



Disability Inclusion Analysis of Lessons Learned and Best Practices of the Government of Canada's Response to the COVID-19 Pandemic



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Acknowledgements

We recognize our presence and work on the territories of the Attawandaron, Mississaugas, Algonquin Anishnaabeg, Kanien'kehà:ka, and Mi'kmaq Peoples. We wish to thank the participants and key informants who gave generously of their knowledge and time. We also thank Gilbert Ghantous, Karla Currie and Jennifer Feeney-Swab from Employment and Social Development Canada for their support of this work.

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Executive summary

Background: The issue

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) calls for the protection and safety of people with disabilities in situations of risk, such as the COVID-19 pandemic. Canada has ratified the UNCRPD. Despite these commitments, the pandemic has disproportionately affected people with disabilities in Canada—not only in the risk of contracting the virus—but in negative impacts, reduced access, and intensified systemic inequities resulting from the policies in response to the pandemic. These effects have been profound for people with disabilities, their families, and their support and care providers, yet largely invisible to those outside the disability community.

The impacts of COVID-19 and related policies can be best understood through an intersectional disability-inclusive framework that considers the experiences of diverse groups of disabled people, including women, children, older adults, people with intellectual and/or psychosocial disabilities, racialized and Indigenous people, and people who live in congregate settings. These groups experience multiple and intersecting forms of discrimination and barriers that shape their experiences in the context of COVID-19.

Any analysis of impacts must also consider the commitment of Canada and other signatory countries to the Sendai Framework for Risk Reduction, an approach that fosters the participation of those who are disproportionately affected by disasters, and integrates a culture, gender, age, and disability perspective.

Objectives

The object of this report is to assist Employment and Social Development Canada to identify a) good or best practices in Canada and beyond to address COVID-19 and people with disabilities and b) lessons learned from the response to the COVID-19 pandemic in Canada.

Results

From our review and analysis of the data and research collected, using our intersectional disability and gender analysis framework (iDGA), and in the context of Canada's human rights commitments, we identified impacts in 19 different thematic areas, from employment and income, to health care and community services, to isolation, social inclusion, and discrimination. From these themes, we identified three broad findings:

1. During the COVID-19 pandemic, we find evidence of **consistent exclusion of people with disabilities** arising from their invisibility. This is the case despite the increased risks they face, and results from inadequate data, lack of targeted policies, restrictive eligibility criteria and disability definitions for programs, lack of policy coordination and complementarity, inaccessible communications and information, and actions or inactions which reinforce or exacerbate existing systemic inequities.

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2. More than that, we find that **experiences of exclusion were often cascading and cumulative**, leading to disproportionately negative impacts on particular groups of people with disabilities, including those who are also low-income, women, racialized, Indigenous, and living in remote communities.
3. We reflect on and identify lessons and good practices that may be useful to “build back better” post-pandemic and **ensure greater disability justice** in future disasters and crises.

Key messages

Takeaways from this report include the following:

- COVID-19 exposed pre-existing systemic exclusion of people with disabilities from policy planning and decision-making.
- Inequities faced by people with disabilities have intensified during the pandemic.
- Disability leaders and organizations offer important insights for ensuring disability justice in the future.
- Now is the time for concrete, comprehensive action from governments and policy makers, including establishing accessibility and inclusion standards related to emergency planning and management, and a national disability benefit.

Methodology

Using the iDGA framework and guided by the UNCRPD and other related human rights commitments, the research team gathered qualitative and quantitative data and conducted a comparative policy analysis in order to achieve its objectives.

To develop a descriptive snapshot of diverse people with disabilities during COVID-19, we gathered Statistics Canada crowdsourced data and community surveys. To assess gaps in data and knowledge and their significance, we reviewed related academic and community literature, good practices from four Organisation for Economic Co-operation and Development (OECD) countries, and guidelines from the United Nations.

Policy data were gathered by scanning websites and identifying relevant documents from five provinces: British Columbia, Alberta, Ontario, Québec, and New Brunswick. The academic and community literature review and a social media scan identified additional policy data. Finally, we interviewed three federal, provincial and regional health key informants; conducted interviews and a focus group with 24 disability leaders; and conducted interviews and focus groups with 30 people with disabilities.

Themes from the data were identified by applying the iDGA framework to the academic, policy, and community literature; social media; and key informant and participant interview and focus group transcripts.

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Section 1: Introduction

1.1 Background and context to the issue

Decades of disability-related research across the world suggests that people with disabilities experience greater effects in situations of risk than non-disabled people. Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) signals the obligations of States Parties, including Canada, to take “all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk.”

The United Nations confirms that COVID-19 should be understood as a situation of risk and requires an intersectional disability-inclusive response.¹ They also note that groups of disabled people, including women, children, older adults, people with intellectual and/or psychosocial disabilities, and people who live in congregate settings, experience multiple and intersecting forms of discrimination and barriers that shape their experiences in the context of COVID-19.

To address situations of risk, Canada and other signatory countries to the Sendai Framework for Risk Reduction committed to a disaster risk reduction approach that “requires empowerment and inclusive, accessible and non-discriminatory participation, paying special attention to people disproportionately affected by disasters, especially the poorest. A gender, age, disability and cultural perspective should be integrated in all policies and practices, and women and youth leadership should be promoted.”²

Recent research by the MacEachen Institute for Public Policy and Governance suggests that emergency services for people with disabilities must consider the following: access to assistive devices, access to medications, accessible communications and information; accessibility of services and facilities; disruptions to care and personal assistance; increased stigma and marginalization; and the use of service/guide animals.³ A roundtable discussion⁴ in response to these findings noted that there was little data disaggregated by different groups of people with disabilities, little standardization of emergency management policies and plans in congregate living settings and the importance of involving people with disabilities in emergency policy development and planning.

1.2 Objectives

This report was developed to assist Employment and Social Development Canada to identify a) good or best practices in Canada and beyond to address COVID-19 and people with disabilities and b) lessons learned from the response to the COVID-19 pandemic in Canada. Using an intersectional disability and gender policy analysis (iDGA) (Appendix 1) and guided by the UNCRPD and other related human rights commitments, the research team has gathered and analyzed comparative policy, qualitative and quantitative data in order to achieve these objectives.

1 United Nations, 2020a; United Nations, 2020b

2 UNDRR, 2015, 13

3 Quigley and Lowe, 2020

4 Lowe and Macgowan, 2020

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1.3 Methods

1.3.1 Doing research in COVID times

Undertaking a major research project in three months during the COVID pandemic involved additional significant challenges and limitations. For the qualitative research, we received an expedited review and approval from the University of Guelph Research Ethics Board on October 9, 2020. Our initial draft report was due on November 16. In non-COVID times, recruiting and implementing key informant interviews, participant focus groups and interviews in that time framework would be challenging. With the added complexity of doing all of this by phone or online, with key informants and participants in the midst of dealing with the pandemic in their own lives and work, made this extraordinarily demanding.

With that complexity in mind, it is not surprising that we have had limited success in getting key informant interviews with policy makers, especially those in public health. They were in the midst of dealing with a pandemic. One public health communications person told us explicitly that their priorities had to be in other areas than doing research interviews.

We also had challenges in getting participants in some regions of the country. COVID times means that there are fewer personal networks within which to share recruitment information and some people with disabilities have limited access to the internet or phones. We believe that with more time to do recruitment we may have been able to increase the number of participants. But we also found that the data was reaching saturation, with many similar themes arising in participant stories.

We also addressed this gap by undertaking a social media scan and reviewing the websites of many national and regional disability organizations to see what is available already from them. This information was included in our analysis.

1.3.2 Sources of data

The research team drew on multiple sources of quantitative, qualitative and policy data (see Appendix 2 for details).

Section 2

To develop the descriptive snapshot of diverse people with disabilities during COVID-19, we primarily used Statistics Canada crowdsourced data and community surveys. Crowdsourced surveys provide a window into the experiences of people with disabilities across Canada during the COVID-19 pandemic and can help validate information from other sources. Because crowdsourced surveys solicit participation through a public opt-in process, they are not conducted according to probabilistic sampling measures and caution should be exercised when generalizing the findings to the Canadian public or disability community as a whole. The community surveys we relied upon had varying sample sizes and sampling methods: some were crowdsourced, and some were conducted according to probabilistic sampling. When data from community surveys is introduced in Section 2, we note the specific sample size and methodology.

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To assess gaps in data and knowledge and their significance, we reviewed related academic and community literature, good practices from four OECD countries, guidelines from the United Nations and asked key informants and focus group participants.

Section 3

Each theme in this section answers the same questions.

- What are the [thematic] impacts of the COVID pandemic on people with disabilities?
- How do people with disabilities describe these impacts?
- What have been the COVID-related policy responses by Canadian governments?
- What lessons can we learn from the COVID pandemic [thematic] impacts on people with disabilities?

To identify and analyze the impacts that diverse people with disabilities experience as a result of COVID-19 and related policy measures, we used the iDGA to identify key themes from the academic, policy and community literature, the social media scan, key informant and participant interviews, and focus group transcripts.

To document disability-related policy responses to COVID-19 in Canada, including the inclusion of people with disabilities in the policy and program development and planning, we scanned the websites and identified relevant documents of five provinces—British Columbia, Alberta, Ontario, Québec, and New Brunswick in addition to six health authorities—BC: Provincial Health Services, Vancouver Coastal Health, AB: Alberta Health Services, ON: Toronto Central LHIN, and QC: Santé Montreal and NB: Vitalité. We interviewed three federal, provincial, and regional health key informants and 24 disability leaders to supplement the document scan. The academic and community literature review and social media scan identified additional policy data.

Section 4

This section highlights key lessons learned, good practices, and recommendations. We identified these drawing from our analysis of the academic, policy, and community literature; the OECD and transnational scan; and the responses of people with disabilities, their support/care providers, and disability organizations in interviews and focus groups.

1.4 Human rights frameworks

The United Nations Committee on the Rights of Persons with Disabilities⁵ issued a guidance note for addressing the rights of people with disabilities during the COVID pandemic which echoes the rights noted by the Ontario Human Rights Commission (OHRC). Drawing on the contributions of people with disabilities, their families and representative organizations, the COVID-19 Disability Rights Monitor report⁶ uses a human

5 UNCRPD, 2020

6 Brennan, 2020

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rights-based approach to identify key themes and impacts. These include access to health care, access to food and essential supplies, conditions in institutions and access to community support and services. This report also identifies the disproportionate impacts on particular groups: children with disabilities; women and girls with disabilities; homeless people with disabilities; and people with disabilities in remote and rural areas.

As the OHRC⁷ argued, existing human rights frameworks are essential to consider when addressing COVID-19. The Commission identifies six principles to ensure human rights when preventing and treating COVID-19. They note the importance of access to services, including the right to health and life; the right to an adequate standard of living including food and clothing; the right to work; the right to housing; the right to education. The Commission recognizes that some measures may infringe on rights and argues for strict limits on these. In addition, they note the importance of addressing the rights of Indigenous peoples, and responding to racism, ageism, ableism and other forms of discrimination. Finally, they note the disproportionate impacts of COVID-19 on specific groups including women, children, those in prisons or other institutions, immigrants, refugees and temporary foreign workers.

These various human rights frameworks for addressing the impacts of measures to address COVID-19 confirm what we learned in this research. They also remind us of the importance of using a human rights approach to identify good practices and lessons learned in addressing COVID-19.

1.5 Intersectional Disability and Gender Analysis Framework (iDGA)

Drawing on the UNCRPD, other international human rights instruments and existing tools for intersectional and gender-based analysis + (GBA+), the research team developed a policy analysis framework called the intersectional disability and gender analysis (iDGA) framework (see Appendix 1).

Intersectional policy analysis provides an innovative structure for critical policy analysis. It can capture different dimensions of policy contexts including history, politics, everyday lived experiences, diverse knowledges and intersecting social locations; and can generate transformative insights, knowledge, policy solutions and actions.⁸

The iDGA framework is a series of questions that was used to inform search strategies; code results; and guide how we think about the analysis. In particular, we used the iDGA framework to analyze policies and policy literature related to Canada and specific OECD countries and international organizations; academic and community literature; social media; and focus group and interview transcripts.

7 OHRC, 2020

8 Hankivsky et al., 2014; Hankivsky and Mussell, 2018; Hankivsky and Jordan-Zachery, 2019

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1.6 What or who is included in diverse people with disabilities?

We intend all our research and analysis to be as intersectional as possible given the data available. We use the phrase “diverse people with disabilities” to indicate that commitment to intersectionality. This includes examining experiences based on:

- age
- caregiving and support relationships
- children, presence of
- disability and impairment type
- employment
- ethnicity/race
- family status
- gender
- immigration status
- income
- Indigenoussness
- language
- LGBTQ2+
- living or housing arrangements
- rural, urban, remote location

The data we found related to these intersections has many gaps, and the sources of data are not necessarily comparable between different groups. We have chosen to discuss different experiences of living with disabilities using (and noting) the data available and source.

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Section 2: Snapshot of diverse people with disabilities in Canada during COVID-19

One in five Canadians has a disability, making the experience of disability a common one that intersects with a diversity of factors including age, race, gender, sexuality and geography. People with disabilities have disproportionately borne the impacts of the COVID-19 pandemic, in terms of employment loss, the loss of educational and social supports, decreased access to health service, and increased mortality. Using primarily quantitative survey data, Section 2 outlines how people with disabilities in Canada have been affected by the COVID-19 pandemic.

This section relies primarily on two types of data sources for discussing the experiences of people with disabilities during COVID-19: Statistics Canada crowdsourced data, and community surveys. Crowdsourced surveys provide a window into the experiences of people with disabilities across Canada during the COVID-19 pandemic and can help validate information from other sources. In June and July 2020, over 13,000 people with long-term conditions and disabilities participated in Statistics Canada's COVID-19 crowdsource initiative. Because crowdsourced surveys solicit participation through a public opt-in process, they are not conducted according to probabilistic sampling measures, and caution should be exercised when generalizing the findings to the Canadian public or disability community as a whole, as certain groups may be over or underrepresented in the survey.

The community surveys we relied upon had varying sample sizes and sampling methods: some were crowdsourced, and some were conducted according to probabilistic sampling. When data from community surveys is introduced below, we note the specific sample size and methodology.

2.1 Who are diverse people with disabilities in Canada?

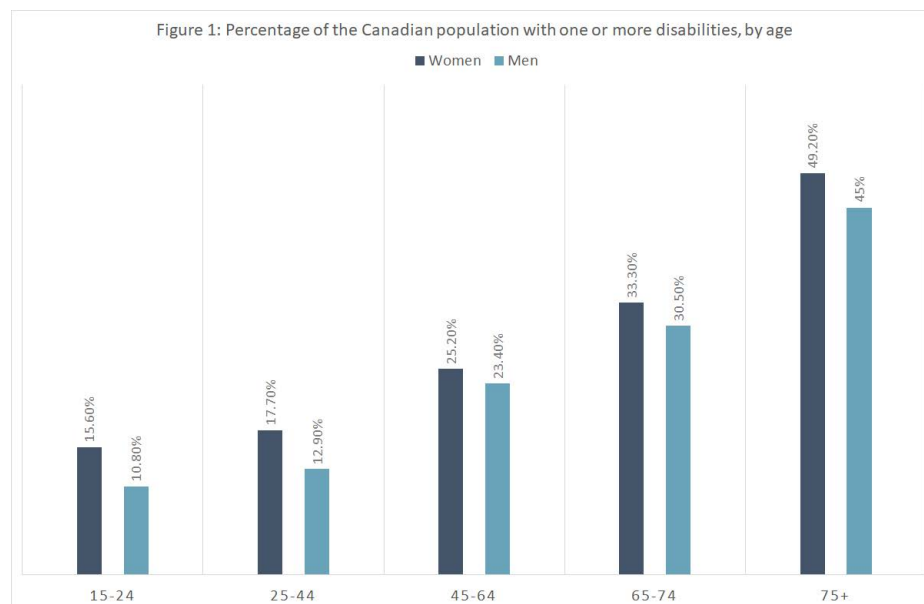
The 2017 Canadian Survey on Disability (CSD) demonstrates that 6.2 million individuals over the age of 15 has one or more disabilities, about 22% of the Canadian population.⁹ The survey reveals that 29% have one disability type, 38% have two or three disability types, and 33% have four or more. The percentage of Canadians with one or more disabilities increases significantly with age (see Figure 1).¹⁰ Women are consistently more likely to have one or more disabilities across all age groups.¹¹

9 Morris et al., 2018

10 Figure 1 uses data from the Canadian Survey on Disability, conducted by Statistics Canada in 2017, as reported in Morris et al., 2018.

11 Berrigan et al., 2020; Burlock, 2017; DAWN Canada, 2019; Morris et al., 2018

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The CSD identifies four severity levels based on number of disability types, level of difficulty in performing tasks, and activity limitations. Approximately 37% of Canadians 15 years of age or older with a disability are identified as having a mild disability, 20% as having a moderate disability, 21% as having a severe disability, and 22% as having a very severe disability. The most common type of disability was pain-related (15%), followed by flexibility (10%), mobility (10%), mental health (7%), seeing (5%), hearing (5%), dexterity (5%), learning (4%), and memory (4%).¹² Mental health related disabilities were the second most common type for Indigenous Canadians behind pain related.¹³ Developmental disability was also included as a disability type with a prevalence of approximately 1%.¹⁴ While most data about disability types is for Canadians 15 years of age or older, between 6.5-8.5% of children in Canada have a developmental disability. Among people with developmental disabilities, more are male (60.5%) compared to female.¹⁵

2.2 How have people with disabilities been affected by the COVID-19 pandemic?

2.2.1 Employment

The 2017 CSD demonstrates that Canadians with disabilities are less likely to be employed and more likely to be precariously employed than those without disabilities.¹⁶ People with disabilities are also more likely than other Canadians to have become unemployed during the pandemic, and if they have remained employed, they are more likely to have experienced reduced working hours. These impacts were greater for youth with disabilities, and people with multiple long-term health conditions.

¹² Morris et al., 2018

¹³ Hahmann et al., 2019

¹⁴ Morris et al., 2018

¹⁵ Berrigan et al., 2020

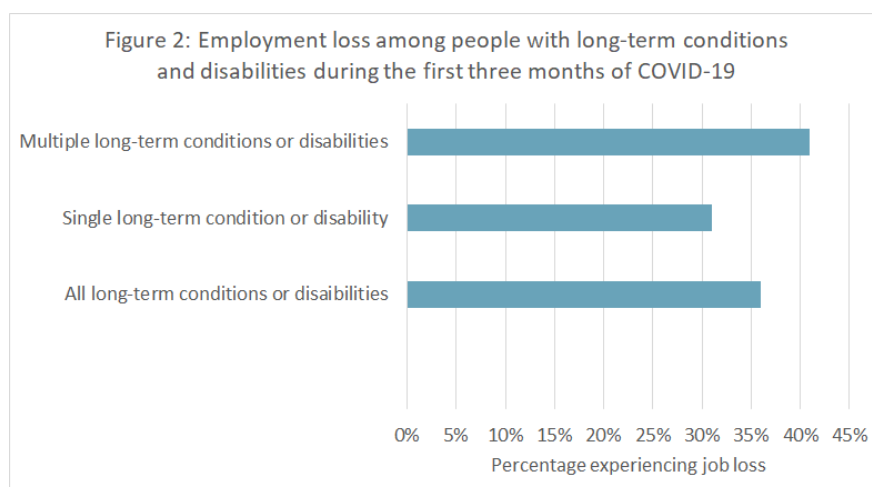
¹⁶ Morris et al., 2018

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Prior to the start of the COVID-19 pandemic in March 2020, employment rates for Canadians with disabilities were significantly lower than those without disabilities (59% compared to 80%). This gap is widened as disability severity increases.¹⁷ Additionally, the prevalence of part-time employment increased as disability severity increases. For those with milder disabilities, the employment rate is higher for men, and among those with more severe disabilities, the employment rate is higher for women between 25-34 years of age.¹⁸ Health conditions, lack of training, availability of jobs, unsuccessful history of attaining employment, and fear of losing supports are barriers for those not participating in the labour force.¹⁹ Of the Canadians aged 25 to 64 who are employed, more than one-third require at least one workplace accommodation, with the most common types being flexible work arrangements (27%), modifications to workspace (15%) and additional supports (6%).²⁰

While there is limited research on the engagement in “work” outside the traditional labour market, caregiving is found to be a prominent form of unpaid labour for women with disabilities. In fact, both women (11%) and men (3.5%) with disabilities are more likely to be a lone parent than those without (7.8% and 2.1% respectively).²¹ More exploration is needed into the experiences of women with disabilities as caregivers.²²

Statistics Canada crowdsourced data collected approximately three months after the start of the pandemic found that 66% of respondents aged 15-64 with a long-term condition or disability, reported being employed prior to the start of the pandemic.^{23,24} Among participants who were employed before the start of the pandemic, over one-third (36%) reported experiencing a temporary or permanent job loss or reduced hours since March (Figure 2).²⁵



17 Morris et al., 2018

18 Morris et al., 2018

19 Berrigan et al., 2020

20 Morris, 2019

21 Burlock, 2017

22 DAWN Canada, 2019

23 Statistics Canada, 2020a

24 This number may be higher than previous Statistics Canada surveys because the crowdsourced surveys over-sampled those with higher educational attainment, and educational attainment is positively associated with labour market attachment.

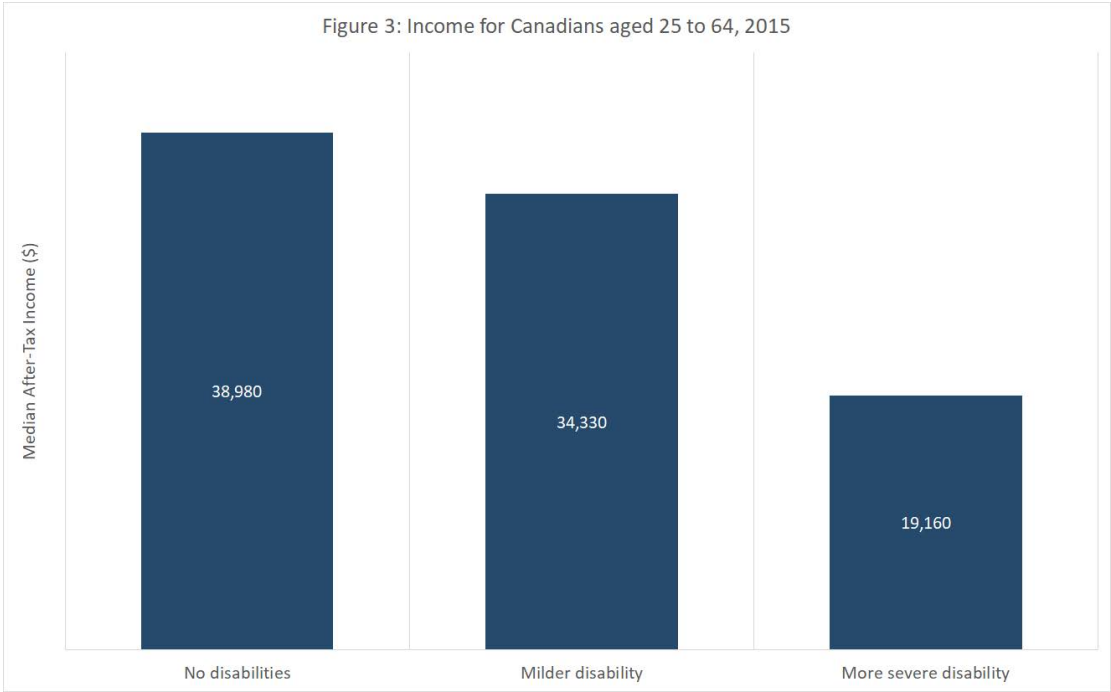
25 Figure 2 uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

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Among participants aged 25 to 64 with long-term conditions and disabilities, those with a high school education or less were more likely than those with at least some university credentials to report a change in employment status.²⁶ Youth from 15-24 with disabilities or long-term conditions were less likely to be employed than people 25-64, with only 39% who reported being currently employed.²⁷

2.2.2 Income

The 2017 CSD shows that people with disabilities are more likely to have a lower income than those without disabilities.²⁸ This gap was exacerbated during the COVID-19 pandemic; people with disabilities have experienced a decline in household income, at the same time, many have experienced increased costs related to food, transportation, and health equipment. These impacts have been greater for people with disabilities who live with children, aged 25 to 64, income is strongly related to severity of disability and gender. The income of those with more severe disabilities (\$19,160) is only half that of those with no disabilities (Figure 3).²⁹ The gender gap in income that is well-documented for those without disabilities, is also true for those with disabilities. Women with milder disabilities had an average income about 75% of men with milder disabilities and women with more severe disabilities had an average income about 90% of men with more severe disabilities.³⁰



26 Statistics Canada, 2020a

27 Statistics Canada, 2020a

28 Morris et al., 2018

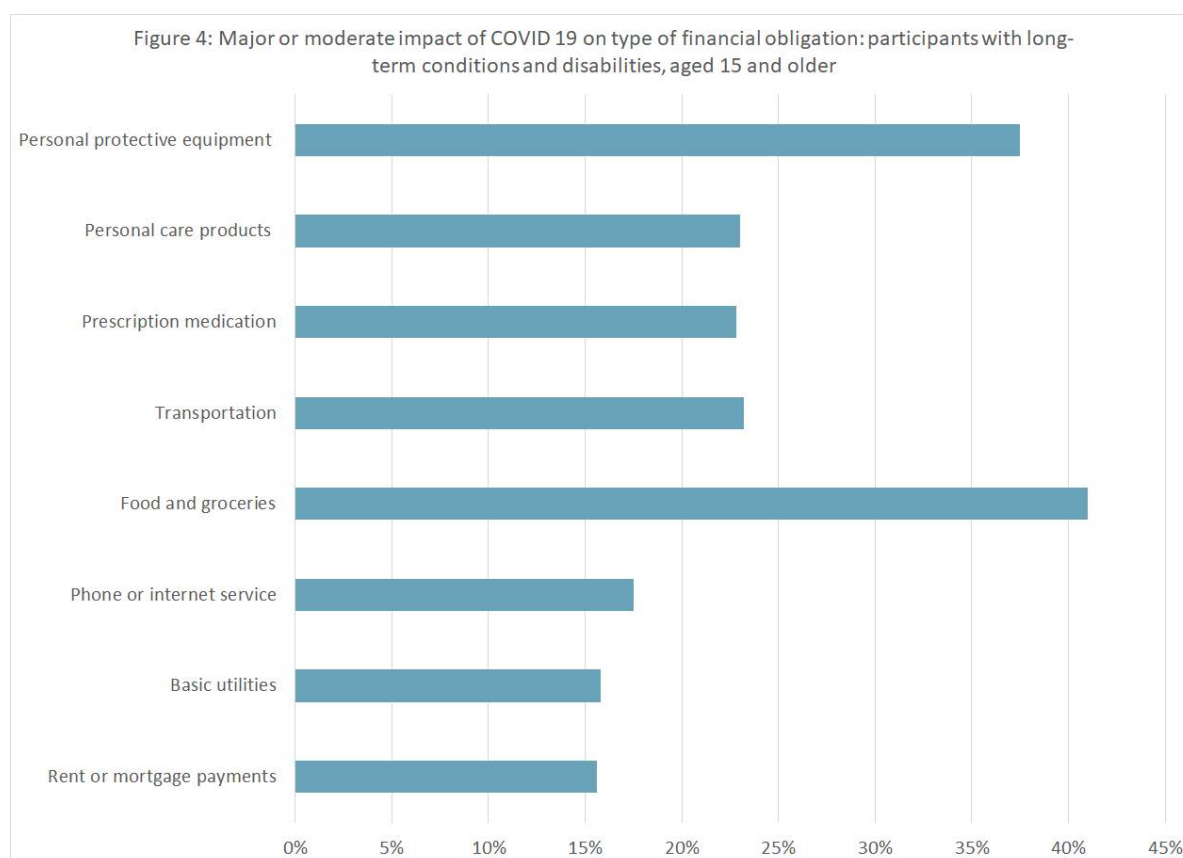
29 Figure 3 uses data from the 2016 Census as reported in Morris et al., 2018.

