours within sound or sight). This way, I can work on projects at the whim of my mind. If it wanders, I wander with it.”

“Long-term strategies for well-being for me include long-term plans. Working out four to five days a week has been a long-term strategy of mine. It has been consistently there to help with mental health and focus and having a clear mind. Long-term goals for me include upgrades to my shop and equipment used. For example, certain increases in modernizing equipment in fiscal year spending plans.”

Community care

The idea of self-care often assumes that every person has the ability to perform self-care, has access to supports and makes use of them. However, self-care can be hard to do and, in many cases, it may not be possible because of external factors (such as stigma or isolation) and societal barriers (such as accessibility limitations). This gap is especially present in some disabled communities where their limitations and needs for care are ignored. By only talking about self-care, this takes the responsibility of care away from the community and places it on the person who requires the help. Part of well-being is understanding our connection to our communities.

Community care is choosing to take care of each other, including oneself and others in the community.¹⁰ This perspective of care is inclusive and works interdependently (which

means people depend on each other) within a cooperative community. It is a type of self-care where people take part in helping and caring in ways that help the community as a whole. Examples of community care are peer support groups, informal networks and “spoon shares” or neighbourhood “pods.”

Mutual aid is when we provide social support or resources to each other, like running errands for someone in need or giving food to people when they cannot afford it. It involves providing voluntary support to people who share a common experience.¹¹ These groups work to meet each other’s needs to survive. They use resources from their community.

Like mutual aid, spoon shares and pods give support as a part of community care. **Spoon shares** are groups that connect people needing short-term or long-term help due to injury, illness, disability or other life challenges.¹¹ **Pods** are made up of people in the neighbourhood or family that a person would go to in case of an emergency (see Activity 6.3).

Community care is choosing to take care of each other (one’s self and others in their community).

Mutual aid involves providing voluntary support to people who share a common experience.

Spoon shares are groups that connect people needing short- and long-term help because of injury, illness disability or other life challenges.

Pods are neighbourhood groups made up of people working to get everyone’s needs met.

Community care can have some challenges. Offering, asking, receiving or declining help may not come easily to an Autistic person. This can be even more challenging when someone struggles with mental health challenges. These social-communication–based actions may be scary, hard or triggering for the Autistic person. However, community care functions on the basis of support and understanding. A person doesn't have to get it right the first time.

“Community care improves well-being just as much, if not more, than self-care. Over-emphasis on self-care is one of the ways society fails at securing the well-being of disabled people.”

Activity 6.3 – Pod Mapping

The *Bay Area Transformative Justice Collective* (2020) created a “Pods and Pod Mapping” worksheet to help people start the process of identifying who could be in their pods.¹² You can find the worksheet at this link:

<https://batjc.wordpress.com/pods-and-pod-mapping-worksheet/>

Community care supports

With online access, community care can reach many people. Group forums, such as those that can be found on Facebook, as well as group chats through various phone apps are just some of the tools that have been used to take part in community care.

It may be difficult to find the right group chat or online forum. Following are some suggested questions to consider when searching for one, as shared by some of our advisers:

- Are the posts on this forum/group chat largely positive? Or negative?
- Is there a lot of fighting or arguing between people on this page/group chat?
- Does the page/group chat have rules about no homophobia/transphobia/racism/sexism, etc.?
- Do I feel happy having been on the page/group chat or am I tired, frustrated or angry when I sign off?

Below are some common resources that can be given or asked for in community care situations:

Common Community Care Resources	
Practical	<ul style="list-style-type: none"> • Household chores (e.g., cleaning, cooking) • Personal hygiene (e.g., buying shampoo, hair cutting) • Equipment or supplies (e.g., laptop, office supplies)
Travel	<ul style="list-style-type: none"> • Rides to appointments or grocery stores • Walking escorts
Relief	<ul style="list-style-type: none"> • Respite (e.g., child or pet care) • Encouragement, support or advice
Share	<ul style="list-style-type: none"> • Sharing resources (e.g., job postings) • Sharing lived experiences
Service	<ul style="list-style-type: none"> • Recommendations for low-income housing or LGBTQIA2S+ friendly services • Help with completing forms or taxes

In times of emergencies or crises, communities need to work together and care for each other. For disabled people, their lives may have more frequent emergencies and crises than non-disabled people.

Autistic experiences with community care

“The best thing that I have found to support me, is community. The autism community understands Autistic people. I run several online support and community groups, and it is those communities where I have found the best advice. The spectrum is huge, so if one group isn't a good fit, another will be. Autistic people online (there are few in-person groups) are a great resource. A lot of mental health issues are a result of isolation from other Autistics, so meeting up online, sharing experiences and sharing coping skills really has a positive influence on self-esteem. Knowing you are heard, understood and supported by others *like you* is the best.”

“For me, I find national and regional Autistic-led support groups to be immensely helpful to ask for local and regional resources, because there’s virtually always someone who has sought the same support that I am seeking, and they tend to have the best recommendations for who and what is helpful and what is not. These groups have saved me from waiting on wait-lists for things that aren’t actually helpful in the end, many times. They’ve also provided names and programs to be referred to that my doctors haven’t even been aware of.

“I would like to share that one of my biggest and most successful self-care strategies is asking for help. I pose questions to similarly affected individuals and I ask for advice on how they’ve solved the same problems I’m dealing with. Hearing from other people who are like me and who have shared lived experience is one of the most hopeful and helpful parts of self-care that I do for myself. It makes me feel like I’m not alone. It also helps me to organize to remove these problems and barriers for others, and that helps me to cope.

Societal support of Autistic well-being

Asking for help is considered a sign of strength and maturity, and a sign of heightened self-awareness. Non-Autistic people ask for help as well—it is not just something that Autistic people do. There is a lot that society can do to improve Autistic mental health and well-being. It is not up to the Autistic person alone to understand well-being. To feel capable and successful, Autistic adults may need some supports in their environments: at home, at school, at work, at volunteer places and more. This section talks about what Autistic people may need.

Universal design

The best way society can change is to make things more universally accessible as much as possible, so people do not have to constantly request for individual accommodations. Ideally, environments should be built for all kinds of people from the start, and then adjustments should only be needed for any remaining gaps or barriers.

Universal design is the creation and design of products and environments that allow everyone with all levels of ability to access, understand, use and participate in society. It includes the following aspects:

Universal design is the creation and design of products and environments that allow everyone to access, understand, use and participate in society.

- **Physical accessibility**¹³

The design is accommodating, comfortable and useful for a wide range of physical disabilities. Some examples include:

- main entrances that have wheelchair-accessible ramps and automatic doors
- accessible elevators at the workplace
- signs with braille that say the names and numbers of rooms or buildings
- rooms with enough space for wheelchair users.

- **Sensory accessibility**¹³

The design is safe and provides critical information effectively, regardless of sensory abilities. Some examples include:

- available hearing aids (sound devices, microphones) or noise-cancelling earmuffs
- available visual aids (e.g., closed captioning or image descriptions)
- available American Sign Language interpreter
- safe place that does not trigger people with chemical and light allergies and sensitivities
- nut-free policies
- fragrance-free policies.

- **Cognitive accessibility**¹³

The design is easy to understand, regardless of the person's experience, language, knowledge and concentration level. Some examples include:

- making a schedule and sending it to people in advance
- providing options for accommodation requests
- using name tags and colour communication badges to support social interaction
- allowing for space and time to take breaks
- providing information in plain language
- offering alternatives to interviews for hiring, such as demonstration tasks, walking interviews, supplying interview questions in advance and allowing written responses.

Supports for Autistic people

Specific supports will vary according to the person, but it is important to have a community-based approach when supplying supports for Autistic people. It takes a combination of understanding autism, having respectful community support (Autistic adults, service providers and family members working together – not separately) and allowing for individual adjustments for Autistic adults to thrive. One idea an adviser suggested is to “bring in an autism educator and trainer to educate management and staff on accommodations and antibullying policies and practices.”

Possible supports and accommodations	
Environments	<p>Making the environments more inclusive. For example:</p> <ul style="list-style-type: none"> • Smaller meeting sizes are ideal, as it can be easier and less overwhelming for Autistic people. • Allow more personal space in meetings and in workspaces (e.g., private cubicles or office with a door) to lower nearby stimulation. • Allow fidget materials. • Allow the use of ear plugs or headphones, or sunglasses to block the sensory input. • Provide or modify equipment (e.g., adjustable desks). • Use visual aids. • Allow plants and therapy pets to soothe stress. • Use less fluorescent lighting. • Provide access via elevators. • Provide gender-neutral and wheelchair-accessible washrooms. • Create a quiet space (designated spaces where anyone can go to recharge). • Provide private work spaces. • Provide on-site job coaching that includes teaching the hidden curriculum of the workplace.
Schedules	<p>Having clear schedules and predictable transitions aided by multiple cues (visual and audio). For example:</p> <ul style="list-style-type: none"> • Prioritize tasks and give a defined deadline for completion. • Give breaks. • Have fixed routines. • Be flexible with routines. • Allow modification in schedules. • Allow extra time to complete work. • Offer longer or shorter sessions. • Offer flexible work hours or options to work from home.

<p>Tasks</p>	<p>Restructuring tasks to provide opportunities to do, present or communicate in an Autistic person's preferred way. For example:</p> <ul style="list-style-type: none"> • Provide extra training or one-on-one time. • Provide the choice of self-recorded presentations. • Provide options to opt out of group presentations. • Encourage different ways of interviewing for a job.
<p>Support services</p>	<p>Providing qualified assistants or support services. For example:</p> <ul style="list-style-type: none"> • It can be helpful for an Autistic person to have access to an experienced advocate or mentor, who can help with navigating and potentially finding solutions to being in different environments.
<p>Communication supports</p>	<p>Offering different ways of communicating. Some Autistic people do not like phone calls, not just because of the sensory difficulties, but it may also be hard for them to start conversations, know when to speak and know what to say. At times, some Autistic people may need tools such as augmentative and alternative communication (ACC). AAC includes communication devices, systems, strategies and other tools to replace or support speech. For example:</p> <ul style="list-style-type: none"> • Provide repetition for cognitive processing. • Provide communication badges. • Allow for multimodal communication (there are lots of AAC devices that do this). • Provide different ways of communicating (e.g., email, videoconference, social media, text). • Keep instructions clear and concise; use unambiguous language.

Ways to support Autistic people

Autistic acceptance

Autistic acceptance is the acceptance of autism and Autistic differences and recognizing that Autistic people have the right to be and to live their authentic selves. This requires work from the non-Autistic community to recognize their own biases and to acknowledge that all Autistic people are their own person. Acceptance includes understanding that autism is diverse and embracing it. It involves making Autistic voices heard and understanding that they are experts of their lived experiences.

Autistic acceptance is the acceptance of autism and Autistic differences and recognizing that people have the right to be and to live their authentic selves.

“Societal support is limited in many ways, such as mental health and understanding in certain groups. Even Autistic government-funded groups at times do not have us included as voices as the main stakeholders. This is extremely detrimental to the accuracy of what these groups and government funding can do to help the body of people they say they represent.”

“Society often puts the onus on Autistic or otherwise-disabled people to ‘do better’ or ‘get better’ or ‘fit’ and less on what society can do to help people in the community. It’s rather like bridge-building. Both sides need to work hard—I can only build a bridge halfway, but if I see that people on the other side (the non-Autistic community) aren’t working hard, then why should I work hard for them? What am I building a bridge for? I can’t build the whole thing myself.”

Reassurance

Reassuring the Autistic person that there are no invalid or ridiculous questions, and that it is okay to ask for clarification or more details, can be very helpful.

Helping or encouraging a person to clarify what needs to happen, when and how, and helping them write up their own plan, can be empowering.

Patience

If an Autistic person is struggling, it is also useful to help them think about what aspects of the situation they can control, what they can’t control and if there’s anything they can do to feel more in control. This might be anything from deciding on an end time for an event to learning to better identify what their stressors might be and having a plan for how to counter them.

If you are with an Autistic person experiencing a meltdown, do not crowd them or overwhelm them with questions and concerns. Be calm and reassuring; let them take their time and listen to what they might need. One Autistic adviser said: “I find being offered water very helpful. So, asking beforehand if an Autistic person has instructions in case of meltdowns, or maybe even a card (instruction) or MedicAlert bracelet.” These may be very useful for some Autistic people but may be inappropriate for others.

Some Autistic people may not be able to communicate verbally when in distress, even if they are usually very articulate. If necessary and possible, help them get to a safe and quiet place away from things like bright lights, loud noises and other people.

Connecting

It can also help for non-Autistic people in an Autistic person's life to try to connect with them based on their interests, and on their terms. **Socializing may be exhausting for many Autistic people, when they must mask and worry about non-Autistic expectations**, but socializing may still be wanted. Therefore, it's important that the person can feel safe in being allowed to be themselves, to define their own boundaries and to say when they need alone time.

Many Autistic people spend a lot of their lives masking to fit in socially or putting extra energy into navigating a non-Autistic social situation. It can be very helpful for non-Autistic people to try to learn ways to make it safe for Autistic people to remove the mask and exist as their authentic Autistic selves. It is good to be direct about social expectations and boundaries, as well as being honest and openly reassuring about common concerns, such as being excluded or isolated.

"I am immensely grateful for the social networks of my family and friends that I do have. I may not have or ever have the biggest social network as my life continues, but right now I do feel that there is always at least one person in my current network that I can talk to and/or get tips from on serious or positive thoughts I'm having. My social relationships are all on a basis of respect and partnership."

Advocating with Autistic adults

It can also help when non-Autistic people **advocate with Autistic adults**. This means helping an Autistic person to express their needs, protect their rights, represent their interests and access services they may need. As one adviser said: "I think the most important thing to keep in mind for a non-Autistic in advocating for Autistics is to elevate the voices of Autistics rather than speaking over them."

It is important to know when advocacy is the right thing to do. **Being a good ally means knowing when to pass the microphone on to the Autistic person and empowering them to use it.** Non-Autistic advocates should be careful not to advocate for what they believe the Autistic person needs, and instead focus on what the Autistic person is expressing that they need.

Being an Autistic ally can include the following qualities¹²:

- understanding autism and/or mental health
- challenging ableist attitudes in environments that may continue to be biased against Autistic people
- asking the Autistic person what type of support they need
- building trust with Autistic people
- having patience and accountability in working together with Autistic people
- showing assertiveness in representing Autistic people
- having a willingness to learn about Autistic people's rights, advocacy and activism history
- viewing advocacy as a partnership with Autistic people
- supporting Autistic self-advocacy.

Autistic experiences with finding supports in society

“Writing up your own plan, or writing with assistance, is so important. Many of the parents and schools I’ve talked to do not have the student involved in the writing of their IEP (individual education plan), and it’s infuriating that a learning plan is made up in the absence of the learner. Especially as everyone says they want that Autistic/disabled person to become independent—but then divorce them from empowering decision-making that is directly about them! Put the individual back in the individual education plan.

“Often, disabled people in general are treated as too stupid to know what’s best for us. By giving that person a voice back, a chance to say ‘I do know what’s best’ or ‘I have some ideas about how I want things to go’ returns agency and power back to that person. Too often, stuff is done for us in our absence because ‘It’s just faster this way’ or ‘They don’t know what’s best anyhow.’ It’s insulting.”

“When my sons were of legal age and they first went to a nightclub/bar, there was loud music and strobe lights on. It was very interesting when the person they were with asked the waitress if maybe the music could be turned down a bit and the lights up a bit, as no one was really there yet. The waitress looked at him a bit odd and then said: ‘Sure, till it gets busier, no worries.’ She could have said no, but having someone along to show it never hurts to ask has helped my boys to know it’s okay to self-advocate for themselves, too.”

“Attending an Autistic-led conference for the first time was an eye-opener for me. With supports ready and waiting to be accessed and the day planned out to be less intimidating and more supportive, I couldn’t believe the difference in experience at this autism conference. The seminars were calmly lit, the sound levels low (with FM system, sign language and easy-to-read handouts available for those who needed them), the PowerPoints well-written and not overstuffed so as to be easy to follow, the Snoezelen room, the break room . . .”

Short-term self-care strategies

Short-term strategies mean that these strategies can be done whenever a person wants in order to immediately boost well-being. These strategies are sometimes called **“quick wins.”** But these quick wins can combine together to have a big benefit (see Activity 6.4). If a person does not care for themselves in the short term, it may affect their well-being over time.

Short-term strategies (also known as “quick wins”) mean strategies that can be done whenever a person wants in order to get an immediate boost of well-being.

Short-term strategies are unique to each person, and it can change depending on the day or time, who is around them and other factors. What may be fun or pleasurable for one person may not be fun or pleasurable for another. Below are just some of the short-term strategies Autistic adults have used for a “quick win.”

