

# Plain Language Position on Access to Healthcare



This document is a position statement. It is from Inclusion Canada. It is about access to healthcare. Our position statements guide our advocacy and our work. They help us define how we see inclusion.

## Overview

People with intellectual disabilities have rights. They have the right to the highest quality of healthcare. They have the right to healthcare without discrimination. But this is not always available to them in Canada. They can't always access good healthcare. This needs to be fixed. All people with intellectual disabilities must have the same access to healthcare as everyone else.

Inclusion Canada has actions that we recommend. These actions will help to fix the current barriers. These actions will help to build strength into the system. This will help make it more inclusive and person-directed. These actions are an organized way to change the system.

It is not just these actions that are needed. There needs to be effort put into ways to fix ableism in the healthcare system. Ableism in healthcare has a bad effect on health.

[Click here to go to our calls to action.](#)

***There are stories in this position statement. They are about accessing healthcare. The stories show the real barriers that people face.***

***Justin's Story:*** Justin lives with his twin brother Sam. Sam noticed that Justin was behaving differently. He was struggling to leave the house. He didn't seem to be enjoying his favourite pastimes. Sam spoke to his networks. He asked them to recommend a therapist. But not just any therapist, one that knew how to treat people with intellectual disabilities. Everyone agreed that the best option was Dr. Jones. But there was a problem. Dr. Jones was not accepting new patients. So Sam helped Justin look for other options. But they were told, "Sorry I don't have the expertise you need," time after time. Meanwhile, Justin's mental health got worse. He was admitted to hospital in crisis.

## Policy Context

### Why is access to healthcare a priority for Inclusion Canada?

Access to healthcare has a deep affect on people's lives. This is why it is a main priority for us. People with an intellectual disability are more likely than others to need access to healthcare. But they are less likely to get the same access as everyone else.

- Intellectual disability is not a sickness. It is not a disease. It is not a cause of death. But it is known that other medical conditions sometimes come with it. These medical conditions need to be treated through healthcare. People with both an intellectual disability and a medical condition face barriers. They are often kept in hospital for a long time. This is not good for them, or anybody. It means people are more likely to get an infection. It often causes people more physical and mental harm.
- People with an intellectual disability have shorter life spans than other people. But dying younger than other people is not natural or expected. Ableism is a belief about disability. It views not having a disability as 'normal.' It views 'normal' as the preferred way to be. But ableism is discrimination. It is like racism and sexism. Ableism can make people sick. People who are ableist treat people with disabilities unfairly. Health care staff ignore the lived experience that people with disabilities have. Staff blame any symptoms on the person's disability. Staff take away their support. Ableism makes them believe there is nothing that can be done to help. This is the root cause of many barriers in accessing healthcare in Canada.
- The goal of quality healthcare with dignity is within our reach. Some Canadians with an intellectual disability have had positive experiences. They have been able to get good healthcare all their lives. This is what they have in common.
  - They have strong support systems in their lives.
  - They know how to be self-advocates.
  - They have decided how they will make medical decisions.
  - They have been seeing their doctors for a long while.
  - They have doctors who are well trained and are open minded.

These kinds of success stories show what is possible.

## What needs to be done?

Healthcare is decided in each of the provinces and territories. But the United Nations Convention on the Rights of Persons with Disabilities applies to all of Canada. There are no exceptions. This means the federal government does have an important role. They need to be part of the actions. They need to help advance access to healthcare for people with an intellectual disability.

All people in Canada want access to good healthcare. It is a top priority across the country. Decision makers are changing the way they do things. This is being informed by what happened during COVID-19. The health and wellness of people with disabilities needs to be a priority. The needs of people with intellectual disabilities and their families cannot be ignored. These needs cannot be an afterthought. These needs do not take second place to the needs of the general public.

