

EXECUTIVE SUMMARY

This participatory community-based research study reveals that current healthcare systems across Canada largely fail to adequately meet the unique needs of persons with intellectual disabilities and/or persons with autism. In exploring current practices and understandings of healthcare systems related to how they provide—or do not provide—services for individuals with intellectual disabilities and/or persons with autism, as well as the ways by which family members and advocates intervene when healthcare services fail to meet standards of practice, interviews with 21 stakeholders across Canada were conducted. The findings of this qualitative methods study revealed numerous systemic barriers and attitudinal barriers that negatively impact the healthcare of persons with intellectual disabilities and/or persons with autism.

Alongside this data collection, an abridged literature review was conducted to corroborate the study's findings and underpin its recommendations related to healthcare policies. These recommendations are offered as potential healthcare enhancements to mitigate the systemic barriers and attitudinal barriers to quality healthcare for persons with intellectual disabilities and/or persons with autism. A second phase of this study may be conducted to further investigate evidence-based strategies that address the barriers revealed through this research.

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ACKNOWLEDGEMENTS

If you have a friend, family member, neighbour, or work associate who has an Intellectual Disability or Autism, or, if indeed you have lived experience of these, you know firsthand how difficult it can be to receive good health and medical care. As members of the Human Rights Committee of Community Living Manitoba, we all shared experiences of how people we cared about had been poorly treated by the health system—in ways that did not reflect their inherent value and their full human rights.

We would like to acknowledge the Board of Directors of Community Living Manitoba for sharing this concern and for their support and funding of this project. We acknowledge their abiding commitment to the pursuit of fulsome and equal health care for every Manitoban.

We would also like to acknowledge Dr. Terra Johnston, the researcher on this project. She captured what the committee was trying to accomplish and identified historical health care issues that carry on to this day for people with Intellectual Disabilities and Autism. She went beyond personal stories to identify trends and summarize issues within Manitoba and the broader community.

Lastly, we would also like to acknowledge the time, knowledge and experience that was shared by all the contributors including service providers, advocates, allies and of course people who have experienced firsthand the inequities of the health care system. They have provided the foundation that will, ideally, lead to solutions that will improve health and medical care.

ABOUT COMMUNITY LIVING MANITOBA

Community Living Manitoba is dedicated to the full inclusion of persons of all ages who live with an intellectual disability. Living, working and learning in an inclusive community means that all people — including those with an intellectual disability — have a variety of opportunities to contribute to their communities.

We are a board governed, grassroots organization that has always been comprised of self-advocates, family and community members, as well as members of Local Branches throughout the province.

Our vision: An inclusive Manitoba in which people with an intellectual disability are valued equally and are able to participate fully in all aspects of Society.

Our mission: The Manitoba Association for Community Living is a registered charity leading the way to building an inclusive Manitoba for individuals with an intellectual disability. We do this through strengthening families, defending rights and transforming communities into places where everyone can belong.

For more information on Community Living Manitoba, contact us at:
204-786-1607 or aclmb@aclmb.ca.



INTRODUCTION

This participatory community-based research study, called *Exploring Healthcare Experiences of Persons with Intellectual Disabilities and/or Persons with Autism*, was guided by a steering committee comprised of the following members of the Community Living Manitoba Human Rights Committee: Debra Roach, Cheryl Martens, and Sid Rogers. Conducted by Dr. Terra Johnston (PhD, RSW), with funding support provided by Community Living Manitoba, this research study examined the quality of experiences of persons with intellectual disabilities and/or persons with autism with healthcare systems across Canada and in Manitoba. Our research study also took into consideration the impacts of COVID-19 on healthcare system experiences.

To ensure our research findings are easy to interpret and free of any stigmatizing language, this report was reviewed by our steering committee and stakeholders, including persons with lived experience. Further, to uphold standards of validity and reliability in qualitative research, preliminary data findings were presented to our research participants for their review, feedback, and corroboration.

Pending confirmation of continued funding support, subsequent phases of our research study may focus on recommending strategies for addressing the issues revealed from our research. Preliminary work in this area is found in the Healthcare Policy Recommendations section of this report.

RESEARCH SCOPE AND DATA COLLECTION METHODS

Our research study was guided by the following **research questions**:

1. How are healthcare systems performing in recognizing, understanding, and serving the needs of persons with intellectual disabilities?
2. What do families and support professionals need to know about their rights and legitimate expectations with regard to navigating healthcare systems and advocating on behalf of persons with intellectual disabilities?

With regard to the first question, we explored current practices and understandings of healthcare systems related to how they provide—or do not provide—services for individuals with intellectual disabilities and/or persons with autism. With regard to the second question, we explored the ways by which family members and advocates intervene when healthcare services fail to meet standards of practice.

To explore these research questions, we conducted interviews with 21 stakeholders across Canada, including persons with lived experience, support professionals, advocates, researchers and policy makers. See [Appendix A and B](#), respectively, for the informed consent form and the interview guide used to support this qualitative data collection. **Our research participants represented the following jurisdictions:**

- National (3 interviewees)
- Manitoba (9 interviewees)
- British Columbia (1 interviewee)
- Alberta (1 interviewee)
- Saskatchewan (1 interviewee)
- Ontario (1 interviewee)
- Quebec (1 interviewee)
- Nova Scotia (1 interviewee)
- New Brunswick (1 interviewee)
- Yukon (1 interviewee)
- Northwest Territories (1 interviewee)

In addition to these interviews, we conducted an **abridged literature review** to investigate our two research questions. The findings of the literature review are integrated with the data findings from our interviews. See [Appendix D](#) for a reference listing of the reviewed literature.

RESEARCH FINDINGS

The following section provides an overview of experiences and issues related to healthcare for persons with intellectual disabilities and/or persons with autism, informed by the feedback collected through our research study and our abridged literature review.

Social Injustices: Past and Present

While the legacy of social injustice and human rights violations, including practices of **eugenics**, against persons with intellectual disabilities and/or persons with autism was not a focus of our interviews, several interviewees offered this **important context** when describing the unique needs of persons with intellectual disabilities and/or persons with autism and their experiences with healthcare systems.

In the words of one interviewee: ***“There is a history of eugenics for people with disabilities. Terrible things happened, and not all that long ago”***. [J.F.]

The egregious historical practices of eugenics must be recognized in today's context of healthcare provision and access for persons with disabilities.

Historical practices of **institutionalization** were also raised by several interviewees as another important contextual factor that influences the current status of healthcare provision and access for persons with intellectual disabilities and/or persons with autism.

In the words of two of our research participants:

“Even though institutionalization is [largely] in the past, persons with an intellectual disability may still carry an institutional mindset, and it is important to recognize this and be sensitive to this”. [C.B.]

“After [our jurisdiction] closed its large institutions in 1996, at that point when people were moving en masse into community we created something in [our jurisdiction] called the [name of program for specialized medical service for persons with intellectual disabilities]. We had this regulated body...to ensure equity across the province...and that office was really a pillar for over a decade. And then the funding started to dwindle, and the idea was there would be a wholistic approach to healthcare and that people would be able to get their healthcare in the same way as the rest of the citizens. Now did that happen? No.” [K.V.]

Given these findings, it is important for healthcare policy makers and healthcare professionals to understand this historic social injustice, recognize its current day impacts, and, through concerted efforts such as trauma-informed training, develop **practice guidelines** that remedy these past harms and establish positive relationships going forward.

This data finding is reflected in the academic literature, particularly as it relates to the limited capacity of current-day healthcare systems in meeting the healthcare needs of persons with intellectual disabilities and/or persons with autism. According to some policy experts, while the shift toward community-based living for persons with intellectual disabilities—which began in the 1970s and 1980s—was widely heralded by the disability community, the capacity of community-based healthcare (e.g., physician clinics, primary healthcare centres) was not strengthened to successfully meet the resulting increased demand¹.

In this way, the shift toward community-based living should be seen as just one part of the solution—albeit a fundamental one—toward righting the past wrongs against persons with disabilities. Further steps must be taken, including the sufficient resourcing of healthcare systems (as well as education and social service systems) that truly meet the varied and unique needs of all Canadians. Recognizing the continued impact of historic social injustice against persons with disabilities, including persons with intellectual disabilities and/or persons with autism, is essential in **reconciling this legacy of harm and ensuring the human rights of all persons, including the right to quality healthcare, are upheld at long last.**

¹ Balogh, Hunter & Ouellette-Kuntz, 2015

With regard to the current context of healthcare access as a protected human right, nearly all of our research participants indicated they knew of incidents whereby the right to accessible healthcare for persons with intellectual disabilities and/or persons with autism was compromised or denied; thus, suggesting **the legacy of social injustice against persons with intellectual disabilities and/or persons with autism continues to cause harm to this day**. Further, when referencing accessibility legislation Acts, policies and/or international treaty law (e.g., Accessibility for Manitobans Act; Accessibility for Ontarians with Disabilities Act; Canada’s Charter of Rights and Freedoms; United Nations Convention on the Rights of Persons with Disabilities), all of our research participants stated that, in their opinion, accessibility legislation has failed to make a positive difference in the lives of persons with disabilities.

In the words of six of our research participants:

“The verdict is still out on the AMA [Accessibility for Manitobans Act]”. [J.F.]

“The AODA [Accessibility for Ontarians with Disabilities Act] has made no positive difference”. [C.B.]

“In Manitoba, the limited focus on the design of public spaces will not address issues of inaccessibility concerning the built environments of healthcare settings”. [L.F.]

“The problem is there are no human rights police”. [B.U.]

“One of the most intense needs [related to healthcare] is around access and health equity and how [persons with intellectual disabilities and/or persons with autism] can even just get through the door”. [S.W.]

“There are gaps of inequity to gaping holes [of inequity]”. [K.V.]

This finding suggests that provincial, national, and international accessibility legislation, in and of themselves, are not enough to ensure accessibility. Such policy instruments must be accompanied by:

- resources (e.g., financial grants, education and training) that support systems to be accessible;
- complaint mechanisms that facilitate the timely resolution of inaccessibility issues;
- compliance frameworks that monitor and evaluate system accessibility; and
- remedial efforts that ensure inaccessibility issues, and repeat offenders of such issues, are responded to appropriately.

Fiscal Rationale

Notwithstanding the human rights argument for accessible quality healthcare for persons with intellectual disabilities and/or persons with autism², as mentioned above, there is a strong fiscal rationale to be made in support of improving accessibility and quality of healthcare for this population³. Canadian data suggests children and adults with intellectual disabilities comprise 1-3% of the population⁴, though they have healthcare costs that are higher compared to the general population⁵.

Evidence suggests persons with an intellectual disability experience a higher rate of health problems than the general population (e.g., psychiatric disorders, seizure disorders, gastrointestinal disorders and infections, dental disease) and this higher rate of health problems is associated with a higher healthcare expenditure rate⁶. A recent Ontario-based fiscal analysis illustrates that persons with intellectual disabilities, in general, have healthcare costs that are **four times higher** compared to persons without intellectual disabilities⁷. Further, persons with intellectual disabilities who have greater healthcare needs are more likely to be female, older, living in group homes, and receiving disability income support⁸. The high healthcare costs for persons with intellectual disabilities are associated with:

- greater hospitalization rates, especially psychiatric hospitalization;
- continuing care/rehabilitation; and
- medication costs⁹.

With regard to the above finding that persons with intellectual disabilities experience hospitalization at rates higher than persons without intellectual disabilities¹⁰, there is evidence to suggest that this may reflect problems with access to **preventive healthcare**, including health promotion, screenings and early intervention. The most common reasons for hospitalization for persons with intellectual disabilities are related to mental health disorders and dental disease¹¹. In response to this finding, **enhancements to preventive healthcare, including mental health promotion and preventive dental care, must be considered as fiscally-sound healthcare policy**¹².

² Silvers, 2004

³ Balogh, Hunter & Ouellette-Kuntz, 2015; Lunsky, De Oliveira, Wilton & Wodchis, 2019

⁴ Nachshen, Martin-Storey, Campisi, Schwartzman & Servin, 2005

⁵ Lunsky, De Oliveira, Wilton & Wodchis, 2019

⁶ Balogh, Hunter & Ouellette-Kuntz, 2015; Nachshen, Martin-Storey, Campisi, Schwartzman & Servin, 2005

⁷ Lunsky, De Oliveira, Wilton & Wodchis, 2019

⁸ Lunsky, De Oliveira, Wilton & Wodchis, 2019

⁹ Lunsky, De Oliveira, Wilton & Wodchis, 2019; Balogh, Hunter & Ouellette-Kuntz, 2015

¹⁰ Balogh, Hunter & Ouellette-Kuntz, 2015

¹¹ Balogh, Hunter & Ouellette-Kuntz, 2015

¹² Balogh, Hunter & Ouellette-Kuntz, 2015; Lunsky, De Oliveira, Wilton & Wodchis, 2019

This finding from the academic literature is corroborated by our research study whereby several of our research participants identified a lack of mental health supports, including diagnostic services, for individuals with intellectual disabilities and/or autism, especially children as a significant limitation in current healthcare systems across Canada. Additionally, several of our research participants identified issues with dental care systems, including rigid coverage policies that do not accommodate the visitation needs of persons with intellectual disabilities and/or persons with autism. These examples are further detailed in the subsequent Illness Prevention and Health Promotion section.

Illness Prevention and Health Promotion

According to the academic literature, there are a number of unique healthcare needs for persons with intellectual disabilities and/or persons with autism. As described above, persons with intellectual disabilities are less likely to receive *preventive healthcare* at the same rate as persons without intellectual disabilities; indeed, nearly **45% of persons with intellectual disabilities do not receive recommended preventive care** through their primary care provider¹³, including optometry, physiotherapy, and pap tests¹⁴.

This finding of the academic literature was also reflected in our research study; nearly all of our research participants indicated the lack of preventive healthcare as a significant risk factor to the health and well-being of persons with intellectual disabilities and/or persons with autism. As indicated by our research participants, cancer screenings such as pap tests, mammograms, and prostate exams were commonly cited as examples of preventive healthcare that are largely not offered, unless requested, to persons with intellectual disabilities and/or persons with autism.

Another finding from the academic literature indicates that persons with intellectual disabilities “higher rates of obesity”, with prevalence rates twice as high compared to persons without intellectual disability, a health risk that is likely related to a sedentary lifestyle¹⁵. Again, this finding from the literature was reflected in our research study, with several research participants stating that the health and well-being of persons with intellectual disabilities and/or persons with autism is often compromised by **insufficient resources that support healthy living**. These research participants pointed to enhanced health promotion strategies, such as:

- exercise, sport and recreation;

¹³ Ouellette-Kuntz, Smith, Fulford & Cobigo, 2018

¹⁴ Maltais, Morin & Tasse, 2020

¹⁵ Nachshen, Martin-Storey, Campisi, Schwartzman & Servin, 2005, p. 249

- social connection;
- mental wellness and self-care; and
- nutrition education.

Indeed, it was suggested by several research participants that expanded resources, including free to low-cost health promotion programming (e.g., gym memberships, walking groups, cooking classes, arts and crafts) with transportation and participation facilitated by support professionals, must be recognized as important investments in the healthcare system for persons with intellectual disabilities and/or persons with autism. Importantly, an emphasis was placed on the value of **social engagement and community inclusion**, as an essential component of health promotion strategies.

Mental healthcare is an important consideration in the healthcare of persons with intellectual disabilities and/or persons with autism. According to the academic literature, persons with intellectual disabilities have a higher prevalence of mental health problems in comparison to persons without intellectual disabilities¹⁶. And, because of inaccessible and poorly equipped mental health services for persons with intellectual disabilities, these individuals must often turn to emergency hospital care in times of a psychiatric crisis¹⁷.

Further, caregivers of persons with intellectual disabilities (e.g., family members and support professionals) indicate a lack of services; services that are not provided with dignity, respect and understanding of intellectual disability; **diagnostic overshadowing**¹⁸; and overmedication as prevalent concerns related to mental healthcare for persons with intellectual disabilities¹⁹. **Additional specialized services and enhanced training for service providers** are recommended to meet the established need for mental health services for persons with intellectual disabilities²⁰.

This finding from the academic literature was also corroborated by our research participants.

In the words of three of our research participants:

“Loneliness has a huge impact on health and mental health. And a person’s social needs are not met just because they live in a group home setting”. [J.F.]

“People with intellectual disabilities typically have poorer health than their non-disabled peers and many of their health concerns could potentially be avoidable should they have equitable access to early screening or appropriate support when seeking medical attention”. [S.W.]

¹⁶ Brown, Cobigo, Lunsky, Dennis & Vigod, 2016; Lunsky, Garcin, Morin, Cobigo & Bradley, 2007; Weiss, Lunsky, Gracey, Canrinus & Morris, 2009

¹⁷ Weiss, Lunsky, Gracey, Canrinus & Morris, 2009

¹⁸ See page 9 for definition.

¹⁹ Weiss, Lunsky, Gracey, Canrinus & Morris, 2009

²⁰ Lunsky, Garcin, Morin, Cobigo & Bradley, 2007; (Weiss, Lunsky, Gracey, Canrinus & Morris, 2009

"This population does not receive early screenings like annual pap tests, and it is important we ask why". [S.W.]

"They [persons with disabilities] get the bare minimum for dental care, bare minimum for vision care, bare minimum for medical coverage...they [persons with disabilities] cannot access wellness in the same way". [K.V.]

"For mental healthcare, there really is not the service system to support people, so they get juggled around. So early intervention is not really a thing...if you are presenting with a mental health symptom or crisis you'll often get--well that's a behaviour that's not mental health." [K.V.]

Further, our research participants identified several other areas of illness prevention and health promotion that are currently limited in their capacity to meet the needs of persons with intellectual disabilities and/or persons with autism. These include:

- Substance use treatment
- Diabetes care
- Seniors care
- Hearing loss
- End of life care
- Healthcare in Corrections/Justice
- Gynecological healthcare for women with mobility challenges

Systemic Barriers to Access

As detailed below, the current healthcare systems across Canada reflect multiple systemic barriers that disproportionately impact a population of people with the highest medical needs.

Lack of Training

As described in the above section, individuals with intellectual and developmental disabilities face greater challenges in accessing healthcare services, especially healthcare specialists²¹. As a result, health conditions are often undiagnosed or diagnosed later in persons with intellectual disabilities and/or persons with autism²². Further, when persons with intellectual disabilities do access healthcare services, their healthcare provider might not be adequately trained to

²¹ Maltais, Morin & Tasse, 2020

²² Maltais, Morin & Tasse, 2020

support their unique needs, such as communication differences, environmental sensitivities, and undiagnosed pain²³.

This finding from the academic literature is corroborated by our research study. All of our research participants indicated **lack of training among healthcare providers as one of the most significant barriers** in providing healthcare to persons with intellectual disabilities and/or persons with autism. Further, according to our research participants, this lack of training among healthcare providers is the likely reason for chronic undiagnosed pain (e.g., tooth pain, constipation) among persons with intellectual disabilities and/or persons with autism. Many of our research participants suggest undiagnosed pain among persons with intellectual disabilities and/or persons with autism is commonly associated with diagnostic overshadowing (i.e., over-attributing a person's symptoms and/or behavior to their disability), which then results in over-medication (e.g., sedating a person to minimize their 'challenging behaviours' versus treating their undiagnosed pain). To this end, many of our research participants cited **specialized training and resource tools that help healthcare professionals diagnose pain** in non-speaking patients as an urgent recommendation required to end this common injustice in healthcare practices.

In the words of five of our research participants:

"All too often they [healthcare providers] throw medication at the problem instead of looking for the root cause". [G.R.]

"Some oppositional behaviours are interpreted by healthcare professionals as a refusal of care associated with the disability, instead of being taken as a symptom of a real illness". [S.C.]

"Our healthcare system needs better tools to help doctors to diagnose pain, especially for people who are non-speaking". [M.W.]

"A lot of our healthcare professionals don't have access to training within their respective field, so if you've never seen someone with an intellectual disability and you have no clinical experience supporting them, then when they encounter them, we see that healthcare professionals are well-meaning, but they don't have the experience they need." [M.W.]

"It's not to say that there aren't healthcare practitioners, from dentists to nurses to surgeons who haven't exemplified what is best practice [in providing healthcare to persons with intellectual disabilities and/or persons with autism], but the challenge is they are not in sufficient numbers. It's a systemic issue in many ways." [B.U.]

"The first thing a physician should do is look for undiagnosed pain". [L.F.]

²³ Maltais, Morin & Tasse, 2020

Communication and Time

According to the academic literature, persons with intellectual disabilities and/or persons with autism are more likely to experience **communication barriers** related to healthcare, including challenges in understanding which health services are important to obtain in order to support their health and how certain symptoms they experience may lead to more serious medical issues²⁴. This finding is corroborated by our research participants, all of whom indicated communication challenges as a systemic barrier to accessible healthcare.

Connected to this systemic barrier is the added **challenge of time** in a fast-paced, fee-for-service healthcare system. To this end, all of our research participants indicated problems with a standard 15-minute appointment time per individual per health concern. Time limitations present unique barriers for persons with intellectual disabilities and/or persons with autism, given their higher prevalence rates of medical conditions (as described in the Fiscal Rationale section) and the additional obstacles they face in accessing healthcare, such as mobility challenges, arranging accessible transportation, and securing a caregiver to attend their appointment with them.

In the words of seven of our research participants:

“How do you get to the nuances of pain or symptoms in a short visit with a non-speaking individual or a person with an intellectual disability?”. [C.B.]

“If that patient [a person with an intellectual disability] feels rushed, they may shut down”. [M.W.]

“In our healthcare system you are restricted to one area of [medical] concern, and if you have multiple concerns, you have to book multiple appointments, and if you have sensitivities, lack of transportation, etc., you want to be able to cover as much as possible with one visit”. [P.N.]

“The pace at which our society operates can be really exclusionary, and yes, it shows up in the healthcare system, but it is a cross-cutting concern. If you’re a person who is marginalized and trying to survive day to day, it might take a little longer for you to equip yourself and engage in a consultation process. It [this fast pace] puts up a barrier in a doctor’s office or in a hospital.” [N.H.]

“Dismissing behaviour as just part of someone’s disability is not acceptable, behaviour is communication and it’s important we do a deep dive to really understand what the underlying issues are...we need to find ways that people with diverse cognitive disabilities are supported and heard.” [S.W.]

²⁴ Maltais, Morin & Tasse, 2020

“Different communication methods [of persons with intellectual disabilities and/or persons with autism] require extra time...time to listen...time to accommodate communication devices, and also better training [for the healthcare system] to understand why and how to take this extra time.” [B.U.]

“Not all, but some [healthcare professionals] don't talk to them [persons with intellectual disabilities and/or persons with autism] they talk around them”. [C.P.]

“If someone needs extra time or extra space [to get their healthcare needs met] the system is not really set up for that”. [K.V.]

Unsupported Needs

A Canadian study suggests persons with intellectual disabilities who live alone or with family members, compared to persons with intellectual disabilities who live in congregate care or group home settings, may experience poorer access to healthcare²⁵. This finding is supported by another study²⁶ which suggests persons with intellectual disabilities who live in group home settings compared to independent living settings experience better health outcomes; however, it must be noted that persons with intellectual disabilities who live alone in supported living arrangements, self-report greater satisfaction concerning their independence, freedom and privacy²⁷.

To this end, persons with intellectual disabilities and/or persons with autism who live independently may require enhanced support to ensure their healthcare needs are being met; though, importantly, this support should be offered in a way that respects and nurtures their independence. An example of such a support is the **Comprehensive Health Assessment Program**, described further in the Healthcare Policy Recommendations section.

The finding that persons with intellectual disabilities and/or persons with autism who live independently in community without supports may experience more barriers to healthcare access compared to counterparts who are supported by family members, caregivers, or support professionals was corroborated by several of our research participants.

In the words of two of our research participants:

“These folks [persons with intellectual disabilities and/or persons with autism who live independently] may face multiple barriers, such as poverty and a lack of housing, and may fall through the cracks in our healthcare system”. [J.F.]

²⁵ National Association of State Directors of Developmental Disabilities Services & Human Services Research Institute, 2019 cited in Maltais, Morin & Tasse, 2020

²⁶ Stainton, Brown, Crawford, Hole & Charles, 2011

²⁷ Stainton, Brown, Crawford, Hole & Charles, 2011

“My worry as an advocate is when you don’t have that support system, and you get rushed through and you don’t necessarily understand what is happening and that has created an inequity in our system.” [K.V.]

Complicating Disadvantages

Examining the healthcare experiences of persons with intellectual disabilities and/or persons with autism through an **intersectionality lens** reveals the complicating nature of multiple barriers. For example, Newcomers (immigrants or refugees) with intellectual disabilities experience greater incidences of mental health disorders, including psychosis²⁸; adults 40 years and older with intellectual disabilities experience a larger prevalence of unmet healthcare needs²⁹; and children with intellectual disabilities who have co-occurring mental health disorders, especially those who live in low socio-economic households³⁰ and those who live in households with high levels of family dysfunction³¹ experience a greater likelihood of negative health outcomes.

When asked to identify healthcare barriers through an intersectionality lens, our research participants indicated a number of factors and variables that complicate the healthcare needs of persons with an intellectual disability and/or persons with autism, including **gender** (e.g., those who identify as female, non-binary, or transgendered), **age** (e.g., childhood to adulthood transition years; older adults), sexual identity (e.g., LGBTQ), **race and ethnicity** (e.g., Indigenous, persons of colour), those who live in **isolated communities**, and those who have a history with the **child welfare system**.

In the words of six of our research participants:

“Women are often under-diagnosed for autism”. [S.U.]

“Women with intellectual disabilities are more vulnerable to violence, including sexual violence”. [J.F.]

“Our healthcare system is not timely, so often children age out of care and once they become adults the opportunity to receive their entitlements runs out”. [J.S.]

“We do not have a good system in place to support transgender persons who have an intellectual disability”. [L.F.]

“There is a rotating door of doctors in rural communities”. [L.E.]

²⁸ Durbin, Jung, Chung, Lin, Balogh & Lunskey, 2021; Durbin, Jung, Chung, Lin, Balogh & Lunskey, 2019

²⁹ Baumbush, Moody, Hole, Jokinen & Stainton, 2019; Martin, Ouellette-Kuntz & McKenzie, 2017a; Martin, Ouellette-Kuntz & McKenzie, 2017b; Shooshtari, Naghipur & Zhang, 2012

³⁰ Nachshen, Martin-Storey, Campisi, Stack, Schwartzman & Serbin, 2009

³¹ Stewart, Hassani, Poss & Hirdes, 2017

“There is also entrenched racism in our healthcare system. So, if you are not white, middle-class, with a support network, and with the intersection of a disability, you’re going to have a much different experience in [our jurisdiction]”. [K.V.]

Attitudinal Barriers to Access

In addition to the systemic barriers identified in the previous section, there is strong evidence to suggest **attitudinal barriers** exist within the healthcare profession, and that these attitudinal barriers impact negatively on the healthcare services accessed by persons with intellectual disabilities and/or persons with autism³².

For example, according to the academic literature, some physicians may be reluctant to perform surgical procedures on persons with intellectual disabilities due to their belief that these patients will be unable to ensure proper aftercare³³. Further, physicians can find it difficult to assess the need for surgery for persons with intellectual disabilities and/or persons with autism due to communication differences. Some research suggests there are underlying attitudinal barriers among physicians wherein they do not believe persons with intellectual disabilities need the same level of care as the general population³⁴.

In a recent USA-based study, only 50% of physicians strongly agreed that they would welcome people with disabilities as patients; while more than 80% of polled physicians reported that people with significant disability have a “worse” quality of life compared to people without disability³⁵. Moreover, 20% of physicians agreed that the USA-based healthcare system treated persons with disability unfairly³⁶. While this is a USA-based study, it provides evidence to suggest attitudinal barriers exist among physicians, and, in turn, that these barriers impact on the healthcare services provided to and accessed by persons with intellectual disabilities and/or persons with autism.

This finding was corroborated by several of our research participants who provided examples such as:

- physicians commonly begin the medical appointment by asking of the caregiver if a patient with an intellectual disability has a DNR (Do Not Resuscitate order);

³² Balogh, Hunter & Ouellette-Kuntz, 2015; Lezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Donelan, Lagu & Campbell, 2021; Ouellette-Kuntz, Burge, Henry, Bradley & Leichner, 2003; Sue & Mar 2021

³³ Balogh, Hunter & Ouellette-Kuntz, 2015

³⁴ Balogh, Hunter & Ouellette-Kuntz, 2015

³⁵ Lezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Donelan, Lagu & Campbell, 2021

³⁶ Lezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Donelan, Lagu & Campbell, 2021

- physicians do not attempt to communicate with a patient with an intellectual disability, rather they speak to and look at the caregiver instead; and
- physicians rarely provide reproductive healthcare to patients with an intellectual disability due to the misconception that this patient population does not have sexual health needs.

In the words of three of our research participants:

“Persons with disability often rate their quality of life higher than their doctor would rate it...so those assumptions about disability, layered in with other forms of discrimination, has an impact”. [N.H.]

“Physicians can have assumptions that treatments are too stressful, traumatic or difficult for a person with an intellectual disability, so they are not offered, chemotherapy, for example.” [M.W.]

"Assumptions and biases are very much a problem, they [healthcare professionals] may see a person as only their disability instead of, for example, seeing a woman, regardless of disability, as needing a pap test or a mammogram." [S.W.]

These same research participants attributed attitudinal barriers within the healthcare profession to a **lack of specialized education and training** in providing healthcare to persons with disabilities, including persons with intellectual disabilities and/or persons with autism, and a lack of experience in treating this patient population. Nearly all of our research participants suggested enhanced training and education, embedded within curricula (versus one-off workshops), and specialized resource tools to mitigate attitudinal barriers. For example, trauma-informed training that facilitates an understanding of past and current social injustices, as described earlier, would provide important context in positioning accessible healthcare as a human right to which persons with intellectual disabilities and/or persons with autism are entitled.

In addition to the finding of attitudinal barriers within healthcare systems, the academic literature also suggests persons with intellectual disabilities and their family members/caregivers are less likely to experience a positive relationship with their healthcare provider compared to persons without intellectual disabilities, a finding of special concern given the established relationship between positive health outcomes and a positive relationship between patients and healthcare providers³⁷.

This finding of the academic literature was also reflected in our research. Two participants who are the parents of adult children with intellectual disabilities described many of their relationships with the healthcare professionals of their children, over the course of decades, as

³⁷ Aston, Breau & MacLeod, 2014

being of **poor quality, characterized by a lack of bedside manner and empathy, and a rushed healthcare system** that could not accommodate their need for extra time and communication.

In the words of four of our research participants, including those with lived experience as parents of a person with an intellectual disability:

"It was hard to find a physician, no one wanted him as a patient". [M.F.]

"All parents have hopes for their kids, disability or not. So, in thinking of hopes, how can you start moving toward that...in a healthcare context its having a system that's person-centred and person-directed...so they can live their best life". [C.B.]

"Behavioural issues were seen as being a part of his disability, instead of digging into the root of the problem, which, in our case was pain." [M.F.]

"We need a healthcare system that builds families back up, to give them permission to be positive". [C.B.]

"Parents [of persons with intellectual disabilities and/or persons with autism] may feel a reluctance to rock the boat. I have absolutely seen that." [L.F.]

The attitudinal barriers noted in the literature and brought forward by several of our research participants (e.g., physicians commonly begin the medical appointment by asking of the caregiver if a patient with an intellectual disability has a DNR) provide important context in the current policy debate over Medical Assistance in Dying (MAID). For example, we know of many people in the disability community who have expressed fear that **attitudinal biases toward persons with disabilities may influence life or death decision-making related to healthcare**. Our research findings provide evidence that legitimize this fear. The continued impact of attitudinal barriers toward persons with disabilities should be considered in healthcare policy related to end-of-life decision-making.

COVID-19 Impacts

While there is little academic literature regarding the impacts of COVID-19 on persons with intellectual disabilities and/or persons with autism and their experiences with healthcare systems, our research study provides timely anecdotal evidence on the pandemic. Indeed, the **pandemic has negatively impacted** on persons with intellectual disabilities and/or persons with autism with respect to their health and well-being, their access to healthcare, and their access to health promotion activities.

In the words of four of our research participants:

“Group homes want to keep people safe, but the restrictions are over-reaching...very restrictive, in some instances [they were] not even allowed outside on their property...It has been devastating for this population”. [P.N.]

“COVID has trampled over their human rights”. [C.B.]

“Support persons were not always allowed [in hospitals or clinics], especially at beginning”. [J.F.]

“Families had to take on a lot of caregiving during COVID shutdowns, which has been hard on families”. [G.R.]

HEALTHCARE POLICY RECOMMENDATIONS

With the deinstitutionalization movement in Canada came the integration of community-based healthcare services for persons with intellectual disabilities and/or persons with autism. In response to the community living movement, the capacity of Canada’s healthcare system was not adequately established to meet the increased need for healthcare services by persons with intellectual disabilities. An important step to redress this oversight and finally strengthen Canada’s healthcare system so that it can fully meet the needs of persons with intellectual disabilities and/or persons with autism is through physician and interprofessional healthcare provider training³⁸. Indeed, there is emerging evidence to suggest **a new training curriculum, developed by Queen’s University**, can increase knowledge, skills and positive attitudinal change in the healthcare professionals who receive such training³⁹.

Further, the close monitoring of the healthcare needs of persons with intellectual disabilities is a healthcare policy matter of great importance—both from a social justice perspective and a fiscal one. Resources such as the **Canadian Guidelines for Primary Care of Adults with Developmental Disabilities** are recommended strategies to ensure Canada’s healthcare system meets the needs of persons with intellectual disabilities. In addition to these resources, however, is careful monitoring and evaluation to ensure they are implemented and followed⁴⁰. An emerging best practice in monitoring the healthcare needs of persons with intellectual

³⁸ Jones, McQueen, Lowe, Minnes & Rischke, 2015

³⁹ Jones, McQueen, Lowe, Minnes & Rischke, 2015

⁴⁰ Maltais, Morin & Tasse, 2020

disabilities is the **Comprehensive Health Assessment Program (CHAP)**⁴¹. A recent Manitoba-based evaluation of CHAP suggests it is a beneficial program that leads to improved continuity of care by ensuring regular health checks and screenings for persons with intellectual disabilities. Moreover, CHAP facilitates the systematic collection and sharing of medical history information among a person's healthcare team, which supports the identification of health problems and timely follow-up care⁴².

Our research participants offered many recommendations on how to better serve the healthcare needs of persons with intellectual disabilities and/or persons with autism, including those that align with the principles of CHAP.

In the words of seven of our research participants:

"An advocate is the most important requirement for people like [our child] and for us as parents. We have fought so hard for [our child] that it has affected our health. Advocates...must get to know the [person] and [their] history, be respected by the medical staff, be willing to help brainstorm solutions to problem, and be there long-term to get to know [them]." [M.F.]

"Family members and caregivers need healthcare information in plain language, without medical jargon...and more communication between the healthcare system and families". [S.C.]

"What we really need is a social movement". [B.U.]

"Content should include info about intellectual disabilities, rights and consent, self-determination, communication and pain identification, and challenging behaviours." [S.C.]

"We need to make sure people are in the driver's seat for their own health care". [L.F.]

"Our healthcare system must be person-centred and person-directed for everyone, including persons with intellectual disabilities". [C.B.]

"Support organizations need legal training to better understand human rights, accessibility legislations and recourse for instances where access has been denied/unavailable." [S.U.]

"No one is tracking this [inequity], it's all anecdotal so [instances of inequity] are diminished as a one-off. The commitment to data is a really important piece." [K.V.]

⁴¹ Shoostari, Temple, Waldman, Abraham, Ouellette-Kuntz & Lennox, 2017

⁴² Shoostari, Temple, Waldman, Abraham, Ouellette-Kuntz & Lennox, 2017

CONCLUSION

This participatory community-based research study reveals that current healthcare systems across Canada largely fail to adequately meet the unique needs of persons with intellectual disabilities and/or persons with autism. Indeed, as reported by most of our research participants, there have been many recent instances whereby the right to accessible healthcare has been denied to persons with intellectual disabilities and/or persons with autism. Grounded by the recognition of historical social injustice and continued human rights violations against persons with intellectual disabilities and/or persons with autism, our findings suggest concerted efforts are required to, at long last, develop healthcare policies and practices that truly remedy these past harms.

It is our hope that this report will lead to **subsequent phases of work that focus on recommending strategies** for addressing the issues we have revealed through our research. To this end, we will ensure updates on any potential next steps are shared with all of the research participants who contributed to this study. The strategies and resources our research participants have developed to support healthcare access for persons with intellectual disabilities and/or persons with autism are shared in **Appendix C**. These resources have been developed in collaboration with persons with lived experience, including self-advocates, and in this way, should be prioritized in future planning.

APPENDIX A: INFORMED CONSENT

Given that interviews were completed by phone or video-based conference, the following consent form was provided verbally by Dr. Terra Johnston and completed verbally by research participants.

My name is Dr. Terra Johnston. I am a PhD-trained researcher contracted by the Community Living Manitoba Board's Human Rights Committee. We are conducting a study called "Quality Health Interactions and Persons with Intellectual Disabilities", which is a federally funded research project that will examine the quality of experiences of persons with intellectual disabilities (including persons with autism) with healthcare systems across Canada and in Manitoba. Our research project will also take into consideration the impacts of COVID-19 on healthcare system experiences.

Our research project is driven by the following research questions:

-How are healthcare systems performing in recognizing, understanding, and serving the needs of persons with intellectual disabilities?

-What do families and support professionals need to know about their rights and legitimate expectations with regard to navigating healthcare systems and advocating on behalf of persons with intellectual disabilities?

With regard to the first question, we will explore current practices and understandings of healthcare systems related to how they provide (or don't provide) services for individuals with intellectual disabilities. With regard to the second question, we will explore the ways by which family members and advocates intervene when healthcare services fail to meet standards of practice.

Pending confirmation of continued funding support, subsequent phases of our research project may focus on prioritizing and implementing recommended strategies for addressing the issues revealed in phase one.

As part of our research study, I will be conducting interviews with 20 stakeholders across Canada. In addition to these interviews, I will also be conducting an abridged literature review to investigate our two research questions.

Before we begin our interview, I would like to request your permission to digitally record our conversation. In accordance with privacy legislation and my code of ethics, I will store the digital file in a password protected e-folder and I will destroy the file upon the conclusion of the research study. [if verbal consent provided, recording made]

Please note that the interview questions I provided to you in advance are meant to guide our conversation, but we will have the freedom to explore any topics you wish to bring to my attention. Last, do you have any questions before we start? Ok, let's begin.

APPENDIX B: INTERVIEW QUESTIONS

Introduction: In thinking about these questions, please consider all aspects of healthcare, including preventative healthcare, dental, vision, mental healthcare, substance misuse treatment.

Q1. In your experience and opinion, what are the unique healthcare needs of persons with intellectual disabilities and persons with autism?

Q2. In what ways, if any, are the needs of persons with intellectual disabilities and persons with autism unique compared to the needs of persons with other types of disabilities.?

Q3. With respect to the needs you identified, do any of the following factors impact on persons with intellectual disabilities and persons with autism: gender, age, race/ethnic background, family support, social support, socioeconomic status, geography?

Q4. In what ways, if any, has COVID-19 impacted the healthcare services received by persons with intellectual disabilities and persons with autism?

Q5. In what ways, if any, has COVID-19 impacted other public services received by persons with intellectual disabilities and persons with autism?

Q6. In what ways do family members support persons with intellectual disabilities and persons with autism, in order to have their unique healthcare needs met?

Q7. What additional resources, if any, do family members need to support their advocacy efforts on behalf of persons with intellectual disabilities and persons with autism?

Q8. In what ways do support professionals assist persons with intellectual disabilities and persons with autism, in order to have their unique healthcare needs met?

Q9. What additional resources, if any, do support professionals need to support their advocacy efforts on behalf of persons with intellectual disabilities and persons with autism?

Q10. In what ways, if any, has the Accessibility for Manitobans Act helped persons with intellectual disabilities and persons with autism to have their healthcare needs met? In what ways, if any, has it not helped?

APPENDIX C: RESOURCES

New Brunswick Association for Community Living
Intellectual Disability, Mental Health and Rights-Based Approaches
<https://nbacl.nb.ca/module-pages/intellectual-disability-mental-health-and-rights-based-approaches/>

New Brunswick Association for Community Living
Not Just Talk--Easy Read Guides on Mental Health
<https://nbacl.nb.ca/module-pages/not-just-talk-easy-read-guides-on-mental-health/>

Inclusion Saskatchewan

Health Passport: A Plain Language Health Care Tool for People in Saskatchewan

[https://7b6cc965-3fed-4f57-9074-](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_ecfdc50b1e2a42f98bac556d3c8a2e91.pdf)

[90f8363e9ac7.filesusr.com/ugd/df5183_ecfdc50b1e2a42f98bac556d3c8a2e91.pdf](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_ecfdc50b1e2a42f98bac556d3c8a2e91.pdf)

Inclusion Saskatchewan

Alternatives to Guardianship

[https://7b6cc965-3fed-4f57-9074-](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_389cd59b80214b3286cc6a36d2f0561e.pdf)

[90f8363e9ac7.filesusr.com/ugd/df5183_389cd59b80214b3286cc6a36d2f0561e.pdf](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_389cd59b80214b3286cc6a36d2f0561e.pdf)

Inclusion Saskatchewan

Plain Language Introduction to Supported Decision Making Guide

[https://7b6cc965-3fed-4f57-9074-](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf)

[90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf)

Inclusion Saskatchewan

Plain Language Vaccine Screening Questions: [https://7b6cc965-3fed-4f57-9074-](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_31fc0d2cc0794afeb1917947ad799351.pdf)

[90f8363e9ac7.filesusr.com/ugd/df5183_31fc0d2cc0794afeb1917947ad799351.pdf](https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_31fc0d2cc0794afeb1917947ad799351.pdf)

Government of Canada

Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: What do staff tell us?

<https://www.canada.ca/en/public-health/services/reports-publications/health-promotion-chronic-disease-prevention-canada-research-policy-practice/vol-38-no-10-2018/barriers-facilitators-improving-health-care-adults-intellectual-developmental-disabilities.html>

Health Care Access Research and Developmental Disabilities

Including People with Developmental Disabilities as a Priority Group in Canada's COVID-19 Vaccination Program: Key Considerations

<https://www.porticonetwork.ca/web/hcardd/news/-/blogs/research-evidence-regarding-covid-19-and-developmental-disabilities>

Health Care Access Research and Developmental Disabilities

Implementing Health Checks for Adults with Developmental Disabilities: A Tool Kit for Primary Care Providers

https://www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb

Health Care Access Research and Developmental Disabilities
Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario

<https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>

Surrey Place: Developmental Disabilities Primary Care Program

<https://ddprimarycare.surreyplace.ca/>

Canadian Family Physician

Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines

<https://www.cfp.ca/content/64/4/254>

APPENDIX D: REFERENCES

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