Short-term (“quick win”) strategies	
Psychological	<p>These activities involve nurturing one’s sense of growth or accomplishment:</p> <ul style="list-style-type: none"> • Focusing on passions and intense interests • Planning and problem-solving • Writing • Asking questions (e.g., being curious, investigating or researching topics) • Eating comfort food (e.g., chocolate or candy) • Enjoying music (e.g., listening to favourite sounds or songs) • Learning a skill (e.g., woodworking, knitting) • Doing something creative (e.g., painting, drawing) • Getting chores done • Giving oneself permission to feel upset and frustrated, and permission to overcome these feelings • Thinking about things that give feelings of happiness, calmness, comfort and safety • Looking for or holding on to a comfort item (e.g., stuffed animal)
Physical	<p>These activities involve movement:</p> <ul style="list-style-type: none"> • Stimming (i.e., self-stimulatory behaviour, from rocking and stroking certain textures to watching colourful lights or fidgeting with an object) • Structuring days to include fun activities • Eating • Sleeping • Laughing • Sitting or swinging on a hammock or swing • Walking, running • Gardening • Dancing • Listening to music or singing • Enjoying the beauty of nature (e.g., going for a walk) • Taking a long hot or cold shower • Having consensual sex • Masturbating • Doing yoga • Working out • Taking medication that helps
Social	<p>These activities involve connecting with others:</p> <ul style="list-style-type: none"> • Playing with or hugging a pet • Talking to a trusted/safe person or close friend • Getting together with family or friends or interest groups • Meeting online with other Autistic adults or neurosiblings (other people with different disabilities) • Joining online and in-person communities • Watching a favourite TV show or movie with others • Taking a break from socializing • Playing games • Going to the gym or the bar

Environmental	<p>These activities involve reducing outside factors or sensory overload:</p> <ul style="list-style-type: none">• Laying on a sensory surface that's appealing to the person (e.g., grass)• Going to a sensory room• Going to a quiet room with dim lighting• Using noise-cancelling headphones or earplugs• Listening to soothing sounds• Touching soothing textures• Putting on sunglasses or a hat to block out lights• Using a weighted blanket• Going swimming• Napping• Problem-solving to overcome barriers
Spiritual	<p>These activities involve doing things that bring a person closer to their beliefs and/or a sense of purpose that can help guide or comfort them:</p> <ul style="list-style-type: none">• Meditating• Practicing yoga or martial arts• Praying• Being in nature• Reading spiritual or religious texts• Connecting with a spiritual or religious community• Meeting with a mentor, Elder or religious elder

Activity 6.4 – Quick Wins

Strengths: One quick win involves recognizing your strengths. Think about five of your greatest strengths (e.g., your sense of humour, the way you think, your skills). List them below.

1. _____
2. _____
3. _____
4. _____
5. _____

Role models: Another quick win can involve identifying role models (famous or not). These could be other people who have overcome adversity in life and whom you admire because of the way they take care of themselves, both in calm and in challenging periods. Think specifically about why you are choosing these particular role models and identify the characteristics that you appreciate them in.

Role model: _____

Why did you choose this person? _____

Role model: _____

Why did you choose this person? - _____

Autistic experiences with short-term self-care strategies

“I have a self-care shoebox where I put in a few small candy bars, some video games and movies, fidget toys and the like. Or at times I say to myself, ‘How can I relax today?’ and make a list of activities I would find enjoyable and pick a few from the list.”

“One of the really therapeutic things I’ve learned is that, although I may not connect socially with other people very much or very often, I can still exercise that muscle of back-and-forth interaction or relating with something outside of myself in different ways—like by singing along in harmony with a song. I’m interacting with it, keeping in time with the rhythm, improvising harmonies, tuning in to the emotional feelings of the music, expressing myself in relation to it. This all takes focus and timing and involves my own initiation of input and response in some way. Or dancing to music or playing an instrument along to music is another way to interact with music.

“At the end of it, I feel like I’ve just had a conversation but without experiencing the stress of being misunderstood, judged or criticized that usually comes with interacting with people. It’s cathartic and feels good. To me, it feels like a healthy and safe way to express myself, interact, connect and relate.”

“I have recently rediscovered how important the physical act of writing is to me. I do a variety of self-care activities in my spare time, as mentioned earlier, such as word searches (which are a great mental jogger for me in coming up with my own pun jokes), mandala colouring books, seeing my favourite TV shows and movies, socializing (e.g., going for a cup of coffee, out to lunch with at least one friend), walking, reading and the gym. I also like writing, too. However, I had not been physically writing for months and I did not realize how important this physical short-term strategy is for my own self-care. Now that I have started putting pen to paper again in this journal brand called *The Five-Minute Journal*, I’ve been feeling an internal lightness that I had not felt in a long time. So, now I consciously know that I need to more regularly add writing to my personal arsenal of self-care strategies.”

1. Check-ins about the basics

Part of self-care is noticing what is happening to the body and mind (see Activity 6.5). When situations or thoughts are very stressful or overwhelming, it may be helpful for Autistic adults to take their time to check in with activities that can help to take care of the body and mind.

Activity 6.5 – Check-in Questions

One quick way to check in is to use the HALT acronym and ask yourself:
Are you hungry, angry, lonely or tired?

Below are further questions to ask yourself daily to check your usual:

- Did I have something to eat or drink?
- Did I sleep?
- What am I feeling today?
- What is occupying my thoughts today?
- Have I had time to go outside?
- Have I had time to go for a walk, if possible?
- Have I washed, showered or cleaned up?

It is not always easy to understand why a person is feeling certain ways. It can be difficult for some Autistic adults to recognize or tune in to their body's distress signals. For example, sensory differences may make it difficult to identify whether an Autistic person is experiencing low mood, irritability, hunger or pain. They might feel angry, but once they eat, they feel better. As one adviser said, "Alexithymia makes it incredibly difficult to process how I'm feeling at any given time. It takes time and concerted effort and certainly not something I'm able to do as a quick check-in."

Activity 6.6 below can be used as a tool to check in with well-being. When days are full of stressors, it can be hard to see how well usual needs are met.

Activity 6.6 – Interactive Self-Care Flowchart⁸

This interactive game called **You Feel Like Shit: An Interactive Self-Care Guide**, created by Jace Harr (2015), is an easy and helpful chart for people who struggle with learning how to recognize their inner signals and for those who may not be good at looking after themselves.¹⁴ Follow this link to access the game:

https://philome.la/jace_harr/you-feel-like-shit-an-interactive-self-care-guide/play/index.html.

2. Self-compassion

Self-compassion is about taking a gentle approach with oneself in the moment. It involves recognizing and appreciating personal strengths and being kind to ourselves. It is also being content with who you are. This can take a lot of practice (see Activity 6.7). Autistic people can be particularly hard on themselves and may hyper-focus on small mistakes, social mistakes and things they should have done. They can start to focus on what they think they are doing wrong, instead of all the things they are doing right.

Self-compassion is about taking a gentle approach with oneself in the moment.

Acknowledging your strengths and giving yourself the permission to be imperfect may involve learning to think in new ways about situations. For example, acknowledging positive aspects about oneself— such as a good sense of humour, perseverance, motivation, physical or verbal abilities—is particularly important when a person is stressed. This can improve self-esteem, self-worth and mental health.

Dr. Kristin Neff (www.self-compassion.org) describes self-compassion as three processes:

1. **Self-kindness**: Being understanding to oneself when feeling inadequate or that one has failed or is struggling.
2. **Common humanity**: Recognizing that being imperfect is okay and that people are affected by many factors outside of themselves.

3. **Mindfulness**^b: Being aware of one's thoughts and feelings, in a non-judgmental way.

Activity 6.7 – Gauge Your Self-Compassion

Dr. Neff suggests asking yourself the following questions to gauge your self-compassion:

- How do you typically react to yourself?
- What types of things do you typically judge and criticize yourself for (appearance, academics, relationships, etc.)?
- What type of language do you use with yourself when you notice some flaw or you make a mistake? Do you insult yourself or do you take a kinder and more understanding tone?
- When you are being highly self-critical, how does this make you feel inside?
- When you notice something about yourself you don't like, do you tend to feel cut off from others or do you feel connected with your fellow humans who are also imperfect?
- What are the consequences of being so hard on yourself? Does it make you more motivated and happier, or discouraged and depressed?
- How do you think you would feel if you could truly love and accept yourself exactly as you are? Does this possibility scare you, give you hope, or both?
- How do you typically react to life difficulties?

^b The practice of mindfulness originates from Buddhism and the early teaching of the Buddha. It was popularized for therapeutic purposes in Western society by Jon Kabat-Zinn (1990).

3. Positive self-talk

One way to think about difficult situations in new ways is using **positive self-talk**. It may be helpful to talk yourself through situations that can be stressful or complicated with a positive mindset. For example, a person may tell themselves: “I am doing the very best I can. I’m only human. I am caring and loving.” Letting yourself experience emotions is important when coping with difficult circumstances. Sometimes it may not be appropriate to speak out loud, but a person can think these thoughts or write them down.

Positive self-talk means talking to yourself through situations that are stressful or challenging with a positive mindset.

Autistic experiences with short-term strategies

“‘Taking a break’ and ‘pampering’ yourself by dressing up or going for something like a makeover, shopping, etc.: all the things the other women listed for ‘coping strategies’ were the opposite of what calms my nerves and senses. My answer for ‘coping’ was to focus on the issue at hand, go over every detail and connections until I’ve pulled together some understanding and solution moving forward—then I get that release from the anxiety. But taking breaks from it will just make me more anxious. I need to study it, dissect it and make sense of it, then I’ll feel better. No bubble bath or pedicure is going to help me feel better. It will only add more unfamiliar and/or superfluous sensory input that increases the overwhelm and overload . . . Reducing stimuli and being allowed to ruminate, dissect, find connections and create possible solution options helps me get through the anxiety to the other side of relief.”

“Getting it done if something needs doing or sorting and analyzing information to figure out what/where I went wrong is the only solution to stress for me. If the problem is within myself, then I examine myself (hopefully fairly, not harshly), and then I can decide whether I had any control, any responsibility, for the outcome. If the answer is no, I did not have power over or control of what happened, then I am not responsible.”

“Using visualizations has really helped me to deal with my anxiety and monitor myself. By coding my anxiety I’ve found ways to say, ‘I can handle this’ or ‘I need to leave this situation.’ And sometimes having a plan in place to handle anxiety makes me feel safer or able to stick with a situation longer.”

“I know some Autistic adults who avoid doing things that provide comfort and pleasure because they are scared it will make them look like a child. They have been shamed for it in the past. Things like carrying a stuffed animal around, thumb-sucking, even rocking back and forth and fidgeting. Without going into how shaming people for looking like children also demeans children, Autistic people should not be shamed for self-care. Engaging in self-care is a sign of maturity and growth. It means understanding and doing things to care for oneself. As we grow up, we regress in that understanding. It’s why there is this whole self-care movement to learn it all over again. I’m a budding researcher, an organizer and a changemaker—and I carry a stuffed animal with me. Get used to it.”

Long-term self-care strategies

1. Recognize and address challenges

When experiencing many challenges, it may be helpful to try to identify and prioritize them. It may prevent a person from feeling overwhelmed and can help set them up to be more successful. It is not always easy to prioritize needs.

Sometimes, a person struggling to improve well-being or mental health looks to others to “fix” the problem or may want to get rid of it completely. Sometimes this is possible. Some challenges cannot be fixed quickly or easily though. Sometimes, changing how we think about the problem or the ways of coping with the problem may be helpful instead (see Activity 6.8). A person can learn ways of coping with the problem, to move forward and thrive despite it, instead of believing they must get rid of it from their lives entirely.

Activity - 6.8 Worksheets on challenging thoughts and coping

Courtney Ackerman's Positive Psychology blog (2020) provides many useful worksheets to use in the long term and is a useful resource:

- For help dealing with challenging thoughts, read the ideas suggested in these blogs: <https://positivepsychology.com/blog/>
- If you're interested in other coping worksheets, you'll find more here: <https://positivepsychology.com/coping-skills-worksheets/>

2. Set boundaries

Boundaries are rules and limits that a person sets for how others should treat them safely and respectfully. Personal boundaries allow people to feel comfortable in their space. It ensures that the relationships between people are respectful, appropriate and caring. Some boundaries are simple, and others are complex.

Boundaries are rules and limits that a person sets for how others should treat them respectfully and safely.

For some people, if boundaries are not set, situations may be confusing and can lead to frustrations and challenges in relationships and friendships. Being clear on boundaries can keep people safe and may reduce the chances of relationships or interactions that are hurtful or harmful. Boundaries can help to keep a person safe from people who would take advantage of them (psychological, physically or financially).

Both Autistic and non-Autistic people can find setting boundaries very difficult. Setting boundaries can be distressing in the beginning. For example, a person may not know when to communicate, they may think they are overreacting or they may not want to upset the other person. Autistic people may have had experiences, including of past interventions, where they were taught to suppress their natural way of expressing their boundaries. Relearning how to express boundaries in a way that works for them is a process and can take time.

“I have difficulty with boundaries and saying no to people. I tend to just go along with things, even if it’s not what I want or if I’m scared or uncomfortable. I’m not sure if it stems from being expected to put up with bad sensory situations (being told to grin and bear it, not to show people that I’m in pain or upset when loud noises happen), being yelled at for asking for help/social anxiety or having to face down fear due to my anxiety.”

“When talking to close friends and family, I say, ‘I am not always good at knowing how I come across, so if you don’t tell me, I can’t know, so you can’t hold it against me.’ That way, I can be me and not *always* try to be perfect in tone, volume, conversation turn-taking, eye contact, etc., as sometimes I am just too tired to try. This is me saying: ‘Sometimes I just need to be me, so if you can accept that and not try to change me, that would be great.’ Which I also say to people.”

Samantha Craft (a.k.a. Marcelle Ciampi), Autistic author and senior manager of diversity, equity and inclusion at Ultronauts Inc., wrote about boundaries and advised on how to set them in her blog, *Everyday Autistic*, and we provide some of these in the table that follows.¹⁵ More resources are available at <https://myspectrumsuite.com>. The suggestions, sample responses and tips that follow were compiled from first-hand experience and anecdotal information in Craft’s communication with Autistic adults worldwide, and multiple resources. Some of the sample responses below can also be used to recognize when other people want their boundaries respected. For some Autistic people, some of these tips may require direct instruction.

Tips and responses for setting boundaries	
Preparation	<p>Preparing for interactions is crucial to successful boundary-setting, as is being aware of your values and the key reasons for your boundaries.</p> <ul style="list-style-type: none"> • Respecting yourself is important. It is not selfish. • Setting limits is needed. Without it, personal strain and burnout can happen faster. • There is a potential for miscommunication, bitterness and resentment when you are quiet. • Setting healthy boundaries is not the same as creating conflict, but it can create conflict if the other party is dismissive or invalidating. • Take care of yourself first. It is a kind and healthy thing to do. If you do not, you can be easily exposed to burnout or possible danger. • It's okay to feel uncomfortable (you may feel anxious) setting boundaries. • Examine roadblocks to healthy boundaries. This can happen through a discussion with a professional or trusted person, or by reading related literature. • Examine feelings associated with setting boundaries. For example, "I am afraid of boundaries because I _____ (fear hurting another's feelings, fear rejection, fear confrontation, will feel guilty, am afraid of what others will think about me)."
Analyze and support	<p>Analyze situations and seek the necessary support.</p> <ul style="list-style-type: none"> • What emotion(s) is underneath the initial discomfort? (e.g., anger, sense of danger, feeling invaded, personal space violated). Some people may not be able to answer this question and that is okay. • Practise identifying emotions when someone has violated a boundary by making notes of when these situations happen, how you felt and how you reacted. • It's okay to feel slow in recognizing situations and when boundaries are crossed. Learning this might be new and it takes time. Don't shame yourself about it. • Work on increasing your awareness level when your boundaries are violated. • Check in with a trusted person or support group if you are uncertain if a boundary has been crossed.
Action	<p>Below are some things to keep in mind when you are ready to set boundaries.</p> <ul style="list-style-type: none"> • Respect yourself. • Remember, you have the choice to ignore someone and walk away. • You get to decide the boundaries you set for yourself—the who, what, where, and when of your life without explaining the why. Nobody is owed an explanation or justification for your feelings. • Be as direct as possible. • Don't assume others know or understand your limits. • If you are able to, state your limits clearly and precisely, with as few words as possible. • Don't provide more information than needed. • Don't engage in an extended conversation, unless it's with someone with whom you have an invested and important relationship that you wish to keep.