30 Morris et al., 2018

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Canadians with disabilities are also twice as likely to live with poverty or low income compared to those without disabilities.³¹ Twenty-three per cent of Canadians with a disability report a low-income compared to 9% of those without disabilities. Women with disabilities make up between 26-33% of all Canadians living in poverty.³² Also, 46% of Canadian women who have experienced homelessness had a disability, and 37% of Canadian men who have experienced homelessness had a disability.³³

As of July 2020, 31% of participants aged 15 to 64 with long-term conditions or disabilities reported their overall household income had decreased.³⁴ Among those who said that their household income had declined, over half (56%) reported that it had decreased by more than \$1,000 per month. At the same time as experiencing a decline in income, many participants noted they were facing increased costs of day-to-day necessities, especially groceries and personal protective equipment (Figure 4).³⁵



31 Morris et al., 2018

32 Crawford, 2015; Burlock, 2017

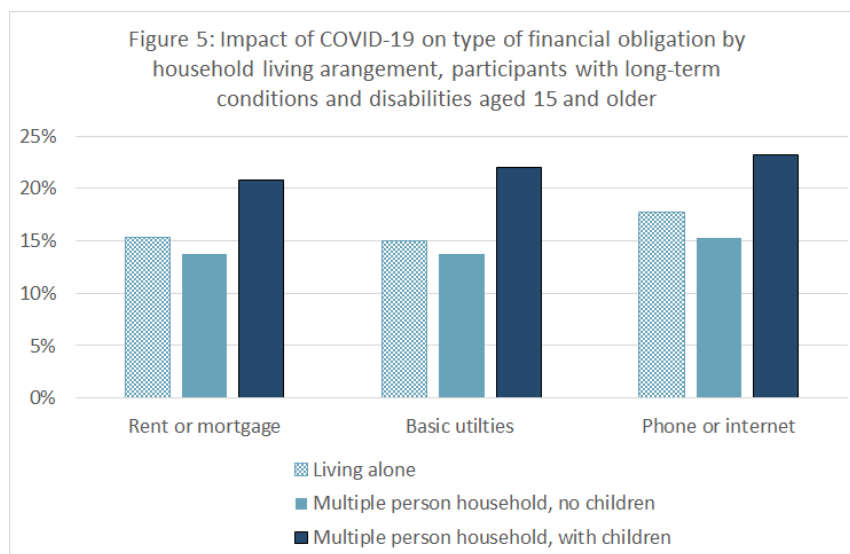
33 Cotter, 2018

34 Statistics Canada, 2020a

35 Figure 4 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey "Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities." From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

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Households with children were more likely to report that their household income had decreased (37%), compared with households without children (33%) and those living alone (20%).³⁶ They were also more likely to report a major or moderate increase in the cost of housing, utilities, and internet/phone since the start of the pandemic (Figure 5).³⁷



2.2.3 Education

The 2017 CSD shows that children and youth with disabilities have additional barriers to education compared with those without disabilities.³⁸ The COVID-19 pandemic has increased these barriers to education for children and youth with disabilities and has increased stress among caregivers concerned with the educational participation of children and youth with disabilities.

Canadians with disabilities have lower rates of education compared to those without disabilities. For example, the percentage of Canadians not completing high school or post-secondary education is 9.7% for people without disabilities and 18.3% for people with disabilities. This is even higher for people with developmental disabilities, at 40%.³⁹ Again, severity of disability has a relationship with school enrolment. For example, men and women aged 15-24 with more severe disabilities are neither employed or in school more than double those with milder disabilities.⁴⁰ The Canadian Human Rights Commission (CHRC) identified the top four barriers to education for people with disabilities in Canada: (1) lack of accommodation/support, (2) lack of

36 Statistics Canada, 2020a

37 Figure 5 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey "Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities." From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

38 Statistics Canada, 2019

39 Berrigan et al., 2020

40 Berrigan et al., 2020

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services/funding, (3) ineffective conflict resolution methods, and (4) lack of supports on Indigenous reserves.⁴¹ Barriers to education are even higher for those with developmental disabilities.⁴² The CHRC states that for those with developmental disabilities, the options and accessibility of education is lacking, with 22.5% of children needing to attend school outside of their communities and 30% only having the option of separate schools or classes.⁴³

The COVID-19 pandemic has worsened barriers to education for children and youth with disabilities. Statistics Canada crowdsourced data reports that 58% of parents of children with disabilities were very or extremely concerned about their children's academic success.⁴⁴ CanChild conducted a crowdsourced survey of 161 people who were mostly the parents or guardians of children with disabilities, of whom 93% identified as women and 79% of respondents were from Ontario.⁴⁵ As such, the survey is not representative, but can provide insights on the experiences of caregivers to children with disabilities during the pandemic, and the gendered dimensions of caregiving. Survey results reported in Oct. 2020 found that 37% of respondents reported receiving no support for their children's online education needs during the pandemic, which limited the ability of their child to participate in classroom activities.⁴⁶ Common barriers to education reported by parents and caregivers to children with disabilities included:

- Children needing high levels parental support to stay focused and complete work, including parental modification of the curriculum
- Inadequate internet in rural areas
- An absence of Educational Assistant support for online learning
- An inability for parents to work-from-home and support their children's education simultaneously.⁴⁷

Statistics Canada crowdsourced data suggests educational exclusion is increasing stress on families. Just over three-quarters (76%) of parents of children with disabilities were very or extremely concerned about managing their children's behaviours, stress levels, and anxiety and emotions compared with 57% of parents of children without disabilities.⁴⁸ This finding is complemented by the findings of a BCEd Access Society's April 2020 survey of 1055 parents and caregivers to children with disabilities in British Columbia, intended to better understand the challenges facing parents and children with disabilities, and ability to access targeted provincial programs. The survey was crowdsourced over 2.5 days in April 2020 and included participants from all regions of British Columbia. Thirty-three percent of respondents reported needing more family mental health supports immediately to cope with the pandemic, yet 60% of respondents reported being unable to access any of the emergency pandemic funding released for "special needs kids" by the British Columbia

41 DAWN Canada, 2019

42 DAWN Canada, 2020

43 CHRC, 2020

44 Arim et al., 2020

45 De Camargo et al., 2020

46 De Camargo et al., 2020

47 De Camargo et al., 2020

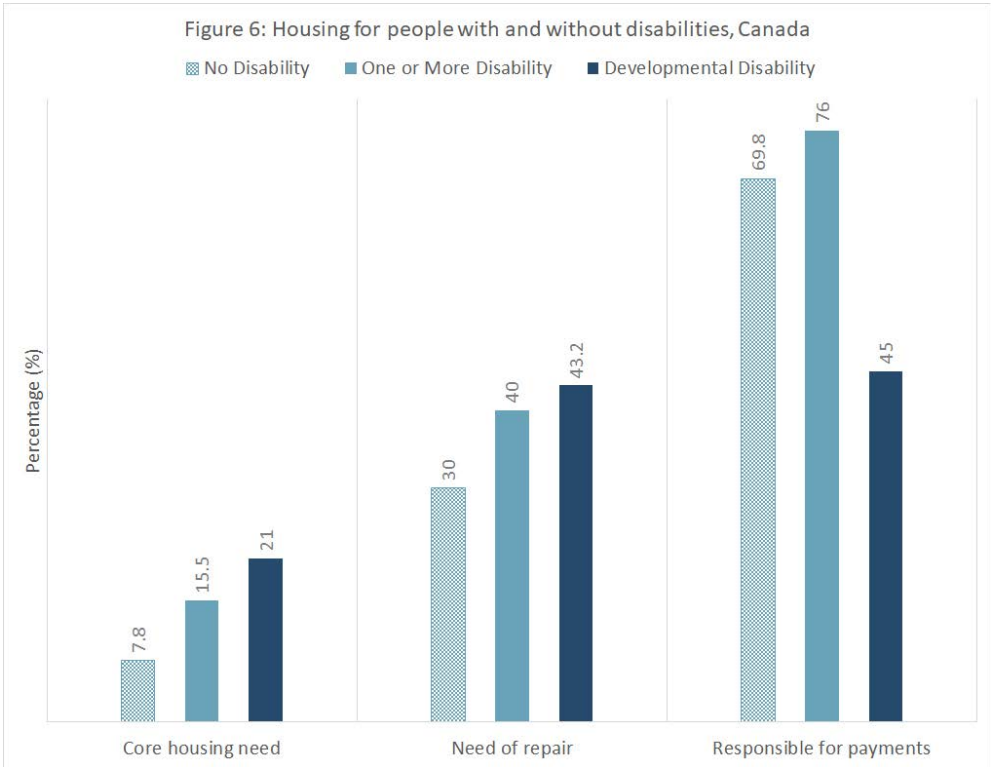
48 Arim et al., 2020

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Ministry of Children and Family Development.⁴⁹ These gaps are concerning given that, as documented above, people with disabilities living with children are more likely to have experienced increased costs during the pandemic, and more likely to have experienced a decrease in their household income.

2.2.4 Housing

Information on housing and living conditions/locations of Canadians with disabilities is limited. The percentage of people living rurally with a disability is similar to the percentage of people without a disability living rurally (18.5% compared to 17.9%). Canadians with disabilities face additional barriers in accessing adequate, affordable and safe housing.⁵⁰ Figure 6⁵¹ demonstrates that people with disabilities, especially those with developmental disabilities, are more likely than non-disabled people to be in core housing need, more likely to be in housing needing repair, and less likely to be a home maintainer.⁵² This is a particular challenge for women with disabilities, especially those with low-income or relying on social assistance. Children with disabilities also have a higher rate of living in inadequate homes. Though it is older data, it is estimated that 12.2% of children with disabilities are in housing needing major repair, compared to 7% of children without disabilities.⁵³



49 BCEd Access Society, 2020

50 DAWN Canada, 2019

51 Figure 6 uses data from the Statistics Canada 2017 Canadian Survey on Disability, as reported in Berrigan et al., 2020.

52 Berrigan et al., 2020

53 Hanvey, 2001

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Canadians with disabilities are more likely to live alone compared to those without disabilities: among women, 24.6% with disabilities live alone, compared to 12.3% without disabilities. For men, the comparable figures are 18.3% and 11.7%. For Canadians with disabilities who do not live alone and require help with daily activities, the most common form of support was from family members within their households.⁵⁴

2.2.5 Congregate living settings

The 2016 Census data reveals that just under 700,000 people live in congregate living settings, of which 491,000 live in medical facilities. A further 65,790 Canadians lived in residential care settings for people with disabilities or addictions, of which 11,320 or 17% are under the age of 65.⁵⁵ This does not include those with disabilities who live in other collective dwellings such as nursing homes, residences for senior citizens, correctional facilities, or shelters.⁵⁶ As of November 8th, 2020, 840 outbreaks of COVID-19 have occurred in congregate care settings across Canada, leading to 8,345 deaths. These deaths disproportionately impact people with disabilities, as the majority of residents in these settings. Comparative data from BC and Ontario⁵⁷ suggests that people living with dementia make up over 63% of residents in both settings, and most residents live with multiple disabilities and health conditions. Similarly, advocates have raised concerns that congregate settings like correctional facilities pose an increased risk of COVID-19 transmission and mortality for people with disabilities. Studies have demonstrated that incarcerated populations, particularly incarcerated women, have a higher incidence of intellectual and mental health disabilities than the general population.⁵⁸ People who are unhoused also have an elevated incidence of disability.⁵⁹ Crowded accommodations heighten the risk of COVID-19 in both carceral settings and shelters, which poses a risk to disabled people in these settings.

2.2.6 Social Exclusion and Isolation

Social exclusion and isolation, experienced by Canadians with disabilities even prior to the pandemic, have heightened the impacts of the COVID-19, particularly for those living in congregate settings, and those reliant on institutional programming for social activities.

Social exclusion disproportionately impacts people with disabilities in Canada. A 2019 Angus Reid study found that people with physical disabilities were twice as likely to be socially excluded than people without disabilities, with 38% reporting high levels of loneliness and isolation.⁶⁰ In 2018, 55% of all discrimination complaints to the Canadian Human Rights Tribunal were grounded in disability, indicating a lack of social inclusion.⁶¹ Social exclusion can be experienced differently depending on the disability. For example, people with intellectual or mental health disabilities experience institutionalization in large institutions, long-term care facilities, nursing homes, group homes, and other facilities. Stigma is also experienced by people with

54 Burlock, 2017

55 Stienstra, 2020

56 Statistics Canada, 2016

57 Liu et al., 2020

58 AEBC, 2010; Crocker et al., 2007; Kouyoumdjian et al., 2016

59 Ayano et al., 2019; Durbin et al., 2018

60 Angus Reid, 2019

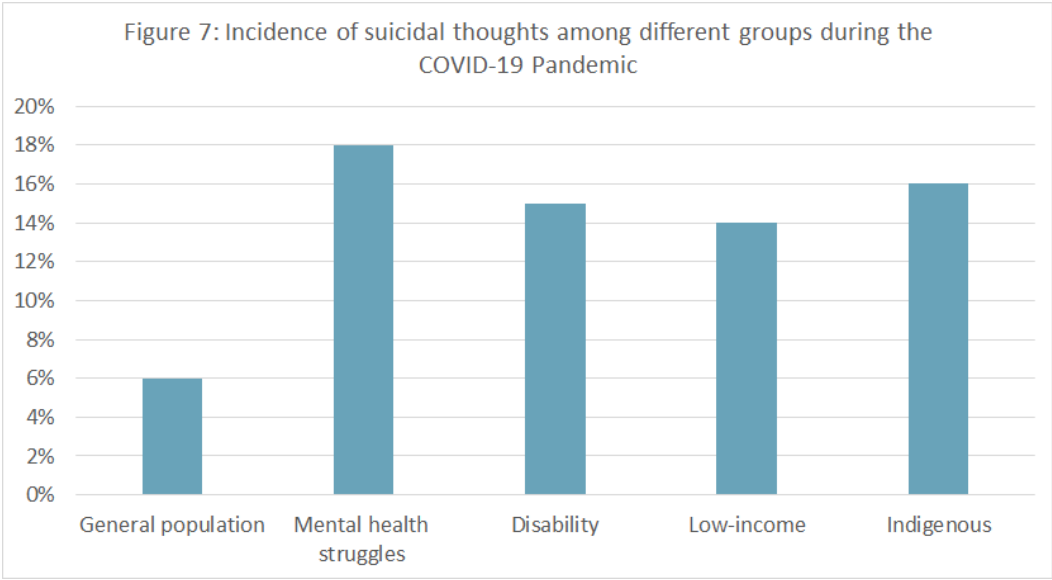
61 CHRT 2018

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disabilities which can impact the ability to Canadians with disabilities to survive. Social exclusion affects the health and well-being of people with disabilities.⁶²

The COVID-19 pandemic has heightened social exclusion and isolation for people with disabilities. Many have experienced the loss of regular social programming and services.⁶³ Those living in congregate settings have been unable to interact regularly with family members and friends for long periods of time.⁶⁴ Many have been unable to leave their long-term care homes.⁶⁵ Of people in Canada who are living at home but receiving long-term care support, 96% rely on an unpaid caregiver.⁶⁶ A recent report during the COVID-19 pandemic found a third of unpaid caregivers, often spouses, parents and children, are distressed.⁶⁷ Distress can include feelings of anger or depression, or the inability to continue with caring activities, all of which impact the wellbeing of not only caregivers but also disabled people as recipients of care.

A recent study of wellbeing during the COVID-19 pandemic found that people with disabilities have been three times as likely to experience suicidal thoughts since the start of the pandemic as the general population.⁶⁸ The incidence of suicidal thoughts was also heightened for people who were low-income and Indigenous (Figure 7).⁶⁹ These findings suggest the importance of an intersectional lens for understanding the compounding impacts of multiple factors of structural marginalization.



62 Richmond, Ross & Egeland, 2007

63 Hoye, 2020

64 Ireton, 2020; Pelley, 2020

65 Pelley, 2020

66 CIHI, 2020

67 CIHI, 2020

68 CMHA, 2020

69 Figure 7 uses data from a survey conducted by the Canadian Mental Health Association and University of British Columbia, as reported in CMHA, 2020. The survey was conducted from May 14th-29th, 2020, among a representative sample of 3,000 people living in Canada ages 18 and up,

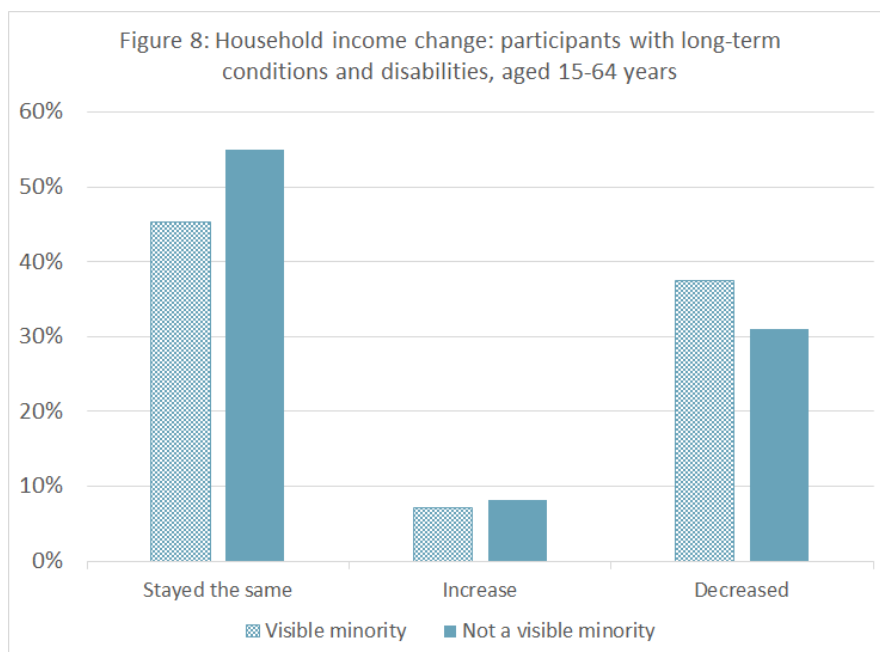
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2.2.7 Disability and Discrimination: Racialized and LGBTQ2 People with Disabilities during COVID-19

The negative impacts of the COVID-19 pandemic on people with disabilities are heightened for those who experience intersecting forms of structural marginalization or exclusion. During the COVID-19 pandemic, people with disabilities who are also racialized, and/or LGBTQ2, are more likely to be experiencing financial hardship, and more likely to report declines in their mental and physical health.

The negative health impacts of discrimination on the basis of race, ethnicity, sexual orientation, and gender expression are well documented. Statistics Canada data suggests that discrimination can take multiple forms and can overlap within groups.⁷⁰ While existing data is imperfect, it strongly suggests that racialized and LGBTQ2 people with disabilities have experienced compounding impacts of the pandemic, due to their membership in multiple groups that experience structural conditions that exacerbate negative impacts of the pandemic.

Statistics Canada crowdsourced data found that people with disabilities who also identified as visible minorities were less likely to say their income had remained the same throughout the pandemic, and more likely to report a decrease in income (Figure 8).⁷¹

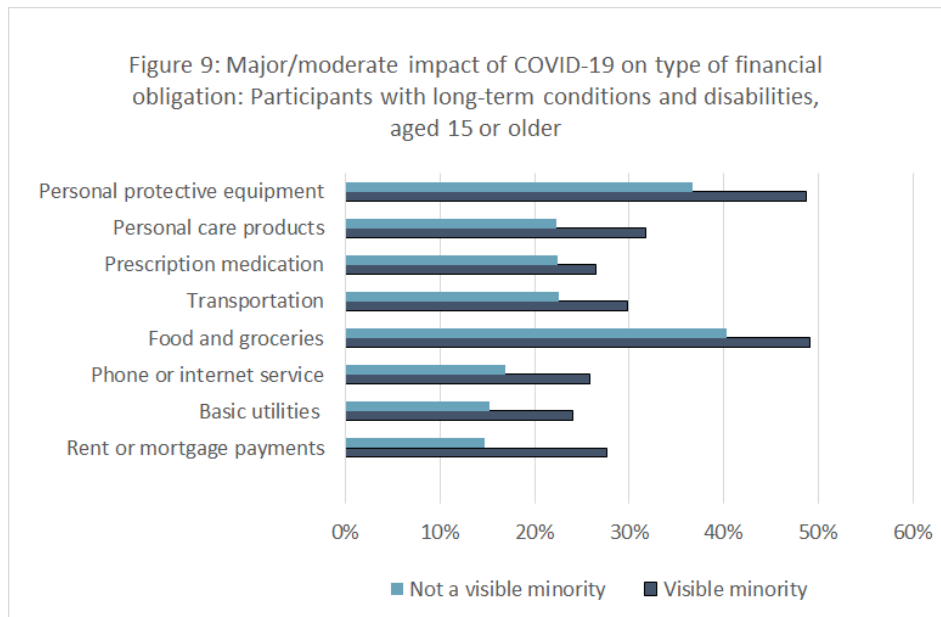


70 Statistics Canada, 2020b

71 Figure 8 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey "Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities." From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

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At the same time, people with disabilities who also identified as visible minorities were more likely to report facing a major or moderate increase in the costs of basic necessities than other respondents across all types of financial obligations (Figure 9).⁷²



These findings are supported by Egale’s national survey intended to capture the experiences of LGBTQ2 people during COVID-19. The Egale survey was conducted in June 2020 using a random sample of research panel participants, with weighting by age, gender, region and sexual orientation using Statistics Canada’s data. The survey report draws on a representative national sample size of 1,500 Canadians. Egale’s survey found that members of the LGBTQ2 community were more likely to have a physical or mental health condition that increased their vulnerability to respiratory diseases, than non-LGBTQ2 respondents. Moreover, this effect was exaggerated for people who identified as LGBTQ2 and Black, Indigenous and People of Colour (BIPOC), with 40% reporting a condition that made them more vulnerable to COVID-19, 36% reporting a physical disability, and 35% reporting a mental disability.⁷³

Statistics Canada crowdsourced data indicates that COVID-19 has coincided with both increased experiences of discrimination, particularly among South Asian and Black respondents, and also an increase in negative mental health symptoms.⁷⁴

72 Figure 9 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

73 Egale, 2020

74 Statistics Canada, 2020b

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While this data does not specify whether these mental health symptoms are debilitating, it strongly implies the experience of discrimination is related to a decline in mental health including for disabled members of visible minority populations. Statistics Canada crowdsourced data similarly reports 37% of what they term “sexual minority” participants have experienced discrimination based on sexual orientation, but a further 28% have also experienced discrimination based on disability.⁷⁵ On the whole, this data strongly suggests that when experiences of racialization, LGBTQ2 status, and disability coincide, the impacts of the COVID-19 pandemic have been compounding, negatively affecting the wellbeing of members of these communities.

2.2.8 Indigenous Peoples with Disabilities

Data from the 2017 Aboriginal Peoples Survey illustrates that Indigenous people are more likely to have one or more disabilities; this is also true for First Nations people living off reserve (32%) and Metis (30%), compared to 22% of non-Indigenous people.⁷⁶ More Indigenous women experience disabilities than Indigenous men. Indigenous disabled people, who are also more likely to be experiencing financial hardship during the COVID-19 pandemic, are more likely to report declines in their mental and physical health.