***Johanna's Story:** Johanna's family doctor retired. She spent a long time waiting for a new doctor. She waited longer than most other people had to. Johanna needed her new doctor's office to be on the bus route. She didn't have enough money to make trips using the accessible taxi. She finally found a doctor and had her first appointment. The doctor was surprised that Johanna had never had a mammogram. They had a chat. Johanna was asked why she refused to do the test. But Johanna did not remember ever being asked about doing it. So the doctor help Johanna book an appointment at the hospital. The hospital had an accessible machine to do mammograms. They picked a date that was a few months away. This would give Johanna time to save the money for transportation to the appointment. Johanna tested positive for breast cancer. It was advanced already. This should have been found out sooner.*

## Discussion

**Here are some examples of how ableism makes people sick.**

- Education helps people. It helps people to get a well-paying job. It helps people to make decisions about their health. People with an intellectual disability have less access to education than other people. They are less likely to have the chance to get a higher education. Learn more at [Inclusive Education Canada](#).
- A well-paying job gives people options. They can spend money on things that keep them healthy. They have money for regular social activities. This helps a person's well-being. People with an intellectual disability are less likely to have a

job. They are less likely to have a full-time job. Learn more from our [position on work and jobs](#).

- A well-paying job allows people to buy the things they need. It gives them money for healthy food. It gives them money for safe housing. It gives them money for good transportation. It gives them money for the other things they need. People with an intellectual disability are more likely to be poor. They are more likely to live in poverty than other people. Learn more from our [positions on income security for individuals](#) and [income security for families](#).
- Housing has an impact on people's health. It has a positive impact when housing is safe, accessible and stable. Person-directed housing is good for people. Being homeless is not good for a person's health. Having to live in an institution is not good for a person's health. These have negative impacts on peoples' health. Learn more from our [position on housing](#).

#### **Here are some examples of the barriers in Canada's healthcare system.**

- **Primary healthcare:** Most primary care clinics are small and crowded. There is a lot going on in terms of noise and activity. It can make people agitated and upset. The appointments are often rushed. The information is not easy to understand. Health care staff don't always treat people with an intellectual disability with respect. It is a risk for people to show fear or that they are upset. They risk getting labeled. They may be seen as difficult or violent. This can lead to them being sedated or restrained.
- **Medical decision-making:** A person's right to choose can be at risk in medical settings. Supported decision-making would help fix this. But it is not being used across Canada like it should be. Learn more from our [position statement on legal capacity](#).
- **Diagnostics and disease prevention:** People with an intellectual disability are less likely to have regular medical tests. They are less likely to have Pap tests, mammograms, or colonoscopies. This happens for many reasons. For example, medical staff may decide that the test will cause too much distress to the person. The clinic may not have a way to transfer a person who uses a wheelchair. The person may need a screening to be adapted for them. For example, they may need to be sedated for a MRI. Follow up tests are not always booked. The person may have limited times that they can book an appointment. All these things are barriers to medical testing.

- **Healthcare in times of emergency:** People with an intellectual disability were not treated well in healthcare during the COVID-19 pandemic. Some provinces used a person's intellectual disability to triage them out of life-saving care. Support people were not allowed in the hospitals. This left many people without support or help with communication. People with intellectual disabilities were more likely to test positive for Covid. They were more likely to be hospitalized. They were more likely to die from Covid. They were less likely to have had a Covid vaccine because of the many barriers they faced.
- **Mental healthcare:** Mental healthcare in Canada is not tailored to fit each person and their situation. It is done the same way for everyone. This leaves people with an intellectual disability not getting the right services or enough mental health care. They have fewer options available to them. Mental healthcare staff do not feel like they have the training they need. They don't feel confident to diagnose and treat people with an intellectual disability. Some staff dismiss mental health as part of the intellectual disability. Some people are given too much mental health medication.
- **Medical assistance in dying (MAiD):** Canada made it legal for doctors to help people with disabilities to commit suicide in 2021. People with disabilities have said that the MAiD law has made them have less trust in healthcare. They said it has made accessing healthcare less safe. Learn more from our [position on medical assistance in dying](#).