<p style="text-align: center;">Sample responses</p>	<p>Having “go to” responses to how to express setting a boundary can be helpful. Below are some sample responses to refer to, or to practise with, when needed. You don’t have to use everything on here—you can pick your favourite ones and use them, or you can create your own.</p> <ul style="list-style-type: none"> • “No.” • “Stop!” or “I’d like you to stop.” • “I’m done,” or “I need to go now.” • “No, thank you,” or “No. I am not okay with this,” or “I’m not comfortable with that.” • “Not cool. Don’t do that around me.” • “This is my boundary. This is how much I can take.” • “This is not what I want to do.” • “I’ve learned it works for me best when . . .” • “I noticed you keep asking _____. Why are you asking me that?” • “I disagree and no longer am going to talk about this.”
<p style="text-align: center;">Stay calm and repeat</p>	<p>When setting limits, try to stay calm. Below are some tips to keep in mind when setting limits or responding to others.</p> <ul style="list-style-type: none"> • You don’t have to do this, but if possible, look in the centre of the other person’s forehead in order to appear to be making eye contact. • If needed, write your boundary on a piece of paper and read it aloud. • You do not have to always justify, but there are times when justification is necessary and helpful. Either party may need to understand why you need something to able to accommodate it. • You can feel angry, but if you want to get your point across, perhaps you have to say it calmly first. • Do not apologize. • Set a limit and repeat. (e.g., “I would like you not to cook in the kitchen after 10:00 p.m. Please stop cooking in the kitchen after 10:00 p.m.”) • Avoid indirect words and phrases that take away from being direct, such as: “I was wondering if”; “Can you do me a favour?”; “No big deal, but . . .”
<p style="text-align: center;">Advocate (see the section on self-advocacy below)</p>	<p>Advocate for your limits to be respected, exercise self-care and take actions to ensure you are heard.</p> <ul style="list-style-type: none"> • Know what you will and will not tolerate. • Keep to your words and honour that your needs and boundaries may be different than those of others but are just as valid. • Avoid debates, negotiations, arguments, shaming and threats. • If repeating limits does not have the desired outcome, you do not have to stay or continue stating your case. You can leave, walk away, ask for help, tell someone, etc. • Set limits for the other person. (e.g., “I need time to think if I can be in this relationship”; “I need to speak to someone about this situation before I make a decision”; “I have had enough and am no longer tolerating your behaviour/ this conversation”; “I will get back to you”; “I cannot help you.”) • Never remain in a dangerous situation. Leave and seek help immediately. • Reassure yourself that you did the right thing by standing your ground and looking out for yourself.

3. Build social support and avoid isolation

Many Autistic people find connecting with other like-minded people, the broader Autistic community and others with shared interests very valuable in reducing a sense of isolation. Many Autistic people are wary of non-Autistic-led groups, due to the fear of being misunderstood, labelled or stigmatized. Some Autistic people may say that they feel like they can remove their ‘masks’ around other Autistic people—they may feel seen and understood. It is sometimes referred to as “Autistic oxygen”¹⁶ by some advisers.

“I’ve largely had to build my own support network. I’ve had some government supports on logistics and mental health levels, but limited in a number of ways. I’ve been able to find mental health support from personal connections. I’ve never needed a lot of services; social development has been helpful financially and logistically over the years. Plus, my connections have helped greatly, being a huge networker.”

“When I first got my diagnosis, there wasn’t any group for Autistic adults in my community. While I found this to be discouraging at first, I created my own little circle of support by first creating such a group locally that was social and recreational in nature. Then, I created a support group that is Autistic-led that meets monthly. These opportunities provided others like me a ‘soft place to land’ for the newly diagnosed. For the Autistic adults in my community, it allowed for a place to connect and validate our experiences and to foster Autistic pride.”

Social support can improve self-knowledge and help Autistic people feel more connected with those around them. Accessing this support can be difficult, especially if travelling is hard or if there are no suitable groups nearby. Some Autistic people may find support through online communities. Online interactions can be helpful but can also harmful. It can be a way to connect, but it is important to be safe and know when to disconnect.

Reading books, magazines or blogs by Autistic writers can also be very validating and a good starting point in building social networks. Connecting through video-conferencing can also boost social participation and connectedness with special interest groups, support groups, virtual learning opportunities or individual therapy.

The images below are things to be aware of when building or finding support. **Red flags** (see image below) are attributes or behaviours that people should be careful of. These are qualities to watch out for in relationships and support.



Green flags (see image below) are attributes or behaviours that people should have in relationships. These are the qualities to look for in relationships and support.



4. Become informed

Many people look for formal and informal opportunities to learn more about their diagnosis, mental health and well-being. They find it helpful to learn as much as they can about their situation and how to deal with their challenges, including the causes, signs and ways of helping. The kind of information provided can affect mental health. It is important that Autistic people read explanations about autism that provide accurate and positive information. Negative stereotypes of autism that focus on pathology can foster internalized ableism, which in turn can affect mental health. **The List of Resources at the end of this guide provides a starting point for some self-directed learning for Autistic people, their families and advocates.**

“Using my research skills to become informed in my personal life has helped in moments when I’ve felt more introverted than ever. For example, toward the end of last year I was becoming more withdrawn when I was receiving praise at work from my boss saying I was awesome, because as well as keeping up with getting ready for Christmas (e.g., multiple work Christmas parties, gift making), I was not used to receiving that kind of praise from my supervisor, which did not necessarily include nods specifically to my work skills/projects. So, after initially trying to find out why I was feeling this way, I also looked online over the Christmas holidays for concrete tips on how to nicely receive genuine praise. Now I know that the baseline of simply smiling and saying ‘Thank you, _____’ is a great strategy to use whether or not I’m feeling worthy of that praise in the moment, as it reduces any potential awkwardness for the person who’s giving me the praise and I am graciously receiving it. It’s a win-win for both sides.”

5. Practise Autistic pride

Pride is described as a feeling of being worthy or having pleasure in what a person does or accomplishes. It involves a sense of happiness or confidence about one’s own qualities and characteristics. **Autistic pride** involves an Autistic person feeling proud to be Autistic and celebrating their differences and how Autistic people communicate, experience and understand the world around them (also known as **Autistic culture**¹⁷). It involves having a positive attitude about autism and celebrating these differences.

Every Autistic person is different. However, developing a strong sense of Autistic self-identity and creating a connection with other Autistic friends or acquaintances can be energizing and can lead to hopefulness and belonging. Understanding a person's identity and belonging plays a big role in well-being and self-care.

The idea of practising Autistic pride is expressed through a poem by the late Laura Hershey, a disabled poet, journalist and activist. The poem is called "You Get Proud by Practising" (www.cripcommentary.com/poetry.html#PROUD).

Autistic pride involves an Autistic person feeling proud to be Autistic and celebrating their differences.

Autistic culture is a "shared history, the way autistic people communicate, create, experience and understand the world around us in uniquely Autistic ways."¹⁷

"I think pride is something that one practises, not just experiences. Pride wasn't given to me from the sky. I had to work on it like a skill. If I don't practise it regularly, it is hard to stay proud. Especially when the whole world is constantly gearing up to tell me I am not worthy of pride."

6. Build a self-care plan

Self-care can lead to having more physical and emotional energy to deal with challenges, which can help people in the long term (see Activity 6.9). Being able to soothe, relax and calm oneself involves:

1. knowing what kinds of thoughts and behaviours make you feel better and
2. coming up with a self-care plan that helps you prevent or overcome negative feelings.

Developing a self-care plan can help a person to think about the small steps they can take in their life to have well-being. Imagine what a self-care plan might look like. This plan should address a person's needs in these areas:

- psychological
- emotional
- physical
- social
- spiritual.

The activity on the next page is called the **Biopsychosocial-Spiritual Self-Care Plan**. It can be filled out anytime and used during times of distress or when in good spirits. The point is to be very specific and realistic in the plan, so it can be achieved.

Activity 6.9 – Biopsychosocial-Spiritual Self-Care Plan

Fill out the boxes below with things you can do to exercise self-care. **Remember SMART goals: specific, measurable, achievable, realistic and timely.** It can be hard to set goals, and sometimes we set them too high for ourselves and that is okay. Then we just need to adjust. Below are just some examples of goals you can set:

- “I will go for a walk for 10–20 minutes two times a week.” (Physical)
- “I will go to _____ support group (with or without a friend) once every week.” (Social)
- “I will eat two fruits a day and take a B6 multivitamin.” (Biological)
- “I will message one friend a week.” (Social)
- “I will hug my pet three times a week.” (Emotional)
- “I will say ‘I am doing my best’ to myself if I get stuck on a task.” (Psychological)
- “I will meditate once a week.” (Spiritual)
- “I will write down something I’m grateful for two times a week.” (Spiritual)

Self-Care Plan	
Biological or Physical self-care	Psychological/Emotional self-care
Social self-care	Spiritual self-care

Information sharing, finding supports and self-advocacy

Information sharing

Being able to positively share information about being Autistic with others can be an important component of well-being. Choosing who to share information with and who to seek support from is a personal choice.

Before deciding on who to tell about a diagnosis, it may be helpful to ask the following questions:

1. Who do I feel I should tell?
2. Is this person ready for the discussion?
3. Is this person up for discussing the issues and concerns I have?
4. Is this person consenting for me to talk to them about the issues I'm having?
5. What am I looking for after I disclose?
6. How will I start the discussion? (By email, text, phone, videoconferencing or in person?)
7. What are the potential benefits to me and to the other person?
8. What are the potential risks or negative consequences of my disclosure? (Perhaps this one can be done with a trusted person who will help in recognizing what the potential risks are.)

This decision can differ from person to person. You may want to share information with someone you are close to, but at times, they may not be the right person to talk with. Sometimes the best person to talk to may be someone who is not as close to you or to the situation.

“If you ask someone if they have the time and energy so you can talk to them about ____ and they say yes, chances are they're a decent person to talk to.”

On the next page are some signs to keep in mind to recognize the right person to share information with.

Good Signs	Bad Signs
<ul style="list-style-type: none"> • They make you feel safe and comfortable. • They ask for sources of education or information on autism because they want to learn more about it. • They ask you what you need and how they can support or accommodate that. • They apologize for how they treated you, if they treated you negatively in the past. 	<ul style="list-style-type: none"> • They do not make you feel safe or comfortable. • They say they know what autism is and that they don't need any education on it. • They refuse to learn more about it when you offer. • They refer to autism as a "mental illness." • They say they don't believe you. • They say: "You don't look Autistic" or "You don't seem Autistic."

Even if other people may need to know about a diagnosis, it is important that the Autistic person be able to choose when and how to disclose this information.

Autistic experiences with disclosure

"I used to be wary about disclosing that I'm Autistic. Not so much anymore. I hide it from my family and some others. But, generally, if it's entirely up to me whether or not to have some kind of relationship with someone, then I won't hide it. A large part of the reason for this is that I haven't found it makes a difference in how I'm treated. The ableism I deal with comes from my communication style being a bit 'off' (i.e., different).

"Most people treat me differently than they treat non-Autistics right from the moment they meet me. And the reason saying that I'm Autistic seems to have no effect (good or bad) comes from an issue that anyone with an 'invisible' disability has to deal with: getting people to actually believe them. When I tell someone I'm Autistic, they'll often believe me in the sense that they'll consciously accept that I'm Autistic. But suppose I go into specific detail about what that means by, for example, explaining how my social behaviour is different and how accepting that usually requires they change their behaviour toward me (i.e., to stop trying to understand me by using their non-Autistic social rule book). Then they usually won't believe me and won't make necessary changes to avoid ableist behaviour. They'll tell me that I 'seem normal' or 'don't look Autistic,' demonstrating that, in a strong sense, they don't really accept that I'm Autistic even if they consciously think that they do."

“I have always felt proud of my autism since high school and don't have a problem disclosing it. But before that, I was more shy. I didn't disclose it, it was just something I never really thought about.”

Finding supports

There can be many resources that supply information about local support groups, agencies, clinics or hospitals. It can be hard for Autistic adults to figure out how to access and navigate these resources, if they even do exist—knowing which kind of support is useful and being able to obtain it.

In many parts of the country, there may be little to no supports for Autistic adults. The **List of Resources** at the end of this guide supplies examples of online, local, provincial and national resources as a starting point. Knowing what exists can empower a person to seek support—but **that support should be a good fit for the person.**

Autistic experiences with information-sharing

“I recently applied for a post-secondary program and thought I would, for the first time, register for student services. I thought I would be treated with dignity and respect, but instead it was a nightmare of them wanting family history and many other details that were not relevant to my diagnosis and needs as a student. Knowing what you really are looking for when sharing a diagnosis is important to preparing [for the] possibility of not getting it.”

“Support groups online such as Autistics 4 Autistics and regional Autistic groups can be a big help for Autistic persons with direct problems, as provincial support is limited after the age of 21.”

Self-advocacy

You can think of two kinds of self-advocacy: personal and collective. **Personal self-advocacy** is the process of getting a person's wants and needs met.

This involves letting others know what a person's own needs and wants are. **Collective self-advocacy** is advocating on behalf of one's self and others to improve the conditions and circumstances of a whole group of people. Autistic people should be empowered to take part in all aspects of life, and they have a right to access supports that meet their needs.¹⁸

Personal self-advocacy is the process of getting a person's wants and needs met.

Collective self-advocacy is advocating on behalf of oneself and others like them.

Every adult has the right to choose what to speak out about, what changes they want to make in their lives and what they need to do to bring these changes about. Advocates should have awareness, respect the rights of other people, and consider issues of health and safety. Self-advocacy is not an easy task for some advocates. Some Autistic adults are able to advocate for themselves with or without a partner to help them. Many have had to learn on their own.

If an Autistic person doesn't know where to start with self-advocacy, Kassiane Sibley, an Autistic self-advocate, developed a six-stage plan for successful self-advocacy for Autistic adults. The plan can be found in a chapter called "Help Me Help Myself" in Stephen Shore's book *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*.¹⁹ Part of this plan involves connecting with a partner (a friend, mentor or family member) who is experienced at advocacy or advocating for them.

Advocating when overwhelmed

There are circumstances that cause great stress and can leave a person unable to communicate or organize their thoughts clearly, even if they are usually able to do so. In these situations, it can be helpful to have important information written down. For example, cue cards or phone apps could have phrases like "Don't touch" or "I am Autistic" along with a brief explanation. Contact information can also be placed on cue cards for use in case of emergency.

Autistic rights

Autistic people may grow up with a high degree of oversight and perhaps with caregivers, teachers and professionals telling them what they should be doing. As a result, Autistic people may benefit from being taught that they have intrinsic rights.

Learning how to have these rights respected and upheld is an important life skill and can help boost well-being.

It is important to know that every person has a right to:

- their own body
- their own identity (race, gender, sexuality, culture, etc.)
- their personal space
- respect and validation
- support from health care professionals
- ask for a second opinion
- education about autism and mental health
- information about the latest research and most effective supports or services
- speak to legal representatives.

Autistic experiences with self-advocacy

“My being a self-advocate for myself has been a learning curve. I am very familiar with articulating for myself when it comes to a presentation (e.g., my Autism on the Hill speech in April 2017). However, being a self-advocate for myself at work is much newer to me, and I am learning as I go. I am immensely grateful and lucky that all of my jobs are ones where the people (boss and colleagues) are familiar with disability issues and are proponents for inclusion and meaningful contributions.”

“I started giving talks about autism and being an advocate when I was 18 (18 years ago). When you get up in front of that crowd, your voice is like a sword in your soul. You need to be sure of what you want to say, what your point is and what parts of your truth can be used to get that point across.

“I like to use humour in my talks because I know if I made them laugh, I have their attention—and some of what I have to say will be heavy and hard to hear, so (depending on the talk) I want them to be able to laugh and remember feeling good where I can. And to see that Autistic people, and autism in general, is not all doom and gloom. But above all, your words are like a sword in your soul. You draw your sword only when you’re sure of your strike—because if you aren’t sure, you could wind up cutting something you didn’t mean to.”

“My autism advocacy started in 2007 with Autism Ambassadors and then Inclusion Ambassadors. I have been involved in numerous government and social support groups. NBACL [New Brunswick Association for Community Living] is another. Connect is one of the latest groups to be involved in. Some groups are better suited to Autistics than others. The ones I’ve mentioned have been awesome.”

“Becoming an advocate for my children helped me deal with my own childhood traumas related to growing up Autistic, being misdiagnosed and misunderstood. I knew how to think like my children, and I understood their social difficulties from the inside. Being able to strongly support my children and work for fair and equitable supports and interventions provided me with the beginnings of ASD pride. I wasn’t failing my children the way my parents/teachers/doctors failed me.”

“I have a trans friend who suspected he was Autistic. I attended many appointments with various service providers with him, to advocate and support him as he worked his way through assessment and diagnosis. There were times where having me along really helped the process move, because I was able to reframe the diagnostician's bias, so that my friend was not sent away without answers. Eventually, he was diagnosed by a clinician who was well-versed in assessing people who are not cis male.”

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Autistic Mental Health and Formal Supports

Snapshot

- This section gives brief information about where formal supports can be accessed and what they look like.
- There are different types of supports for Autistic mental health, including but not limited to psychosocial (supports involving others) and medication.
- Mental health supports can be found in different systems of care, such as agencies and hospitals, or from professionals (e.g., psychologists, social workers or psychiatrists).
- There are many types of formal supports, and understanding some of the differences can make it easier to know which support a person may find helpful.
- Medication can be helpful, but it is important to understand the potential side-effects of a medication when making a decision.

Autistic people do better when support is coordinated. This means that everyone working with the Autistic person knows the plan and has a part in it. Instead of getting services separately for each type of challenge, the different types of supports and services work together. If challenges are addressed in this way, people are more likely to experience positive mental health. As mentioned throughout this guide, Autistic people who have mental health challenges are some of the most vulnerable people in society and in our health care system. For many, getting the right supports and services for their individual needs is a long and complex process.