Indigenous participants in Statistics Canada's crowdsourced survey were more likely to report experiencing decline in household income since the start of the COVID-19 pandemic (Figure 10).⁷⁷ They were also more likely to report an increase in costs of basic necessities across all types of financial obligation (Figure 11).⁷⁸

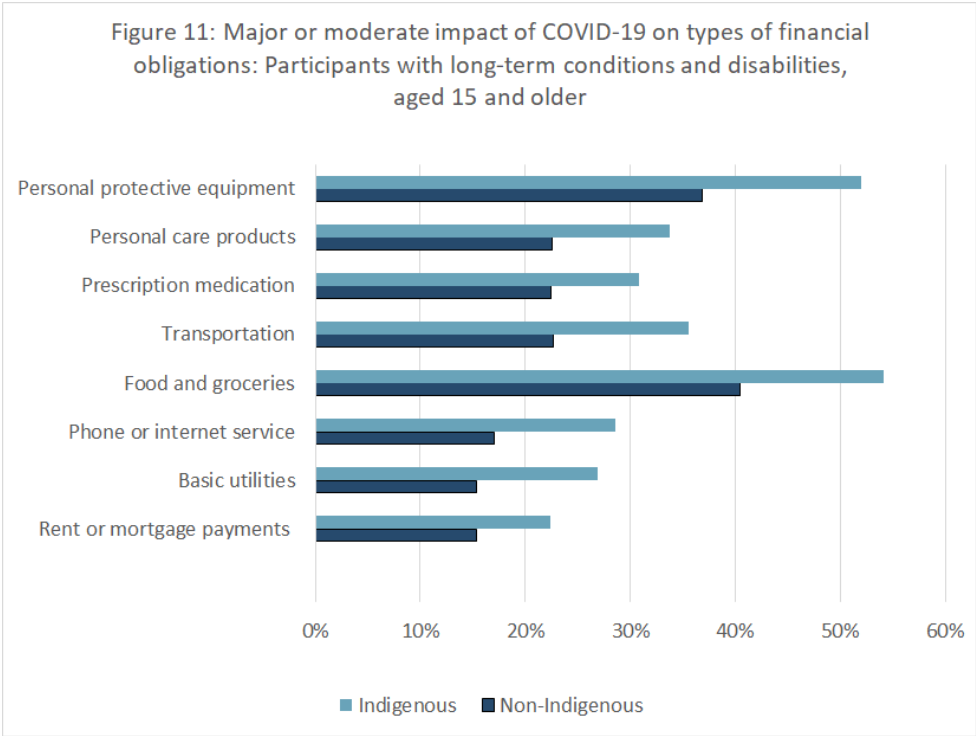
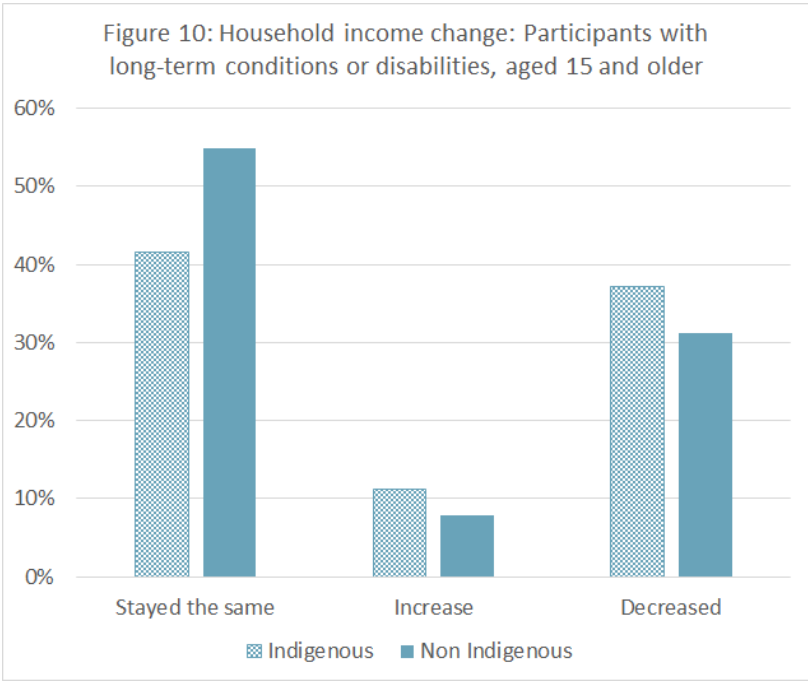
75 Statistics Canada, 2020b

76 Hahmann et al., 2019

77 Figure 10 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling. Figure 11 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

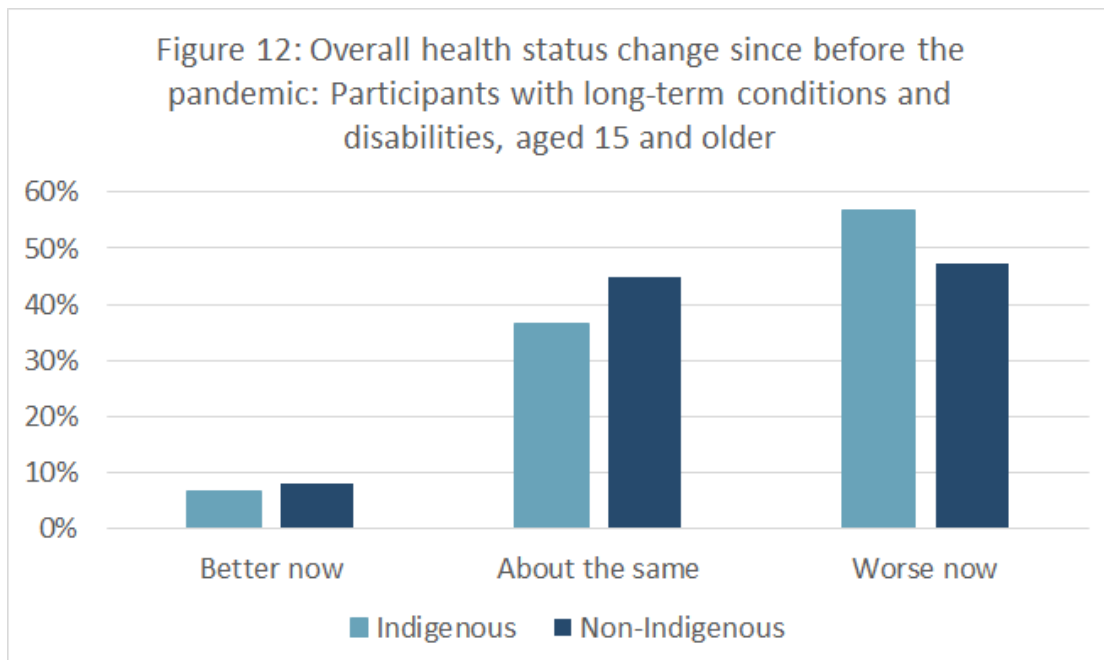
78 Figure 11 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling

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Indigenous respondents were more likely to report a decline in their overall health since the start of the pandemic (Figure 12)⁷⁹ and their mental health than non-Indigenous survey participants.



This may relate to the finding from Statistics Canada crowdsourced data that respondents who identified as Indigenous often reported experiencing discrimination since the start of the pandemic. The most often experienced form of discrimination was based on Indigenous identity (48%). However, 23% of Indigenous respondents also reported experiencing discrimination on the basis of a physical or mental disability.⁸⁰ Indigenous women in particular were more likely to experience discrimination than Indigenous men. Statistics Canada states that during the pandemic Indigenous women have experienced “greater mental health impacts, intimate partner violence and lower perceptions of safety at home and in public” than Indigenous men or non-Indigenous people.⁸¹ Similar to the data on the experience of LGBTQ2 and racialized people with disabilities, this data strongly implies that for Indigenous people the experience of disability can intersect with other forms of discrimination to result in more negative impacts on their life and wellbeing during the COVID-19 pandemic.

79 Figure 12 includes all respondents over the age of 15 and uses data from the Statistics Canada crowdsourced survey “Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities.” From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling..

80 Statistics Canada, 2020b

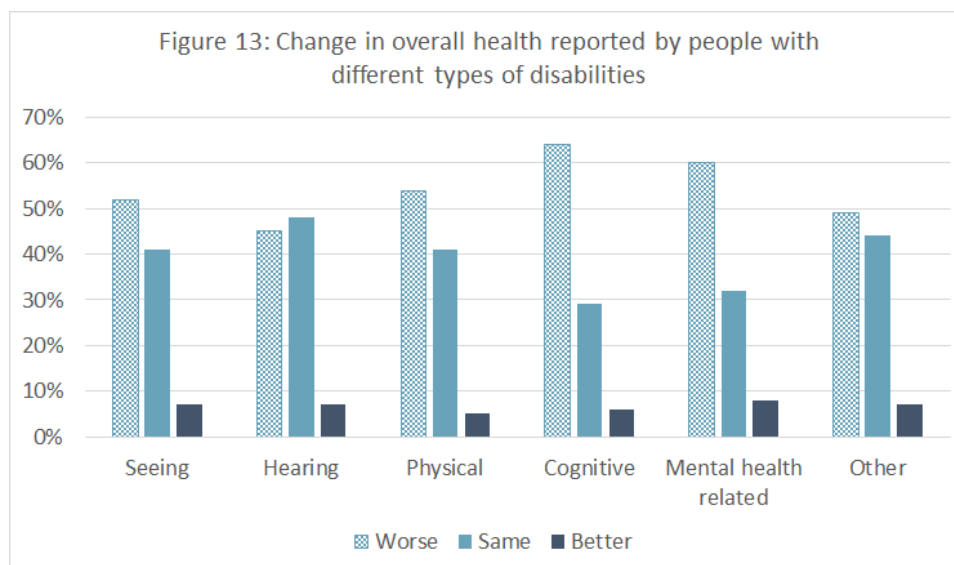
81 Statistics Canada, 2020b

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2.2.9 Health and Access to Health Care during COVID-19

Even prior to the pandemic, many people with disabilities had difficulty getting access to health care and health services because of physical, attitudinal, expertise and systemic barriers.⁸² People with disabilities and long-term conditions have experienced declining health during the COVID-19 pandemic.

Data from Statistics Canada's crowdsourced survey of people with long term conditions and disabilities suggests that roughly half of all participants experienced a decline in their overall health during the first three months of the pandemic, ranging from a low of 45% of people with hearing disabilities reporting worse overall health, to a high of 64% of people with cognitive disabilities reporting worse overall health (Figure 13).⁸³



In addition, 77% of respondents reported requiring a health service for their condition but being unable to receive care due to the pandemic.⁸⁴ Across Canada this ranged from a low of 71% reporting at least one disruption to receiving a health service in Québec, to a high of 87% reporting at least one disruption in Newfoundland and Labrador (Figure 14).⁸⁵

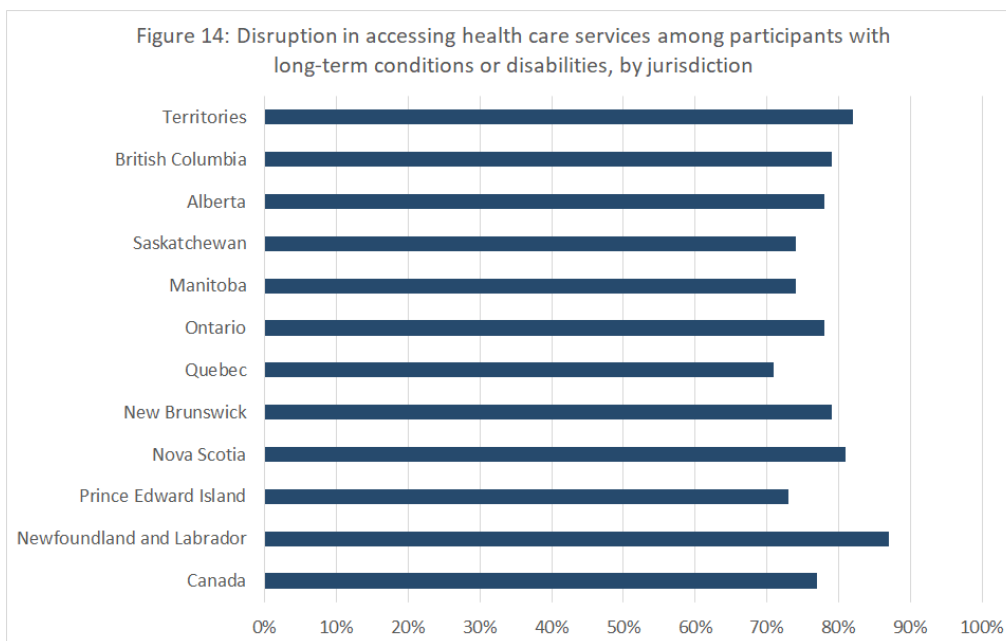
82 Stienstra, 2020; City for All Women Initiative, 2017

83 Figure 13 uses data from the Statistics Canada crowdsourced survey "Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities." From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

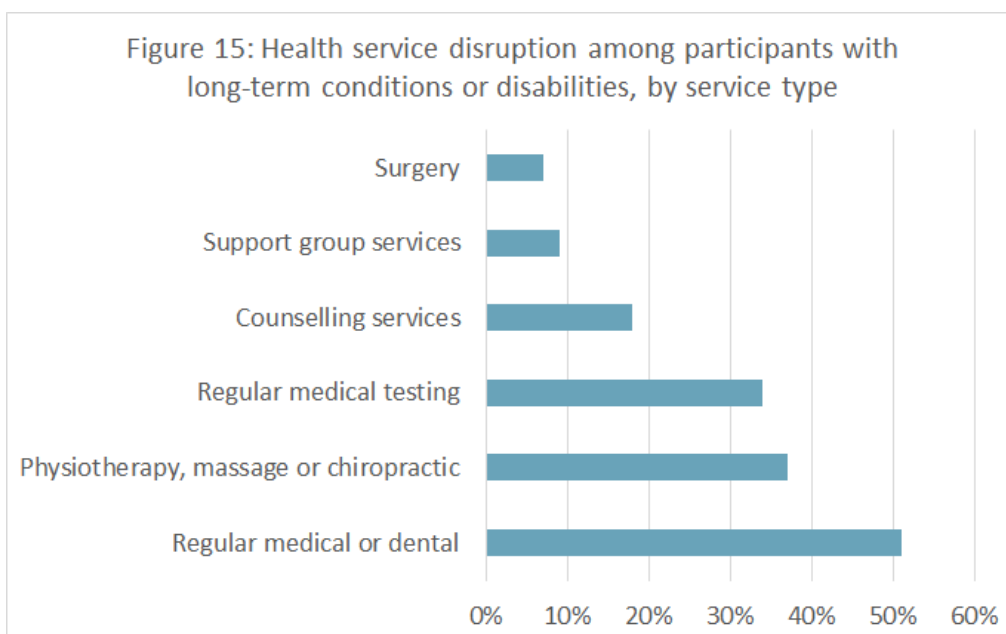
84 Yang et al., 2020

85 Figure 14 uses data from respondents aged 15 or older, from the Statistics Canada crowdsourced survey "Impacts of COVID-19 on Canadians Living with Long-term Conditions and Disabilities." From June 23 to July 6, 2020, approximately 13,000 Canadians with long-term conditions or disabilities participated in this survey. The survey was not conducted according to probabilistic sampling.

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The most common health service disruption reported was for regular medical or dental services (51%), followed by paramedical (37%), testing (34%), and counselling services (18%) (Figure 15).⁸⁶



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Community survey data also indicate that many people had difficulty accessing home supports. BCEd Access Society's survey of parents and caregivers to children with disabilities found that 70% were unable to access respite care during COVID-19. Less than half of respondents (45%) indicated that they had nursing or personal support worker (PSW) support available to them, with 16% stating it was unavailable and 40% stating they were unsure.⁸⁷ However, even those who reported being able to access nursing or PSW support reported a number of limitations related to the pandemic including the following:

- avoiding using this support due to fear of COVID-19 infection
- receiving reduced levels of support that compromise basic care and hygiene
- a lack of personal protective equipment being provided by nursing and/or PSW agencies
- exacerbation of pre-existing barriers to obtaining nursing or PSW support like finances and availability.⁸⁸

The CanChild crowdsourced survey of people with disabilities and/or caregivers also found that 35% of respondents reported virtual medical care (video or phone) was not available to people with disabilities.⁸⁹ A crowdsourced survey by Ability NB of 127 people with disabilities in New Brunswick found 43% reported a decline in the amount of in-home support they received during the pandemic, and 31% reported a decline in the quality of this care.⁹⁰

In terms of COVID-19 screening, Statistics Canada found that 8% of respondents were unable to get to COVID-19 related testing or medical attention due to their long-term condition or disability.⁹¹ The CanChild survey found that while 37% of respondents stated accessible screening was available, 19% of respondents stated accessible screening was not available, and 44% did not know, indicating a lack of information available concerning accessibility at screening centres.⁹² Qualitative responses indicated that the accessibility of screening facilities was a barrier, as well as stress and trauma around the tolerance of tests, particularly for children.⁹³ Other barriers included

- testing that was not wheelchair accessible
- absence of drive-through testing
- absence of testing centres from smaller population centres
- reduction in transportation services.⁹⁴

87 BCEd Access Society, 2020

88 BCEd Access Society, 2020

89 De Camargo et al., 2020

90 CBC News, 2020

91 Yang et al., 2020

92 De Camargo et al., 2020

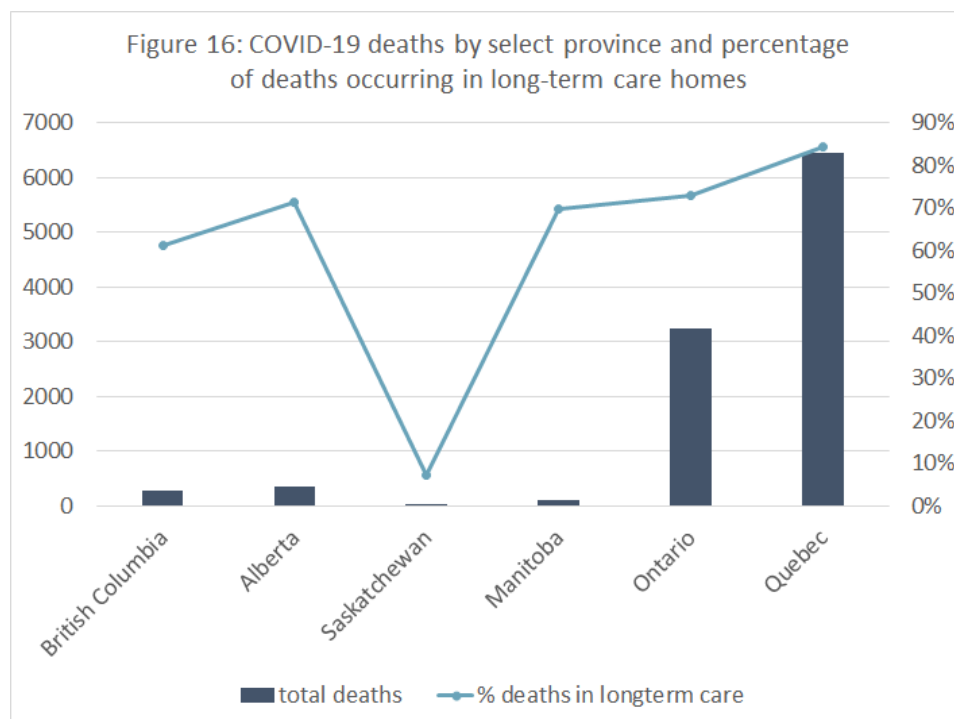
93 De Camargo et al., 2020

94 De Camargo et al., 2020

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2.2.10 Mortality

As of November 8th, 2020, 10,522 deaths have been attributed to COVID-19 in Canada, according to official accounts from provincial and territorial vital statistics offices.⁹⁵ 8,345 of these deaths are of residents of long-term care homes across Canada, meaning 79% of deaths have occurred in long-term care settings.⁹⁶ In most provinces between 65% and 85% of COVID-19 deaths have occurred in long-term care homes (Figure 16).⁹⁷



Excess deaths refer to the number of people who have died during a set timeframe beyond the expected mortality rate. Statistics Canada reports that from March to June 2020, there were more than 7,000 excess deaths across Canada; that is, 7,000 more people died than was expected.⁹⁸ The death rate became consistent with what would be expected in the absence of a pandemic from July to September. However, in October, the excess death rate has begun to climb again, likely in response to the increasing incidence of COVID-19.⁹⁹

95 Government of Canada, 2020

96 Loreto, 2020

97 Figure 16 uses a comprehensive dataset compiled by independent researcher and journalist Nora Loreto, which includes all publicly available information concerning the incidence of mortality due to COVID-19 in long-term care homes. The dataset used in this report is current as of Nov 8, 2020.

98 Statistics Canada, 2020c

99 Statistics Canada, 2020c

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Examining excess deaths helps capture mortality due to the indirect impacts of the pandemic, beyond reporting of direct deaths by vital statistics offices. Using Québec as an example, for March and April 2020, 2,132 deaths due to COVID-19 were reported, but population data suggests there were 2,636 excess deaths in this time frame, meaning this excess of 504 fatalities may be due to indirect impacts of the pandemic.

Unfortunately, data concerning COVID-19 deaths and excess deaths is not available disaggregated by disability status. However, 47% of all Canadians aged 75 or older have a disability¹⁰⁰, and this incidence is higher in long-term care homes, where many residents have disabilities and health conditions that require a high degree of support and care. Moreover, residents in long-term care homes under the age of 65 are almost exclusively people with disabilities. For example, in Ontario alone, 3,000 people under the age of 65 with developmental disabilities live in long-term care homes.¹⁰¹ As a result, the concentration of COVID-19 mortality in long-term care facilities disproportionately affects people with disabilities.

Similarly, although excess deaths are not disaggregated by disability status, the information that is available suggests that people with disabilities are likely overrepresented in any excess deaths during the pandemic. As discussed earlier in the snapshot, people with disabilities reported poor overall health and have had difficulty accessing medical treatment during the pandemic. People with disabilities also reported greater employment loss, greater isolation, and were three times as likely to report experiencing suicidal thoughts during the COVID-19 pandemic. These factors strongly suggest that the COVID-19 pandemic is precipitating a health crisis among people with disabilities, leading to declining physical and mental health and likely indirect mortality. The documented declines in physical and mental health among people with disabilities in Canada are produced through a loss of economic, social and institutional support.

Of particular concern are reports that a lack of physical and emotional supports and/or isolation are leading some people with disabilities and long-term conditions to initiate the Medical Assistance in Dying (MAID) process who otherwise would not be considering this option.¹⁰² In 2019, there were a total of 5,631 MAID deaths in Canada.¹⁰³ A high proportion of MAID recipients have disabilities as evident in their use of disability support services and age. For example, 41% of MAID recipients also required disability support services such as assistive technologies, adaptive equipment, rehabilitation services, personal care services and disability-based income supplements.¹⁰⁴ In addition, over 80% of MAID deaths are among people age 65 or older.¹⁰⁵ The CSD demonstrates the prevalence of disability in this age group is approximately 38%.¹⁰⁶ At least one study in the Canadian Medical Association Journal suggested that MAID patients were younger, higher income, and less likely to reside in an institution than the general population, suggesting that "MAID is unlikely to be driven by social or economic vulnerability."¹⁰⁷

100 Morris et al., 2018

101 Goffin, 2017

102 Mulligan & Yahwar, 2020; Favaro et al. 2020; Peters, 2020; KI-01, KI-05, KI-11

103 Health Canada, 2020

104 Health Canada, 2020

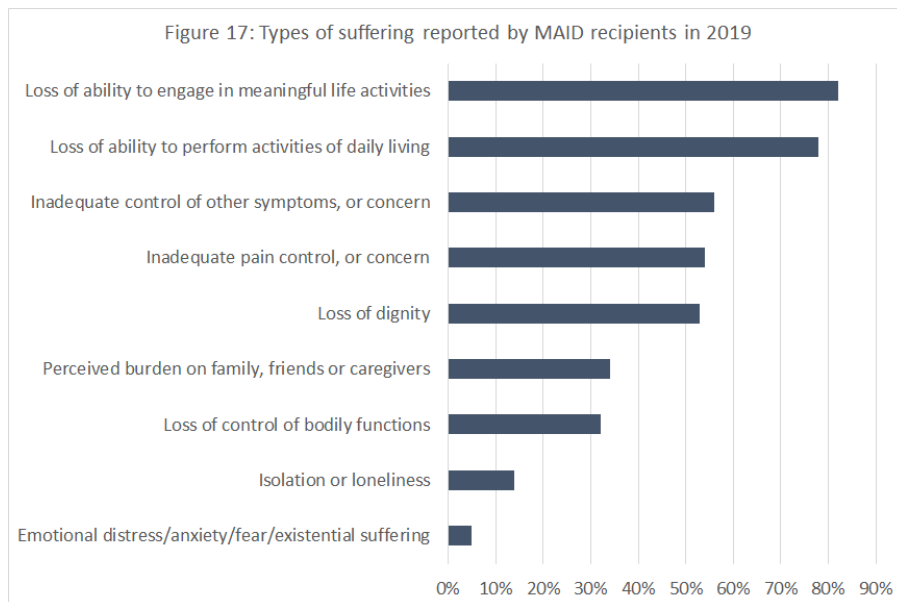
105 Health Canada, 2020

106 Morris et al., 2018

107 Downar et al., 2020

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Yet the disproportionate health, economic and social impacts on people with disabilities documented during the COVID pandemic may also increase the perceptions of suffering for people with disabilities, particularly those experiencing intersecting hardships like low-income and discrimination. One of the criteria for MAID eligibility is based on the person requesting MAID perceiving their suffering as intolerable, which relates to the broader social context. In other words, the absence of social, economic, and health care supports may increase the perception of intolerable suffering among people with disabilities. Many factors associated with suffering leading to MAID requests have been exacerbated for people with disabilities during the COVID-19 pandemic (Figure 17).¹⁰⁸



We are not yet able to document any changes in MAID deaths during the pandemic until further data is available, but given the indicators we discuss, this is an important area to monitor.

The shifting legislative framework for MAID, in the midst of the pandemic, is also changing the context within which MAID is considered an alternative. Under current legislation, MAID access in Canada is contingent on the diagnosis of a grievous and irremediable medical condition. This diagnosis requires individuals to demonstrate that they have a serious and incurable illness, disease or disability; are in an advanced state of an irreversible decline in capability which is causing enduring and intolerable suffering that cannot be relieved under conditions that they consider acceptable; and that their natural death is reasonably foreseeable.¹⁰⁹

¹⁰⁸ Figure 17 uses a dataset compiled by Health Canada concerning all MAID deaths that occurred in Canada in 2019 reported through the federal monitoring system, as reported in Health Canada, 2020. Recipients were able to choose more than one type of suffering.

¹⁰⁹ Bill C-14, 2016

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However, portions of this existing legislation are currently being amended, after the Superior Court of Québec ruled that the “reasonable and foreseeable death” clause infringes on Charter rights to “life, liberty and security of person.”¹¹⁰ In response to this decision, and in consultations on MAID in Canada, the Government of Canada tabled Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying)*, which would extend MAID to individuals where natural death is not reasonably foreseeable.¹¹¹ At the time of this report, Bill C-7 is under consideration in the Senate, having passed the House of Commons in December 2020.

2.2.11 Access to Information about COVID-19

A lack of accessible information about COVID-19 and COVID-19 related supports, was also a theme arising in the data available about the experiences of people with disabilities during the pandemic. More than half the respondents to CanChild’s survey stated that they were unaware of, or unable to find accessible information about COVID-19.¹¹² Similarly, BCEd Access Society found that 58% of respondents were having difficulty assessing whether they were eligible for any financial pandemic supports, and a further 39% needed more clarity on how respite funds could be used during the pandemic.¹¹³

2.3 Where are the gaps in data and knowledge and what is their significance

Despite our best attempts, there are some significant gaps in the data we collected and analyzed. These reflect the state of disability-related data as well as the limitations of doing research during the COVID pandemic. When considered in comparison with the other OECD countries considered in this research, the gaps also point to recommended areas for priority attention.

2.3.1 Lack of data on groups of people

In both quantitative reports and qualitative data gathering, there are specific groups about whom there is little or no data. When we discuss their situation, we do so largely on the basis of media or social media stories, or we infer their situations based on pre-COVID data. These groups or intersections include:

- migrant status, disability and COVID
- intersections of more than two groups (for example, Indigenous people who have disabilities and identify as LGBTQ2)
- disaggregated data on different Indigenous groups (for example, Indigenous people living in large urban centers, Indigenous people living on reserves)
- people with disabilities living in congregate settings especially those living in group homes or psychiatric settings and incarcerated people

110 Truchon c. Procureur général du Canada, 2019

111 Bill C-7, 2021

112 De Camargo et al., 2020

113 BCEd Access Society, 2020

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- housing status, disability and COVID
- mortality data disaggregated by disability

These gaps illustrate the existing limits of Canadian data for an intersectional analysis. Yet from what we know, these groups are often at greater risk of significant impacts from COVID and have limited access to information and programs related to COVID. For example, the challenges of migrant workers during COVID-19 have been well documented in a recent report, including loss of employment, human rights violations, and difficulty accessing health care.¹¹⁴ Yet no data exists connecting migration status to experiences of disability. Without appropriate data, the policies and programs related to COVID cannot successfully understand or respond to their experiences.

2.3.2 Quality and frequency of surveys

Both government and non-government organizations have implemented surveys to gather data on the situations of people with disabilities in the COVID pandemic. Statistics Canada introduced a series of crowdsourced surveys in June and July 2020, which have provided valuable information concerning the impacts of COVID-19 on different groups of people in Canada. However, crowdsourced surveys are not based on probabilistic sampling methods, meaning the information cannot be generalized as respondents do not necessarily represent the general population. We have included data from other surveys conducted by researchers and disability organizations where available, including several surveys which were conducted using more representative sampling methods.¹¹⁵

These surveys are generally done only once and provide limited data about the situations of diverse people with disabilities during COVID. But they are one of the only sources of survey data that we have for Canada during this time.

The United Kingdom offers a different approach to data gathering on disability and COVID. The UK Office for National Statistics has, to date, done three rounds of data collection and commissioned qualitative data. Unfortunately, their data is not disaggregated except by disabled/non-disabled and by types of impairments. Some of their findings¹¹⁶ include that there is a higher level of worry among disabled people as compared with non-disabled people, mostly about wellbeing (58% vs 37%); health (23% vs 7%); access to health care for non-COVID issues (41% vs 16%); access to groceries, medication, and essentials (37% vs 17%). The study also notes that people with disabilities report less concern about personal travel plans, work, or schools and universities. The UK has also been able to identify that 60% of deaths in the UK from COVID have been people with disabilities. Disabled women are 2.4 times more likely to die from COVID 19 and men with disabilities 1.9 times more likely to die. For women with disabilities under 65 it rises to 11.3 times more likely and for men with disabilities 6.5 times more likely.¹¹⁷

114 Caregivers Action Centre et al., 2020

115 Notably the reports completed by Egale and CMHA used more probabilistic sampling methods and/or weighted samples.

116 UK Office for National Statistics, 2020

117 Tidball et al., 2020

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Given the limitations of the Canadian survey data, and recommendations from the United Nations Office for Disaster Risk Relief and other agencies, disaggregated, georeferenced data is essential for an effective government response.¹¹⁸ UN Women recommends that governments “collect, utilize and disseminate data and evidence that is disaggregated by sex, gender identity, and disability, among other factors to develop, implement and advocate for social protection measures related to COVID-19.”¹¹⁹ The COVID-19 Disability Rights Monitoring project notes that data is especially needed about the situations of people with disabilities in institutional settings.¹²⁰

118 UNDRR, 2020; UNHR, 2020; UNICEF, 2020

119 UN Women, 2020

120 Brennan, 2020

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Section 3: Analyzing the impacts of COVID-19 policies on diverse people with disabilities in Canada: Themes, policies, and lessons learned

This section identifies 19 theme areas that illustrate the impacts of COVID-19 and related policies on diverse people with disabilities. Each theme answers the same questions:

- What are the [thematic] impacts of the COVID pandemic on people with disabilities?
- How do people with disabilities describe these impacts?
- What have been the COVID-related policy responses by Canadian governments?
- What lessons can we learn from the COVID pandemic [thematic] impacts on people with disabilities?

To develop the themes and answer these questions we used the findings from Section 2 and the intersectional disability and gender analysis framework (iDGA) to analyze the academic, policy and community literature, the social media scan, key informant and participant interviews, and focus group transcripts.

3.1 Employment

This theme identifies key employment impacts of the COVID-19 pandemic, from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the employment impacts of the COVID pandemic on people with disabilities?

- a) People with disabilities experienced disproportionately high temporary and permanent **job loss**, at almost twice the rate of people without disabilities,¹²¹ with impacts being more severe among:
 - young people with disabilities;
 - women with disabilities;
 - those with lower levels of education; and
 - people reporting more than one impairment or condition.
- b) **Lack of opportunities** resulting from the pandemic compounded inequalities for people with disabilities in the labour market.¹²²

121 Statistics Canada, 2020a

122 MacLeod, 2020

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- c) **Working from home is not an option** for many people with disabilities because they:
- work in industries or positions that are not suitable for home-based work;
 - don't have adequate access to the internet or familiarity with technology;
 - don't have necessary workplace accommodations at home such as accessible technology, ergonomic equipment, big screen monitors, and noise-cancelling headphones; and,
 - were twice as likely as individuals with more severe disabilities to require working from home as an accommodation but 61% less likely to get their needs met compared to individuals with less severe disabilities.¹²³
- ci) Pandemic employment solutions, including working from home, often lead to **greater social isolation** for people with disabilities, many of whom already live alone. This reinforces existing barriers to social inclusion and participation.¹²⁴
- cii) People with disabilities, especially women and those with intellectual disabilities, who are temporarily working from home during the pandemic may **experience prohibitive processes and delays to get a workplace accommodation**.¹²⁵
- ciii) Reduced employment opportunities **exacerbate the financial precarity** of many people with disabilities and reinforce the possibilities of living with poverty.¹²⁶
- civ) COVID-19 **exacerbates existing systemic barriers** to employment for people with disabilities.¹²⁷

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban Ontario man who is racialized and has a mental disability; an Alberta woman, non-racialized, who is a wheelchair user; a racialized Ontario woman who is Deaf; a rural Ontario, non-racialized woman with a physical disability; a rural Ontario woman, non-racialized, who has a physical disability; an urban Ontario woman who is visually impaired; an Ontario-based employment counselor; and an Ontario person who leads a disabled person's organization and is in a leadership role at a rehab hospital.

123 Morris, 2019

124 den Houting, 2020

125 Angus Reid Institute, 2019; Burlock, 2017; Bizier et al., 2015

126 Petit and Tedds, 2020

127 den Houting, 2020; Pineda & Corburn, 2020

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Job loss

"Well, I lost my job. That was the biggest thing. I worked at the airport and since they shut down the most recent hires were laid off, and then they've been telling us we'll be coming back again. But the day keeps getting changed. So, I doubt I'll have a job by the end of all of this, because I only was working for a year with them" (PWD 3).

"Like the work that someone's doing for a member of their family with a disability is not normal family caregiving work that we always assume is part of the family dynamic, so I really think that that shouldn't be treated differently, and it would really help people because of the fact that we know that like women are doing this more often. And then, women do sacrifice employment for these things, right, we have to do that right now during the pandemic" (PWD 17).

Lack of opportunities

"The most vulnerable part, right, would be people who are newcomers. People who are, like we said, with disabilities, I just think what has happened with COVID is, although everything looks beautiful, and online, and technology has really come up, you have either women, men or people with disabilities, who don't have those skills. In order to find those resources, they don't have those skills to advocate for themselves to, for somebody to find those resources. I see a lot of people in the community who have family around them, who are, you know, helping them prepare some resumes. Helping them, you know, navigate, you know, online websites to find information of what they need, what kind of support. I just think we keep forgetting about the people who don't know how to find those for themselves, because there's a lot of people who live on their own" (KI 04).

Working from home is not an option

"I work at a bank. So, banks have been well, depending on what bank you're with. I'm with [name of bank] and [name of bank] has been opened during the whole pandemic. We have we barely closed the new branches and if we have is because someone's maybe got COVID. So they've been closed for two weeks to clean and they come back open again. . . so I've been working full time. . . . So we have to wear masks and we have to have plexiglass in our office. So I was actually very lucky and I do have, because of my asthma and I can't wear a mask all day like I just, I can't do it. So I do have an exemption from wearing a mask while I'm at work, but I have to have the plexiglass up in my office, which, which I'm fine with. But then, when customers are wearing a mask and I have the plexiglass up I can understand people half the time. So that's been a very, very big challenge for me being able to hear my customers" (PWD 5).

"So to drop my schedule like that and have to work from home, it would be really hard for me. I also, again, I have a first child at home. So I think working from home would make me not as productive. Yeah, so I am kind of glad I did. I didn't have to make that transition and I'm kind of hoping that I don't have to at any point" (PWD 5).

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"Going to work, even working from home, that was a big challenge for me, because I didn't have a computer that was accessible...when it came to work at home, I had nothing that was accessible. So I was, you know, going to the office. And just, you know, I am going in when everybody else was working from home, or bringing a few files home and calling clients from here, that type of thing. So, you have to find, I guess different ways of working. But you know, other people don't. Don't have to worry about" (KI FG participant).

Greater social isolation

"I used to work from home one day a week, which I liked working from home. Five days a week it's pretty it's pretty isolating, you know" (PWD 9).

"I am back to work part time just two days a week. It's in retail so I get to see people, and I get to act out and have fun stuff that's helped my depressions and anxieties, but it [isolation] was very hard especially not seeing my daughter" (FG participant).

Workplace accommodations

"What we keep hearing is that employers in the past were not as open to accommodating people with disabilities by allowing for remote working or even part time working at home. And now that has become the norm for everyone who isn't disabled. So, all of a sudden, it's an opportunity, which really is benefiting more and more people which is really quite incredible that it takes a pandemic to do that. And I know in my own job I was able to transition and work at home quite easily" (FG participant).

"Especially with people who have medical issues, who have immune issues and things like that, who, you know, are at increased risk. Right now, I think that employers have done a particularly poor job of accommodating those people. . . . I'm not aware of any employers that have granted accommodations to people who are immune-compromised that work in health care" (KI focus group participant).

"With the right accessible technology and proper accessibility policies in part of the employment, along with employment, inclusive employment policies, people with disabilities should be able to work in a competitive labor market. And COVID has given us evidence. We just have to make sure that we collectively, push for those gains. So once COVID is done suddenly the world doesn't go back to whatever the pre-COVID normal was because that was full of discrimination against persons with disabilities" (KI 07).

What have been the COVID-related policy responses by Canadian governments?¹²⁸

In June 2020, the **federal government** put \$15 million into the National Workplace Accessibility Stream through the Opportunities Fund for Persons with Disabilities. This program provides community organizations with resources to improve workplace accessibility and access to jobs. In September 2020, the federal government announced \$1.5 billion in additional funding for Workforce Development Agreements (WDAs)

¹²⁸ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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with provinces and territories to offer Canadians skills training and employment supports. The WDA program includes specific funding targeted for persons with disabilities and other disadvantaged groups. Approximately 30% of funding is allocated to supporting persons with disabilities.

In September 2020, the **British Columbia government** announced their commitment to creating new grants to support non-profits who hire people living with disabilities. They also announced \$20 million dollars for employment supports for people with disabilities and those facing barriers.

What lessons can we learn from the COVID pandemic impacts on employment and people with disabilities?

- Work from home is not an adequate solution to addressing employment impacts for people with disabilities and needs to be accompanied by measures to address on-going systemic barriers they face.
- National labour standards, including supports to establish strong unions, are needed to recognize and support essential workers.¹²⁹
- With the right accessible technology and workplace accommodations, and inclusive employment policies, people with disabilities will be able to obtain and sustain employment during and post-COVID.

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3.2 Income

This theme identifies key income impacts of the COVID-19 pandemic, drawn from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the income impacts of the COVID pandemic on people with disabilities?

- a) Many people with disabilities faced disproportionately high **decreases in income** since the start of the pandemic,¹³⁰ with impacts more severe among:
 - Indigenous people with disabilities;
 - people with disabilities with lower levels of education; and
 - women with disabilities.
- b) **Day-to-day costs have increased.**¹³¹
- c) Income support measures provided by governments during the pandemic **did not include many people with disabilities.**¹³²
- d) Government measures were seen by many as **"too little, too late"**¹³³ and insufficient to address costs.
- e) Information about and applications for income measures were often **inaccessible** for people with disabilities living alone, older adults, and those without internet access.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: a non-binary, non-racialized Ontario person with a learning disability; a racialized, urban Ontario woman who is Deaf; an urban Alberta woman, non-racialized, who is a wheelchair user; a trans/non-binary person in Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an urban Québec man who is blind; an urban Ontario woman, non-racialized, who is visually impaired; an urban Québec woman who is hearing impaired; and an executive director of an Indigenous disabled persons' organization.

130 Statistics Canada, 2020a

131 Statistics Canada, 2020a

132 Lawrence, 2020; Hudes, 2020

133 Harris, September 18, 2020; Etmanski and O'Grady, 2020

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Decrease in income

"I relied very much on babysitting because that is just so easy for me to turn down when someone asks me, 'hey, can you take this job?' I can say, 'unfortunately not.' And also, community work and both of those things have been thrown off the table because of COVID. So I have virtually no income right now. I'm fortunate that I live with my parents and that I do have their support for certain things like obviously shelter and food and stuff. But I have no money right now to be able to save for school. I have no money to be able to save for recreation or anything. It's taken away some choices in terms of like not only what I can do to receive income but what that income allows me to choose to do. I don't have those choices anymore" (FG participant).

"Actually, I have a, like a part time gig I do privately so I provide in home support for medically fragile children. I basically lost all that income for six months" (PWD 5).

Day-to-day costs have increased

"The attitude of the [building] management, God love them, is these guys are on fixed incomes, they're getting the same support. Nothing has changed for them. True, but their expenses have gone up" (PWD 17).

"So yeah, everything was more expensive. And you know so yeah, we had more expenses. My husband's groceries - I mean I couldn't go to the dollar store and pick up some things for him. And then pick the rest of it up ... I had to get all of it ... or Metro online or RG online and have it delivered to him" (PWD 13).

Income supports did not include many people with disabilities

"Not for me as far as I know, I looked into some benefits, outside of it, but there was nothing as applicable to me as far as I know" (PWD 15).

"Too little, too late"

"ODSP I think is a maximum of \$1200, so people that gets CERB get \$2000. So there's like a recognition that people need \$2000 to survive every month, but yet in ODSP is \$1200" (PWD 13).

"I've heard of people on ODSP getting the extra hundred dollars Really? \$100 that barely covers a one-week grocery delivery and already in poverty. Come on" (PWD 16).

Inaccessible income measures

"I originally applied for EI, since I met the requirement. So I didn't go any time without it. I'm actually going without it right now. Since my EI ran out, and the CERB they're supposed to transfer me over for whatever reason they haven't. And I'm not sure if I should apply to the new program. And I can't get a hold of them because you're so busy and it's actually been causing stress in my life right now" (PWD 13).

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What have been the COVID-related policy responses by Canadian governments?¹³⁴

The federal government initiated the Canada Emergency Student Benefit (CESB) which provided income support to current and recent post-secondary students. Students with disabilities received an additional \$500 a month. The Canada Student Grants for Students with Permanent Disabilities were also doubled as a temporary response to the COVID-19 pandemic.

Some people with disabilities, who were employed or on Employment Insurance, were also eligible for the Canada Emergency Response Benefit (CERB) of \$2,000/month for a maximum of 28 weeks. Some may also be eligible for the EI Emergency Response Benefit (at least \$500/week, or \$300 per week for extended parental benefits) or the Canada Recovery Sickness Benefit (\$500 for up to two weeks) introduced in Parliament in September 2020.

At the same time, the federal government introduced the Canada Recovery Caregiving Benefit (CRCB) which provides \$500/week for up to 26 weeks for eligible Canadians unable to work because they must care for a dependent. As well, the Canada Recovery Benefit (CRB) was introduced, providing \$500/week for up to 26 weeks to workers who are self-employed or are not eligible for EI, who still require income support, and who are available and looking for work.

In September 2020, the federal government announced it would introduce a Disability Inclusion Plan. The proposed plan includes a new Canadian disability benefit, a monthly benefit modelled on the Guaranteed Income Supplement for older adults. Details, including eligibility requirements, have not yet been announced.

In British Columbia, people receiving income or disability assistance could exempt federal employment insurance benefits, including CERB. People on income or disability assistance who were not eligible for CERB would receive an automatic \$300 monthly supplement.

In Alberta, people receiving Assured Income for the Severely Handicapped (AISH) can exempt a portion of CERB.

In Ontario, CESB and CERB were treated as employment earnings for those receiving ODSP. The first \$200 and 50 per cent of each additional dollar received in a month is exempt. For those who collect CERB and become financially ineligible for ODSP, health benefits would not be lost. Some ODSP recipients could access up to \$100/month for extra costs during the first months of the pandemic.

¹³⁴ Information about policy responses came from online information and key informant interview. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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What lessons can we learn from the COVID pandemic impacts on income and people with disabilities?

- Significant income gaps between people with disabilities and without disabilities existed before the pandemic and were exacerbated by the pandemic income replacement measures.¹³⁵
- Long-existing issues in disability assistance were made evident with the CERB funding levels: "It's illustrated to them that government of Canada federally has said look, this is what people need to survive and they can tell you why it's because we use the income system as our baseline, it doesn't matter. They put it out there that \$2,000, a minimum is what you need" (KI 06).
- Better coordination is required between income assistance programs offered by federal and provincial government.¹³⁶ Federal income support programs need clearly defined goals and parameters to prevent inconsistencies across provinces. They should also be fully exempt from income and disability assistance benefits.¹³⁷
- Eligibility for income support programs for people with disabilities is overly strict and excludes many people with disabilities.
- Many people with disabilities were unable to access income support programs during the pandemic. Economic supports need to be improved for the long term, specifically for Canadians with disabilities.¹³⁸
- Income support programs need to recognize disability-related costs.

135 Statistics Canada, 2020a

136 See also Section 3.19

137 Petit & Tedds, 2020

138 Pineda & Corburn, 2020

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3.3 Disability-related costs

This theme identifies key impacts of disability-related costs stemming from the COVID-19 pandemic as well as policy responses. We identified these from the academic, policy, and community literature and media, and through interviews with participants and key informants. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

How do disability-related costs shape impacts of the COVID pandemic on people with disabilities?

- a) Many people with disabilities faced **increased costs of day-to-day necessities**,¹³⁹ especially groceries and personal protective equipment (PPE), during the pandemic. Those most affected by increased costs are:
 - people with disabilities living with children;
 - Indigenous people with disabilities; and
 - people who are immunocompromised or have severe respiratory conditions.
- b) These impacts are made worse by **reduced income and a lack of PPE** provided by nursing or personal support worker agencies.
- c) Disability-related costs may include **finding substitute (and perhaps more expensive) services** when programs are closed due to the pandemic.
- d) The **federal disability one-time payment** is too little, too late.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, non-racialized Ontario woman who is visually impaired; an urban Québec woman with mental and physical disabilities who uses a wheelchair and lives in a congregate setting; a rural, racialized British Columbia woman who is a wheelchair user; an urban, non-racialized Ontario woman with a physical disability; an urban, racialized Ontario woman who is Deaf; an executive vice president of a national disability organization; and an executive director of an Indigenous disabled persons' organization.

Increased costs of day-to-day necessities

"I've been lucky that neighbours and friends went to pick up groceries for me. But I'm sure like [participant] can attest to, from what I hear, you have to pay. You pay a little extra fee. You're not being able to use coupons, price matching, you're paying for delivery. There is a big extra cost. So, I mean that \$600 is not even covering what people are paying in delivery fees" (FG participant).

¹³⁹ Hennessy 2020; Petit and Tedds, 2020; See also Section 3.5

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"So yeah, everything was more expensive and you know so yeah we had more expenses. . . . I had to get all of it probably go or Metro online or RG online and have it delivered to [partner]. And then we found someone in the neighborhood who was willing to do the grocery for him. So, she would do groceries and then she would send me a photo of the bill. And I would just e-transfer her the cash. So, she would do it then she would have it delivered. So that made it a little easier for May and June. . . . Yeah. Yeah, but I mean so his groceries were more expensive because, one. She wasn't shopping for all that like the sale prices, like I did. . . . I would say his groceries were costing about \$100-\$250 more a month" (PWD 4).

Reduced income

"My costs have gone up. Instead of going to the grocery store for stuff I need, I will have it delivered to my house. Instacart is ridiculous the amount of fees they tack on. I was laid off from my job. Talk of the perfect timing, not for pandemic related reasons. I knew it was coming months before the pandemic hit. But the pandemic has affected the kind of postings that are out there" (PWD 2).

Lack of PPE

"So, since the COVID has started, I don't live a normal life anymore, as being at high risk I just don't go out like I use too. So having to depend on family and friends to help you with just the basic everyday things. They are helping me out with all costs of living and that is because I don't make enough to hire others to help. Extra costs like masks, hand sanitizer, wipes, Lysol just for everyday cleaning has added another cost. Even though I use Lysol normally, cleaning wipes I have never bought, so that is costing me a lot more. So, what do you buy, medications, groceries or extras so you can go out?"¹⁴⁰

Finding substitute (and perhaps more expensive) services

"There's talk about getting \$600 right coming soon. From, I believe it's the federal government. But we've yet to see that. I know there's a lot of people that would really appreciate that because the cost of food is going up and cost people pay for rehab is super expensive. A lot of us don't have a choice. We need that kind of rehab, you know, health care services. They're expensive, . . . a lot of those places have got to put costs up because they now have to buy all the PPE equipment, right, damn business, and they can't use it for the whole day they got to change everything after every person. Their cost to keep your business up is gone up, which then translates, you know, you've got to go somewhere. Yeah, right, that cost is going to the people that come to get the services" (PWD 18).

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Federal disability one-time payment

"You're going to be able to qualify for this one-time \$600 payment to cover extra costs that you've incurred. And it's like, well, this is way too late. Because, this should have been thought of, at the very beginning of the pandemic" (PWD 5).

"Yes, it's good, and it's something and it will help, but it won't come anywhere near to addressing the costs. But I mean. . . \$600, if they ever get it, it'll be helpful for them" (KI 1).

"We just got you know measly one-time \$600 yesterday. And to me, to be honest. To me that is such an insult. You know, payback too. If I have a new poverty as an individual, I will return that as you know point of this civil disobedience and really ashamed that nobody in the disability community is doing that because it's like we're being treated like beggars. Yeah, if every other community is able to get \$2,000 starting March 15. Then why the heck we are getting \$600 on October 30 one-time payment right? And then it's advertised on every single channel" (KI 7).

"It's too little, too late, and reaches too few. The \$600 amount is nowhere near the extra monthly costs many people with disabilities have incurred during the pandemic. It was issued four months after most other Canadians have received support and well after the country has emerged from lockdown. And it leaves around 60 percent of Canadians with disabilities behind. Payments also will not be issued until the fall."¹⁴¹

What have been the COVID-related policy responses by Canadian governments?¹⁴²

In July 2020, the **federal government** implemented a one-time non-taxable, non-reportable payment for persons with disabilities of up to \$600 to recognize extraordinary expenses during the COVID pandemic. Those eligible include individuals who (1) have a valid Disability Tax Credit certificate before December 31, 2020, (2) receive Canada Pension Plan disability benefits or Québec Pension Plan disability benefits, or (3) receive disability supports from Veterans Affairs Canada. This payment was first made on October 30, 2020.

People with disabilities who received the GST/HST credit in 2018 received one-time additional GST/HST credit payment in April 2020.

Older people with disabilities may also benefit from the one-time payment of up to \$500. Those eligible for Old Age Security pensions will receive \$300 and those eligible for the Guaranteed Income Supplement receive an additional \$200. For most people, this payment was issued in July 2020.

In April 2020, the **British Columbia government** announced the Emergency Relief Fund for children and youth with special needs and their families: \$225 per month for eligible families for three months (ending September 30, 2020) to be used for meal preparation, grocery shopping, home-making services, caregiver relief support,

¹⁴¹ Etmanski and O'Grady, 2020

¹⁴² Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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or counselling services. British Columbia also increased flexibility for using autism program funding, including an additional three months to use funds, and flexible use of expenses for some programs.

The **Ontario government** temporarily expanded its list of eligible goods and services (including PPE and others) to address the pandemic through the Special Services at Home and Passports programs. Ontario also increased flexibility in submitting and receiving expense claims for essential supports.

In April, the **Québec government** broadened the use of its Service Employment Paycheque so that parents of children with disabilities could use it for at home supports during the pandemic.

The **New Brunswick government** introduced the Emergency Bridging Fund for Vulnerable Post-Secondary Students, a one-time payment of up to \$750 to support students affected by the coronavirus pandemic.

What lessons can we learn from the COVID pandemic impacts on disability-related costs and people with disabilities?

- Eligibility for funds to address disability-related costs left out many people with disabilities, and there were significant delays in implementing related programs. These two issues reinforce existing systemic discrimination against people with disabilities related to additional costs of living with disabilities.
- PPE supplied to care/support recipients as well as to care/support workers could reduce disability-related costs.
- Policies and programs that use a tailored approach to meet the individualized needs of people with disabilities are especially useful, rather than a one-size fits all response.¹⁴³
- Cash transfers need to be made to all persons with disabilities, including those who may not be officially registered or eligible, regardless of their work status.¹⁴⁴

143 UN Women 2020, IASC, 2020a; WHO, 2020; UN General Assembly, 2020

144 UNPRPD, 2020

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3.4 Childcare

This theme identifies key impacts to childcare stemming from the COVID-19 pandemic as well as policy responses. We identified these impacts from the academic, policy and community literature and media and through interviews with participants and key informants. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the childcare impacts of the COVID pandemic on people with disabilities?

- a) **Caregiving responsibilities** of people with disabilities are generally **under-recognized and have increased** since the closures of childcare and schools. Impacts are more severe among:
 - women with disabilities;¹⁴⁵
 - lone parents;
 - parents with disabilities, or parents with children with disabilities, who have to work from home;¹⁴⁶ and
 - front-line workers with disabilities or with children with disabilities, who are most often racialized women and immigrants.
- b) **Parents of children with disabilities have increased stressors** related to childcare,¹⁴⁷ including:
 - reduced supports and limited access to services during COVID-19;
 - a need to find new workers or provide support themselves to keep contacts limited; and
 - heightened concerns for their child's mental health.
- c) Children with disabilities in hospitals or other institutions have **not been able to see their parents or other care providers**.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: the executive vice president of a national disability organization and the leader of a disabled persons' organization who is in a leadership position at a rehab hospital.

145 Canadian Women's Foundation et al., 2020

146 Neece et al., 2020

147 Hennessy, 2020

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Under-recognized and increasing caregiving responsibilities

"Single mothers trying to support kids at home all the time, and no family support, like, with a lot of childcare issues and problems when those all closed down, like, so there were, you know, there's a number of parents with disabilities were marginalized more, for example, than parents without" (KI 1).

Increased stressors for parents of children with disabilities

"Parents are not professionals. So, they did try to follow through the virtual care once it was in place, but they cannot replace a speech therapist or a physiotherapist" (KI 7).

"And many of the immigrants are in frontline jobs they are in the low paying jobs right. They are the one who cannot afford to be on welfare because they may not ever get their citizenship. So they're still working. But then who is looking after their children at home when they are, you know, serving our groceries or when they are working as peers who are nurses, you know, who is looking after their children at home, and especially if those children have medical complex care needs" (KI 7).

Children with disabilities unable to see parents or caregivers

"Imagine a five-year-old kid you know who is in a hospital, and then you are only allowed one parent for 24 seven and that means the mom can't go back and see other children, or the dad can't come and visit and try explaining that to a five-year-old. Why he hasn't seen his father on top of whatever medical distress is under for two weeks?" (KI 7).

What have been the COVID-related policy responses by Canadian governments?¹⁴⁸

The **federal government** created the Indigenous Community Support Fund to which Indigenous communities can apply for funding including to educational and other support for children. The federal government also increased the annual amounts for the Canada Child Benefit to a maximum of \$6,765 per child and the Child Disability Benefit up to \$2,886 per child for 2020-21.

The **British Columbia government** increased flexibility for using funds from the Autism Program, At Home Program and Emergency Relief and Respite programs until March 31, 2021. In April 2020 it introduced the Emergency Relief Fund for children and youth with special needs and their families which provides \$225 per month for eligible families for three months to be used for meal preparation, grocery shopping, home-making services, caregiver relief support, or counselling services.

In April 2020, the **Alberta government** introduced Interim Family Supports for Children with Disabilities and Interim Persons with Developmental Disabilities policies to suspend in-person meetings, support service continuity during the coronavirus pandemic, provide flexibility of services and support families post-pandemic. The Provincial Education Help Line provides advice to families who have questions about their

¹⁴⁸ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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child's education program during the coronavirus pandemic, particularly guardians of children with disabilities.

In April 2020, the **Ontario government** expanded the list of eligible expenses for the Special Services at Home and Passport programs to include goods and services that may make it easier to stay at home and practice social distancing (sensory items, technology, home-based recreation/fitness, PPE, essential service delivery fees, behavioural support plans). They have provided greater flexibility in the Autism in Ontario program. Ontario expanded its list of essential workers to receive emergency childcare to include staff working in developmental services, child welfare and child residential services. Between April and August 2020, Ontario provided a one-time payment of \$250 per child to parents of children up to 21 with special needs.

The **Québec government** developed a self-care guide for parents during COVID including caring for a child with disabilities. In addition, the Service Employment Paycheque fund enables parents of children with disabilities to use it for at home supports in order to reduce the risk of contamination until the end of the pandemic.

The **New Brunswick government** has provided information to families of children with disabilities on home learning through its Family Support for Children with Disabilities Program.

What lessons can we learn from the COVID pandemic impacts on childcare and people with disabilities?

- Closing childcare and educational settings has disproportionately negative impacts on parents with disabilities and families with children with disabilities. It is important to engage families and caregivers in the plans to support childcare with disabilities, including in the plans for childcare during closures.¹⁴⁹
- Childcare is an essential service, but for it to benefit people with disabilities it must be inclusive. Integrating services into more community-oriented programs could enable flexibility in programming and would also promote culturally appropriate and responsive support for the intersecting identities of disabled children and families.¹⁵⁰
- Plans must be considered for when caregivers or family members need to go into quarantine, to ensure children with disabilities receive continued support.¹⁵¹

149 UNICEF, 2020a; UNICEF, 2020b; IASC, 2020b; UNOCHA, 2020

150 Underwood and Parekh, 2020

151 UNICEF, 2020a; UNICEF, 2020b; IASC, 2020b; UNOCHA, 2020

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3.5 Education

This theme identifies key education impacts of the COVID-19 pandemic from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the education impacts of the COVID pandemic on people with disabilities?

- a) The pandemic **worsened existing barriers** and **added new barriers** to education for children and youth with disabilities including:
 - parents needed to provide support for children and modify curriculum themselves;¹⁵²
 - internet access was inadequate including in rural areas;¹⁵³
 - educational assistants were not available for online learning;¹⁵⁴
 - parents had to work from home and assist their children in learning.¹⁵⁵
- b) **People with developmental disabilities experienced more barriers to education** than people with other disabilities because they go to schools outside of their communities or have to attend separate schools or classes in order to receive additional supports.¹⁵⁶

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, non-racialized Ontario woman who is visually impaired; a suburban, non-racialized, non-binary Ontario person with a mental disability; an urban, non-racialized Alberta woman who is a wheelchair user; and an executive vice president of a national disability organization.

Acknowledging worsened/new barriers

"You know, how do you have two parents working from home? Two kids or three kids, four kids, whatever. Trying to learn from home and particularly families of children with disabilities who have additional learning needs some provinces fired all the EAs [educational assistants], laid off all the EAs, I mean, it just went on and on" (KI 01).

152 De Camargo et al., 2020; Wong, Dec. 3, 2020

153 De Camargo et al., 2020

154 De Camargo et al., 2020

155 Statistics Canada, 2020a

156 DAWN Canada, 2020

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"Under the present government, work on having either a health or an education standard seems to have been put on the backburner. But we really do need something on both education for young people with disabilities as they grow and so that they have opportunities that set them up for their futures, for whatever they choose to do, and we definitely need something in light of this pandemic" (FG participant).

"I reached out. The second one of my professors was like you have to have your cameras on or you will lose marks. It doesn't count as participation because it doesn't show where you are. I was like, um, that isn't allowed. It took me two to three weeks to get a one-page document of the policy put in place. It's one page but took me two to three weeks to get it. Emailed it to my professor and to my friends so they could share it, then I realized it only applies to general classes. There are some classes where they can require you to have your camera. Now my choices—school-related choices I have had to fight for them really aggressively and in some ways in certain classes, yeah, that's a choice for me whether or not I want to have my camera on, other times it does impact certain parts of my disability or impacts what I want people to know about me in relation to my disability" (FG participant).

"McGill University is very inaccessible. . . . The ableism on campus is so strong. Like, there would be events in buildings that weren't accessible that were on the subject of disability—they all have to go online now and they were making it like, 'Oh, you can't do anything online.' What? And now they're like oh no we all have to be online. It's like, oh, like when it's convenient to you guys now you're doing that. So I think you know it's proving that the restrictions or like the concerns that were there before about people with disabilities trying to participate remotely were just fake things that people that didn't understand, weren't supporting and now they want to get on board with it all" (PWD 17).

What have been the COVID-related policy responses by Canadian governments?¹⁵⁷

The **federal government** provided a number of funding supports for education, including the following:

- \$75 million in new funding for Indigenous organizations providing community-based services to Indigenous peoples and educational materials to Indigenous children and youth in urban centres and off reserve.
- Canada Emergency Student Benefit (CESB), which provides \$2,000 per month for students and recent graduates with disabilities who are not eligible for CERB.
- Canada Student Grants were doubled for all eligible full-time and part-time students in 2020-21. Students with permanent disabilities would be eligible for up to \$4,000 per month in addition to up to \$6,000 per month for full-time students; and
- A moratorium on repayment of Canada Student Loans.

¹⁵⁷ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in these sources.

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In **British Columbia**, the New Supports for Post-Secondary Students provided \$1.5 million dollars to 20 schools to strengthen support for students with disabilities. The British Columbia Education Restart Plan includes \$3 million dollars to support remote learning for students with disabilities or complex needs.

The **Alberta government's** Provincial Education Help Line provides advice to families who have questions about their child's education program during the coronavirus pandemic, particularly guardians of children with disabilities.

The **Ontario government's** Summer Learning Plan included a focus on continued learning with particular needs and specialized integrated programming for students with physical disabilities (access to educational assistance).

In **Québec**, the Measures for Ensuring Students Success were announced to promote educational success of students for the 2020 back-to-school period. These include direct services for students with disabilities, \$7.3 million dollars to create 75 new special classes to tailor services for students with disabilities.

The **New Brunswick government** introduced an Emergency Bridging Fund for Vulnerable Post-Secondary Students with a one-time payment of \$750 to support students affected by the coronavirus pandemic. The Family Support for Children with Disabilities Program has provided contact information for families with children with disabilities to access information on home learning.

What lessons can we learn from the COVID pandemic impacts on education and people with disabilities?

- Many students with disabilities have not been given the supports they need to actively participate in online schooling. Assistive products, technology and training should be provided if required.¹⁵⁸
- Students with disabilities and their parents have disproportionate challenges in adapting during a pandemic. The federal government should ensure that all education facilities, teaching and learning materials are accessible.¹⁵⁹
- There is a need to develop guidelines focusing on ensuring continued support for students with disabilities within educational institutions.

158 International Disability Alliance, 2020a

159 International Disability Alliance, 2020a

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3.6 Access to food and essential supplies

This theme identifies key impacts of access to food and essential supplies during the COVID-19 pandemic as well as policy responses. We drew these from the academic, policy and community literature and media and through interviews with participants and key informants. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of the COVID pandemic on people with disabilities related to access to food and essential supplies?¹⁶⁰

- a) People with disabilities face **increased costs of day-to-day essentials**, especially groceries, food delivery, and PPE.
- b) They face **additional barriers to accessing food** including getting their food,¹⁶¹ finding people to assist with food purchases, lack of wayfinding in groceries to enable blind shoppers, overloaded on-line shopping, and a lack of choice which led to higher costs.

Those most affected are:

- people with disabilities living alone;
- blind people or those with low vision;
- people with disabilities living with poverty; and
- people with disabilities living in remote areas.

- c) For some people with disabilities, the pandemic changed **where and how often they get food**.¹⁶²

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, racialized Ontario woman who is Deaf; an urban, racialized Ontario man who has a mental disability; an urban, non-racialized Ontario woman who is visually impaired and has a mental disability; an urban, non-racialized Ontario woman who has a physical disability; a trans/non-binary person in urban Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an urban Québec man in his sixties who is blind; an executive vice president of a national disability organization; and the executive director of an Indigenous disabled persons' organization.

¹⁶⁰ See also Section 3.1

¹⁶¹ Buchnea and McKitterick, 2020

¹⁶² den Houting, 2020, Independent Living Canada, 2020

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Increased costs of day-to-day essentials

"The actual fee for the delivery is just crazy which is why I went back because I was doing that at first, I was ordering everything I didn't want to go out anywhere I was too scared. And then finally I was like I can't do this anymore like I have to go and get my groceries" (PWD 05).

"The pandemic made that so much worse, because people's costs went up substantially for everything from groceries to transportation, because they were no longer able to use public transportation" (KI 1).

"There's help for everyone except us. People with disabilities matter too! Food is so expensive now that I have to choose to pay rent or buy food. Government should help us that have disabilities that can't afford to live."¹⁶³

Additional barriers to accessing food

"And it's just not smart for me to be going out and bussing to get my own groceries or even driving myself like I should just my family offers to help out so I just let them, so I've been relying on them to kind of at whatever specific meals and I'm talking about" (PWD 1).

"Because when I was in the very beginning, kind of going, how the heck am I supposed to get any food in my house? Because I couldn't, like, you know, I don't drive and the store was there's one store close enough to walk, but I mean, I can't carry more than two or three items. reached out and provided. It's called a vision mate. And they [CNIB] paired me up with someone who was willing to go, if I gave them a list, and then the money they actually went and shopped for me, that was hugely helpful" (PWD 10).

"There have been a couple of different kinds of barriers, let's say. In the first few weeks of the pandemic, everybody wanted Instacart [on-line delivery service] they were in high demand. So, I wound up not being able to use them and having to register for another two delivery services: INABUGGY was one and I'm drawing a blank on the name of the other one. I was able to get everything I needed, but it was interesting to have to research what kind of services were out there. What was their delivery range?" (PWD 2).

"There's been two times when we've had to self-isolate because we had, we didn't have COVID test, but we had some things that were close enough that we did. Okay. And then there was I also had an injury, where I was unable to do shopping for another like three weeks or so. So, there has been getting food in those instances, which is often like getting friends to pick things up for us. We just were able to get a credit card that doesn't require credit like one where you put money on it, and then. Okay. But we were not eligible for credit so like delivery things like that are kind of complicated. We have some friends who would put things on their credit card and then we would eat transfer them money. So that's some of the supports that we've needed is either people going and getting stuff and bringing it or ordering things for us and then payment" (PWD 12).

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"It changes things like how you get your groceries, what you do on your own and a lot of blind people are worse off than me if they're on their own because they don't have a spouse or they don't have somebody they live with or, you know, they're on their own and they, you know, to go to the grocery store and do the things that they have to do on a day-to-day basis" (PWD 15).

"How much you're getting where you're getting access to food right because we don't want anybody to leave in the community, and... the first time it was hard enough to get food in the cost of food because in the remote communities it's way more expensive" (KI 6).

Where and how often they get food

"So, finance, food insecurity, like, for instance, here in Ajax where I am, I can use the food bank once a month. And because I'm single, like, can only have so many items, right, but that's it, once a month. So then that's great for supplements" (PWD 10).

What have been the COVID-related policy responses by Canadian governments?¹⁶⁴

The **federal government** announced a \$350M for Emergency Community Support Fund to support vulnerable Canadians through charities and non-profit organizations that deliver essential services to those in need. It also created the Surplus Food Purchase Program, a \$50-million fund designed to help redistribute existing and unsold inventories to vulnerable Canadians and announced \$200 million in support for food banks and other local food organizations through the Local Food Infrastructure Fund and the Emergency Food Security Fund. Indigenous communities and people received support through the On-Reserve Income Assistance program which helps them with essential living expenses. Support for Northern communities was announced in April 2020.

The **British Columbia** government's Emergency Relief Fund for children and youth with special needs and their families offers \$225 per month for eligible families to be used for meal preparation, grocery shopping, home-making services, caregiver relief support, or counselling services.

The **Ontario** government's Special Services at Home and Passport programs have extended eligible items to include service delivery fees, PPE among others.

The **New Brunswick** government created an Emergency Bridging Fund for Vulnerable Post-Secondary Students with a one-time payment of up to \$750 to support students affected by the coronavirus pandemic. Eligibility is based on the need for food, shelter, unanticipated medical costs, or additional academic support/accommodations.

¹⁶⁴ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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What lessons can we learn from the COVID pandemic impacts on access to food and essential supplies and people with disabilities?

- People with disabilities are not given priority access to food deliveries and supplies. While most grocery stores created a protected time for older adults and other vulnerable populations to shop, this was not consistently applied and did not extend to online shopping and deliveries.
- Stores need guidance documents and examples of inclusive practices for wayfinding within stores during times of social distancing.
- Access to meal and food security programs needs to be protected and expanded during the pandemic and emergencies.¹⁶⁵

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3.7 Access to information and communications technologies

This theme identifies key impacts of access to information and communications technologies during the COVID-19 pandemic as well as policy responses. We drew these from the academic, policy and community literature and media and through interviews with participants and key informants. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the access to information and communications technologies impacts of the COVID pandemic on people with disabilities?

- a) The **costs of the internet and phones** increased during the pandemic, in part because of increased usage.¹⁶⁶ This has particular impacts on:
 - people with disabilities living with poverty;
 - racialized people with disabilities;
 - Indigenous people with disabilities; and
 - families.
- b) People with disabilities in remote and rural areas have **less access to the internet**.¹⁶⁷
- c) Those who rely on **publicly available computers or internet services are restricted** when public libraries and other sites are closed due to social distancing policies.
- d) People with disabilities have been **excluded from communications, services, and care** because of lack of computer or internet access.¹⁶⁸ This exclusion has a particular impact on:
 - people who are Deaf or hard of hearing;
 - people with intellectual disabilities;
 - older adults with disabilities; and
 - people with mental health disabilities.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: a trans/non-binary person in urban Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; a racialized, rural British Columbia woman who is a wheelchair user; a Québec person who is hearing impaired; an urban Québec man who is blind; the executive vice president of a national disability organization; and an Ontario-based employment counselor.

¹⁶⁶ Statistics Canada, 2020a

¹⁶⁷ De Camargo et al., 2020

¹⁶⁸ De Camargo et al., 2020; see also Sections 3.9, 3.10, and 3.15.

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Cost of internet and phones

"We tend to just get, like, have our friends give us their old ones [mobile phones] for my partner. But we were, we didn't have one for a little while and my partner, like called 311, they spent so much time like reaching out and saying like 'aren't companies like giving away phones right now for people in need?' and, like, they are available at shelters they were available in like very specific areas but we couldn't. We couldn't find one. So I think better access, especially for those of us who are not maybe hooked up with, with specific agencies or for organizations or for whom that would be a barrier to accessing that kind of support" (PWD 12).

Less access to internet

"I'm sitting in my room, I paid my rent on my computer, I can pay my Wi-Fi, right? Yeah, I'm getting my paycheque. I have supports online, I can talk to my coworker. You know, I have all that here in my room. Yeah. Right. And not everybody does. Yeah, I know that. Not everybody does. And we keep forgetting that not everybody does" (KI 4).

Publicly available technology and internet connectivity

"Those supports, they're not, they're not easy to reach, say we were at the YWCA. Maybe you go downstairs, ask another person they were Yeah, I find this they lead you upstairs. Here. By the time I get to where I need. I'm going through a few people. Okay. And we might be okay with that. But, you know, but yeah, so challenges even getting on our computer" (KI 4).

"Wi-Fi services, a lot of people with disabilities get that from the library, the Tim Hortons, the whatever. Well, those you know, a lot of that access dried up people didn't have technology. So when technology became the way to do everything, including your doctor's appointment, when you're when you don't have any, or if you do, if you did have access to it, you don't have to use it. That becomes a real problem" (KI 1).

Exclusion from communication, services, and care

"Everybody started to use Zoom as a way of communication, because it was the only way to continue on networking and I'm doing stuff for outreach, or networking or even information sharing. Since March. So, I literally right now could have 25 meetings on zoom a week, when I let, if I let myself. Yeah, which was. It's a whole new norm because there's a learning curve, right, some people don't want to do that either they don't like it at all so they kind of said no way Jose I'm not comfortable with technology. There's a learning curve. And it also takes away the, the social aspect of it. Having a more kind of personal connection with people, which a lot of people have been missing since March" (PWD 18).

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"No, I think that's actually a really important point because if we're moving everything because of COVID to virtual and technology. There's got to be an investment in that infrastructure, or else we're just gonna leave a very, big, big, big group of people behind. . . . we've had a laptop now for, I think we've had it for three years. And we lived for at least five years or more before that, where I did everything at the library, like we didn't we didn't have any access at all. And I just keep thinking about like, wow, like this time would be so different and it is that way for so many people, right?" (PWD 12).

"I can't push hard enough how accessibility is important, whether it's Braille, whether it's something for the hard of hearing, whether it's ASL and stuff, but it's important for those people who you know on Zoom or whatever, it has to be there, you know, um, for us as blind people. When you use the chat, it's very difficult, because your screen reader will interrupt what's being done in the meeting and what people are doing in the chat. And it's very distracting. And I've been in disabled groups where the chat is used, and all you can do is turn off your screen reader" (PWD 15).

"I think one of the challenges has been around access to communication. You know, that interactive type of communication and now it's kind of just become one way. And also, working with interpreters, we've had to work with them mostly, virtually not in person as we typically do, because we have to socially distance. And then sometimes when I'm using VRI [video remote interpreting], you know, the interpreter and I have to take turns with the phone if we're in the same space. Also, if people are using masks, it causes an echo" (KI focus group participant).

What have been the COVID-related policy responses by Canadian governments?¹⁶⁹

The **federal government's** Accessible Technology Program invested \$1.18 million to develop dynamic and affordable technology that are accessible for Canadians with disabilities.

What lessons can we learn from the COVID pandemic impacts on access to information and communications technologies and people with disabilities?

- Information technologies such as phones and internet have been essential to accessing information and support during the pandemic. However, because so many people with disabilities also live with poverty, the cost of accessing information technology puts these tools out of reach. It is important to consider how to improve the affordability of information technology such as mobile phones or home internet for people with disabilities.
- Similarly, although online services have been popular during the COVID-19 pandemic, some people with disabilities may face financial, physical, or intellectual barriers to accessing this type of service delivery.

¹⁶⁹ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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3.8 Access to housing

This theme identifies key housing impacts of the COVID-19 pandemic, from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the access to housing impacts of the COVID pandemic on people with disabilities?

- a) Canadians with disabilities face **additional barriers in accessing adequate, affordable, and safe housing**.¹⁷⁰ Impacts are more severe among:
 - women with disabilities;
 - people with developmental disabilities; and
 - people with disabilities living with poverty.
- b) **Evictions** during the pandemic can make housing even more challenging.¹⁷¹
- c) Some **pre-existing housing challenges**, including homelessness, have been intensified by the pandemic.¹⁷²

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, racialized man from Ontario who has a mental disability; an urban Québec man who is blind; a non-racialized, non-binary person in suburban Ontario with a mental disability; a trans/non-binary person in Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an Ontario person who is racialized and has a mental disability; an urban Manitoba person with physical disabilities; a disability advocate in Manitoba; and two executive leaders of national disability organizations.

Additional barriers to accessing adequate, affordable, and safe housing

"Being around my family is just not what I like. It's not what's healthy for me and so immediately just without anything COVID just forcing me to stay home more makes that more difficult even if they have work and if I tell them I have a meeting. So right now I'm worried about how if someone's going to try to call me from upstairs even though I told them this morning 'Hey, I have a meeting. Don't call me. Don't talk to me right now for a good two hours.' it's just I grew up in a Punjabi household [where] boundaries are most. . . I'm sure every culture, every family has this to a certain extent, but for growing up like boundaries are a very non-existent thing" (PWD 01).

170 DAWN Canada, 2019

171 May, 2020

172 Berrigan et al., 2020

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"A lot of different things have happened in the last few months and I've had to consider moving out when I'm really—I know that I'm not prepared. And I have had to consider moving out when I know that that would be in some ways obviously it would be a little bit better for me in certain ways, like it would help certain symptoms of my disability but others I really can't manage on my own and I couldn't manage with roommates. I have had to consider that choice anyway knowing that it would be something that would cause some harm" (FG 1).

Evictions

"She says her landlord is evicting her because he can get an additional \$400 a month on Airbnb and she can't afford that. Paying \$1,400 in rent would leave her with \$21 a month for food and all expenses."¹⁷³

"People with disabilities, before COVID, are very at risk of being homeless or near homeless, primarily because of employers and landlords, because they cannot afford a place to live."¹⁷⁴

"I've never had this much uncertainty in my life. . . It's very hard to plan for the next week, let alone the future. . . . If I don't get things together in the next 30 days and have a little bit of certainty on where rent is coming from, I could be homeless."¹⁷⁵

Pre-existing housing challenges

"We live in an accessible unit in a co-op which is incredible. But we know it's an older building our one of our elevators has been broken now for at least two months. . . . we wait sometimes for 45 minutes for the elevator. . . . and enough small enough amount of people that we can go in and you know I've heard that, when our club was built, they didn't have enough money and they put in a used elevator in the beginning. And so this has always been broken and is always breaking. So this is not a COVID new thing this is a systemic thing, but it gets more complicated during COVID" (PWD 12).

"And the housing situation. Right. I mean, we already know that there's a high rate of disability among the homeless population. And now you're talking about a homeless population, that's a great risk, also because nobody is looking out for them in the context of COVID-19" (KI 5).

"I think I have applied for low income housing for two locations in Montreal. I'm 178 [178th on the waitlist] for one area of the city, and 150 for one area another area of the city, but the waiting list is 15 years. You know, so, you know, like for me to get into low-income housing, you know, even though my, my income allows me to get. I'm eligible for that. But it ain't going to happen. Look at I'm 64 years old. You know where am I going to be in 15 years' time" (PWD 15).

"The city is not accepting new subsidy applications due to the pandemic. They've at the very least frozen if you live in a unit that is able to be subsidized, and you just need the subsidy to kick in. They've frozen that part. I would like the city to change its rule on subsidized housing" (PWD 1).

173 Mulligan and Yawar, 2 Sep 2020

174 MacLean, 2020

175 MacLean, 2020

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What have been the COVID-related policy responses by Canadian governments?¹⁷⁶

In March 2020, the **federal government** announced it would provide \$157.5 million in funding to the Reaching Home initiative, a community-based program to support people who are unhoused. In October 2020, it announced the Rapid Housing Initiative, providing \$1 billion to create up to 3,000 new, affordable, permanent housing units across the country.

The **Ontario government** introduced the COVID-19 Residential Relief Fund, which provides relief funding for residential service providers that support vulnerable populations including people with developmental disabilities, children and youth, and emergency shelters for women and children.

What lessons can we learn from the COVID pandemic impacts on access to housing and people with disabilities?

- COVID support measures should also address costs of and access to housing. Very little has been done by Canadian governments to address these concerns.
- People with disabilities are more likely to be at risk of being unhoused because they are more likely to live in poverty. Many were already struggling to pay rent before COVID.¹⁷⁷
- Living with family is not a safe option for everyone; it is not safe to assume that people with disabilities can move in with family or friends, even temporarily.

¹⁷⁶ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

¹⁷⁷ DAWN Canada, 2019

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3.9 Congregate living

This theme identifies key impacts of the COVID-19 pandemic on congregate living from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of the COVID pandemic on people with disabilities who live in congregate settings?

- a) People living in congregate settings have **increased infection risk** due to a lack of PPE in congregate care homes, and increased risk of mental health concerns due to COVID-19 related changes in detention practices.¹⁷⁸
- b) People in long-term care and other congregate settings have experienced **declines in their level of care** that harm their health and well-being. These include inadequate staffing levels, insufficient support with daily activities like eating and bathing, and extreme isolation.
- c) The isolation of people in congregate settings from families and caregivers and the significant decline in social activities and programming have had **negative impacts on disabled people's health and well-being**.¹⁷⁹
- d) Increased isolation in congregate settings led to **increased violence** for people living in those settings.¹⁸⁰

These impacts are greater for:

- older adults living in long-term care homes;
- young people with disabilities living in long-term care settings;
- people with intellectual or mental health disabilities who live in group homes or institutions;
- women with disabilities;
- people who are incarcerated, a high proportion of whom are Indigenous and racialized; and
- migrant workers who are undocumented.

¹⁷⁸ Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

¹⁷⁹ Cortis & van Toorn, 2020

¹⁸⁰ Courtenay & Perera, 2020; Glover et al., 2020

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How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban Ontario woman who is a wheelchair user and lives in a congregate setting; an Ontario man in his thirties who has multiple sclerosis and lives in a long-term care home; an urban Québec woman who is hearing impaired and lives in a congregate setting; the executive vice president of a national disability organization; two international disability advocates from Australia; the executive director of an Indigenous disabled persons' organization; the executive vice president of a national disability organization; and the leader of a disabled persons' organization who is in a leadership position at a rehab hospital.

Increased infection risk

"I don't want to see multiple attendants because where I live. I live in assisted living and there are 15 other people with disabilities that live here. And the agency has not put anything in place to ensure that staff get tested on a regular basis. I asked them when they would be doing that, and they said they don't have any plans to do it in the future as of right now" (FG participant).

"You know, that was another one of my concerns was, you know, what about the staff going home and coming back. . . . I was talking to the director about that and he said, 'well they are taking precautions.' You know, so I have to. . . I just have to trust that you know they are taking precautions. And they are wearing masks. So, you know, I just have to, you know, make sure I keep myself safe. You know, and hopefully nothing will, will you know everything will be okay" (PWD 16).

Decline in level of care

"When you have, you know, there's a capacity issue already within many communities how many organizations do the right thing, without any oversight? You know, the right thing isn't always going to happen. So I really find it, you know, when all these things, it goes back into group homes, long term period, these all seem good and I used to work in long-term care, . . . and we were considered to be one of the better places in the province, and I said I would never let my mother into place. Everybody thought we were thought to be one of the more progressive. . . . people are just you know people that never no range of motion, they were stiff as a board, they'd lie in their own excrement for hours and people wouldn't go and change them because, you know, it was half hour before their shift ended. I was asking if we're supposed to be good, imagine what must be considered to be bad? . . . If you're that bad in time when there is no crisis, how bad are you gonna be when there is a crisis? And we have seen that we've seen that exactly, with people walking off the job, leaving them there. You know, it's just horrible, horrible" (KI 6).

"During this pandemic, we saw clearly that seniors and people with disabilities who actually lived in their own homes, or whatever with supports were way safer. Invest all that money into that" (KI 1).

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Negative impact of isolation on health and well-being

One young resident of a long-term care home says: "I came into a place like this to let my family have some peace. My family is home, pretty much in tears."¹⁸¹

"And nobody's allowed in, and nobody's allowed out, and I'm sorry, but anybody who lives in a congregate care facility is in a very vulnerable position on care for a person with a disability, or your senior. And when nobody else is allowed in that place. And nobody out. It only makes you way more vulnerable" (KI 1).

"The number of deaths in age care facilities was extraordinary. That would have largely been people with disability. And probably the other thing I would say is there were incidences where the powers of a guardian through the guardianship laws, the powers of guardians were actually increased over and above public health orders which enabled guardians to restrict the movement of people so that they were forced to stay until their home or remain within certain confines, et cetera. And obviously people under guardianship, that's largely people with cognitive impairment and people with psychosocial disability" (KI 03).

"And, you know, in the beginning they had no visitor policy. And some of us had to do so much riding and so much advocacy to really for government to understand that families are not visitors. Right. The families are part of the caregiving and well-being of, especially adults with disability but it's really, really important for kids with disabilities who were living in group homes or were in the hospitals" (KI 07).

What have been the COVID-related policy responses by Canadian governments?¹⁸²

The **Ontario government** expanded COVID-19 testing as a strategy to help slow the spread of the virus. A number of priority groups were highlighted to be proactively tested, including Canadians living in congregate care centres (shelters, prisons, group homes). In April 2020, it

- announced a COVID-19 Action Plan for Long-Term Care Homes to help prevent the spread of the virus by focusing on additional testing, containment, addressing staffing challenges and securing personal protective equipment.
- adopted the COVID-19 Action Plan for Vulnerable People on April 23, 2020. The action plan focused on enhanced screening in congregate care settings, visitation limitations, providing masks to workers in congregate care settings, PPE training, and managing outbreaks.
- provided up to \$40 million in a relief fund to support organizations that provide residential services for children and youth, people with developmental disabilities and emergency shelters for women and families.

¹⁸¹ Ireton, 2020

¹⁸² Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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The **Québec government** announced in May 2020 that support within long-term or residential homes can be provided by a family caregiver who do this on a regular basis. They must receive approval from the Québec government and follow specific directives.

What lessons can we learn from the COVID pandemic impacts on people with disabilities?

- Families should not be considered optional visitors of loved ones in congregate living settings.
- Systemic changes to community-living programs, affordable access to care, and training for health care providers is required to decrease the number of people living with disabilities living in congregate care homes.¹⁸³
- While older adults are certainly a large proportion of long-term care residents, it is important to remember people with disabilities when making policies about these settings.

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3.10 Access to community supports and services

This theme identifies key impacts of the COVID-19 pandemic to access to community supports and services, from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

How does access to community supports and services shape impacts of the COVID pandemic on people with disabilities?

- a) During the pandemic, services and supports for people with disabilities were not always classified as “essential” and their **closing or restrictions** greatly affected people with disabilities and their families.¹⁸⁴ Restricted access to services and supports increased impacts on people with disabilities:
 - living in congregate care settings;
 - requiring external supports in their homes; and
 - living in rural or remote areas.
- b) Restrictions on usual supports and services resulted in **decreased mental health** for many people with disabilities.¹⁸⁵
- c) Moving community services online **reduced the quality of support** and **excluded** certain groups of people with disabilities, like people who are Deaf or hard of hearing.
- d) Restrictions on usual activities resulted in increased so-called “challenging” behaviours, use of medication, and risk of placement breakdowns in those living with intellectual disabilities and people with mental health disabilities.¹⁸⁶

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, non-racialized Ontario woman who is visually impaired and has a mental disability; a trans/non-binary person in urban Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an urban Ontario woman who is Deaf; and a racialized man from urban Ontario who has a mental disability.

184 Courtenay & Perera, 2020; den Houting, 2020; Glover et al., 2020; Pineda & Coburn, 2020; Rolland, 2020

185 den Houting, 2020; Rolland, 2020

186 Courtenay & Perera, 2020; den Houting, 2020; Glover et al., 2020

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Closing and restrictions

"And like, I have a friend who's in his 20s. He has Down syndrome. Well, you know, all the programs he was enrolled in have been cancelled. Okay. But there's no, there's no, there's no, there's no alternative" (PWD 10).

"And I think the biggest changes would be around shift in, like, the support structure for, for me and for my partner. In terms of like last external support being available. And so, we're kind of managing a lot more of our support needs with each other. We're doing the bulk of our care between the two of us. So I would say that's a big one" (PWD 12).

Decreased mental health

"So, before I live by myself, I live alone with a guide dog, I had some support coming in to assist me with something. And that organization decided that they weren't going to send support in anymore. And so like, and I know again, I know I know you know, for myself and so speak for myself, so I was isolated to begin with. But now I'm like and I'm a little bit more it's not quite so bad now because I'm doing a few things like getting out and like having a coffee at cameras or going to the pharmacy to pick up my meds. But it it's just and I guess that leads me into another one is mental health wise; it's been a huge like, I deal with depression and anxiety. I have for years. I'm on medication I was, you know, I've been considered stable for a long time. But with you know, the cut off of everything. . . . And the further isolation just really caused a lot of has really I've really been struggling mental health wise" (PWD 10).

Reduced quality of support and exclusion

"It's hard to be like hey join a group like everyone has these Zoom groups but they're not accessible to like for me [as a Deaf person] they're not accessible at all. So there's social groups like from Facebook groups and all that, . . . I don't have the option to join them. . . . I used to volunteer at a camp in the summer and this year the whole thing went virtual, but the entire thing had no captioning so. . ." (PWD 7).

"But just the transition online, even though you know, we're in this information age, I think we're realizing more and more—people like, we have needs, we have social needs that like it means we have to be in person. . . . because in person component is so [explicit] important" (PWD 1).

"And when it comes to deafblind, individuals, they're not able to work with intervenors out in the community like they normally do. So they're isolated all that all the more, because with an intervener, they work in very close proximity. So with social distancing, they're not able to do that, which means that they're just forced to stay home and really not be able to get to get out in the community. And it really impacts mental health, we, we have had people in the community commit suicide as a result, because they haven't been able to have access to counseling, they haven't even, you know, been able to make appointments. In some cases, some people have committed suicide. And, and it's because of the lack of access" (KI focus group participant).

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What have been the COVID-related policy responses by Canadian governments?¹⁸⁷

The federal government invested \$350 million to help community organizations serve vulnerable Canadians during the coronavirus pandemic through the Emergency Community Support Fund, partnering with United Way, Canadian Red Cross and Community Foundations of Canada to distribute the funds. In addition, it invested \$20 million to support organizations that offer community-based projects that reduce isolation, improve the quality of life of older adults, and help them maintain a social support network. The federal government has also established a web-based portal dedicated to mental wellness. The service provides information and support to address mental health and substance use issues, including confidential chat sessions or phone calls with peer support workers, psychologists, and other professionals.

The **British Columbia government** announced updated flexibilities to their Autism Program, At Home Program and Respite and Care Agreements, including additional months to use funding, movement to virtual delivery, and relaxation on expense forms. It also passed Ministerial Order M094, Emergency Program Act which includes disability care and support services as “essential services.”

The **Alberta government** developed interim policies to support service continuity during the pandemic for their Family Supports for Children with Disabilities and Person with Developmental Disabilities programs.

The **Ontario government**, through the COVID-19 Action Plan, Protecting Vulnerable Ontarians, expanded the list of eligible expenses for goods and services under their Passport, Special Services at Home, and Autism in Ontario programs to make staying at home easier. Ontario also provided up to \$40 million, through the COVID-19 Residential Relief Fund, to provide relief funding for residential service providers that support people with developmental disabilities, children and youth, and emergency shelters for women and children. The Ontario Community Support Association will coordinate and subsidize deliveries of meals, medicines and other essential items to low-income seniors and people with disabilities who lack connections or are in supportive or community-based living programs through a \$11 million dollar program.

The **Québec government** broadened the modality of the Service Employment Paycheque fund to include the use of at-home supports.

¹⁸⁷ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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What lessons can we learn from the COVID pandemic impacts on community supports and services and people with disabilities?

- Recognizing essential services in the homes of people with disabilities and in community programs will reduce negative impacts on people with disabilities.¹⁸⁸
- Those who provide support (PSWs, family members, community organizations) also require support to ensure that the essential services are still provided to people with disabilities during the COVID-19 pandemic and future crises.¹⁸⁹
- Building capacity to sustain adequate access to care workers through providing fair pay and good working conditions is essential to an effective, disability-inclusive response to COVID-19.¹⁹⁰
- Impact assessments should be conducted prior to implementing policies that change or restrict access to supports and services, particularly for those with diverse needs.¹⁹¹

188 Harden and Jama, 2020

189 Silver, 2020; Canadian Women's Foundation, 2020

190 Cortis & van Toorn, 2020

191 Antova, 2020

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3.11 Access to health care and services

This theme identifies key impacts of the COVID-19 pandemic on access to health care and services, drawing from the literature and the media and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of the COVID pandemic on the health and access to health care of people with disabilities?

- a) People living with disabilities have a **greater risk of contracting COVID-19**¹⁹² because they are more likely to experience the following:
 - other health conditions;
 - living in a congregate care setting;
 - higher levels of interaction with multiple caregivers; and
 - decreased access to public health measures.
- b) Social distancing and other lockdown procedures had **negative unintended health consequences** for individuals living with disabilities¹⁹³ due to the following:
 - increased isolation;
 - reduced access to care, treatment, and surgery;
 - reduced detection and prevention of mental and physical health concerns; and
 - reduced access to accessibility, assistive devices¹⁹⁴ or disability-related services.
- c) **Triage policies** in response to the pandemic may influence persons with disabilities' perceptions of access to health care and create additional pressure to seek medical assistance in dying or commit suicide.¹⁹⁵
- d) Pandemic responses have **reduced access to and quality of primary and routine care**.
 - Service or care recipients may receive poorer quality of care and violence or abuse because frontline workers have too many demands and there are too few resources.¹⁹⁶

192 Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

193 Glover et al., 2020; Pineda & Coburn, 2020

194 Monsebraaten, 13 Apr 2020

195 ARCH Disability Law Centre, 2020; Gillmore, 2020; Hendry, 2020

196 International Disability Alliance, 2020b

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e) Using the **phone or online platforms for health care appointments** may increase access for some people with disabilities but has created added barriers to accessing care for others.¹⁹⁷ Those at greater risk include the following:

- women with disabilities;
- individuals with intellectual disabilities;
- people with mental health disabilities;
- people who are Deaf or hard of hearing; and
- those who have no or unstable access to internet and other communications technologies.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, non-racialized Ontario woman who is visually impaired and has a mental disability; a trans/non-binary person in urban Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an urban Ontario woman who is a wheelchair user and lives in congregate care; a racialized man from urban Ontario with a mental disability; an urban Québec woman who has mental and physical disabilities and lives in congregate care; and an urban, racialized Ontario woman who is Deaf.

Negative unintended health consequences

"And then medical care has been, you know, I have some specialist appointments and things like that, that a lot of them went to virtual, but not all of them did. So, some of them have been put off and they're still, you know, I'm still waiting for some, some things, you know, important diagnostic testing that was supposed to get done" (PWD 10).

"I feel like there's a lot of. I feel like things are falling to the cracks, with chronic health stuff where follow up isn't happening a lot of appointments got canceled, and they never got rescheduled. . . . Things are getting lost. Okay, getting lost in that process. There's a lot of like, I tell them something but then it's like I never, I never told them it either gets forgotten or lost" (PWD 12).

"It feels like I feel like I have less choice around how I manage my like chronic health stuff, and less access to the things that I was accessing before to manage that, both in terms of support and also in terms of like, you know, using things like food or alternative medicines or things like that" (PWD 12).

"The thing I really want to emphasize is the lack of support from the agency, not only lack of support but what I perceive to be gaslighting. When I initially freaked out about this [the care agency's lack of a pandemic plan], when I said what are we doing, and I was looking for answers, they told me . . . that I was fear mongering. And like it is crazy. Do you know what a pandemic is?" (FG participant).

¹⁹⁷ International Disability Alliance, 2020b; People with Disability Australia, 2020

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Reduced access and quality of primary and routine care

"I have attendant care come into my home to do some of my daily care to provide needs for me. There's been a lot of changeover in staff, so that's a bit, you know, disconcerting and a bit frustrating because as soon as you train one staff, another one comes in. And so, I'm getting through that. It is a frustration, but I'm getting through it" (FG participant).

"I also am supposed to have attendant care, and I haven't had attendant care consistently or regularly even since the middle of March. And I am really struggling. My care agency is not very cooperative or kind about the needs of the clients during the pandemic. They did start taking precautions in the middle of April, which was a little bit late, but that's when they started wearing masks. And since then, like I didn't have care for quite a while, and then last month I was like, well, I'll see one attendant once or twice a week. I don't want to see multiple attendants because where I live, I live in assisted living. . . and they are treating me like they have told me three or four times at least that I can remember that I should consider going on direct funding because I am seeing this one staff who works three times a week, I'm only seeing her about once a week, sometimes twice if I really beg. But they are acting like they're doing me some sort of favour. They're acting like I'm being a brat by only requesting this one staff" (FG participant).

Triage policies¹⁹⁸

"Because we were neglected because we were not deemed as important and we knew we knew very clearly that if we went into the hospital with COVID-19 and there was one respirator and two of us, the person who was not disabled would get the respirator. We knew that, like triage would be such that they would choose to keep the other person alive and not us" (PWD 4).

Phone or online platform appointments

"My interaction with health care providers was always on the phone never on Zoom. . . . It feels like very quick and I don't feel like I can really talk about some of my issues and ask questions that's because it's on the phone it's rushed" (PWD 1).

"When it comes to my own personal stuff like for my own pain management, and my doctor's appointments because I do have a lot of specialists. It's been hard to go do some of those appointments; some are great because they're over the phone but then there's the added barrier of I'm Deaf. So, I'm not getting that face to face, and that basically is connection where I can read your lips and you know I can make sure I understand it's over a phone" (PWD 5).

¹⁹⁸ Triage policies or protocols were mentioned in three interviews (PWD2, PWD 4, PWD 9) and one focus group with persons with disabilities (FG 1), as well as in five key informant interviews (KI 1, KI 3, KI 5, KI 6, KI 7). Triage policies were discussed in the context of discriminatory distribution of critical care. The key informants talked about the importance of adopting a human rights approach in designing and implementing triage protocols.

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"This is actually one of the biggest annoyances. I went to my psychiatrist a couple times and he gave me some medication, and I stopped taking once I was out of school, but since I started school. I actually had to go; I was considering going back on a medication. So, to call them a few times, but since he's only taking patients on the phone. He's become impossible to reach. It's been the biggest frustration is actually getting a hold of services when I need it since it's either on online, or it's on the phone, And there's bigger delays" (PWD 3).

What have been the COVID-related policy responses by Canadian governments?¹⁹⁹

The **Public Health Agency of Canada (PHAC)** released a number of guidelines on COVID-19 and people with disabilities in Canada, including a specific guidance document on COVID-19 and people with disabilities. The guidelines identify many of the impacts discussed here, offer accessible and inclusive practices to assess people with disabilities for COVID-19, and address implications of barriers to health care access. Many of the examples illustrate an intersectional and human rights approach. PHAC also developed a public health ethics framework for use by policy makers and public health professionals that incorporated expert feedback from members of the disability community represented through the COVID-19 Disability Advisory Group. PHAC provided specific guidance for long-term care facilities, shelters for people experiencing homelessness, correctional facilities, and included specific considerations for congregate living.

Through the Safe Restart Agreement announced in July 2020, the **federal government** provided \$19 billion to provinces to assist with: testing, contact tracing, and data management; health care system capacity; vulnerable populations; municipalities; personal protective equipment; childcare; and pan-Canadian sick leave. The funds for vulnerable populations included staffing in long-term care, home care, and palliative care facilities and services. Additional funding for health, economic and social support for Indigenous people and communities was announced in May 2020. This will support health responses to COVID-19 in Indigenous communities.

Several provincial governments established policy frameworks for resource allocations.

In **British Columbia**, health care officials used the "Ethical Decision-Making Framework," which determines that everyone matters equally, and resource allocation decisions must be made consistently, regardless of health conditions (including disability).

Alberta Health Services shared "R Goals of Care Designations during Pandemic Conditions: Ethical Considerations,"²⁰⁰ which advises health care workers to use established procedures for advance care planning and goals of care designation in decision-making and resources allocation. The document emphasizes the importance of equitable decision-making and the importance of triaging all patients using the same criteria.

¹⁹⁹ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

²⁰⁰ Alberta Health Services Clinical Ethics Service, April 7, 2020

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Ontario published the “Clinical Triage Protocol for Major Surge in COVID Pandemic” to help hospitals determine who should receive life-saving care if medical facilities become overstretched during the pandemic. This protocol included exclusion criteria based on severe and moderate cognitive impairments and advanced and irreversible immunodeficiency. After significant opposition from disability organizations in November 2020 the government withdrew the guidelines and said they were not to be used. Disability organizations remain concerned about the discriminatory nature of Ontario’s triage policies because they rely on the Clinical Frailty Scale, a measure deemed discriminatory towards persons with disabilities, and on an estimated 12-month chance of survival.²⁰¹

The **Québec Ministry of Health and Social Services** initially published guidelines used to designate access to critical care beds and ventilators, but the protocol criteria excluded anyone who has a severe cognitive disability due to a progressive illness. A person with Parkinson’s disease, for example, would not be entitled to intensive care in the event that there was a shortage of resources.²⁰² After criticism from disability organizations, they revised the protocol in consultation with them. Most recommendations were integrated, including the removal of exclusion based on specific disabilities and functional autonomy.²⁰³

Other provincial government policies related to health care access include:

Ontario Health established the “Recommendations for COVID-19 Assessment Centres,” which includes a recommendation to ensure that the modality (in-centre, drive-through, in-home) used allows for an inclusive approach to ensure culturally safe care, though there is no direct mention of people with disabilities or accessibility.

Québec published guidelines for people with disabilities outlining how they can protect themselves and prevent the spread of COVID-19.

What lessons can we learn from the COVID pandemic impacts on health care and people with disabilities?

- People with disabilities must be included and valued in the design and implementation of preparedness and response plans.²⁰⁴
- Preventing discrimination based on disability is especially important when ventilator rationing measures and medical triaging are discussed.²⁰⁵

201 Thomson, 2021

202 Hendry, 2020

203 Triage Québec, 2020

204 Kuper et al., 2020

205 Bagenstos, 2020; Mello et al., 2020; Neilson, 2020

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3.12 Social inclusion

This theme identifies key impacts of the COVID-19 pandemic on social inclusion, drawing from the literature and the media and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of the COVID pandemic on the social inclusion of people with disabilities?

- a) **Social distancing** and other pandemic measures reduce social inclusion and especially affect those:
- living in congregate settings because of the strict restrictions on visitors;²⁰⁶
 - living alone, especially those who rely on public transportation; and
 - who are Deaf or hard of hearing, as they may have more difficulty communicating with people if they wear a mask, and they may not have access to closed captions or ASL/LSQ interpretation in online interactions.
- b) People who have **mask-wearing exemptions** may face negative comments and discrimination in public spaces.²⁰⁷

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban Québec woman with mental and physical disabilities who uses a wheelchair and lives in a congregate setting; an urban Ontario woman who is Deaf; and a British Columbia woman who has dementia.

Social distancing

“But it’s very hard on someone who, who has disabilities. And, you know, high risk. You know, people who have lung disease or low lung function, you know, they’re really, really isolated” (PWD 4).

“My mental health took a solid blow during the pandemic. Um, I actually isolated myself like more than I think necessary. . . . part of me was like if this is so serious, we shouldn’t be going anywhere” (PWD 7).

“I mean it [the Québec government] just said people with underlying health, health issues, and the elderly basically over a certain age you have to lock down basically or to self-isolate, but they didn’t go into specifics... They didn’t say like, you know if you’re in this category you can call this number and you can get help, you know you can get more information or whatever, they didn’t do that” (PWD 4).

206 People First, 2020

207 Kohek et al., 2020

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"We used to have a support group meeting [for people with Alzheimer's], twice a month, where there was about 10 of us, and we sat for an hour and a half and, and there's a tremendous bond between all of us, but many of the folks are not and have not been able to use like computers to join Zoom meetings, and sometimes caregivers don't have the time to sort of set that up. So these two gentlemen that I'm thinking of, one at our last caregivers' meeting which was in February, he was always a quiet guy but he was verbal, and if you asked him a question he would respond, and now he is totally non-verbal. . . . and his wife was telling me that he is not even wanting to go out to like to go to the grocery store, and that's really sad" (FG participant).

"If I go out to a store or whatever, I use a mask, and I often will, will, you know, pull my mask down so people can see what I'm trying to mouth. And then I need them to do the same. But I can't ask that of them. And so, the only alternative is to write everything out. So that creates more of a barrier. The other barrier is that people don't know the best way to communicate with me or to interact with Deaf people at large, like that, pulling the mask down is necessary" (KI focus group participant).

What have been the COVID-related policy responses by Canadian governments?²⁰⁸

Under the Family and Visitor Policy, **British Columbia** permitted only essential visits to assisted-living facilities on March 20, 2020. The Policy was revised in June 2020 to allow families to visit relatives in long-term care homes and assisted living facilities.

Alberta Health Services Guidelines permit a family member or disability support worker to support people with disabilities who are in hospital, including those with developmental disabilities, physical disabilities and/or others who need assistance.

In May 2020, the **Québec government** allowed for support within long-term or residential homes to be provided by a family caregiver who can provide support on a regular basis. They must receive approval from the Québec government and follow specific directives.

What lessons can we learn from the COVID pandemic impacts on the social inclusion of people with disabilities?

- Pandemic measures may inadvertently increase discrimination, stigma, and isolation. An intersectional analysis that recognizes diverse impacts will help to identify and address these impacts.
- Social inclusion can have important impacts on individual health and well-being.
- Alternatives to regular in-person social activities can make an enormous difference to people with disabilities; these alternatives should consider the accessibility needs and technology access of participants.

²⁰⁸ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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3.13 Public spaces

This theme identifies key impacts of the COVID-19 pandemic to access to public spaces, from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of the COVID pandemic on public spaces for people with disabilities?

- a) **Navigating public spaces**,²⁰⁹ including outdoor patios, became more complicated for many people with disabilities, including:
 - people who are blind or Deafblind; and
 - people who are wheelchair users.
- b) People who are experiencing homelessness have **less access to public toilet and warming facilities**.²¹⁰
- c) Lack of and/or restricted accessible transportation has reduced the ability of people with disabilities to **travel to essential appointments, COVID testing and other services**.²¹¹
 - Lack or inadequate safety measures in adapted transport put users at risk of contracting COVID-19.
 - Lack of transportation access has contributed to even **greater isolation**.
- d) People with disabilities have had to **increasingly rely on delivery services** to get access to essential food and supplies, often at a greater cost.²¹²
- e) **Restrictions on inter-provincial travel** may decrease access to social supports and services for some people with disabilities.²¹³

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: a trans/non-binary person in urban Ontario who has mental and episodic/chronic disabilities and is a caregiver for a person with a disability; an urban, non-racialized Alberta woman who is a wheelchair user; a rural, racialized British Columbia woman who is a wheelchair user; and an Ontario woman who is a wheelchair user.

209 Ramesar, 2020

210 Moro, 2020

211 De Camargo et al., 2020; Crawford, 2020

212 See Section 3.3

213 Canadian Press, 2020

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Navigating public spaces

"The expansion of patios on two sides, not so useful and in general. . . the ways that stores are being set up the like barricades and tape and all that stuff like it's completely without thought of, like, how did somebody get through this, if they're using a mobility device or if they can stand in line for two hours there. . . I feel like the government is responsible to give direction when they make a rule like that to tell people, and this is how you have to consider accessibility" (PWD 12).

"Here in Calgary, every single place where they've extended a restaurant patio, or they've created a sidewalk on the road. There are ramps every place. I've never been blocked, and the ramps are well situated. I was just so happy. So, even though I might not be going inside. I've been outside along trying to get a lot of sun and fresh air. . . And I've been like so impressed with my city that they haven't ignored wheelchair users in designing these extended patios and diverted sidewalks. . . it was a huge difference for wheelchair users that that in designing for COVID safe spaces that they account for the wheelchair user in public space" (PWD 17).

Access to services

"The biggest worry I have now is taking the, what's called Access Calgary which is the bus for people with disabilities that comes in, takes you door to door. . . people who are riding that might live in institutional settings. . . I'm scared of taking the bus to go to my physio because that's the only way to get there but I just think it's more important that I get back to doing that work just for my body's health. . . So that's why I'm allowing finally other concerns to override the concern about putting myself in situations that might be more risky" (PWD 17).

"So HandyDART is an accessible transportation mode, it's like, for people with disabilities. And I quite often take that with my caregivers to go to medical appointments. I took that up until the 18th of March. But then I was really not sure what the heck to do because HandyDART is a shared ride system. And you never know who's going to be on the bus with you. So, I didn't know what exposure those people were going to have to who they were exposed to. And I'm sitting beside them on the bus. So, that brought up really big issues for me about is a safe should I be doing this? The other thing is, as much as it's affordable and it's a great system. There's a lot of people that use that bus, but every day. How much is that being cleaned. Yeah, right. And you are sitting where someone else has sat, you know, 15-20 minutes before" (PWD 18).

"As someone who lives alone, what am I supposed to do if I need to go to a doctor, for example? I would need to get a friend to meet me—presumably taking public transit to do so—and then they would have to accompany me. At a time when we are supposed to be avoiding non-essential travel, that seems counterintuitive."²¹⁴

214 Craggs, 2020

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What have been the COVID-related policy responses by Canadian governments?²¹⁵

In **British Columbia**, the accessible transit system HandyDART implemented COVID-related steps (reduced capacity and increased pass-ups to keep capacity low) that aimed to increase safety, but also reduced access.

In **Ontario**, some local governments introduced new restrictions on travel for individuals with mobility devices. In Hamilton, for example, the transit system required that people with mobility devices travel with a companion in order to travel and must use rear doors (where no ramps are provided).

In **Québec**, the Société de Transport de Montréal imposed safety measures in its transport system, including social distancing measures. In terms of adapted transportation, they established a limit of one client per minibus or taxi, and suspended toll enforcement.

In **New Brunswick**, access to Québec has been restricted to reduce COVID spread.

What lessons can we learn from the COVID pandemic impacts on public spaces?

- A disability-inclusive policy response should consider both the benefits and harms of lockdown policies.²¹⁶

²¹⁵ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

²¹⁶ Glover et al., 2020

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3.14 Experiences of discrimination

This theme identifies key impacts of the COVID-19 pandemic on experiences of discrimination from the literature and the media and through interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the discrimination impacts of the COVID pandemic on people with disabilities?

- a) During the pandemic, **ableism** in Canada was made more visible by discriminatory triage policies and lack of dedicated emergency response for people with disabilities.²¹⁷
- b) People with disabilities were often **invisible** in discussions of key pandemic impacts such as outbreaks and deaths in long-term care homes, or access to learning.
- c) Disability-specific responses were often **delayed and very limited**.
- d) Experiences of ableism were **intensified by other experiences of discrimination** coming from racism, poverty, colonialism, sexism, homophobia, transphobia among others.²¹⁸

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban Ontario woman who is a wheelchair user and lives in a congregate setting; an urban, racialized Ontario woman who is Deaf; a Québec woman with mental and physical disabilities who uses wheelchair and lives in a congregate setting; a trans/non-binary person from urban Ontario who has physical disabilities and is a caregiver for a person with disabilities; and an executive vice president of a national disability organization.

Ableism

"I really have felt afraid and I'm sure will continue to feel afraid throughout the remainder of this thing that my life won't be valued by health care practitioners or government officials, anybody in general, enough for me to continue to survive if I do get COVID. That's a direct fear that I have. I'm like, looking at writing a will because I don't have a living will at this moment, and like, you know, attaching something to my name that says, I like my life and I don't want to be passed over when it comes to things like ventilators because you've decided for me that my life isn't as valuable as yours" (FG participant).

"Why is, is it considered that an able-bodied person is worth \$2,000 a month, but a person with disabilities is not? We have the same expenses. We have the same, the same needs. . . well, actually, we have, and maybe more. You know, it's, in every case we're an afterthought" (PWD 4).

²¹⁷ Ries and Abbas, 2020; Jama, 2020

²¹⁸ Canadian Women's Foundation et al., 2020

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"I think that based on the systemic ableism, we've already seen discrimination that we've already known has always existed against people with disabilities. As far as the health care system is concerned that we definitely have to have a relook at the new amended MAID legislation, medical assistance in dying legislation, which is basically just going to give people a legal object out of their misery, and only if you have a disability, by the way, not if you live with any other characteristic" (KI 1).

Invisibility

"Disability is very rarely like spoken, like we talk about seniors we talk about vulnerable people, but I'm not hearing disability like actually being acknowledged a lot in regulation and announcements in, you know, even the senior and disability hours like the first like announcement was 'senior and disability' and from then on out it's been only 'senior' on all the signage. . . disability keeps getting dropped or forgotten completely. So, I think that that seems really important along with like consulting with us" (PWD 12).

Delayed and very limited response

"But, you know, overall for people with disabilities. You know, there's still a lot of lot of work to do in general with accessibility and getting the support that we need. So, during this whole thing of just being worse is, it's kind of sad that we're kind of thinking of the people with disabilities last. And that's how that's how I've kind of felt that we've been. We're very, we're very much an afterthought. No one thought about us, when it first started" (PWD 5).

What have been the COVID-related policy responses by Canadian governments?²¹⁹

The **Ontario Human Rights Commission** released a policy outlining the government's human rights obligations during the COVID-19 pandemic. This policy statement establishes that governments must actively sustain the human rights of the population, especially those historically marginalized, like Indigenous and racialized people and people with disabilities.

Ontario's Clinical Triage Protocol for Major Surge in COVID Pandemic recognizes the disproportionate impact of triage policies on marginalized groups but does not acknowledge the disability discrimination of its current criteria.

The **Québec Ministry of Health and Social Services** revised its triage policies in collaboration with disability organizations, including the Québec Intellectual Disability Society.

What lessons can we learn?

- Without an intentional intersectional and human rights approach, measures like triage protocols will perpetuate and intensify existing discrimination.
- These experiences of discrimination point to the need for policymakers to engage disability organizations and advocates in the development of emergency responses.

219 Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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3.15 Experiences of violence

This theme identifies key impacts of the COVID-19 pandemic on experiences of violence, drawing from the literature and the media, and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

What are the impacts of experiences of violence among people with disabilities during the COVID-19 pandemic?

- a) During the pandemic, there was **an increase in severe instances of sexual assault and of intimate-partner violence** reported.²²⁰
- b) **Care-related forms of violence**, such as neglect, isolation, care restriction, and the use of health information to control someone also increased.²²¹
- c) Women's shelters have had to **limit the number of families** because of social distancing and safety measures.²²²
- d) **Increased isolation** has made many women and their children more vulnerable to control and abuse.²²³

Those especially affected include:

- women with disabilities;
- Indigenous women with disabilities;
- people with intellectual disabilities; and
- people living in congregate settings.

How do people with disabilities describe these impacts?

The quotations below were gathered from two Australian disability advocates.

Increase in instances of severe violence

"Women were affected in the sense that there was an increase in violence—violence, abuse, neglect. All forms of violence. Not only domestic violence in terms of if you lived in the community and in your family home. But domestic violence within institutional settings such as group homes or boarding homes as we have here. And other institutional environments, ok? So that was—that became problematic.

220 Trudell & Whitmore, 2020; Canadian Women's Foundation et al., 2020

221 Trudell & Whitmore, 2020

222 Trudell & Whitmore, 2020

223 Canadian Women's Foundation et al., 2020

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The government response to that, it became a general issue. But it had specific ramifications for women with disabilities. And so the government response to that was to provide more money for the support services, the domestic violence support services. But often they don't, they're not accessible or they don't reach women with disability and they certainly don't respond to women with disability in any institutional environments" (KI 3).

Care-related forms of violence

"Predominantly people with cognitive impairment [were affected]. Psychosocial disability particularly. I think people with dementia, older people with disability in age care facilities. The number of deaths in age care facilities was extraordinary. That would have largely been people with disability. And probably the other thing I would say is there were incidences where the powers of a guardian through the guardianship laws, the powers of guardians were actually increased over and above public health orders which enabled guardians to restrict the movement of people so that they were forced to stay until their home or remain within certain confines, et cetera. And obviously people under guardianship, that's largely people with cognitive impairment and people with psychosocial disability" (KI 3).

Increased isolation

"You also had people in terms of, you know, living in group homes or institutional environments. They pretty quickly went into lockdown. Yes, there were a lot of, you know, restrictions on movement, but often those lockdowns went beyond public health orders. So they were stricter and more, you know, more restrictive, including locking people in their rooms in group homes so they couldn't intermingle. This was particularly the case with people with so-called labeled challenging behaviour, which of course exacerbated the challenging behaviour. Increased incidences of violence and abuse. So you had significant domestic violence, you know, being experienced by women with disabilities in group home environments, et cetera" (KI 3).

What have been the COVID-related policy responses by Canadian governments?²²⁴

The **federal government** announced \$40 million to organizations supporting survivors of gender-based violence. This funding contributed to helping more than 500 women's shelters, transition houses, and sexual assault centres across the country. It also provided additional funds to Women's Shelters Canada for distribution to shelters across Canada (\$20.54 million), to the Canadian Women's Foundation for distribution to sexual assault centers in Canada (\$3 million), and to the Government of Québec for distribution across women's shelters and sexual assault centers (\$6.46 million). In October 2020, the federal government announced an additional commitment of \$50 million to organizations providing support and services to survivors of gender-based violence.

224 Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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What lessons can we learn from the COVID pandemic impacts on people with disabilities?

- An intersectional approach is needed to prevent gender-based violence and provide support to survivors. An intersectional response recognizes the increased risk and consequences of violence for women with disabilities, Indigenous women, Black and racialized women, immigrant, refugee, and non-status women, trans, non-binary, and gender diverse people, and other historically marginalized groups.²²⁵
- There needs to be sustained funding to gender-based violence organizations in order to provide adequate infrastructure and services for women with disabilities and those with complex needs.

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3.16 Access to information about COVID-19 and related policies

This theme describes how access to information about COVID-19 policies affected people with disabilities, drawing from the literature and the media and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

How did access to information about COVID-19 and related policies impact people with disabilities?

- a) Access to information and **awareness of where to find information about COVID-19** is limited for the majority of those living with disabilities.²²⁶
- b) People with disabilities frequently encountered unclear and conflicting messages, and **inaccessible communication formats**. These communication barriers for individuals living with disabilities with impacts are more severe among:
 - those who are young;²²⁷
 - those who have sensory disabilities;²²⁸ and
 - those with intellectual disabilities.²²⁹
- c) Even months into the pandemic, communications about the emergency and public instructions and **signage often neglected to consider the needs of people who are blind**.²³⁰

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an executive vice president of a national disability organization; the president and CEO of a rehabilitation organization; a racialized, rural British Columbia woman who is a wheelchair user; and a Nova Scotia woman who is blind.

Awareness of where to find information about COVID-19

"People with disabilities, really those that have pre-existing conditions and at high risk were also the fear of getting it and the lack of information. So, the fear that that created, as well. That not knowing. And that not being able to manage it was a significant impact. It was a significant impact for me in the early days. That lack of information. That lack of access to critical things that you needed like lack of access to PPE was really scary. How were you going to manage? How could you even try and control the transmission process if you couldn't have access to what you needed?" (KI 2).

226 De Camargo et al., 2020

227 Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

228 Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

229 Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

230 Ramesar, 2020

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"You get this, you know, glossy little sheet thing, you know, in the mail and the phone number with it is a bit of a headache, because quite often it's a 1-800 number, where it's not a real person, it's an automated thing. I don't find it super helpful. There's a lot of people. . . I mean I'm very literate with computers and literate in general, but there's people who do not do well with the 'press one for this press two for this.' And they'll just give up, and then they call someone like me and say 'I need a real person who can help me navigate the system. Can you take 10 minutes and actually explain this to me in real language, and I can understand about what this means to me?'" (PWD 18).

"The \$600 one-time payment for our community, that's a huge challenge, because there hasn't been any sign language translation provided to explain what this what this \$600 payment is. It's only provided in English text. And sometimes that, you know, that's a barrier in and of itself. Sometimes, if you if the Deaf person is able to get someone to call in, they have to wait for 30 minutes. So that means that they're not getting full access to information like the rest of the population" (KI focus group participant).

Inaccessible communication formats

"The government had arranged ASL and LSQ interpretation, but the broadcasters left the signers out of the frame. This example points to the coordination required to ensure that information is available to people wherever they access the information" (KI 1).

Public signage

"I think it would be great to have some tactile markings on the ground [at grocery stores] and contrast too, because for those who are partially sighted, having good contrasting colours for the arrows is important."²³¹

What have been the COVID-related policy responses by Canadian governments?²³²

The **federal government** announced \$1.1 million in funding to support national disability organizations through the Social Development Partnership Program - Disability Component. The purpose of the funding is to enhance communications and engagement activities to better address the impact of COVID-19 on persons with disabilities. In addition, the Accessible Technology Program invested \$1.18 million to develop dynamic and affordable technology that is accessible for Canadians with disabilities. The Treasury Board of Canada Secretariat issued best practices for accessible communications during the pandemic.

The **British Columbia government** uses its Advisory Group for Accessibility as a provincial disability advisory group, including for COVID-19 issues. The crown corporation Community Living British Columbia offers plain language information for individuals and families on COVID-19.

²³¹ Ramesar, 2020

²³² Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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The **Alberta** Provincial Education Help Line provides advice to families who have questions about their child's education program during the coronavirus pandemic, particularly guardians of children with disabilities.

The **Ontario government** implemented a communication channel between the public and government officials, which allows members of the community to submit their ideas related to the COVID-19 pandemic.

The **Québec government** developed a self-care guide for parents during COVID-19, including caring for a child with a disability; guidelines explaining how people with disabilities can protect themselves and prevent the spread of COVID-19; and information about continued support for students with disabilities within educational institutions.

New Brunswick's Family Support for Children with Disabilities Program has provided contact information for families with children with disabilities to access information on home learning.

What lessons can we learn from evaluating the access to information about COVID-19 and related policies for people with disabilities?

- Communications about COVID-19 are most effective when they consider the diverse needs of the target audience and are easy to find, understand, and use.
- To ensure that information about COVID-19 reaches vulnerable populations, information must be available in a variety of formats: Braille, large print, audio, video with captions and sign language, and W3C/AODA compliant digital technologies.²³³
- Communication materials and information should be available in Indigenous languages and shared through representatives of Indigenous communities to ensure accessibility and cultural appropriateness for Indigenous persons with disabilities.
- Organizations of people with disabilities play a key role in bridging gaps, helping disseminate information and translating complex messages for members of the community.
- The best way to ensure that communication will be effective is to engage members of the disability community in developing and testing communications materials and messaging from the beginning.

233 Kuper et al., 2020; Pineda & Corburn, 2020; Sabatello et al., 2020; Jumreornvong et al., 2020

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3.17 Support for disability organizations

This theme describes how COVID-19 policies impacted support for disability organizations, drawing from the literature and the media and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned.

What are the impacts of the COVID pandemic on disability organizations?

- a) Disabled people's organizations (DPOs) provide support, **bridge gaps in access** to information and **hold governments accountable** for human rights implementation including during a pandemic.
- b) The pandemic **reoriented the work of DPOs** and disability organizations to provide information and support related to the pandemic.
- c) Disabled people's organizations had **reduced capacity resulting from closures and restrictions**, having to work from home, coordinating schedules, and reduced funding.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an executive vice president of a national disability organization; the president and CEO of a rehabilitation organization; and a BC woman who is a wheelchair user.

Reorienting to respond to the pandemic

"Our work as an organization, you know, pivoted quite a bit I mean, some things kind of that we were working on had to get sort of set over here. While we responded to the crisis, so we had to dedicate people to answer emails and phones, we made sure that we had staff that were like, really well-versed in benefits, and, you know, what was coming out every day? And what was available to them? And, and could answer questions. And, you know, and we were dedicating a lot of time to our social media channels and our website and our, in terms of getting out proper information. And so it you know, there was a lot of that, and then my own personal time, a lot of it got a lot of it, like it took my life over" (KI 1).

Reduced capacity

"As we're working from home, like both of us, right, I mean, the whole organization, why we meet every week, twice a week, actually, and we know, what kind of support do you need? What do you need what clients need, which is great, because we're advocating and we're advocating for ourselves. But the other part of it is, when they're not in these programs, so you're not in a program and you lost your job, and you have no support, that's going to take a toll on you. Because then it's going to take us another six months, just to build that self-confidence, build our self-esteem, and support everybody to go back to normal. So yes, things have happened online, which are amazing. But yeah, like we said, if there is no one on one support, or any supports like that, we should have a system where if people want to learn how to do something, they just go for free and learn it

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instead of having to apply into a program be accepted. And then you get the chance to learn about it" (KI 4).

"Like every other organization had to go through kind of an adjustment period and it's like, I'm talking it took us at least two months. From March until May before we before we were really even semi functional. And that's because we had to go very quickly right from being in the office to home. And it was a really difficult time for the team, and for me as their supervisor. The first thing that happens once we kind of settled into the, the remote work, working remotely because really, like I said, it was hard to be productive in March and April really like I said it was, we're just kind of coping right now" (KI 5).

Bridging gaps in access

"A significant amount of our time got redirected to making sure that individuals and families had accurate information, that they had support that they had, you know, advocacy when they needed it, that they knew what, you know, benefits were may or may not be available to them, that you know, that their voices were heard through the process" (KI 1).

Holding governments accountable

"If you think about how quickly this crisis was upon the government, and how quickly they had to act in terms of the serve and a lot of the things they rolled out. . . . I think objectively, you have to be fair to them and say they did some things quite well in the beginning and learned a lot through this process. But the thing that I think about the, you know, the whole issue of there was no money that went to people disabilities and no mention of them. These begin to reveal the cracks in the space between say a minister like Carla Qualtrough and Justin Trudeau" (KI 5).

What have been the COVID-related policy responses by Canadian governments?²³⁴

In May 2020, **the federal government** announced the Emergency Community Support Fund, a \$350 million investment to support charities and non-profit organizations serving vulnerable populations during the pandemic. A second round of grants was announced in October 2020. In addition, it announced \$1.1 million in funding to support national disability organizations through the Social Development Partnership Program - Disability Component to enhance communications and engagement activities to better address the impact of COVID-19 on persons with disabilities.

The **federal government** established the COVID-19 Disability Advisory Group (CDAG), advising the Minister responsible for Employment, Workforce Development and Disability Inclusion. Their report and recommendations were released in December 2020.

²³⁴ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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What lessons can we learn from the COVID pandemic impacts on disability organizations and people with disabilities?

- The Accessible Canada Act²³⁵ mandates engagement and consultation with people with disabilities. Yet, the impacts of the COVID-19 pandemic on people with disabilities and disabled people's organizations suggest that consultation has been minimal during the pandemic.
- Disability organizations, which have a strong understanding of the needs of their constituents, have been a largely untapped source of advice and guidance when it comes to COVID-19 policy. Building these organizations into the policymaking process has the potential to ensure that policymaking is better coordinated, more cost-effective, and more impactful.
- Disability organizations can help ensure that policies and programs are tailored to meet the individualized needs of people with disabilities by working with support networks and community organizations.
- To ensure that emergency responses are inclusive, at every stage of the process engage diverse organizations and individuals with disabilities, including Indigenous people, older adults, and women, girls, non-binary, trans, and gender non-conforming persons.

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3.18 Inclusion of people with disabilities, their families and care/support providers and disability organizations in policy development and implementation

This theme identifies how people with disabilities, their families, and care providers have experienced inclusion and exclusion in the development and implementation of the government's COVID response, using data from the literature, the media, and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

How have people with disabilities, their families and care/support providers, and disability organizations been included in policy development and implementation?

- a) Individuals, families, and caregivers report **minimal consultation** and **lack of representation**, despite the Accessible Canada Act, which mandates the engagement and consultation with people with disabilities.
- b) Certain **policies were exclusionary** to some people with disabilities and may have had different outcomes if consultation occurred, including:
 - mask wearing policies and exemptions;
 - closure of day programs and community access activities; and
 - family visits to residents of congregate care.

How do people with disabilities describe this inclusion?

The quotations below were gathered from the following individuals: an urban Québec woman who is hearing impaired; an urban, racialized Ontario woman who is visually impaired; a trans/non-binary person who has a physical disability and is a caregiver for a person with a disability; an urban, non-racialized Ontario woman who is visually impaired and has a mental disability; an urban, non-racialized Ontario woman who has physical disabilities and lives in a congregate setting; and the executive director of an Indigenous disabled persons' organization.

Minimal consultation

"It's not like people with disabilities fell from the face of the earth and said, we're here know what to do with us. Yeah. Hello. We have been here since beginning of time. So, why are people only why they only waking up now and saying, You know what, we have people with disabilities here. . . . we should not be a 'problem.' Because we are part of your society. We are all living here, part of your society" (PWD 16).

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"I mean obviously people who make these decisions for people with disability, most of the time are not disabled themselves" (PWD 5).

"His [Rod Phillips'] office actually not only got in touch with me, but he set up a personal Zoom call with me, okay. And I went in to that armed for bear with figures and facts and percentages and cost increases, and then you know. . . . I had his undivided attention for 20 minutes. Like he actually listened to me, he told me, he was very grateful for the fact that I was I had come with numbers, because, you know, he's a numbers guy. He went so far as to say, you know, how much do you think extra would be helpful? You know, and so he heard what I had to say. And then nothing happened. . . . people with disabilities, we vote. And we're a huge voting bloc in the province. So, we're watching what you're doing. And we're going to remember" (PWD 10).

"We have an opportunity to make that positive change there but also keeping the pace of governments, 'hey look, this is a lesson learned from the pandemic. We told you before, you can't now say it wasn't true. You had to say you haven't addressed it, let's get on to how do we do this.' I think right now, it would be prudent for every province and territory disability advisory group to [approach] their minister or their premier, so that they can deal with issues and actually I'm going to float something or more in relation to the CRPD, but they should have this open line to the government to see look, this is this doesn't matter what that should be a permanent thing should not be at the whim of the party. This is what we must do" (KI 6).

Lack of representation

"I just don't think there is enough representation from people with disabilities in government. I don't think there ever could be enough, whether it is provincial or federal level. I'm sure there are people with disabilities in government, but I'm not seeing them really up front. I'm wondering if there is, how hidden are they? Like we need more of a voice in the government level. There's all kinds of agencies out there that have a voice, but they're not being heard" (FG participant).

Exclusionary policies

"I think another piece that's come up a lot with all of these interactions around like with frontline workers, like, denying access requests or being abusive. I can't ignore the fact that they're traumatized that they're strapped like, you know, my partner, asking for an accommodation around masks like the staff person came back afterwards and actually the staff person tried really hard to accommodate the request. And I think actually pushed themselves beyond their own capacity in doing so and was maybe not so helpful because of. They were kind of pushing themselves beyond their own comfort and we're not supported and, but they kind of shared with us that like folks are traumatized, and that there are like frontline providers who are gonna have a hard time providing care without masks. . . . I think really impacts people with disabilities because we work with these systems" (PWD 12).

"And some of us had to do so much writing and so much advocacy. . . for government to understand that families are not visitors. The families are part of the caregiving and wellbeing of, especially adults with

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disability but it's really, really important for kids with disabilities who were living in group homes or were in the hospitals. So as senior It is really heartbreaking. That when you hear the stories that families could not visit their parents and parents died alone" (KI 06).

What have been the inclusive COVID-related policy responses by Canadian governments?²³⁶

The **federal government** established a COVID-19 Disability Advisory Group to advise the Minister on lived experiences of Canadians with disabilities during the coronavirus pandemic. It reported in December 2020. As well, through the Social Development Partnership Program, the federal government announced \$6.4 million would be invested to develop best practice tools and resources for accessible workplaces, accessible service design/delivery and communication between disability stakeholders and the private sector. An additional \$1.1 million will support national disability organizations to enhance their communication and engagement activities to address the impact of the coronavirus pandemic on Canadians with disabilities.

What lessons can we learn from the COVID pandemic impacts on inclusion of people with disabilities and their families and care/support providers, and disability organizations in policy development and implementation?

- Addressing the disproportionate impacts of COVID-19 on individuals living with disabilities and ensuring an inclusive response requires that policies are either created with or reviewed by people with disabilities and disability rights advocates.
- Inclusion of marginalized voices is not enough; for policymaking to be truly inclusive, governments must engage in a meaningful way with disability organizations, providing resources that enable organizations to connect and engage with members of their communities.
- Local and national organizations of persons with disabilities have unique access to diverse individuals with disabilities, including Indigenous people with disabilities, older adults with disabilities, women, girls, non-binary, trans, and gender non-conforming persons with disabilities. These organizations are well-positioned to provide input on policy development and implementation.
- For policies and programs for people with disabilities to be inclusive, they must also consider the essential role that many families and caregivers play.
- Implementing accountability measures could help ensure that emergency response policies and programs include the full diversity of people with disabilities.
- Engaging people with disabilities in policy making is an important step in changing the narrative of people with disabilities from victims of COVID-19 responses to users and champions of COVID-19 responses.

²³⁶ Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

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3.19 Coordination across jurisdictions

This theme identifies how COVID-19 policies were coordinated across jurisdictions, including where there was complementarity, drawing from the literature, media, and from interviews with participants and key informants. We also note policy responses from Canadian governments. From these sources we pinpoint lessons learned from the experiences of people with disabilities during COVID-19.

How did coordination (or lack thereof) between jurisdictions during the COVID pandemic impact people with disabilities?

- a) Long-term care facilities are mostly funded and regulated by the provinces. Yet, their ability to provide adequate resources to long-term care has been decreasing due to **COVID-related reduction in tax revenues and the increasing aging population**.²³⁷
- b) **Funding provided through federal COVID-19 programs often triggered clawbacks** from other levels of government.

Those most affected include:
 - those on social assistance or disability benefits;²³⁸ and
 - students with disabilities.²³⁹
- c) **Using the Disability Tax Credit (DTC) as the basis for federal pandemic funding** excluded a significant proportion of people with disabilities.
- d) **Indigenous communities faced unique jurisdictional complications** that interfered with the sovereignty of Indigenous communities, placing Indigenous people with disabilities in the middle of jurisdictional disagreements.

How do people with disabilities describe these impacts?

The quotations below were gathered from the following individuals: an urban, non-racialized Ontario woman who is visually impaired and has a mental disability; the executive director of a national disability organization; and a chief scientific officer of a children's disability network.

237 Béland and Marier, 2020

238 Bell, 2020; Huncar, 2020

239 Zwicker, 2020

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Funding clawbacks

"When your income goes up then of course they want to cut back a little bit" (PWD 10).

"Currently, persons with disabilities receiving provincial disability income assistance are deemed ineligible for the \$2,000 a month CERB – or have had their funding clawed back at different rates depending on the province. This means most persons with disabilities on income assistance receive significantly less than the amount received by CERB recipients, and this varies by province."²⁴⁰

"And the other thing is in order to access support is there seems to be a lot of confusion and messaging. . . . I've heard, you know, one level of government says this. But yet, that same level of government in a different department will say that plus or minus something or will say in a different way or will contradict it completely" (PWD 10).

Using the DTC as the basis for federal pandemic funding

"The issue is that many Canadians with disability who should receive this funding are not DTC recipients and consequently won't receive the support they need. This is a policy design problem—and the federal government knows the shortcomings of the DTC. It should not have been used as the basis for pandemic funding. In principle, the DTC could be an efficient way to administer pandemic related support. But the pandemic is again highlighting long-standing problems with the gateway function of the DTC. Issues accessing the DTC include problems with the eligibility criteria and assessment, complex application procedures, inconsistent communications and co-ordination with other benefits."²⁴¹

Understanding how jurisdictional issues affect Indigenous communities

"It was really powerful to have [advocate] as one of the advisors, because of course he was able to help [Minister] Miller hear the complexity of the position people with disabilities are in in this space around Indigenous sovereignty, because the government of Canada can't tell Indigenous nations what to do with some things. But people with disabilities to reduce this get caught between the two governments and priorities. Even. And like I said, they don't become a priority it's the power struggle instead. And so he'll be at the table for these conversations with Miller was important because he was able to help Miller understand the jurisdictional issues and how important it is for them to write stuff in that protects right people with disabilities not being pushed around in their jurisdiction" (KI 5).

240 Zwicker, 2020

241 Zwicker, 2020

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How have COVID-related policy responses been coordinated across jurisdictions by Canadian governments?²⁴²

In January 2020, the **Public Health Agency of Canada** implemented the Federal/Provincial/Territorial Public Health Response Plan for Biological Events to improve coordination across the country. The federal government also established a Special Advisory Committee on the Novel Coronavirus to advise Deputy Ministers of Health across Canada on the coordination, public health policy, and technical content related to the COVID-19 outbreak.

The **federal government** reported that COVID-19 information is being shared between federal, provincial, and territorial governments to monitor where the virus is occurring and who is most affected.²⁴³

What lessons can we learn from the COVID pandemic impacts?

- Systems exist for coordinating policies and programs across jurisdictions. These systems should be used to manage federal and provincial funding and benefit overlaps for people with disabilities.
- Funding coordination issues can be anticipated and addressed in the policy design.²⁴⁴

²⁴² Information about policy responses came from online information and key informant interviews. Sources are listed in the References. If nothing is listed for a jurisdiction it is because we did not find anything in those sources.

²⁴³ PHAC, June 11, 2020

²⁴⁴ Zwicker, 2020

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Section 4: Key lessons learned and good practices

From our review and analysis of the data and research collected using our intersectional disability and gender analysis framework, and in the context of Canada's human rights commitments, we identified three broad findings.

1. During the COVID-19 pandemic, we find evidence of **consistent exclusion of people with disabilities** arising from their invisibility. This is the case despite the increased risks they face, and results from inadequate data, lack of targeted policies, restrictive eligibility criteria and disability definitions for programs, lack of policy coordination and complementarity, inaccessible communications and information, and actions or inactions which reinforce or exacerbate existing systemic inequities.
2. More than that, we find that **experiences of exclusion were often cascading and cumulative**, leading to disproportionately negative impacts on particular groups of people with disabilities, including those who are also low-income, women, racialized, Indigenous, and living in remote communities.
3. We reflect on and identify lessons and good practices that may be useful to "build back better" post-pandemic and **ensure greater disability justice** in future disasters and crises.

4.1 Consistent exclusion of people with disabilities during the COVID-19 pandemic

4.1.1 Invisible despite increased risks

People with disabilities have significant risk of getting COVID-19²⁴⁵ and have disproportionately borne the impacts of the pandemic, yet their experiences and stories remain largely invisible to the public and decision-makers.

Most dramatic is the framing of COVID-19 related deaths that fails to note the high proportion of people with disabilities among these deaths. Few commentators, reporters, and researchers recognize that most people in long-term care settings are those with complex needs who require assistance in daily living,²⁴⁶ that is, people with disabilities. Few understand that young people with disabilities also live in long-term care settings, group homes and other congregate settings. All have been rendered invisible in how we understand and respond to the COVID-19 crisis.

Invisibility was tangible when broadcasts from political leaders, intended to share information about COVID-19 with all Canadians, failed to include sign-language interpretation so that Deaf people could have access. At times this was an oversight from organizers, and at others it was a gap by broadcasters. In all cases it preserved invisibility.

245 Courtenay & Perera, 2020; den Houting, 2020; Kuper et al., 2020

246 Liu et al., 2020

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This invisibility was maintained by policies and programs which were intended to be universal, but because of their lack of intersectional analysis, failed to address the negative impacts on diverse people with disabilities. As we illustrated in Section 3, closure of schools and a move to on-line education increased the challenges, especially for parents of children with disabilities, and failed to ensure access to education for students with disabilities. Social distancing practices and visitor restriction policies in long-term care homes and hospitals increased isolation for people who are in vulnerable situations and already isolated. Mask requirements reduced the possibilities for communications by Deaf and hard-of-hearing people, and increased stigma and discrimination for those who were exempted from wearing masks.

Good practice: Intersectional policy development and analysis will help to identify who is affected, but governments need to go the next step to create and implement measures, both targeted and universal, that include all people with disabilities. For example, UN Women argues that governments need to address “the particular impact of COVID-19 on women, girls, non-binary, trans, and gender non-conforming persons with disabilities and [take] a twin-track approach to recommending action, ensuring that these individuals are included in mainstream immediate response and long-term recovery efforts and that efforts are targeted specifically at the intersection of gender and disability.”²⁴⁷ A twin-track approach will not be sufficient to bring an intersectional approach. Canada requires one that recognizes that people’s experiences will be affected by gender, disability, race, Indigeneity, and other social dimensions.

4.1.2 Inadequate data

The invisibility of people with disabilities is also intensified by a lack of data about their experiences of living in COVID-times. As we noted in Section 2, the data available illustrates that people with disabilities have disproportionately borne the impacts of the COVID-19 pandemic, in terms of employment loss, the loss of educational and social supports, decreased access to health service, and increased mortality. Much of the data that exists comes from crowdsourced surveys by Statistics Canada (with the concerns we noted in Section 2). Additional surveys came from non-governmental organizations and researchers. These surveys are generally done only once and provide limited data about the situations of diverse people with disabilities during COVID. In particular, there are significant gaps in intersectional data on specific groups of people with disabilities, noted in Section 2, which means we have to rely on first-person accounts or reports from organizations to illustrate their situations.

Good practice: Using the example of the United Kingdom’s COVID data gathering related to people with disabilities,²⁴⁸ governments should gather intersectional data during emergencies at regular intervals, and ensure this data adequately reflects the situations of diverse people with disabilities. On-going pressure in some parts of Canada to disaggregate data by race and Indigenous status²⁴⁹ also indicates the need for this approach.

²⁴⁷ UN Women, 2020

²⁴⁸ UK Office for National Statistics, 2020

²⁴⁹ Wiafe and Smith, 2020; Skye, 2020

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4.1.3 Lack of targeted policies

Across the country there are few COVID-19 related policies targeted to people with disabilities to address the disproportionate impacts experienced in costs of living, lost or reduced income, decreased supports or increased health, and livelihoods risk. What does exist is very modest.

For example:

- The federal government's one-time payment of \$600 to people with disabilities is widely seen as "too little, too late" to meet the extra disability-related costs that have arisen from the pandemic and excludes many people with disabilities.
- British Columbia provided a \$300/month income supplement for people and created the Emergency Relief fund for children with special needs and their families, providing \$225/month for three months, but many people had significant difficulties accessing these funds.
- Some of the other provinces, including Ontario and Québec, have adjusted the type of expenses that can be claimed, without increasing funds or initiating new programs.
- New Brunswick established the Emergency Bridging Fund for Vulnerable Post-Secondary Students, with a one-time payment of \$750 for those affected by the pandemic.

Many of these programs required people to "opt in." At the same time, many people experienced increased difficulties getting in contact with the case worker to do this because they were unable to get phone or internet access or their case workers had higher workloads. An automatic increase rather than requiring applications would eliminate many of these pandemic-related challenges.

The Public Health Agency of Canada (PHAC) developed guidelines on COVID-19 and people with disabilities in Canada. These offer important guidance but are difficult to find on-line and not widely available outside of the PHAC website.

Good practice: New Zealand's Ministry of Health has developed a COVID-19 Health and Disability System Response Plan²⁵⁰ that is a model in many ways for pandemic and emergency preparations that address accessibility and disability inclusion. It begins by recognizing that treaty principles between the Māori people of New Zealand and the Crown were integrated into the COVID-19 response.

4.1.4 Restrictive eligibility criteria and disability definitions for programs

Targeted disability-related pandemic programs have used existing definitions of disability and eligibility criteria which often exclude many people with disabilities.

For example, the federal one-time payment requires applicants to be a recipient of either a Disability Tax Credit (DTC) from the Canada Revenue Agency, a Canada or Québec pension plan disability benefit or disability supports provided by Veterans Affairs Canada. The DTC is widely recognized as under-used by people with

250 New Zealand, 2020; Ministry of Health NZ, 2020

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disabilities in part because it is a non-refundable tax credit and therefore of benefit only when people receive employment income and because of the interpretation of who is eligible by the individuals themselves and their health provider who must document their eligibility.²⁵¹ The shortcomings of the DTC have been documented for many years.²⁵²

The exclusion of groups of people with disabilities because of the disability definitions and eligibility also occurred in other countries including Australia. Programs to mitigate the economic impact of COVID-19 largely missed assisting Autistic people who relied on disability benefits since additional stimulus was tied to existing unemployment or student benefits.²⁵³

Good practice: The United Nations Partnership on the Rights of Persons with Disabilities suggests extending income supports to all persons with disabilities, including those who may not be officially registered or eligible, and regardless of their work status.²⁵⁴ Given that it is well known that people with disabilities are more likely to live in poverty and face barriers to accessing government programs, governments should look for ways to widen access rather than narrow it.

4.1.5 Lack of policy coordination and complementarity

Two areas identified in Section 3, income assistance and long-term care, demonstrate the lack of policy coordination and complementarity between various levels of government in Canada. This lack of coordination and complementarity has worsened the negative impacts of the COVID-19 pandemic on diverse people with disabilities.

The federal government's Canada Emergency Response Benefit (CERB) provided recipients \$2000/month. This was in stark contrast to the amount people with disabilities received on social or disability assistance in any province which is highest in Alberta at \$1685/month.²⁵⁵ Of the provinces considered here only British Columbia fully exempts the CERB payment from income assistance clawbacks. In the other provinces, part or all of the provincial income assistance was clawed back if people also received CERB.

The lack of policy coordination has increased the negative impacts on income experienced by many people with disabilities before the pandemic and discussed in Section 3. But the impact has not only been on income, the lack of coordination also reinforces stigma associated with living with disabilities. As one key informant noted "the value of somebody that was a contributing member of society is \$2,000, but the value of somebody with a disability on an everyday basis, on average across the country is 1,000 bucks."²⁵⁶

The pandemic-related issues in long-term care also illustrate the significant lack of coordination between provinces and the federal government. Long-term care facilities are primarily funded and regulated by the

251 Zwicker and Dunn, 2018

252 Disability Advisory Committee, 2019

253 den Houting, 2020

254 UNPRPD, 2020

255 Petit and Tedds, 2020, S34. Note that the Northwest Territories rate for people with disabilities is an outlier at \$2,383/month

256 KI 02

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provinces. Yet, their ability to provide adequate resources to long-term care has been decreasing due to COVID-related reduction in tax revenues and the increasing ageing population.²⁵⁷ The federal government's contribution to provincial health, through the Canada Health Transfer, is roughly 32%.²⁵⁸

As we noted in Section 2, people with disabilities in long-term care make up the majority of deaths as a result of COVID-19. It is clear that long-term care policies have not adapted to the changing nature of their needs. Although decades of advocacy and research illustrate the importance of supporting long-term care, funding for long-term care homes has remained constant in all provinces. In Québec, for example, the number of beds available in provincially funded long-term care facilities has decreased, which has led to restricted admission criteria, extended waiting lists, and an increasing number of private facilities. The 2017-2018 Ombudsperson's annual report found that privatization, in some cases, has led to inadequate monitoring and care for individuals.²⁵⁹

4.1.6 Inaccessible communications and information

In emergencies and crises, access to communications and information are critical. During the COVID-19 pandemic in Canada, there are persistent gaps in accessible and inclusive information and communications.

As we noted in Section 2, many people with disabilities were unaware of, or unable to find, accessible information about COVID-19. They also noted they had difficulty assessing whether they were eligible for any financial pandemic supports. Section 3 documents that pandemic communications and information were often unclear, conflicting and inaccessible. This was true in government briefings, stores, and online information. This has led to many Canadians with disabilities feeling excluded from COVID-19 messaging or unable to access benefits to which they were entitled.

In addition, the move to providing information and services online further excludes those who rely on public information sites like libraries (which were closed at various points in the pandemic) or who cannot afford cell phones or internet service. Social distancing policies limited the possibilities of personal networks to support information sharing.

Good practices: The federal government's Accessible Technology program is a good practice to increase access for people with disabilities. In the US, hundreds of telecommunication companies have signed the "Keep Americans Connected" pledge, which supports the uninterrupted provision of two months of free access to broadband and telephone connection.²⁶⁰

257 Béland and Marier, 2020

258 Giroux, 2020

259 Béland and Marier, 2020

260 Duong and Karlawish, 2020

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4.1.7 Actions and inactions that reinforce or exacerbate systemic inequities

Several areas, identified in Sections 2 and 3, demonstrate how specific actions or inactions have reinforced or made existing systemic inequities worse for diverse people with disabilities.

Care provision:

Women with disabilities, especially those who are racialized, are more likely to work as essential workers in paid care settings (long-term care, childcare and education), but the pandemic also increased their unpaid care responsibilities. Their paid care work can increase their risk to COVID-19. Their unpaid care work increases their stress, anxiety and possibility of burnout²⁶¹ while reducing their availability for paid work.

Essential services:

Decisions by federal and provincial governments to designate certain services essential and others non-essential have had negative impacts on the independence of many people with disabilities. For example, in Ontario when the Assistive Devices Program was not deemed essential, wheelchair users could not get their wheelchairs repaired. This left them at home, isolated and reliant on the support of others to meet their needs.

Health and access to health care:

People with disabilities have long had substantial barriers to access and significant unmet needs in health care.²⁶² One significant barrier has been the attitudes and knowledge of health care providers about disability. Reductions in health care services during the pandemic and the move to on-line health care provision has worsened this situation and decreased the quality of physical and mental health and well-being of diverse people with disabilities. Most noteworthy has been the development and implementation of triage policies which reinforce the devaluation of people with disabilities and suggest that they are expendable in a pandemic. These policies confirm the ableist adage "better off dead than disabled."²⁶³

Income:

Many people with disabilities, including Indigenous peoples, racialized people, and people who live with children, saw their income decrease during the pandemic and their costs increase. These decreases and the limited policy responses by government reinforce systemic inequities that leave people with disabilities living with poverty.

Unemployment:

People with disabilities, especially women and young people, were disproportionately affected by un- and underemployment during pandemic. Inequality for people with disabilities in the job market has long been a reality, but during the pandemic unemployment and job loss have gotten worse due to a lack of opportunities.

261 CIHI, 2020

262 Stienstra, 2020

263 Stienstra, 2020, 43

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Violence:

Pandemic lockdowns and social distancing increased incidences of violence and abuse experienced by women with disabilities and those living in congregate living settings. While government funds went to organizations addressing violence, shelters are often inaccessible to women with disabilities. As well, these strategies have done little to address violence, abuse, neglect, and deaths in care settings. This lack of response suggests that the ableist view that people with disabilities are unworthy of rights and protections²⁶⁴ remains solidly in place in Canadian society.

4.2 Cascading and cumulative experiences of exclusion

For some people with disabilities, experiences of exclusion and discrimination build on each other, so they are cumulative. In other situations, one experience of exclusion or discrimination may act as a domino, cascading towards greater exclusion.

One example of cascading experiences of exclusion is Michelle MacGugan's experiences around personal attendant care.²⁶⁵ Michelle is an Indigenous woman from Dene Tha' First Nation in Alberta. She is a wheelchair user and requires personal support workers for many parts of her life. She has had limited personal attendant care, which led to additional health complications. With the COVID-19 pandemic, she worries that if personal support workers don't come to address her physical needs, she may end up in a long-term care home and be more at risk of getting COVID-19. She is staying isolated and feeling the loss of contact with family members.

The systemic inequities mentioned in section 4.1.7 are cumulative experiences of exclusion. As well, a number of participants and media stories illustrated cumulative experiences of exclusion. Their situations during the pandemic made their lives much worse than before it and they saw little reason to remain alive. For some it has led them to consider and initiate Medical Assistance in Dying (MAID).²⁶⁶ Others, even those who were familiar with and involved in the disability advocacy community, committed suicide. As we noted in Section 2, people with disabilities were three times more likely to experience suicidal thoughts. People living with low income and Indigenous people with disabilities experienced these most often. These feelings of hopelessness and fear are made worse by the invisibility and exclusion discussed above. They are made worse when health care providers invite people with disabilities to consider MAID as an option.²⁶⁷ They are made worse when governments discuss extending MAID to include situations that are not close to death rather than extending the necessary supports and services to enable people with disabilities to live with dignity.²⁶⁸

264 Stienstra, 2020, 41

265 Monsebraaten, April 17, 2020

266 Mulligan and Yahwar, 2020; Peters, 2020

267 Harris, Nov. 10, 2020

268 Penning and Angus Reid, 2020

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4.3 Ensuring greater disability justice

People with disabilities experience significant negative impacts from the COVID-19 pandemic and have systemic inequities reinforced. Yet the pandemic has also opened new windows for policy actions. Three areas demonstrate how greater disability justice can be achieved during and after the pandemic.

Disability leaders and organizations offer important insights for ensuring disability justice.

While it was often difficult for us to contact individual people with disabilities because of the pandemic, disability leaders made themselves available both through interviews with us and by comments they shared with the media and on social media. Their knowledge and insights sharpened our understanding of the impacts of COVID-19 related policies on diverse people with disabilities.

Disability organizations and leaders are essential participants in policy development and analysis and need to be at the decision-making tables as full participants. The federal and British Columbia governments recognized their important contributions by creating disability advisory groups around COVID-19. All governments—federal, provincial, territorial, municipal and Indigenous—need to bring them to pandemic and post-pandemic decision-making in a robust and consistent manner, listening to and acting upon their advice.

Disability leaders are often innovators, introducing and acting upon ideas for disability justice well before they become mainstream. The Disability Justice Network of Ontario is a case in point. They have built intersectional coalitions for action during the pandemic, offering mutual assistance at the community level in Hamilton, Ontario. In November 2020, they brought together other leaders for an initial discussion on how to ensure disability justice in Canada after the pandemic. Another disability leader introduced us to the idea of Indigenous care homes in northern and remote settings. This would help to ensure culturally appropriate care, close to families and communities, with respect for Elders.

When we bring disability leaders and organizations into the discussions of emergency planning and preparations, we will ensure more inclusive practices and better solutions.

Accessibility and inclusion standards are essential

So many of the tragedies and horrors of the COVID-19 pandemic could have been lessened with emergency planning that addressed accessibility and inclusion. If long-term care homes were required to meet accessibility and inclusion standards, and there was funding to ensure they did, fewer people with disabilities who live in congregate care settings would have died.

If we included intersectional disability data in our mortality, health, education, violence, employment, housing and other statistics, we would have a better basis from which to develop policies and respond to emergencies.

We will achieve better disability justice when accessibility and inclusion standards measure and evaluate the

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extent to which the human rights and dignity of those most often excluded and marginalised are proactively protected.

A national disability benefit is an important next step

Many of the negative impacts discussed in Sections 2 and 3 stem from loss of income that relates to the systemic inequities experienced by diverse people with disabilities.

The Canadian Disability Benefit announced in the September 2020 federal Throne Speech is one step to addressing these gaping holes made especially evident through the pandemic. While some are optimistic about what the benefit could mean and look like,²⁶⁹ others note that the proposed parameters are not inclusive of the diversity of people with disabilities as they could exclude sponsored immigrants and those with a mental illness.²⁷⁰

One thing is certain: given the disproportionately negative impacts of the COVID-19 pandemic on diverse people with disabilities, the next steps by governments and policy makers must be concrete and comprehensive.

269 Prince, 2020

270 BakerLaw, 2020

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Section 5: Concluding comments

We heard two radically different thoughts about what opportunities the COVID-19 pandemic provides related to people with disabilities.

One Australian colleague suggested that the pandemic had solidified existing inequalities and could close the curtain on gains made by people with disabilities.

Another key informant from Canada suggested that COVID has opened the curtains on the inequities experienced by people with disabilities and could be a catalyst for change.

Both are possible futures.

The lessons from COVID and good practices identified suggest that the coming months, including the rebuilding post-COVID, offer an exceptional opening to redress the systemic inequalities long experienced by people with disabilities and more recently exposed by the pandemic. This report has identified key steps for federal, provincial, territorial, local and Indigenous governments to take.

But the opening for action is time-limited before the horrors exposed by COVID will be forgotten and complacency will set in. We urge you to act on those areas identified as priorities by diverse people with disabilities, their families and support/care providers, and disability organizations.

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Section 6: References

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Appendices

Appendix 1: Intersectional Disability and Gender Analysis Framework

Questions:

1. What are the effects of COVID-19 policy measures and on whom?

- Who benefits from COVID-19 measures and who does not?
- Which people with disabilities benefit and are excluded because of how disability is defined?
- Which people with disabilities benefit and are excluded because of eligibility criteria?
- Which people with disabilities benefit and are excluded from which policies?
- How do the above inclusions and exclusions link more generally to the diversity of people with disabilities (gender, Indigenous, disability and impairment type, age, presence of children and other caring responsibilities, ethnicity/race, rural/urban, living arrangements, language, immigration status)?
- What are the particular ways that various Indigenous peoples with disabilities are included or excluded? What is the role of Indigenous governments in these processes?
- Are there any cumulative and/or cascading impacts of inclusion or exclusion? