

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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