This section briefly talks about where an Autistic person can receive formal supports (these are external supports) and what those supports may look like.

It is important to note that there are people who will not feel comfortable with receiving mental health supports because of past experiences with supports that were dismissive, discriminatory or abusive. In addition, not everyone will be comfortable with, or benefit from, psychosocial supports or medication. Some people feel may want support or feel more comfortable talking to close friends or family members. Financially, some Autistic people who do not receive supports from publicly funded agencies or insurance, or who lack disability welfare, may not be able to afford or access services they need.

Where to go for support?

Autistic advocacy groups may be a good place to start. Those who lead these groups will have insight into the policies of health care and can provide Autistic people with advice or checklists to consider when looking for supports.

While each province and territory in Canada has a different health care and mental health system, there are general structures that are similar and may be familiar. There are many systems to navigate to receive the most helpful resource or support. These systems include but are not limited to: health care, community services, autism-specific organizations, community mental health services and social services. The table below highlights what some of these systems are.

Generally, there are few mental health supports for Autistic people and there is a lot of inconsistency, which leads to a lot of confusion for Autistic people and their family members. Services are often fragmented, which means they are provided separately from each other and may not know what other services are doing. Agencies may also try to give the same supports and approaches as are provided to non-Autistic people, without consideration for autism, and this may not be helpful.

	<p>What type of support is this and what is involved?</p>	<p>What services do they provide?</p>	<p>Who provides the support?</p>
<p>Autism-specific agencies</p>	<ul style="list-style-type: none"> • Gives specific support to Autistic people and to their families. • They may accept self-referrals or referrals from families. • After a first intake assessment, the person will be referred to the most appropriate service. 	<ul style="list-style-type: none"> • Some agencies supply only one or two types of services (e.g., case management, therapy, education programs, social support, etc.). • These agencies may make a referral to a specialized service provider if they think it is needed. • The referrals may be fee-based, which can make the referral ineffective when affordability is an issue. 	<ul style="list-style-type: none"> • Social workers, child youth workers (for under 18), psychotherapists, psychologists, therapy trainees, etc. • Some providers may not have the same training in autism, so the services may not be the same for each agency. • Some providers may not be trained specifically about mental health.
<p>Community mental health agencies</p>	<ul style="list-style-type: none"> • Specific focus on mental health. • Their services may not be uniquely tailored to each person. • Services and supports may also be helpful to other family members. 	<ul style="list-style-type: none"> • These agencies may provide case management, counselling, group therapy, nursing and other kinds of mental health support. • They may also have recreational and vocational programs for people with mental health problems. 	<ul style="list-style-type: none"> • Social workers, child youth workers (for under 18), psychotherapists, psychologists, therapy trainees, etc. There may also be psychiatrists, physicians and nurses connected to community mental health agencies. • Providers may not have expertise in autism. They may be unaware of the approaches that are most effective when working with Autistic people.

<p>Primary care</p>	<ul style="list-style-type: none"> • The day-to-day health care provided by a health care professional. • They can examine a person’s physical health and family history and rule out problems that could be adding to or changing a person’s mood, thinking or behaviour. 	<ul style="list-style-type: none"> • At times, primary care providers can do a mental health assessment, particularly for more common conditions such as depression or anxiety. Sometimes, they will suggest that a person see a psychiatrist or other mental health professional. • A referral from a doctor is almost always needed before a person can see a psychiatrist. Family doctors often have a list of psychiatrists that they make referrals to, but the lists may not include psychiatrists with knowledge about autism. <ul style="list-style-type: none"> • Mental health referrals may vary depending on where you receive them. It can take between a few weeks, six months or a couple of years. 	<ul style="list-style-type: none"> • Primary care providers (e.g., family doctors, nurse practitioners, family health teams) are often the first professionals that people talk to about a mental health problem. • Family doctors often do not have expertise of autism in adulthood. They may be unaware of the approaches that are most effective when working with Autistic patients. • Although family doctors or nurses may not have expertise in autism, they often have expertise and a long-term relationship with the patient, and sometimes the family. <p>Given that understanding mental health problems in autism involves knowing how someone is different than their usual, the doctor can see how things are not the same. Also, they may have a trusting relationship and can connect what is happening in mental health with what is happening in other parts of health.</p>
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<p style="text-align: center;">Hospital emergency departments</p>	<ul style="list-style-type: none"> • An Autistic person can go to the emergency department of a hospital as a last resort. • If the situation does not require immediate medical care, the next step may be a more in-depth assessment from a crisis worker. • Sometimes these visits end up in hospital admissions, and other times care recommendations are made and the person returns home. • The clinical environment in an emergency department holds unique sensory issues for Autistic people, such as bright lighting, high-pitched sounds and random noises, all of which could be triggering and cause stress, adding to the experience of crisis. 	<ul style="list-style-type: none"> • Services are provided for urgent medical attention, such as serious conditions and injuries. • There is access to a wide range of health care specialists and diagnostic equipment. • People do not need a referral to use this service. 	<ul style="list-style-type: none"> • Often a nurse or social worker. • People may also see an emergency medical doctor or psychiatrist. • The emergency room can be an entry into inpatient psychiatric care if a person’s mental health is such that they cannot safely manage back home. Inpatient care settings in a hospital tend to work in partnership with hospital outpatient services with a goal of transferring care and making smooth transitions into the community. • Most hospitals do not have emergency room staff who are educated in the unique ways of communicating that can be a part of autism.
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At all these settings, assessments may be completed to provide a starting point for support.

Assessment

Assessments usually start with a conversation with the health or mental health care provider. Questionnaires are often part of the assessment. The health care provider investigates the reasons for why a person may experience mental health challenges, such as environmental and psychological causes.

The process of identifying mental health challenges:

The following diagram shows a simplified process of identifying mental health challenges; however, the process may differ with every case.



The process begins with meeting a professional, and information is then collected through interviews or activities, including finding out the person's main concerns, their history and symptoms. Sometimes, more information is collected from a person's family or caregiver. From there, professionals review the information and communicate their first impressions.

A **formulation** is the term mental health professionals use to describe their impressions and conclusions that result from an assessment. Sometimes a formulation will include diagnostic labels (i.e., a diagnosis or multiple diagnoses), and other times the formulation will be more descriptive, such as describing the mental health challenge. The formulation is a summary of the entire assessment and is meant to pull all the information together to summarize impressions in a meaningful and helpful way.

What are psychosocial supports?

The term “psychosocial support” can mean a few things. It can mean that it is a type of support that provides help through psychological and social methods. It involves psychological aspects of what the Autistic person is experiencing (e.g., how they feel, how they think and how they act) and the social aspect of support from others. The social aspects of “psychosocial” also acknowledge that an Autistic people’s feelings and behaviours may be influenced by, and related to, how they interact with other people.

The purpose of finding supports is to improve how a person feels and to help them to do things that they enjoy or love in life. It is important to know what types of supports are available to make certain that the right support is accessed.

What are different types of psychosocial supports?

Psychoeducation

Psychoeducation is education about mental health problems. People who know about their problems are better prepared to make informed choices. Psychoeducation is meant to provide information so that Autistic people may be better informed and prepared. Knowledge may help them and their families deal with their problems by increasing understanding of them, and may help people to make plans to prevent future problems. Psychoeducation sessions may include discussions about:

- what causes mental health problems
- the help that can be provided
- how to self-manage the problems (if possible)
- how to prevent future mental health problems
- what resources are available in a community.

Psychotherapy

Psychotherapy is a type of psychosocial support that involves talking to another person, and for this reason it is sometimes called “talk therapy.” It helps people with their problems by looking at how they think, act and interact with others.

Psychotherapy can also be called “counselling.” Counselling is often used when the approach is focused on giving advice or decreasing immediate distress, rather than on helping with deeper change. Although lots of times, psychotherapy and counseling are used interchangeably.

There are many types of psychotherapies. Psychotherapy can be provided as one-on-one support or in a group situation. Sometimes the focus can be on the person, while other times it can be on a family or a couple. Most types of psychotherapy involve:

- one other person who is a professional
- sessions that are personal and private
- a focus on forming a healing type of relationship
- language to communicate (either spoken language, sign language, written language).

Psychotherapy can be either short-term or long-term:

- Short-term therapy has a specific focus and structure: this type of support usually lasts no longer than 10 to 20 sessions.
- In long-term therapy, the process is often less structured.

What are different types of commonly provided psychotherapy?

Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) is based on the theory that thoughts (cognitions) have an important influence on how people behave and feel. There is research indicating that CBT may be helpful for some Autistic people to help with mental health challenges.^{1,2} During CBT sessions, therapists help people notice thoughts (e.g., negative thoughts) and behaviours (e.g., harmful behaviours that result from those negative thoughts) that are unhelpful to the person, and help them to develop healthier ways of thinking and behaving (e.g., healthier skills and habits). In CBT sessions, the Autistic person and therapist may develop and select goals and strategies together. There is an emphasis on practising the skills between sessions.

Trauma-informed therapy

Many psychotherapies focus on a person’s history of trauma. These approaches are often called trauma-informed therapies, which can include trauma-informed CBT as well. Some other types of psychotherapies that are meant to help a person cope with traumatic experiences include:

- Eye movement desensitization and reprocessing (EMDR): an integrated psychotherapy approach using guided eye movements to relieve negative feelings related to traumatic events.
- Emotion-focused therapy (EFT): a therapeutic approach that focuses on increasing emotion awareness, improving emotion regulation and the process of changing one emotion to another.

Dialectical behaviour therapy

Dialectical behaviour therapy (DBT) is a type of cognitive-behavioural therapy. It is used to treat a range of behaviour and emotional problems. In DBT, people learn about how their personal background and life experiences affect how they control their emotions and how they interact with other people. It has been shown to be helpful for some Autistic people.³ DBT combines Western cognitive-behavioural techniques and Eastern Zen philosophies. It teaches several skills that can help with emotion regulation and overall well-being.

These skills include:

- how to become more aware of thoughts and actions (also called “mindfulness”)
- how to tolerate distress and emotional pain
- how to manage emotions
- how to better communicate with others (for Autistic people, the] social-communication aspects can be talked about more openly, and these difficulties are validated)
- how to improve relationships with other people in an Autistic person’s life.

Acceptance and commitment therapy

Acceptance and commitment therapy (ACT) encourages people to be okay with their thoughts and feelings rather than fighting or feeling guilty about them. ACT focuses on developing “psychological flexibility,” which is when a person is aware of, and connected to, their thoughts and feelings, and can stay with or change their behaviours in ways that lead to outcomes that are important (valued) by the person. ACT aims to validate a person’s difficulties and does not judge those difficulties. ACT combines mindfulness skills with self-acceptance. In the case of ACT, people may commit to facing problems head-on rather than avoiding their stresses, in a safe and supportive way. ACT may also aim to help a person understand their personal values by clarifying what is important to them in life.

Family therapy

Family therapy is a form of talk therapy that includes at least one member of a person's family. The therapist helps the family members to communicate and interact in a healthier way together. A family therapist often does this by explaining the perspectives of the family members to each other, to improve the perspective taking of each family member about why the others may say or do certain things. The purpose is often to improve family relationships.

Couples therapy

Couples therapy helps by reducing relationship distress. Romantic relationships can positively influence a person's life experience. However, maintaining a romantic relationship can be hard work that requires supporting and understanding each partner's needs. Couples therapy can be useful in any relationship (e.g., neurodiverse, Autistic or non-Autistic) where there are challenges that may include conflicts or difficulties with connection, intimacy or communication. For some Autistic people in romantic relationships, couples therapy may be useful to improve communication and understanding between romantic partners.^{4,5}

Psychodynamic therapy

Psychodynamic psychotherapy, also referred to as an insight-oriented therapy, is based on the theory that unconscious processes (which a person may not be aware of) influence choices and behaviour. This approach often aims to help people with unresolved issues that are often thought to have been caused by relationship problems in their past or from past traumatic events.

Autistic experiences with psychotherapy

"I've done CBT and talk therapy—both I found helpful. Mostly I need someone to talk at who won't judge and may be able to 'see' the situation from a different angle and offer good, trustworthy advice. I also need someone to 'confess' to; if my thoughts are caught in a loop, if I have nasty intrusive thoughts that disgust me, if I think I've done something super bad, I need to tell someone or it will eat away at my insides until I'm in a panicked spiral."

“I have had early language therapy when I was young, and in high school I’ve had CBT therapy for OCD, which did not help effectively. They tried using thought stopping, which does not work very effectively with people on the spectrum, at least not from my end and experience. What is most helpful, and validating, is talking to other Autistics that have had similar issues and understand your position and point of view. That’s on my angle. My cousin has had, and is having, therapy from a broken-up relationship and it really helps him on those issues. His brother, [who] is also Autistic but is higher support needs, has had speech and other therapy that was not as successful in the speech category and did not progress as much as what family wanted.”

Other forms of psychosocial supports

Various other therapies may focus on a person’s sensory experience and may provide new ways to improve the ability to cope with distress and improve a person’s emotional state. They may also offer creative opportunities to express emotions and involve positive interactions with another person. These therapies are often meant to also build self-esteem or help a person to develop better ways of coping with stress.

Music therapy

Music therapy involves a music therapist who works to build connections between a person’s emotions and the music that is either listened to or created in the music therapy session.

Art therapy

Art therapy involves artistic expression helped by an art therapist. Just like music therapy, it connects feelings to artistic expression through the creation of art while focusing on feelings.

Peer support groups

A peer support group involves a group of people who have similar difficulties. Group members can share their challenges in a safe, supportive environment. Sometimes peer support groups are led by a professional and sometimes they are led by a peer.

Questions to ask when looking to take part in a group

1. Are they Autistic-informed or Autistic-led?
2. Does this group welcome new members?
3. Does the professional or group members respect me?
4. Is the group relevant to my situation, concerns and needs?
5. Are there any requirements for attending this group (e.g., a membership fee)?
6. Is the professional or group respectful and inclusive of members from diverse backgrounds (e.g., a range of cultural, gender, racial, religious and economic backgrounds)?
7. Do the sessions or group offer both support and education?
8. Are the individual or group sessions ongoing or is it time-limited?
9. Does the professional or group have a positive attitude toward professional help for families?
10. Who helps the session or group, and how is the group process managed?

Animal or pet therapy

Animal-assisted therapy incorporates the use of animals, such as dogs or horses, to help people cope with mental health difficulties (e.g., anxiety, depression). Animals may provide comfort or alert if a person is in danger. The type of animal therapy can vary depending on what the person's challenges are.

“If one treatment doesn't work for you, you *haven't* failed, it's just not a good fit. Try another, and another one. In the end, you may find something that works for you. But if not, *don't* think you are too broken, when it's the failure of the system to properly support you, not your failure.”

Finding a good support person or therapist

Successful therapy can depend on having a supportive, comfortable relationship with a trusted support person or therapist. Many different kinds of professionals can be therapists, including doctors, social workers, psychologists or others. Therapists can be trained in different types of psychotherapy. They may work in hospitals, clinics or private practice.

Below are some things to consider before choosing a therapist:

- The personal aspect of feeling connected with that person. As one adviser said: “It's okay if you don't like them, you can find another therapist.”
- Trust your gut when deciding if you like your therapist or not. If you feel bad whenever you are around them and you don't know why, it may not be the right place for you.

For some Autistic adults, it may be important that the therapist has experience with autism. It is okay to ask the person if they do. Finding a therapist with expertise or specialization in autism may help to avoid experiences that are not helpful.

Advisers outlined the following things to look for and things to watch out for when seeking a good support person or therapist:

Things to look for	Things to watch out for
<ul style="list-style-type: none"> • They ask for consent. • Really listens to what you say, even when they disagree. • Willing to listen and work with your needs/wants. • Open-mindedness and willingness to learn you. • Focuses on understanding why you act/feel the way you do. • Gets your input about why you act/feel the way you do. • Accepts your Autistic traits (such as stimming, echolalia, lack of eye contact, sensory needs): <ul style="list-style-type: none"> • Doesn't try to reduce or get rid of your Autistic traits. • Doesn't interpret Autistic traits as symptoms of some underlying condition. • Gives all relevant information so you can make informed decisions rather than making decisions for you. • Understands the difference between a meltdown and a tantrum (if applicable). • Looks for different ways to communicate, that work for you (if applicable). • Respects your rights a person and your identity. • Is honest. • Is patient. • Focuses on emotional well-being. • Sets good boundaries. 	<ul style="list-style-type: none"> • Is dismissive of things you say when they disagree. • Is not interested in why you act/feel the way you do. • Ignores your input about why you act/feel the way you do. • Pathologizes Autistic traits (such as stimming, echolalia, lack of eye contact, sensory needs). • Tries to reduce or get rid of Autistic traits. • Interprets Autistic traits as symptoms of some underlying condition. • Withholds information to get you to make decisions that they think are in your in best interest. • Doesn't understand the difference between a meltdown and a tantrum (if applicable). • Insists that speech is the only acceptable way to communicate (if applicable). • Focuses on weaknesses. • Expects you to be able to advocate for your needs when you are not able to. • Puts you down. • Doubts your autism diagnosis. • Is unwilling to accommodate or be flexible to autism-related challenges.

