

# Position on Access to Healthcare



This document is Inclusion Canada's position statement on access to healthcare. At Inclusion Canada, our position statements guide our advocacy and our work. They help to define our vision of inclusion.

## Overview

People with an intellectual disability have a right to the highest attainable standard of health, without discrimination.<sup>1</sup> This right is not being fully realized in Canada. To achieve this right, all people with an intellectual disability must be granted equitable access to healthcare.

Inclusion Canada recommends that equitable access to healthcare be pursued by [addressing existing barriers](#), [building capacity for inclusive person-directed care](#), and [taking a coordinated approach to change](#). These efforts must be paired with broader initiatives that respond to systemic ableism and its relationship with prevailing social determinants of ill health.

[To move directly to our calls to action, click here.](#)

***Anonymized stories throughout this document shine a light on the barriers faced by people with an intellectual disability in accessing healthcare.***

***Justin's Story:*** Justin lives with his twin brother Sam. Sam noticed that Justin was struggling to leave the house and didn't seem to be enjoying his favorite pastimes. Sam asked his networks to recommend a therapist confident in treating people with an intellectual disability. Everyone agreed that the best option was Dr. Jones. The only problem was that Dr. Jones wasn't accepting new patients. Sam helped Justin look for other options and was repeatedly told, "Sorry I don't have the expertise you need." Meanwhile, Justin's mental health deteriorated until he was admitted to hospital in crisis.

## Policy Context

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

Access to healthcare is a priority for Inclusion Canada because it profoundly affects people's lives. People with an intellectual disability are both more likely to require

access to healthcare and less likely to be granted equitable access.

- Intellectual disability is not a sickness, disease, or cause of death.<sup>ii</sup> However, it is known to co-occur with medical conditions that require access to healthcare.<sup>iii</sup> People with an intellectual disability and co-occurring medical condition can be problematically subjected to extended hospital stays, which, for all people, are known to increase risk of infection and physical and psychological harm.<sup>iv</sup>
- People with an intellectual disability have a shorter lifespan than the general population.<sup>v</sup> And yet we know that premature death is not natural or given. Ableism is the belief that it is “normal” to not have a disability and that “normal” is preferred.<sup>vi</sup> Ableism, like sexism, racism, and other forms of discrimination, makes people sick. Ableism also leads health system personnel to ignore lived experience, blame symptoms on a person’s disability, and withdraw support in the belief that nothing they do will help.<sup>vii</sup> It is the root cause of the many barriers that people with an intellectual disability face in accessing healthcare in Canada.
- Dignified quality healthcare is achievable. Certain Canadians with an intellectual disability have had positive experiences accessing healthcare throughout their life. This is particularly the case for those with strong support systems, practiced in self-advocacy, with an established approach to medical decision-making, and/or those with longer-term relationships with well-trained and open-minded physicians. These individual success stories demonstrate what is possible.

### **What needs to be done?**

While health is an issue of provincial jurisdiction in Canada, the provisions of the UN *Convention on the Rights of Persons with Disabilities* (CRPD) extend to all parts of federal states without any limitations or exceptions.<sup>viii</sup> This means that the federal government has an important role to play in advancing access to healthcare for people with an intellectual disability.

Equitable access to quality healthcare is a top priority for Canadians. As decision-makers progress toward reform in response to the COVID-19 pandemic, the health and wellness of people with intellectual and other disabilities must be prioritized. The unique needs of people with an intellectual disability and their families can no longer be treated as an afterthought to the priorities of the public at large.

***Johanna's Story:** When Johanna's family physician retired, she spent longer than most waiting for a new doctor. Her new doctor's office needed to be on a public transit route, as Johanna's limited budget didn't allow for additional trips by accessible taxi. At their first appointment, Johanna's new doctor said he was surprised that she had never had a mammogram. He asked Johanna why she refused past screenings, but Johanna had no recollection of ever being asked about cancer screening. Johanna's doctor helped her to book an appointment at the hospital, which has an accessible mammography machine. They chose to book the appointment a few months out so that Johanna could put money aside for transportation costs. Johanna tested positive for advanced-stage breast cancer which should have been caught sooner.*

## Discussion

**Examples of how ableism makes people with an intellectual disability sick are as follows:**

- Education helps a person to get a well-paying job and to make decisions about their health. People with an intellectual disability have limited access to education and are less likely to have the opportunity to pursue higher education. Learn more at [Inclusive Education Canada](#).
- A well-paying job enables a person to spend money on things that keep them healthy and provides routine and social networks that promote well-being. People with an intellectual disability are more likely to be underemployed and unemployed. Learn more from the Inclusion Canada [position on work and jobs](#).
- A sufficient and consistent income allows a person to afford nutritious foods, safe housing, reliable transportation, and other necessities. People with an intellectual disability are significantly more likely than the general population to live in poverty. Learn more from the Inclusion Canada [positions on income security for individuals](#), and [income security for families](#).
- Safe, accessible, stable, and person-directed housing has a positive impact on a person's health. Being institutionalized or homeless has a negative impact on a person's health. Learn more from the Inclusion Canada [position on housing](#).

**Examples of barriers that people with an intellectual disability face in Canada's healthcare systems are as follows:**

- Primary healthcare: Most primary care clinics are cramped and overstimulating. Medical appointments are often rushed. Information is rarely easy to understand. Health system personnel don't always treat people with an intellectual disability

with respect. When a person expresses their fear or displeasure, they risk being labeled as uncooperative or violent, often leading to sedation or the use of restraints.

- Medical decision-making: A person's right to choose can come under threat in medical settings. Supported decision-making is not yet the norm in Canada. Learn more from the Inclusion Canada [position statement on legal capacity](#).
- Diagnostics and disease prevention: People with an intellectual disability are less likely to have routine cancer screenings including Pap tests, mammograms, and colonoscopies.<sup>ix</sup> This can happen for many reasons, including a medical professional deciding that the test will cause too much distress, a clinic not having enough assistance or equipment to transfer a person from their wheelchair,<sup>x</sup> a person requiring specialized screening (e.g., a sedated MRI), and the need to book a follow-up appointment due to limitations on appointment times - adding both administrative and logistical barriers to testing.<sup>xi</sup>
- Healthcare in times of emergency: During the COVID-19 pandemic, some provinces made having an intellectual disability a reason to be triaged out of life-saving care. Vital support people were not allowed to enter hospitals. Despite being more likely to test positive for COVID-19, to be hospitalized from COVID-19, and to die from COVID-19,<sup>xii</sup> vaccine uptake has been low due to a multitude of barriers.<sup>xiii</sup>
- Mental healthcare: Canada's one-size-fits-most approach to mental healthcare leaves people with an intellectual disability underserved and with fewer options available to them. Many mental health professionals do not feel equipped to diagnose and treat people with an intellectual disability and co-occurring mental illness. Some people have their symptoms brushed off as behaviors or as part of life with an intellectual disability. Others are over-medicated with psychiatric medications.<sup>xiv</sup>
- Medical assistance in dying (MAiD): In 2021, Canada legalized doctor assisted suicide for eligible people with disabilities. Persons with intellectual and other disabilities report that Canada's MAiD law has eroded trust and made accessing healthcare less safe. Learn more from Inclusion Canada's [position on medical assistance in dying](#).

***Nicolas' Story:** Nicolas' negative experience began in triage. Nicolas' parents could see that the nurses were uncomfortable around him, maybe even afraid. When he was admitted, they administered a large dose of medication to manage Nicolas' pain and – his parents suspect – his behavior. Because Nicolas was over-medicated, he didn't excel in his follow-up physiotherapy. Because his physiotherapy treatment plan didn't advance as anticipated, his discharge was delayed, and it was suggested that Nicolas may benefit from long-term use of a wheelchair. As is very common, Nicolas acquired an infection while hospitalized.*

## **Inclusion Canada is of the view that urgent action is required in the following areas:**

### **Address Barriers through Systems and Culture Change**

- Enable person-directed care and promote individualized access plans. Make accommodations such as in-home appointments, sensory friendly supports and exam spaces, and longer appointments widely available.
- Enable medical decision making using a supported decision-making model. Protect people with an intellectual disability's right to decide.
- Improve access to information. Provide widespread access to health information in plain language and easy-to-understand formats.
- Integrate care and invest in patient navigation. Provide support both to people with an intellectual disability, to their families, and paid staff as they navigate complex and all too often siloed healthcare systems.
- Make routine training on disability, ableism, and related barriers mandatory for professionals, staff, and students working within the field of healthcare and medicine, including those providing mental health care. The training should be designed and led by persons with intellectual and other disabilities and their families.

### **Build capacity for inclusive person-directed care**

- Equip all health system personnel with the foundational knowledge necessary to facilitate people with an intellectual disability's access to healthcare at every access point within their community. Promote universal access to inclusive

healthcare across Canada.<sup>xv</sup>

- Develop a network of professional expertise. All health system personnel must be able to consult with, and as appropriate refer to, colleagues who have greater expertise in the assessment, accommodation, or treatment of persons with an intellectual disability.
- Champion and firmly establish universal design in healthcare and avoid segregation within specialty clinics.

As per the UN CRPD: “‘Universal design’ means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. ‘Universal design’ does not exclude [accommodation] for particular groups of persons with disabilities where this is needed.”

- Recognize lived experience:
  - Listen to self-advocates; they know their bodies best.
  - Designate and empower essential support people. Families<sup>xvi</sup> and trusted support staff play a vital role in assisting people with an intellectual disability to access healthcare; they are familiar with a person’s preferences, baseline, and communication style.

**Wren’s Story:** *Wren is the parent of a person with an intellectual disability living in a remote prairie town. When Wren’s daughter complained of an earache, she booked her an appointment at her town’s drop-in clinic. Upon arrival, the administrative staff asked if Wren knew about the new specialty clinic that had just opened in a nearby city that provides care to “people like her daughter.” Wren explained that it is important that her daughter be able to access healthcare close to home, alongside her neighbours, just like anybody else, and that a referral to a specialist would only be beneficial if her daughter’s pain was symptomatic of her disability, which she did not believe to be the case in this instance. Wren’s daughter’s ear infection quickly improved with an antibiotic.*

## Take a Coordinated Approach to Improving Access to Healthcare

- Invest in research. Develop a national health policy and systems research agenda on disability. Pilot initiatives aimed at reducing barriers and advancing access to healthcare for persons with an intellectual disability. As a Learning Health System, implement, evaluate, and evolve health improvement projects.

- Monitor and evaluate the extent to which the health sector is enabling or supporting access to healthcare. Monitor which interventions work and where improvements are needed.
- Fund and implement a national intellectual disability mental health strategy.
- Integrate disability inclusion into preparedness and response plans for health emergencies.

**To improve health equity for this population across Canada,**

- Adopt a federally coordinated health equity strategy for people with intellectual and other disabilities. The health equity strategy should address a) access to healthcare, b) social determinants of health, and c) medical ableism. The health equity strategy should engage a broad spectrum of medical professionals and be co-designed with people with an intellectual disability and their families.
- Integrate disability inclusion into all emergent health systems change efforts. Equitable access to healthcare is on policy reform agendas across Canada. People with an intellectual disability and their families in all their diversity must be adequately considered and included. This work cannot wait.

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<sup>i</sup> See article 25 of the UN Convention on the Rights of the Persons with Disabilities: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities#article-25>

<sup>ii</sup> Stankiewicz, Elizabeth et al. 2018. Patterns of mortality among adults with intellectual disabilities in Ontario. *Canadian Journal of Public Health* (109) 866-872: <https://www.jstor.org/stable/10.2307/27174110>

<sup>iii</sup> Intellectual disability is known to co-occur with medical conditions such as thyroid dysfunction, epilepsy, cardiac disease, dementia, obesity, diabetes, and some psychiatric conditions. This is not an exhaustive list.

<sup>iv</sup> The lived experience of self advocates and family members within the Inclusion Canada federation align with those captured in this UK based study, which indicates that people with intellectual and developmental disabilities are more likely, in hospital, to “experience harm... leading to an excess length-of-stay in hospital and increased mortality risk.” Friebel, Rocco, and Laia Maynou. 2022. Assessing the dangers of a hospital stay for patients with developmental disability in England, 2017-2019. *Health Affairs* (Vol 41 no 10). <https://www.healthaffairs.org/doi/10.1377/hlthaff.2022.00493>

<sup>v</sup> Pimlott, Nicholas. 2019. Aging with intellectual and developmental disabilities : Family physicians can make a difference. *Canadian Family Physician* (Vol 65): [https://www.cfp.ca/content/cfp/65/Suppl\\_1/S3.full.pdf](https://www.cfp.ca/content/cfp/65/Suppl_1/S3.full.pdf)

<sup>vi</sup> For more information, see Inclusion Canada’s campaign “This is Ableism” at <https://inclusioncanada.ca/this-is-ableism/>

<sup>vii</sup> Villines, Zawn. 2021. What is ableism, and what is its impact? *Medical News Today*. <https://www.medicalnewstoday.com/articles/ableism>

<sup>viii</sup> See Article 4 of the UN Convention on the Rights of Persons with Disabilities: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities#article-4>

<sup>ix</sup> Breau, Genevieve, et al. 2022. Family physicians’ and trainees’ experiences regarding cancer screening with patients with intellectual disability: An interpretive description study. *Journal of Intellectual Disabilities* (27:1): <https://journals.sagepub.com/doi/full/10.1177/17446295211044041>

<sup>x</sup> Devaney, Julie et al. 2009. Navigating healthcare: gateways to cancer screening. *Disability and Society* (24:6) 739-751. <https://www.tandfonline.com/doi/abs/10.1080/09687590903160233>

<sup>xi</sup> Breau, Genevieve, et al. 2022 and Devaney, Julie et al. 2009

<sup>xii</sup> Lunskey et al. 2022. COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada. *Disability and Health Journal* Jan 15 (1). <https://pubmed.ncbi.nlm.nih.gov/34340949/>

<sup>xiii</sup> For example, in a series of focus groups, families reported that without relevant information, they worried their family member was the exception to the rule that vaccines are safe, and that they feared going into a vaccine clinic without necessary support on hand. Additionally, more than 70% of people with an intellectual disability found vaccine information overwhelming and difficult to understand.

<sup>xiv</sup> Lunskey et al. 2018. Antipsychotic Use With and Without Comorbid Psychiatric Diagnosis Among Adults with Intellectual and Developmental Disabilities. *Canadian Journal of Psychiatry*. <https://pubmed.ncbi.nlm.nih.gov/28830241/>

<sup>xv</sup> We are aware that there is already work underway to improve access to healthcare for people with intellectual disabilities. For example, see the [2018 Canadian Consensus Guidelines on Primary Care for Adults with Intellectual or Developmental Disabilities](#).

<sup>xvi</sup> At Inclusion Canada, we understand a family to consist of two or more people, living together or apart, related by blood, marriage, adoption, or a commitment to support one another.