**Nicolas' Story:** *Nicolas had a bad experience with his healthcare. It began at the hospital in triage. Nicolas was anxious and a little loud while they waited. Nicolas' parents could see the way the nurses reacted to him. They were uncomfortable and maybe even afraid of him. Nicolas was finally admitted to the hospital. He was given a big dose of medicine right away. This was for his pain. But Nicolas' parents think it was also to control his behaviour. They think the hospital gave him too much. Nicolas was kept on the high dose of medication. He did poorly in physiotherapy because of this. This also meant that he didn't get out of hospital when he was supposed to. He also got an infection in hospital. This meant he had to wait even longer. The hospital soon began suggesting that Nicolas should look at using a wheelchair.*

## Urgent action is needed in the following areas

### Change the system and culture to fix and prevent barriers

- Make sure people can direct their own care. Promote plans for healthcare access that are made for individuals. Make accommodations like the following.
  - Have in-home appointments.
  - Have sensory friendly supports and exam spaces.
  - Have longer appointments.
  - Make more appointment times available.
- Use a supported decision-making model. Protect the right to decide for people with intellectual disabilities. Make sure they can make their own medical decisions.
- Improve access to information. Make sure information is widely available. Make sure information is in plain language and easy-to-use formats.
- Coordinate healthcare so different parts are linked to each other. Invest in people who can help patients to navigate the system. Provide support to people with an intellectual disability. Make sure to support their families and paid staff. They often help a person to get through the complicated healthcare system.
- Require regular training. Make it available to professionals, staff and students. Make sure it is available to those working in healthcare, medicine and mental health care. Training needs to involve people with disabilities. It should be created and led by people with intellectual disabilities and their families.

### Build capacity for inclusive care that is person-directed

- Make sure all health care staff know how to help people with an intellectual disability. Health care staff need to know about the access points in healthcare. They need to know how to communicate with people and their families. Promote broad access to inclusive healthcare across the country.
- Develop a network of experts. All health care staff must have access to the experts. They must be able to consult with those who have more experience and skills. They must be able to refer patients if needed. The experts will know about how to assess, accommodate and treat people with an intellectual disability.

- Advocate for universal design in the healthcare system. Make sure it is well established. Make sure specialty clinics are not separated or divided.

The Convention has a definition of ‘universal design.’ It means that everything can be used by everybody. This means products and places and spaces can be used in the same way by people with disabilities and people without disabilities. It means programs and services can be used by all people. Universal design does not leave out any group of people with disabilities.

- Recognize the lived experiences of self-advocates.
  - Listen to self-advocates. They know their bodies better than anyone else.
  - Select key support people. Give them the power to help. They know the person well. They know what the person prefers. They know how the person communicates. Families and trusted support staff can play a vital role. They can help the person to access healthcare.

**Wren’s Story:** *Wren is a parent. She lives in a small prairie town. She has a daughter with an intellectual disability. Wren’s daughter had an earache. So Wren made an appointment at the clinic in town. They went to the appointment. The desk staff asked Wren if she knew about the new specialty clinic. Staff told Wren it was in the city, about an hour away. Staff also told Wren the clinic was for “people like her daughter.” Wren spoke to the staff about this. She told the staff that it was important for her daughter to get healthcare close to home. That she should be able to use this clinic like everyone else in town. Wren said a referral could be useful at times. But a referral would only help if her daughter’s pain was related to her disability. Wren did not think it was at this time. Wren’s daughter finished her appointment. She had an ear infection. She was given antibiotics and it cleared up.*

### **Take a coordinated approach to improving access to healthcare**

- Spend money on research. Have an agenda on disability. Develop a national health policy. Do research on the systems and disability. Try new things that will reduce barriers. Try new things that will make access to healthcare easier for people with an intellectual disability. Do projects that will improve the system. Evaluate the projects. Make changes to the system that will help people with disabilities.
- Watch and evaluate the healthcare system. Find out which parts are doing a

good job with access to healthcare. Find out which parts need to be improved.

- Make a national mental health plan for people with an intellectual disability. Make sure there is money to put it in place across the country.
- Make sure disability is part of all emergency plans. Make sure disability inclusion is in preparedness plans. Make sure it is in health emergency plans.

### **Improve how people with intellectual disabilities are treated in the healthcare system**

- Put a good plan in place. Make sure people with intellectual and other disabilities are treated fairly in the healthcare system. The plan should include the following areas.
  - Access to healthcare
  - The non-medical part of a person's health
  - Being treated unfairly in the medical system

The plan should have input from many different medical professionals. The plan should be co-designed. It should be made with input from people with an intellectual disability and their families.

- Put disability inclusion into all new health systems. Put it on policy agendas. Make sure there is a policy on fair and equal access to healthcare. People with an intellectual disability and their families are diverse. They must be considered and included in all health systems. This work cannot wait.