Autistic experiences with psychosocial supports

“I have had mostly bad experiences with psychosocial supports, largely due to the fact that about half of these were provided at a gender clinic, which I found very unpleasant for many reasons. I urgently wanted hormone therapy, but it took me years before he gave me a referral. Any benefits the talk therapy could have given were outweighed by the lack of autonomy I experienced and the stress of not knowing when or if I would get the treatment I actually sought.

“This bad experience coloured future interactions with psychosocial professionals—I would say trauma caused by bad experiences is one of the most prevalent problems clients of these services face.”

“I have not used or needed to try psychosocial supports since I graduated high school. However, my middle sister currently does an online dance therapy class twice a week that is conducted by a therapist we had when we were younger. Tips that I can provide [are]: Be honest with yourself when deciding whether the psychosocial support you are currently using is working for you or not. If it’s not, move onto something else; but if it is, stick with it. Also, ask the social networks that you do have to help you find psychosocial supports that you can access and can try (e.g., try to find ones that are in your local community). Doing your own research on the subject would also help, too.”

“My baseline question nowadays for anyone that I am seeking help from is if they have an actual working familiarity with autism and Autistic people. I have been given bad therapists, bad medications and bad supports that have harmed me and made me feel as though—even when I am actively seeking help—I am still failing or doing something wrong. I have been labelled ‘non-compliant’ for not being able to do what has been recommended for me to do, even though they are causing me harm. These days, I tend to grill care providers ahead of time to ensure that I will receive quality care, but this also yields suboptimal results because it tends to put people on the defensive, even though I am just trying to make sure that they are even able to help me before I make myself vulnerable to them.”

Considering medication as mental health support

Medication can be an important part of mental health support. In many cases, medication may be helpful if it is combined with some psychosocial support or community care (see **Section 6**).

Caution: Always consult with a qualified medical professional if you would like to know more about medications, including those mentioned here.

Medications for mental health problems

When a person experiences a mental health problem (e.g., a mood disorder, an anxiety disorder, schizophrenia), medication may be one part of an overall support plan. Medications that affect how the brain works and lead to changes in emotions, thoughts, feelings or behaviour are known as “psychotropic medications.” These kinds of medications mainly aim to adjust chemicals in the brain to reduce symptoms. This can help to reduce the frequency or severity of difficulties. There are some common types of medications, which are divided up based on the problems that they were originally developed to treat:

Antidepressants

Antidepressants were originally used to treat depression, but they are used for lots of other reasons, such as chronic pain, bulimia, premenstrual dysphoric disorder, chronic fatigue syndrome and anxiety disorders. In fact, antidepressants, especially the kind known as selective serotonin reuptake inhibitors (SSRIs), such as Prozac, are used more often to treat anxiety problems than are traditional anti-anxiety medications, like Valium.

Mood stabilizers

Mood stabilizers are used to help control mood swings (extreme highs and lows) often connected to bipolar disorder, and to prevent further episodes of this condition. Lithium was the first mood stabilizer and is still considered a useful medication. Other medications used to stabilize mood include anticonvulsants, which were originally developed to treat epilepsy as diazepam (Valium) and lorazepam (Ativan). While they are legitimate medications for treating anxiety and sleep disorders, they can become

extremely addictive if used daily for more than four weeks. An anti-anxiety medication that can be used for a longer period of time is buspirone (BuSpar).

Anti-anxiety medications/sedatives

The main group of medications of this kind consist of benzodiazepines, such as diazepam (Valium) and lorazepam (Ativan). While they are legitimate medications for treating anxiety and sleep disorders, they can become extremely addictive if used daily for more than four weeks. An anti-anxiety medication that can be used for a longer period of time is buspirone (BuSpar).

Antipsychotics

Antipsychotic medications often aim to reduce the effect of dopamine (a chemical) in the brain. They are traditionally used to treat schizophrenia and other psychotic disorders. The newer antipsychotics are now also being used as mood stabilizers, as anti-anxiety medication and as a medication for depression.

Stimulants

Stimulant medication increases the activity of different neurotransmitters in the brain, such as dopamine and norepinephrine. They are often prescribed to increase a person's ability to focus and concentrate and reduce hyperactivity, which is when a person can find themselves being overly active and impulsive. Common stimulant medication includes Adderall, Concerta and Ritalin.

Medications for symptom management

Using medication for mental health problems for Autistic people can be complex. Most of the research that has been done on medications for mental health problems has been done with non-Autistic people.

Improvements vary from person to person. Finding the best medication for each person should be done carefully and in consultation with a medical professional or team. It is important to know what each medication is targeting and what the problem looked like before starting a medication, to see how the problem improves with medication. **Autistic people should be involved in the decision-making process and be given information about the benefits and risks, including the side-effects of medications.** It is important to be aware that medications can interact with one another; ask the doctor about this to prevent problems.

There are a number of useful questions to ask a prescribing doctor about medications:

Questions to ask a doctor about psychotropic medication

1. What is the name of the medication, how does it work and what is it supposed to do?
2. How and when is it taken, and when should a person stop taking it?
3. What food, drinks or other medications should be avoided while taking the prescribed medication?
4. Should the medication be taken with food or on an empty stomach?
5. Is it safe to drink alcohol or use recreational drugs (e.g., cannabis) while on this medication?
6. What are the side-effects, and what should be done if they occur?
7. Have all areas been considered, such as nutrition, sleep, hormones, other medication?
8. Where is information about this medication available?

Identifying and minimizing side-effects

It is important to understand that almost all medications have the potential for side-effects. Not everyone experiences side-effects, or to the same degree, and there are often practical solutions to dealing with them. Sometimes side-effects can be a problem when an Autistic person is taking different medications at the same time. Sometimes side-effects can happen when the medication dose is too high for them, and lower doses may be just as helpful and have fewer side-effects.

It is important to pay attention to side-effects because they can lead to more distress or more problems, and an Autistic person needs to be able to share their experiences with the medical team. Careful monitoring is essential, especially when the person taking the medication cannot communicate their experience with the medication and report side-effects. Along with having a support team (i.e., a group of people who can supply support: family, doctor, pharmacist,

therapist, friend, etc.), it can be helpful to note potential side-effects of each medication and figure out ways to watch for them.

Side-effects may increase or decrease over time and can range from mild discomfort to problems that are severe enough to make it impossible to cope with day-to-day life. People often stop taking medication because of unpleasant side-effects without reporting them to anyone. **It can be dangerous to stop or change medication without consulting a health care professional.**

A support team can suggest ways to minimize side-effects. Strategies include:

- taking the medication in smaller doses spread over the day
- taking medication with food
- taking another medication to treat specific side-effects
- changing the time of day that the medication is taken
- changing the medication.

It is sometimes surprising how much of a difference even a very small adjustment can make in how someone responds to medication or in how a person is affected by side-effects. For example, while a higher dose may be needed at certain times (e.g., if symptoms of anxiety are worse because of a prolonged stressor), a person may at different times be able to have the same relief from their symptoms at a lower dose. How much medication a person takes may also need to be changed over time.

Some Autistic people may not feel listened to by their doctors or may feel that their doctors are not being upfront about medication side-effects or that they are downplaying them. Some Autistic people may be concerned that a doctor will be upset if a patient decides not to try a medication that was recommended or decides not to continue on a medication. An Autistic person may benefit from taking someone (e.g., a relative, friend or mentor) with them to doctor appointments, to ask questions about medications and their side-effects.

Autistic experiences with medication

“Antidepressants helped me ‘tread water’ emotionally when I was at my lowest points, but I certainly do not see them as adequate permanent solutions for me. A band-aid doesn't heal the root cause of a wound.”

“I have been on Abilify, which I found did not help at all. I have been on venlafaxine, which might have helped initially, but eventually I felt like I was as depressed as before. Alarmed by the possibility that I might be developing a tolerance, and that this might make my depression worse in the long term, I talked to my psychiatrist about gradually going off it. He did not support this, and meetings with him were few and far between. So, I took things into my own hands and went off ‘cold turkey,’ against the advice of everybody who cared to give it. I was very sick for about a month, but I was not busy at this time, so I could suffer through it without real loss. At the end of it, I actually felt much better. I am not sure whether this was a chemical effect per se or due to the pride of having gone off a drug notoriously difficult to get off. I wished I had known when I first agreed to take it just how difficult it is to get off a drug like that.”

“I have been on Zoloft for over 10 years. Generally, it has really helped. I take it every day. When I was younger, a psychiatrist I had seen said he wanted to put me on a low dose of an antipsychotic medication along with the 200 mg of Zoloft. It was very effective for a while, but neurological side-effect symptoms which I was warned could be permanent started, even if being small at first. The risk of being on a certain drug of high power such as an antipsychotic medication was a risk I should have been told about from the get-go, but that was a long time ago. A list of side-effects is always helpful to watch for. No matter how small.”

Medication interactions

Medications are used to treat different problems and they may work differently when combined with each other, so it's important that the person who prescribes the medication has a complete list of medications that a person is taking. A medication interaction is when one medication changes the action or effects of another medication. Some interactions may have minor effects, while other ones can be dangerous and even life-threatening.

When medications are taken together, they may:

- Act independently of one another.
 - For example, alcohol does not seem to interfere with the action of vitamins or oral contraceptives, or vice versa.
- Increase each other's effects.
 - This could happen because each medication affects the same brain system or because one drug changes the concentration of the other in the body. For example, alcohol and antihistamines are both central nervous system “depressants.” If taken together they can increase the effect of the depressant, which can be dangerous.
- Decrease each other's intended effects.
 - This could happen when one medication “blocks” or prevents the effect of the other medication. It could also happen when two drugs have opposite effects on the brain.

Monitoring medication

It is important to make sure that an Autistic person and/or their family member or trusted person knows the name and dose of each medication they are taking and why it has been prescribed. The easiest way to do this is to get a printout from a local pharmacy that lists current and past prescriptions. This information should be stored in an accessible place in case there is an emergency or a visit to a doctor who does not have a current medication list on file. Here are some things to consider when monitoring medications (see Activity 7.1):

- Rank symptoms of the problem on a scale of 1 to 10 (where 1 is “no improvement” and 10 is “a lot of improvement”) and report any improvement.
- Track emotions and behaviours in a journal to figure out if a medication is working (e.g., what happened when a certain dosage was changed?).
- Note side-effects and discuss them with a support team.
- Check with a doctor and/or pharmacist for medication interactions before taking any new medication (prescription or over the counter).
- Input is important when making medication changes. Report on how the change is going: Are symptoms worse? Are side-effects better?
- It is also important to review medications every so often, and it is okay to ask your health professional to review them with you.

Activity 7.1 – Medication and Side-Effect Tracking

This sheet can be used to monitor medication and side-effects.

Date	Medication	Dose	Symptom	Symptom improvement (rate from 1-10)	Side-effects

At times, it may be impossible to know how much of a change is due to a change in a person's life situation and how much is due to a medication. If there are significant life events or changes in an Autistic person's routine or living situation, consider pausing any changes to medication.

Ongoing medication

In some situations, medication will be short-term, as in the case of a sleeping pill for temporary difficulty with sleeping. For an episode of depression, medication could be longer term. For schizophrenia, the period of medication could be indefinite to prevent symptoms from returning. Some mental health problems are lifelong, so support with medications may be ongoing. Others are temporary, so it is important to examine whether the medication should be continued by having regular medication follow-up appointments.

When medications are not working

It is important to give feedback to a support team or health professional about how well medication is working. Any time a new medication is prescribed, it is a good idea to schedule a follow-up meeting to consider whether the medication change is working.

Some Autistic people with mental health challenges may be prescribed medications without proper monitoring and follow-up. Some medications require regular monitoring for side-effects (e.g., regular blood work to monitor the effects of antipsychotics on the body). Once medications are prescribed, a regular review of current medications, their effects, side-effects and the need for each should be undertaken (e.g., as part of an annual medical check-up or more regularly if mental health symptoms are not adequately treated).

Stopping medication

Autistic people and their families can feel uncertain about long-term medication use. They may want to stop their medication because they:

- experience unpleasant side-effects
- feel well and no longer see the need to take medications
- get messages from others that medications are harmful and not necessary
- have concerns about medication interactions.

Stopping medication should be supervised by a qualified health professional. Stopping or changing medication should be done carefully; usually a gradual approach is important rather than a sudden stop.

Medication can be an important part of support for Autistic people with mental health challenges, but finding the most effective medication, or combination of medications, can be a long, frustrating process. It can be helpful to learn about the benefits and risks of the medication and to talk to support persons or your doctor about how the medication is working and its side-effects. Making sure that the medication and dosage are reviewed regularly is also helpful. It is also okay to ask for a second opinion.

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Navigating Crises, Emergencies and Pandemics

Snapshot

- Autistic people are at an increased risk of mental health problems, self-injury and suicide.
- Crisis, emergencies and times of uncertainty are experienced differently by each person, and the mental health effects of these events can be long-lasting.
- During a crisis, it is important to ask, “Whose crisis is it?”
- Having a plan of action for times of crisis and uncertainty may help to reduce anxiety associated with the event.
- Creating Mental Health Safety Plans and Crisis Cards can help Autistic people during a crisis.

Content warning: Parts of this section contain detailed discussion about crisis, suicide, emergencies and pandemics, including triggers and symptoms. Reading about these things could be triggering for some people.

Autistic people are at an increased risk of experiencing a mental health crisis. This is influenced by social, psychological and biological factors (see **Section 5**).

Following are some things that could play a part in complicating mental health crisis and which can increase the likelihood of traumatic outcomes:

- Mental health professionals may not be sufficiently trained in understanding autism, which can lead to experiences with services that are not able to adapt support to Autistic people.
- In many places, there are a lack of appropriate services and supports available for Autistic adults, which can make accessing help in a timely manner very difficult.

- There is a lack of appropriate validated assessments to identify mental health problems, such as depression and suicidality in Autistic adults.
- The emergency room department can be a triggering environment for Autistic people who have sensory sensitivities to bright lights, high-pitched sounds, constant noise and/or touch during examination. Additionally, insufficient time to process the information provided by health care providers can place added stress.
- Due to social-communication differences, non-Autistic people may have difficulty understanding the concerns expressed by Autistic adults.

Without practical crisis plans and supports, Autistic adults may develop even more complex support needs. This can negatively affect Autistic adults' experiences with daily challenges and may increase the intensity of the crisis and the number of supports they need.

Understanding crises

Crisis

The term “**crisis**” may mean different things to different people and it can depend on who is experiencing it, how they understand the causes of it, their environments and other circumstances. That is why it is said to be subjective. A crisis is when a person experiences a disruptive event or situation with a level of difficulty that goes beyond their current resources or coping mechanisms, and there is distress. Crisis makes doing everyday activities even more challenging. A crisis may occur with little or no warning.

Crisis is when a person experiences a disruptive event or situation with a level of difficulty that goes beyond their current resources or coping mechanisms, and there is distress.

Crisis looks like a drastic change in behaviour that is alarming to the individual or at least for the person who is seeing it in someone else (e.g., someone suddenly becoming very withdrawn or springing into distressing actions such as wanting to run from the setting they are in while still angry or upset). The spectrum of crisis reactions can range from becoming withdrawn and wanting to leave the situation, to wanting to act out and becoming physical (e.g., punching an object/a person).

In **Section 6**, this guide suggests using the Brief Distress Scale activity to understand whether a person is in crisis and whether action is needed. This activity can also be used to check when distress starts to become a crisis.

Mental health crisis

The term “**mental health crisis**” is also known as a psychiatric emergency. According to the American Psychiatric Association, a mental health crisis has two key factors:

1. A critical mental health event that requires immediate intervention.
2. The lack of perceived or available resources to manage the event.

Sometimes crises happen suddenly. An event may occur that triggers a person beyond their usual coping, and they are at such a point of distress that they are in an emergency situation. Other times, issues can unfold slowly and may build up to a point where the person feels that they cannot ignore it or take it anymore. Sometimes:

- A sudden change in daily routine triggers a crisis that escalates into an emergency.
- There is nothing that can be done to prevent a crisis.
- Other people can prevent or trigger a crisis.

The perception of a situation may vary; one person may think that a situation is a crisis that needs immediate action, while someone else may not. There can be times that an Autistic person may feel they are in crisis but that those around them, like professionals or family members, don't see it. Other times, a mental health care provider or family member may feel that there is a crisis, while an Autistic person is not as concerned.

In these situations, it is important to ask, “**Whose crisis is it?**” The answer will help with understanding who is asking for support: the person, their family member, other caregivers or all of them?

Outside help may be needed. This can come from the person's doctor or therapist, a mobile crisis service or crisis line, or other emergency supports.

During a crisis

When an Autistic person experiences a crisis, people should:

- try to be calm and supportive
- keep verbal communication to a minimum
- ask if they wish to talk to their support network and offer to call a contact for them

- if they have a Mental Health Safety Plan (see below), offer to contact a person on this plan, like a doctor, support worker, case manager or whoever else has been identified.

Following through on these suggestions may help to prevent a crisis from becoming an emergency. However, sometimes an emergency cannot be avoided.

Autistic experiences with crisis

“When experiencing a crisis, I like to go to a private space and be able to write out what I’m feeling. That has always helped me when negative feelings are outweighing positive feelings in the moment, and I have mentioned earlier in my personal experience for the guide that living in this time of pandemic has shown me how cathartic concrete writing can be for me.”

“When I’ve been extremely distressed (this has been rare), I would get extremely withdrawn, want to flee the scene and feel ashamed that I didn’t pick up the warning signs leading to the situation. One example was when I received unwanted attention at a party I was at during the beginning of this year.”

“A crisis looks like I am inert. I often cannot move and may need physical prompting to do so. I am overwhelmed by simple, ordinary demands and move very, very slowly. Negative thoughts take over, and executive skills fall apart. Anything I do takes several times longer than it should, if I can attempt it at all. I do try, because I want to feel better. When experiencing a crisis, I want people to be mindful of my dignity first and foremost. I am a private person, and to cry in front of people is mortifying for me. I do not want people to overreact. I do not want anyone to touch me. I cannot hug anyone when I am anxious, so in crisis it is not an option. Simple, directive statements telling me/reminding me what I can do to feel better help. For example, ‘Let’s go for a walk together,’ ‘Let’s go to a quieter room’ and ‘I am here when you want to talk.’”

“The primary issue is lack of social connections. When my loneliness, and the depression and anxiety that come from that, is sufficiently bad, then I might be in crisis. A necessary, and often absent, support need is support from friends. I tend to be socially isolated because people keep me at arm’s length . . . As a result, I occasionally become preoccupied with thoughts of suicide and get so anxious and depressed that it is very difficult, if not impossible, to take care of my daily tasks or responsibilities.”

“A crisis for me happens when there are too many challenges for me to face, both in my personal life and my environment, and too much is expected of me. I am overworked and bombarded with information and stress. There is so much that is dependent on me functioning and fixing my problems that I reach an escalated state where I can’t turn off my brain or process information. I can’t fix or problem-solve the challenges that I am facing because I am completely overwhelmed by the pressure and outside stimulus.”

Emergency

A mental health emergency is a situation that involves an immediate danger that a person will harm either themselves or someone else.

Examples of emergencies include:

- threats of suicide
- threats of physical violence
- extremely impaired judgment
- inability to care for oneself (e.g., eating, grooming)
- serious physical injury or illness.

Individuals seeking emergency care services can face many challenges. Possible experiences include decreased ability or complete inability to communicate, sensory sensitivity related to the hospital setting, and difficulties with high-intensity situations and environments. Other experiences include inappropriate care, such as long waits for help, restraints, staff showing insufficient knowledge of autism and the needs of the Autistic person being ignored. These are some of the reasons why many Autistic people may hesitate to contact 9-1-1 during their crisis.

If a crisis becomes an emergency

If a person threatens to harm themselves or others, it is important to try to de-escalate the situation. Below are verbal and non-verbal behaviours that can be used to help.

Behaviours that can be useful during a crisis	
Verbal	<ul style="list-style-type: none"> • Give your undivided attention – Ensure that the person feels validated and important by paying attention to them. Do not passively listen, really pay attention. Try to understand what they are experiencing. • Be non-judgmental – Be empathic and do not criticize a person’s actions, reasons or how they respond to questions. • Focus on feelings – Allow the person to express their feelings by creating a safe space for them to share. Example of a probing statement: “That must feel pretty scary/hard.” • Allow silence – Avoid the need to fill in silence in crisis situations. If a person doesn’t respond at once, give them time to process the question or think about their answers. Perhaps they just need a person to be with them. • Ask what they need – Ask the person in crisis what they need to make things better in the moment. When they do not know, they may know what would not be helpful, so you can ask that, too.
Non-verbal	<ul style="list-style-type: none"> • Respect personal space – Provide the space people need to feel comfortable; this can vary from person to person. It is important to respect a person’s need for personal space, especially in a crisis. Do not touch them, but if you have to, always ask consent. • Be aware of your body language – It is important to be aware of your posture, facial expressions or gestures that may appear defensive or threatening (e.g., shaking a finger, putting hands on hips, rolling eyes).

Supporting Autistic people in crisis

Being prepared can help prevent a situation from developing into a crisis and ease a person's pain and anxiety if a crisis does occur. Having a support team in place is good.

This support team can involve any services and trusted people that are identified as potentially helpful, including a person from a social network. This could be a family member or a friend. Have their phone numbers or other contact information on hand, and make sure that they have agreed to be part of the team and they

understand in advance the helpful ways to respond in terms of their actions and demeanour. There are many ways to prepare for a crisis, such as developing a **Mental Health Safety Plan** or preparing **Crisis Cards**.

Creating a Mental Health Safety Plan

A Mental Health Safety Plan can be helpful in times of crisis. It's a tool that can be used to promote safe practices during a crisis and help the person experiencing the crisis to better cope.

The following guidelines, adapted from Dr. Cassidy, University of Nottingham, can help create an action plan tailored to a person's needs in a crisis. This plan can be completed alone or with help from a support team.

Guidelines to filling out a Mental Health Safety Plan	
<p>Step 1 Know the warning signs of a crisis</p>	<ul style="list-style-type: none"> • What are thoughts, images, moods, situations or behaviours that might show that a crisis might be developing or that you're not doing so well? • Try to list at least one.
<p>Step 2 Identify activities you can do by yourself to help take your mind off things</p>	<ul style="list-style-type: none"> • What are three activities you can do by yourself to try to take your mind off things without talking to someone else? • If you can't list three, start with one.
<p>Step 3 Think of who you can reach out to or places you can go to help take your mind off things</p>	<ul style="list-style-type: none"> • Try to identify at least two people you can call or reach out to, or two places you can go, without yet asking for help. This is to try to distract yourself from the crisis growing bigger and trying to decrease it. • Write down their names, their relationship to you, their phone number and the address of a safe place, so that you always have it handy.
<p>Step 4 List, in order, the names and numbers of who you can contact in a crisis to ask for help</p>	<ul style="list-style-type: none"> • Who's the first person you would contact who can help to get you through a crisis? • Who else can you think of? Write their number down in case you need to contact them. • If you can't think of anyone, list any number or contact information you may have from an advocacy or peer support group. • Call a suicide prevention and support line. In Canada, you can call 1-833456-4566 for Crisis Services Canada or you can text the Crisis Text Line "HOME" to 686868 any time for any type of crisis. They are available 24/7. • As a last resort, dial 9-1-1 or your emergency line.

<p style="text-align: center;">Step 5</p> <p style="text-align: center;">Identify the things that supportive people can do to help you stay safe</p>	<ul style="list-style-type: none"> • What can your support team do to help you stay safe? <ul style="list-style-type: none"> · Are there any weapons in the home? Can they lock them up? What about things like rope? Can they help you get rid of it? · Medicine—can they lock it up or can someone be in charge of giving it to you every day?
<p style="text-align: center;">Step 6</p> <p style="text-align: center;">Identify how others can support you personally when you are in a crisis</p>	<ul style="list-style-type: none"> • What are some ways that others can help you while you are in a crisis? • How do you want others to communicate with you? (e.g., speaking softly, visual supports, etc.) • What will trigger you more (e.g., loud noises, being touched)? • Who do you want them to contact?

The following is a sample sheet that can be used to create a personal Mental Health Safety Plan, considering these 6 steps. Consider how the crisis plan can be shared with other people (family members, friends, emergency or hospital staff, etc.).

(Insert Name) _____'s Mental Health Safety Plan^a

Warning signs

1. _____

2. _____

3. _____

Activities I can do by myself to try and take my mind off things

1. _____

2. _____

3. _____

People and places to help take my mind off thing

People I can go to:

1. Name: _____
Relationship: _____
Number: _____

2. Name: _____
Relationship: _____
Number: _____

Places I can go:

1. _____
2. _____
3. _____

People I can contact for help when I'm in a crisis

Name #1: _____
Relationship #1: _____
Phone Number #1: _____

Name #2: _____
Relationship #2: _____
Phone Number #2: _____

Name #3: _____
Relationship #3: _____
Phone Number #3: _____

Ways that supportive people can help me stay safe

1. _____

2. _____

3. _____

How can other people help support me?

1. _____

2. _____

3. _____

^a The original version of the Autism Adapted Safety Plan was developed by Dr. Sarah Cassidy, University of Nottingham, UK. It is available free to download at <https://sites.google.com/view/mentalhealthinautism/resources/safety-plan>.

Crisis Cards

Some Autistic people and their family members have found it very helpful to write important information on a card or a piece of paper folded small enough to be carried with them wherever they go. The paper may be placed in a visible part of the person's wallet, or they can take photos of it on their phone.

A Crisis Card usually has important information for others (e.g., friends, health care workers, strangers) to be aware of if the Autistic person experiences a mental health crisis while away from home. The card can have information such as:

- important phone numbers: who to call in a crisis or an emergency, including who to call first and who to call as a back-up
- their mental health care provider
- their family doctor
- the centre/agency at which they currently receive or have previously received inpatient or outpatient care
- a list of current medications, the proper dosage for each and when they are to be taken (it may be helpful to include the name and phone number of the pharmacy where the prescriptions are usually filled)
- a list of medications to which they are allergic
- any medications used in the past that did not work or that were not taken due to side-effects (list such medications in one column and list side-effects in a second column)
- tips for effectively communicating with the person and working with them when they are in crisis (communication cards; topics of interest to them for either engagement or distraction; comforting foods; self-calming activities like stimming, music or fidget toys).

MyHealth Passport, developed by the Good 2 Go transition program at the Hospital for Sick Children, is an online interactive tool that organizes information into a wallet-sized card that can be downloaded and printed. Different types of passports can be created, such as one for mental health or autism.

There are other tools available online, such as the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit. AASPIRE is a community of academic and Autistic people who conduct research that aims to improve the lives of Autistic people. This Healthcare toolkit has forms and worksheets that may be helpful as a person navigates through the health care system, such as a Symptoms Worksheet and an Autism Healthcare Accommodations Tool.

Suicide

One of the most terrifying aspects of a serious mental health episode can be hearing a person talk about suicide. Any talk, even joking, about suicide *must* be taken seriously.

Suicidal thinking or attempts typically occur during a severe mental health episode when the person feels helpless and hopeless and is in a state of despair. Although the feelings are often temporary, at the time the person may not believe that the feelings of hopelessness and helplessness will pass. It can be helpful to acknowledge a person's feelings while offering to help them find other solutions.

Lack of support for Autistic adults is related to an increased risk of depression and suicidality.¹ Autistic adults also report having more unmet needs than non-Autistic adults,¹ and Autistic people face challenges in accessing appropriate mental health supports, especially when in crisis.² Although they face higher risk of suicidality, they are less likely to access mental health supports.

Warning signs of suicide

There are several warning signs that a person is considering suicide. They may:

- discuss suicide and what it would be like to have things end
- be concerned with providing for children, other family members or pets
- give away possessions unexpectedly
- prefer to stay home and isolate more than usual
- express feelings of worthlessness, such as “I’m no good to anybody”
- feel hopeless about the future, reflected in comments such as “What’s the use?” that are expressed repeatedly
- talk about voices that tell them to do something dangerous.

What to do if you find someone during or after a suicide attempt

- Dial 9-1-1 or your emergency line immediately (the number varies from place to place).
- If you know first aid and are comfortable providing it, administer it immediately.
- Get someone to go with them to the hospital or to stay with you at home.
- Do not try to handle the emergency alone: contact a support group to help you with your immediate reactions and long-term feelings.

The impact of a pandemic on Autistic adults

While this guide was being written, the COVID-19 pandemic happened. As a result, society and how people live their lives were changed abruptly. The uncertainty, fear and changes were felt worldwide, and the pandemic experience was wide-ranging, in some cases isolating people and causing a disruption to their regular routines. Autistic people were affected physically, economically, socially and psychologically.

Physical

There are some Autistic people who have physical disabilities and chronic illnesses and medical conditions. Even in the best of times, Autistic people often struggle to access appropriate health care. All these factors may increase risk of illness if the Autistic person gets COVID-19. Another consequence of the pandemic is that health care has been harder to access and some people are frightened to use health care when needed because of fears of getting COVID-19; this means that health conditions can get worse or remain untreated.

Economical

Many Autistic people are particularly vulnerable to the pandemic's economic effects, with so many people already experiencing underemployment and unemployment prior to COVID-19. The pandemic puts them at a further disadvantage in society because they may not be able to keep paying for rent or be able to buy food as part of their health.

Social

Some Autistic people may feel more stressed about the changes to their daily routines caused by the pandemic (e.g., work changes or job loss, loss of outside activities such as networking or socializing).

Prior to the pandemic, access to social and formal supports were limited for Autistic people. With the physical distancing measures that have been put in place to reduce the spread of COVID-19, in-person supports are even harder to access. Additionally, information surrounding the pandemic and the related policy and political events not being written in plain language makes it difficult for some Autistic adults to feel well-informed.

Some Autistic people may feel relief from the usual social stressors they would normally face, and which have been removed because of COVID-19, such as in-person social events, school, work and appointments. However, many Autistic adults struggle with new social interaction difficulties directly related to the pandemic, such as being unable to read faces because of face masks and having difficulty with the back-and-forth flow of social interaction during video calls.

Psychological

If an Autistic person was already likely to experience low positive mental health and more likely than the general population to experience crisis, the mental health consequences of a pandemic can be devastating. Autistic people often face loneliness and social isolation, so losing access to their support network during the pandemic could have a serious effect on their overall mental health. Experiencing a pandemic may be associated with anxiety, depression and posttraumatic stress.

Lessons from the COVID-19 pandemic

The effect of the pandemic is likely very significant for many Autistic people. Stress because of unexpected change and uncertainty, high risk of vulnerability, and health problems could all be magnified. It is important to identify the lessons the pandemic has provided for society and use what we've learned to inform future practices.

1. We need to remember that all people are essential, and that the government should not discriminate against Autistic people and disabled people. People can ensure that the suggestions and policies during a pandemic are truly inclusive.
2. We need to create credible resources and tools that are informed by the Autistic community and the disability-rights community, and make sure that we are using a lens of accommodation. Autistic people need to be consulted in the development of pandemic-specific tips and tools offered to the Autistic community, and for adults specifically. For example, autism-tailored information and advice, and tips for accessing existing resources.
3. Autistic people need continued support, whether online or in person. Many Autistic people who did not need regular support before the pandemic report needing it now, but they do not know how to access the right services.³ When offering online support, do not assume that everyone's socioeconomic status, communication, technology access or family are the same. For instance, some Autistic people may not have access to technology or to private space, or they may experience anxiety on voice or video calls. Phone support may be difficult or impossible for some Autistic adults who may want to see the faces of those speaking to help them interpret intent of communication. Offer different, creative and inclusive resources or solutions for those who need more support.
4. It would be positive if, because of the pandemic, people come together and become more accommodating in general. For example, some Autistic people have reported receiving crucial support from within the Autistic community as they share their experiences and resources (e.g., community care).³ Others have reported that the pandemic brought a sense of autism acceptance, and that accommodations that Autistic people have already been asking for are now occurring more broadly, such as being able to access health care virtually or being able to work from home.

Autistic experiences with COVID-19

“I have struggled with the pandemic because the few in-person social interactions with the friends I have in my real life have been stripped from me. At the same time, however, participating in events online has become normalized for all and I am busier than ever. I am able to attend webinars and concerts and educational series that I would have never had access to previously. However, I do struggle with things like arrows on the ground telling you where to go in stores, and distance markers. I really struggle with physical directions even at the best of times, and I often find myself lost and not knowing what to do in situations that would have been easy for me previously. I am also really struggling with people who don’t wear masks and who do not physically distance, and I am genuinely fearful of people who break the rules and put myself and others at risk. As far as my mental health [goes], I have survived by relying on the Autistic community online. In some ways, I feel that I am uniquely suited to enduring a pandemic because I am Autistic and I already had robust Autistic-led support structures available to me, whereas moving primarily online for these supports and interactions is a new experience for others.”

“My experience with COVID-19 has been a difficult but more fortunate one, since I did not lose most of my jobs when mid-March came around. I miss in-person office interactions with the work team and being able to go to places without a face mask. And at the start of the pandemic, I did not feel comfortable to spend Easter with anyone other than my roommate, so I didn’t spend it with my family (an unfortunate first). However, they passed an Easter dinner to me and my roommate at the front of the building we live in, and then the rest of our interactions were behind the front-entrance glass and door as we waved, blew kisses and they put up “We love you” poster signs. However, it has also been a time for reflection and working on my own mental health, so that when all pre-COVID-19 activities such as work parties can be done again, I can approach them with renewed energy and not take them for granted. I’ve maintained my mental health with colouring, leisure writing, walking, at-home exercises and (now that it’s possible) going to the gym (while abiding by COVID-19 protocols).”

“I am struggling through COVID-19. I believe this is primarily because of the pandemic’s impact on others; many of my usual supports are currently overtaxed, and I am having much fewer conversations with friends as a result of their crises. As for my own mental health, I am prioritizing this but am struggling. I am mainly trying to keep up routines and get enough necessities such as food.”

“COVID-19 has been a relief of the crammed schedule, but stressful with lack of social interactions and outings. The new rules and regulations and the federal financial as well as provincial financial situation are worrisome. I worry about family getting sick, including parents that are in the higher risk bracket. I maintain with projects, online presentations and working out, etc.”

“During my experience with the COVID pandemic and lockdown, the hardest part for me is when I’m living with a single parent in my 20s. I did not have a lot of privacy and I was on my social media every day. It was hard for me to get out of that emotional prison. The best way to deal with the situation while the ASD person is in emotional distress: never gaslight someone for giving you discomfort. If both parties are emotionally offended or getting defensive, they would need their own privacy to be left alone, instead of being invaded. Privacy for me was what I needed, and I needed to take myself out of the situation.”

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For Family Caregivers

Snapshot

- This section highlights advice and tips from our Autistic advisers for family caregivers on how to help them maintain their well-being.
- This section also highlights what Autistic people would like their caregivers to know.
- Autistic caregivers experience parenting differently than non-Autistic caregivers.

“Until our daughter was diagnosed with autism, I didn’t feel like much of a caregiver. I didn’t understand what the world looked like, sounded like, felt like or smelled like for her. She needed help, and we felt helpless. Our family has always had lots of love and an abundance of patience. Unfortunately for our daughter, love and patience helped, but it wasn’t enough. When she was diagnosed at 17, we became armed with information and we started to speak the same language. It was like being handed a key to unlocking how to communicate with each other. Since becoming aware that we are the parents of an Autistic female, we have had the joy of seeing the world from a different lens. The stress and trepidation that accompanied every vacation, outing and family celebration has been replaced with sensitivity, tolerance, flexibility and calm. Parenting an Autistic child (now adult) has allowed us to visit her beautiful world: a world where numbers are colours and music has movement. We have learned that life doesn’t end if we miss a concert or a flight and that sometimes it is even better to stay home. We have learned that some things do not need to be fixed, and sometimes a silent cuddle is the most perfect answer.”

What Autistic advisers would like caregivers to know

“Give tools and opportunities for Autistic people to politely and firmly communicate what they want for any short- or long-term wants/needs/goals they have.”

“If you think we have done something wrong (in what you would consider as an error), please be careful of how you address the issue with us. As Autistic people, we are often keenly sensitive to being corrected. This may be because of a lifetime of being corrected by everyone—caregivers, teachers, relatives, siblings, peers, co-workers, even strangers.

“This constant experience of being corrected may be tied to the different aspects of the Autistic experience. For example, we often take longer to learn our life skills, we may move slower than you expect (especially when anxious) and we may struggle with executive functioning skills and social interactions. When our slower speed inconveniences others or we do a task of social approach that does not meet with approval—we are caught, and our shortcomings are pointed out. In any case, **please use positive language to help us gain skills and confidence**. Just as important: figure out how to teach us the skill and understanding that resulted in what others would consider an error.”

“Sensory issues are not ‘all in my head’ (and they bothered me long before I understood their nature, or even what the issues were). Sensory differences can cause behavioural and emotional responses in Autistic people.”

“If an Autistic person seems to be experiencing a higher degree of mental health problems/distress or low positive mental health, do not automatically pinpoint it to autism as the cause. We are all formed and informed by a variety of factors (e.g., social, biological), all of which impact us positively and negatively as human beings.”

“Do not shame us for our social-communication skills or make excuses for our communication skills. It may not seem right to you, but it is right to me. It can be very challenging for us to live our lives knowing that we may tick someone off on any given day and have no idea why or what we did. These interactions can end employment, personal relationships and friendships.

“Remember: Autism is a different way of communicating and interacting with others. We often have to be taught directly what non-Autistic people simply pick up intuitively. If there is something we did that others found inappropriate or offensive, this may mean there is a social expectation that we were not taught or need to adapt to. Prepare us for new situations. Sometimes simply telling us in advance about the hidden social rules of an upcoming social situation can improve our skill and confidence. This helps us avoid being shamed and blamed when our responses are misunderstood.”

“Do not let your Autistic family member be bullied by a sibling, a caregiver or any other relative. **Home needs to be a safe space.** When a caregiver or sibling is a bully or an abuser, it can ruin the relationship we have with that person for life. We often don’t address interpersonal conflict, so if these family members hurt us, that may define our relationship and how we respond to that relative for a very long time (forever, even).”

“A good rule of thumb for when it comes to supports (e.g., medical, therapy): really try to use more than one method. It doesn't necessarily mean having to switch therapies or support (although, that might be needed too). It may be a matter of doing a different activity (e.g., mandala colouring books and yoga are two current prominent, different and viable options for promoting relaxation).”

“Be mindful of how you advocate and how you approach advocacy. Learn about autism, not just in the sense of what autism is, but . . . what disability is socially. What’s our history? What social implications does that have on people? Because autism isn’t living separately from humans, it’s a part of us. And humans—even Autistic ones—have social culture.”

Family relationships

Caregivers

Being a caregiver to Autistic people is a journey. Some caregivers of Autistic people work to co-ordinate services and care for their family member. Caregivers can also struggle to cope when their Autistic family member experiences mental health problems or low positive mental health. They can describe feeling frustrated, sad, angry, hopeless, stressed, or overwhelmed.

However, they can also report feeling empowered, content, loved, hopeful, happy and secure in their role as caregivers to support their Autistic family member. Each caregiver and family reaction depends on the situation at hand and resources, coping skills, strategies and other life events surrounding the family.

Caregivers may feel a sense of responsibility about their family member's care and well-being across the lifespan. Caregivers of Autistic people have the potential to grow as people, increase their patience and change their priorities. They may learn to pick their battles wisely. They can find allies in other families, advocacy groups and helpful professionals.

Some family members may find it difficult to soothe their own anxieties and to disengage themselves from their life stresses. They may feel unable or too guilty to take time for themselves to relax, care for their own emotional and physical health and rebuild their coping resources. In some cases, there might be a lack of available respite opportunities, especially in disadvantaged communities.

"I have never felt angry or resentful of the things I do for my son, or the amount of support that he needs. He is one of the best human beings I have ever known in my life. Where it has impacted me is my relationship with others who do not understand my son. They may see support with life skills as enabling, or his inability, so far, to master certain life skills as a weakness of character rather than a visual motor issue, fine and gross motor difficulties, executive functioning differences that mean poor attention, focus and working memory. If someone is not respectful and kind to my son, I cannot have them in my life. This is true of partners and of any extended family members."

Sometimes family members may feel guilt when they experience negative emotions. It is important for caregivers to notice and accept when they feel extremely tired or have negative feelings. Ignoring these negative emotions may seem to help in the short term, but it can lead to exhaustion, depression, isolation and hopelessness. This will not be helpful for them or their Autistic family member. Remember that many family caregivers can experience difficult circumstances and negative feelings related to their caregiving roles or responsibilities.

Caregiver experiences with Autistic family members

“Being the caregiver of two Autistic sons has helped me see that you don’t have to be ‘neurotypical’ to make an important contribution to the world. I am more patient and accepting now. I am better at assessing and accepting the world as it is, as opposed to how I might want to see it. I am learning that ‘success’ means different things to different people. Our family defines it in terms of personal well-being and purpose as opposed to material things (although we love some nice material things!).”

“I would want my Autistic sons to know that I accept them and see them just as they are and [that I] want to make a place (or help them make/find a place) where they can live a life that is meaningful to them. I treasure how kind and empathetic they are. I sometimes forget that we experience the world differently, and I wish I could experience it the way they do. I am trying to teach them as much as possible how to navigate on their own.”

“My relationship with my adult Autistic child is not one of unbalanced power where I make decisions. Everything is collaborative with ultimate decisions falling to him. It has been very empowering and useful for my son to be an equal part of the process. By ‘process,’ I mean deciding on next steps in life, in gaining skills and ability or in seeking mental health support. I am present and connected to give information, to question, to guide—but he has to decide.”

Caregiver stressors

As each family is unique, specific reasons for stress differ from family to family. However, families do report some common sources of caregiver stress. We discuss some of them below.

Frustrations with systems, funders and programs

Dealing with different systems (government, health, education, social services, employment counselling, etc.) is time-consuming, stressful and hard to navigate:

- There is a lot of paperwork involved.
- It's not easy to figure out and work with the system, and at times the information provided is not clear.

Lack of appropriate services

Autistic people often fall through the gaps in services and funding. Even when services are available, professionals may not understand the needs or support necessary for Autistic well-being.

Worries about the future

When thinking about the future, caregivers are concerned about the vulnerability of their loved ones. Some common concerns include:

- Dependence on funding and/or services that might not be offered consistently.
- Lack of safety and security when the time comes when they are unable to care for their family member, due to their own poor health, aging or death.
- Lack of family or friends to be alternate guardians or trustees when they are not able to care for their family member.
- The challenge of making a will and participating in estate planning to provide for a person with a disability (and also wanting to be fair to any other children).
- Will they find love? Maintain lasting relationships and social connections?

Personal stress

Many caregivers can report being exhausted and unable to perform self-care. This can be especially true for caregivers whose Autistic adult-age children have very high physical support needs (those who are not independent with toileting or bathing, who cannot control their body or whose responses to the environment can be a safety risk). At times, only one caregiver may end up doing all the advocacy, support and care for their Autistic family member.

Other stressors may include a lack of access to affordable, knowledgeable professionals who work with Autistic people and their families, or not being able to go to work, take care of other family members or attend to other things in their lives.

Receiving a late diagnosis

For caregivers who have late-diagnosed Autistic family members, they may face the following challenges:

- It can be difficult and expensive to get an assessment or re-assessment.
- There are long wait-lists to get assessments.
- Once a diagnosis is received, it can be a lot of work to understand what is involved, what to do to help, what services are available and how to access them.

Financial stress

Caregivers of Autistic people may earn less money or have to work fewer hours than other caregivers. At times, they may have to take off unpaid workdays to support their Autistic family member. Caregivers may also have added expenses such as therapy, medicine and housing. These challenges may be especially experienced by single-caregiver households or households with other medical difficulties.

Social stress

Some caregivers may have difficulty connecting with other family members because they may not understand autism or how to support Autistic people.

At times, extended family members may be critical of the caregivers or their family member. Some people experience pressure from relatives to be a “perfect” caregiver or family. Some caregivers may be unable to connect with their friends or community because they may be occupied or because social attitudes toward disabled people are too negative.

“We have lost many friends and much of my family because of our differences. We were never well-off, but we struggle financially because of choices my husband and I have had to make, to stop working in full-time jobs (with pensions) because we needed to be available during workdays to meet our sons’ needs. There’s guilt associated with this—not being able to provide as well as we’d like to, because of having to make these choices.”

You can use the **Brief Family Distress Scale**¹ to quickly decide where you are in terms of distress, which is often the result of on-going stressors without support. This scale is like a “distress thermometer” and offers a quick way to communicate to others, including service providers, how well you think you are managing and how urgently you feel you need help.

Brief Family Distress Scale¹

On a scale from 1 to 10, rate where you and your family are right now in terms of crisis by picking one of the following statements:

- 1 - Everything is fine, my family and I are not in crisis at all.
- 2 - Everything is fine but sometimes we have our difficulties.
- 3 - Things are sometimes stressful, but we can deal with the problems if they arise.
- 4 - Things are often stressful, but we are managing to deal with the problems when they arise.
- 5 - This is very stressful, but we are getting by with a lot of effort.
- 6 - We have to work extremely hard every moment of every day to avoid having a crisis.
- 7 - We won't be able to handle things. If one more thing goes wrong – we will be in crisis.
- 8 - We are currently in crisis, but we are dealing with it ourselves.
- 9 - We are currently in crisis and have asked for help from crisis services (emergency room, hospital, community crisis).
- 10 - We are currently in crisis, and it could not get any worse.

Marriage and partnerships

Marriages and partnerships can be affected by daily stressors. There can be stress for many reasons, and the following are potential strategies that have been suggested to maintain positive relationships during times of stress.

Caregiver strategies for relationships

1. Keep the lines of communication open between partners.
2. Rely on each other for support.
3. Seek help from each other or from others outside the relationship, such as couples' counselling.
4. Make time for family members, like going to a movie or another activity to nurture your relationships.
5. Attend some of your family member's appointments together.
6. Give each other time to deal with stress in your own ways.
7. Try hands-on activities instead of only talking.
8. Learn about your family member's difficulties together.
9. Ask for information to share with each other.
10. Increase your partner's involvement slowly, rather than expecting too much too soon.
11. Connect with other families of people in the same situation as you.
12. See yourself as a "team."
13. Remember the big picture of what your common goals are.
14. Recognize that family members may have uneven parenting responsibilities. Caregivers should communicate with each other about what their expectations are.

Siblings

Siblings may worry about mental health problems, or they may have the same diagnoses. They may worry about the stress and strain that their caregivers are experiencing and may take on some of the roles in helping. At the same time, siblings may sometimes resent the time that caregivers spend supporting an Autistic sibling. There may be feelings of guilt for not being able to support their sibling in the way that is needed or they may not understand them.

How can caregivers help siblings cope?

1. Help them learn about autism and mental health and how they interact and affect each other.
2. Share feelings and encourage your family members to talk about how they feel. For example, what they are experiencing and how their Autistic sibling's experiences affect them.
3. Help them build a new relationship with their Autistic sibling and create different ways of being with them.
4. Explain that other extended family members may feel uncomfortable or embarrassed, but that doesn't mean they need to be uncomfortable or ashamed of their Autistic sibling.
5. Help them develop realistic expectations of themselves, as some siblings may feel like they have to behave perfectly or excel at different parts of their life.
6. Celebrate the accomplishments and achievements of all family members.
7. Discuss the issue of stigma and why it happens, as well as effective ways to deal with it and address it with others.
8. Spend alone time with each family member, talking or doing their preferred activities.
9. Encourage siblings to have interests outside of the family. An outside activity can help build friendships, skills and self-esteem.
10. Help siblings connect with a peer group of other siblings.
11. Strengthen your family members' support system. Sometimes it's important for siblings to have an adult outside of the family (e.g., friend, support team) to confide in.

Sibling experiences

“As an #ActuallyAutistic and also a sibling of a non-Autistic brother and sister, their experiences with me are different than my experiences. My brother and sister were good with me most times, but of course, we fought as most siblings did. They did a lot of exposure and exploring with me and would engage with me when I was younger; played games and looked after me very well. That has helped with my overall growth in my very younger and later years as well.”

Autistic caregivers

Autistic caregivers are often forgotten in conversations about parenting. Autistic caregivers can experience times when their roles as caregivers can be difficult.² These difficulties include but are not limited to: a lack of tailored support, challenges communicating with professionals (e.g., doctors, teachers), low opinions of parenting from others (e.g., being judged by other caregivers) and perhaps being at a higher risk for depression after birth. Executive functioning difficulties may make the smooth running of a household difficult.²

It also can be common for Autistic caregivers to feel isolated and judged. Their social struggles and unique differences can make fitting into parenting groups difficult, leaving them feeling alone. Their struggles and differences can also make them feel “less than” non-Autistic caregivers. Some Autistic caregivers live in fear that they will be judged “unfit” to be caregivers and will have their children taken away from them due to discrimination and misunderstanding.²

Strengths of Autistic caregivers

Neurotype alone (e.g., Autistic or non-Autistic) does not decide anyone’s capability of doing anything, including parenting. Autistic people can be good caregivers who raise fantastic kids, Autistic and non-Autistic alike. Similar to non-Autistic people, Autistic caregivers find parenthood rewarding² and are able to prioritize their child’s needs above their own and seek ways to boost their child’s self-confidence.

Autistic people can be incredible caregivers to Autistic children. They know what it is like, because they think and experience the world differently also. They may understand why their child is doing something that other people may not understand—because they know their child’s way of thinking and perceiving the world.³ Autistic caregivers can provide their family member with autism-specific coping skills and things that have helped them get through the non-Autistic world.

Autistic caregiver needs

Below are several things that may help support Autistic caregivers:

- A support system among Autistic caregivers for the sake of solidarity and idea-sharing. Being an Autistic caregiver is a unique experience; having other Autistic caregivers to turn to for social support and validation is essential.

- Awareness and understanding to reduce stigma and stereotypes and foster compassion and empathy.
- Education/mentoring programs that could help Autistic caregivers with things that don't come naturally to them. For example, help with family communication, including between caregiver, child and partner.
- Some parents may feel that they could benefit from structured coaching or mentorship. For instance, advocacy groups, parenting support groups, peer-to-peer supports or parenting programs.
- An advocate to aid in communication with schools, doctors and other professionals. Situations where parents are expected to advocate for their children can be intimidating or hard to navigate.

Autistic caregiver experiences

“Being an Autistic parent helped me to be a better parent to my Autistic child and has made me a better person as well. For example, he cannot tolerate raised voices, so from the time he was two years old, I did not holler in the house. I would find calm ways to express my urgency, upset or excitement. Raising him allowed me to immerse myself in the autism culture in hope of finding ways to address his learning, sensory and social-interacting needs. I read every book, paper, website I could get hold of and never stopped. When I discovered something that helped him, I felt compelled to share it so that other children could benefit. I am an Autistic advocate whose strength is in navigating school supports and identifying learning challenges to help Autistic students thrive in school. I am able to do this because of the gift of raising my Autistic son. It is worth noting that Autistic traits, including tenacity and focus on areas of strong interest, helped me to help him—and now to help others.”

Strategies for caregivers

Activity 8.1 below is an activity you can do to check how different areas of your life are doing. It may help you to communicate with professionals about your support needs.

Activity 8.1: Personal Impact Log

This log will help you think about your situation and how it affects your physical, emotional, social and spiritual health.

Physical health	Emotional health
Social life	Spiritual life

There are no easy answers for coping with caregiver stress. Many families know exactly what they need to relieve stress, but what they need may not be available. Following are some suggestions and advice our caregiver advisers have suggested. These tips on coping are offered knowing that they don't work for everyone and that they are a lot easier said than done.

Learn and celebrate Autistic culture

Autistic culture is the shared history of Autistic people and how they move, communicate, experience and understand the world around them in their own way.⁴ Learning about your Autistic family member's culture can help you to appreciate, accept and enjoy them as they are.

There is no right or wrong way

Keep in mind that there is no one right or wrong way to be a caregiver. It is okay if you do not have all the answers. Many caregivers find that there is a lot of trial and error involved in building a good life.

Find the humour in life

Take time to laugh daily, even if it's simply through reading, social media or television. Humour can be a great stress reliever.

Remember you are not alone

Connecting with other families and support groups is a source of support that many caregivers find useful. You may find inspiration, hope and creative solutions to problems by communicating with other families. If it's not possible to connect, there are books, films and websites written by Autistic adults and caregivers. Accessing these types of materials can also make you feel less alone.

Make use of supports and funding

Some families may not take advantage of financial support, such as the disability tax credit, because they think they are not entitled or that others deserve it. You do not need to be in the worst possible situation to deserve funding or a tax break. It can be okay to accept help.

Access respite care

Accessing respite services can allow caregivers an opportunity to engage in a hobby or other relaxing activity, spend some time alone, get chores and errands done, visit a friend or participate more fully in other activities.

Respite (or relief) can be found from multiple sources. Through your personal network is often a great way to find a person that is a good match for your family. This means letting others know what you need. The other way is through respite agency services.

Take time for yourself

Self-care is essential, it is not selfish. If the caregivers are burnt-out, everyone can suffer. Refer to **Section 6** of this guide for some activities to try.

Take care of your health

Caregivers may neglect their own health, particularly when they are overwhelmed by the needs of others. Caregivers can be prone to stress-related challenges (experiencing distress or low mental health) or physical problems such as chronic pain and headaches. Remember to try and find time for some exercise (even if it's just a for a short walk) and to get enough sleep—these can improve your mood and outlook.

Pursue activities with your Autistic family member

Caregivers can join clubs that are of interest to them and their child. Sharing interests can build a deeper connection and relationship—it allows you to get to know them more as people.

Develop advocacy and assertiveness skills

Learn how to advocate effectively on behalf of or with your Autistic family member. You may find workshops on how to effectively advocate useful. You can also contact disability organizations for help or read literature on the topic. Below are some suggestions on advocacy.

When advocating, start by explaining your family's vision of a good life (especially your Autistic family member's vision). One way to advocate effectively is to explain your child's strengths. When you advocate, it be helpful to be assertive, rather than aggressive or passive. Aggression may result in being dismissed as unreasonable or it may elicit a variety of other resistive responses. Passivity may result in you or your family not receiving important resources and services.

When attending a meeting where you expect to advocate:

- Try to start on a positive note—do not attack or blame.
- Clearly state your concern.
- Be clear in your own mind what you want from others.
- Bring a list you can refer to.
- If a new idea or surprise is introduced during a meeting, don't be pushed into making a decision—ask for a day or two to think about it.
- Bring someone with you to serve as a support and to take notes when at meetings with professionals.
- Record who has agreed to do what and when it will be done, and send a copy to everyone who was at the meeting.

What family caregiver advisers would like caregivers to know

“If one caregiver is impatient, rude or hostile to their Autistic family member, it causes harm and often has implications that can last a lifetime. If your partner is contributing to or even causing your Autistic family member's mental health challenges, please do something to protect your child. Autistic people deal with enough bullies out there in the world. Home should be a safe place.”

“There are very few professionals who really understand what it means to be Autistic. With that in mind, only seek help from professionals with a high degree of knowledge, experience and understanding of Autistic culture.”

“Never accept advice you know is wrong. Trust your gut. Reach out to Autistic-led support groups to learn more about the Autistic experience. Increase your understanding, and you will naturally change your support for and actions on behalf of your Autistic family member.”

“Live your life. Model how to handle mistakes. Show, by example, how to work through disappointment, frustration, anger and being overwhelmed. Narrate your experiences when your Autistic family member is with you and when it is appropriate to do so. This will help the Autistic family member to grow up and know what to say and do when these feelings take root.”

“One of the most under-appreciated aspects of the Autistic experience is the intolerance of uncertainty. Be respectful of this reality: let your child know in advance when plans change, when plans are being made, when their help may be needed with a chore. Last-minute demands can, by nature of the Autistic experience, be very difficult. Now you know this. Now you can find another approach. This one small step can help your child to feel more at ease in your presence, and less anxious as a result.”

“Sensory differences are real. Learn what they are and respect them. Don’t make a big deal out of accommodating them, and don’t make excuses for your difficult relatives who interpret sensory needs as whiny, dramatic or bad parenting. If anyone doubts you, ask them to wear a mohair (type of fabric) sweater on a hot day and challenge them to maintain a cheerful, focused demeanour.”

“Autism is a different way of learning, interacting with others and experiencing the sensory world. That may sound very abstract, but if you can learn what each of these mean for your Autistic family member, it can make all the difference in the world. It can help you view any hurdles your Autistic child may be experiencing from an autism perspective. Educated caregivers who respect Autistic culture can be very effective and appreciated allies.”

“Keep your Autistic family member’s strengths and positive attributes in mind, especially when times are hard and there is a lot of conflict in the relationship.”

“Seeking professional support and strategies on how to communicate with your verbal Autistic family member may reduce conflict or arguments and escalation because of frustrations.”

“If your Autistic family member (especially pre-teenagers) seems to be struggling with mental health challenges, especially increasing isolating behaviour, rumination, social anxiety and/or paranoia, ask your health care practitioner and/or mental health professional about autism.”

“Self-care is essential for caregivers and siblings. It is one of the ways to ensure resilience and empathy for your child/sibling.”

“Plan for the future, especially when it comes to securing affordable, independent, supported housing for your Autistic teenager as they emerge into adulthood. Families experience two critical periods with their Autistic family member: early adulthood and early seniorhood, and stresses can be reduced with advanced planning.”

“Teach the adult Autistic person how to advocate for themselves in a scaffolded way. Parents will not always be there. This will help them to feel more confident. It will also alleviate stress and worry from the caregivers, who worry endlessly about how their adult child will manage without them. ”

“The Autistic person is not trying to be malicious—they are trying to express a need of some kind. Imagine if you didn’t speak the language everyone else spoke and people consistently misunderstood what you needed. Try not to take ‘behaviour’ personally—try to step back and assess what the person’s goals are.”

“Always remember to give your Autistic family member space if they need it. Sometimes it takes time to process difficulties and expressing their emotions.”

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List of Resources

Note: While there are many mental health resources available, the list featured in this section is not complete, and it highlights Autistic-led organizations. The information provided below is not an endorsement or recommendation of any opinion, information, services, materials, organizations or individuals contained within the list.

Autistic-led organizations

- Autistic 4 Autistics (A4A) Ontario: <https://a4aontario.com>
- Autistic Inclusive Meets: <https://autisticinclusivemeets.org>
- Autistic Mutual Aid society Edinburgh (AMASE): <https://amase.org.uk>
- Autism Network International: www.autreat.com
- Autistic Self-Advocacy Network (ASAN): <https://autisticadvocacy.org>
- Autistics United Canada: www.autisticsunitedca.org
- Autistic Women & Nonbinary Network (AWN): <https://awnnetwork.org>
- London Autistics Standing Together: <https://londonautistics.wordpress.com>

Compilation of resources (online and print materials)

- A4A List: <https://a4aontario.com/resources/>
- Actually Autistic Blogs List: <https://anautismobserver.wordpress.com/>
- Autistics United List: www.autisticsunitedca.org/resource-list.html
- Autistics Aloud Magazine: <https://www.autisticsaloud.ca/>
- ASAN Resource Library: <https://autisticadvocacy.org/resources/>
- AMASE Resources: <https://amase.org.uk/resources/>
- AWM Resource Library: <https://awnnetwork.org/resource-library/>
- Finding Autism Resources: <https://geekclubbooks.com/resources/>
- London Autistics Resource lists: <https://londonautistics.wordpress.com/resources-2/>

- Ed Wiley Autism Acceptance Lending Library – Neurodiversity Library: <https://neurodiversitylibrary.org/neurodivergent-narwhals/>
- Thinking Person’s Guide to Autism Resource List: www.thinkingautismguide.com/p/resources.html

Guides and toolkits

- A guide for Autism researchers – *Avoiding Ableist Language: Suggestions for Autism Researchers* (2020): www.liebertpub.com/doi/10.1089/aut.2020.0014
- AASPIRE – Academic-Autistic Spectrum Partnership in Research and Education (United States):
 - Website: <https://aaspire.org>
 - AASPIRE Healthcare Toolkit: <https://autismandhealth.org>
- Ambitious about Autism (United Kingdom):
 - Website: www.ambitiousaboutautism.org.uk
 - Know Your Normal Toolkit: www.ambitiousaboutautism.org.uk/sites/default/files/toolkits/know-your-normal-toolkit-ambitious-about-autism.pdf
- Autism Toolbox by Scottish Autism (Scotland): www.autismtoolbox.co.uk
- Shaping Autism Research (United Kingdom): www.shapingautismresearch.co.uk/post/163944360130/its-here-a-starter-pack-for-participatory-autism
- The Participatory Autism Research Collective (United Kingdom): <https://participatoryautismresearch.wordpress.com>

Crisis lines

If you are in an emergency, in crisis or need someone to talk to, below is a list of Canadian nation- and province/territory-wide phone numbers to contact. They are free and available 24 hours a day, seven days a week.

Crisis lines	
Canada-wide	<p>Canada Suicide Prevention Service 1 833 456-4566 (24/7 toll-free) TEXT: 45645</p> <p>Indigenous Hope for Wellness Help Line 1 855 242-3310</p> <p>Kids Help Phone (20 years and under) 1 800 668-6868</p> <p>Trans Lifeline 1 877 330-6366 (does not do non-consensual active rescue)</p> <p>Assaulted Women's Helpline 1 866 863-0511</p> <p>Emergency Department 9-1-1</p>
Alberta	<p>Mental Health Help Line 1 877 303-2642</p>
British Columbia	<p>Crisis Line Association of B.C. 1 800 SUICIDE (784-2433) 310-6789 (no area code needed)</p>
Manitoba	<p>Klinic Crisis Line 1 888 322-3019 1 877 435-7170 (suicide support line)</p>

New Brunswick	Chimo Help Line 1 800 667-5005
Newfoundland & Labrador	Mental Health Crisis Centre 1 888 737-4668
Northwest Territories	NWT Help Line 1 800 661-0844
Nova Scotia	Mental Health Mobile Crisis Team 1 888 429-8167
Nunavut	Kamatsiaqtut Nunavut Help Line 1 800 265-3333
Ontario	Connex Ontario 1 866 531-2600
Quebec	Quebec National Crisis Line/ Centre de prévention du suicide de Québec 1 866 APPELLE (277-3553)
Saskatchewan	Professional Health Advice and Mental Health Support 8-1-1
Yukon	Yukon Distress & Support Line 1 844 533-3030

Glossary of Terms

Terms	Definition
Ableism	<p>“A system that places value on people’s bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person’s appearance and/or their ability to satisfactorily [re]produce, excel and ‘behave.’ You do not have to be disabled to experience ableism.” (www.talilalewis.com/blog/ableism-2020-an-updated-definition)</p>
Assigned gender at birth (AGAB) language	<p>AGAB language is used to describe the gender a person was classified as by others at birth based on physical traits.</p> <p>For example: “assigned female at birth,” “assigned male at birth.”</p>
Allistic	<p>A term for people who are not Autistic.</p>
Antidepressant	<p>Umbrella term for medications designed to treat depression.</p>
Assimilation	<p>Trying to fit in with everyone else.</p> <p>For example, always sitting next to the same person in class; engaging in small talk with strangers even if you don’t want to.</p>
Autigender	<p>A gender expressed by some transgender Autistic people that indicates that their sense of gender is deeply influenced by their autism.</p>

Autism community	A community of Autistics, families/caregivers of Autistics, and service providers.
Autistic community	A community of Autistic people.
Autistic culture	It is a shared history, the way Autistic people communicate, create, experience and understand the world around us in uniquely Autistic ways.
Catatonia	<p>A syndrome of psychomotor disturbances variously characterized by periods of stupor, negativism, physical rigidity, mutism or excessive motor activity, waxy flexibility, unusual mannerisms, echolalia, echopraxia.</p> <p>The syndrome is most associated with certain psychiatric conditions, mood disorders or other conditions.</p>
Compensation	Finding ways around things that are naturally difficult for Autistic people.
Echolalia	A person's repetition of words or phrases they have heard from others. Common among Autistic people, especially younger children.
Functioning labels	Unhelpful terms, such as high-functioning or low-functioning, that purport to describe an Autistic person's overall mental abilities and are typically assigned by a person's ability or inability to communicate verbally and their perceived intelligence.
Gaslighting	Psychologically manipulating someone into doubting their own understanding of reality or of themselves.

<p>Healthism</p>	<p>A worldview that sees good health as a personal, moral responsibility and sees the life of an unhealthy person as less worthy than that of a healthy one, and blames people for their bad health.</p>
<p>Infantilization</p>	<p>Behaviour or speech that inappropriately treats someone like a child. Commonly experienced by people with a wide variety of disabilities, particularly autism and other developmental disabilities.</p>
<p>Internalized ableism</p>	<p>When a disabled person believes and accepts assumptions of society that perceives disability and difference as inherently defective, unfortunate, and having less inherent value than someone who is not seen as ‘different.’</p>
<p>Intolerance of uncertainty</p>	<p>Difficulty or inability to tolerate not knowing what to expect; many Autistic people have intolerance of uncertainty.</p>
<p>Neurotypical</p>	<p>A person whose mind is not characterized by any condition such as autism or ADHD, learning disability, etc.</p>
<p>Neurodivergent</p>	<p>Describes a person who has a brain/mind that works in ways that is significantly far away from standards made by society. Commonly shortened to ND.</p>
<p>Neurodiversity</p>	<p>Coined by Judy Singer. The natural diversity in human brains and minds.</p>
<p>Neurosiblings</p>	<p>Term used by the neurodivergent community to refer to other neurodivergent people. This is to highlight that they are united through their neurologies.</p>

Pathologize	To inappropriately treat someone or something as though there is something medically or psychologically wrong with them.
Perseveration	Persistent repetition of topics of discussion after they have stopped to be socially appropriate; tendency to get stuck talking about the same thing long after communication partners have lost interest.
Resilience	A person's ability to react well to, and recover from, trauma and distress.
Resilience factors	Aspects of a person, or their circumstances, that are thought to improve their resilience. An example of this is a robust social network of supportive others.
Self-stigma	When you believe that you are inferior because of your unique characteristics or personal traits.
Sensory overload	The state of being overwhelmed by the level or amount of sensory stimulation; relatively common among Autistic people and other neurodivergent people.
Side-effect	An extra effect of a treatment beyond its main purpose. For example, gaining weight or losing weight very quickly when taking a medication for improving mood.
Social hangover	The need an Autistic person may have to recover from a period of socializing; recovery often means destressing by taking time to be alone in a calm environment.
Social injury	A social interaction that causes emotional, physical or psychological harm.

<p>Stimming</p>	<p>The practice of repetitive physical mannerisms, such as twitching fingers or flapping hands to help with mental focus or emotional regulation.</p> <p>Stimming can also be a part of Autistic body language (e.g., happy stims, anxious stims) that is used to communicate with others. Some stimming may not have a purpose, and that is okay, too.</p>
<p>Suicidal ideation</p>	<p>Thoughts of suicide, such as imagining a suicide attempt or thinking of how the world would be without oneself.</p>
<p>Therapeutic alliance</p>	<p>The degree to which a particular therapist-and-client pair have a positive relationship, which is helpful in therapy.</p>
<p>Trauma</p>	<p>An umbrella term for lasting responses to a highly painful or upsetting event, such as intense worry that the event will happen again or avoidance of things that remind one of the event.</p>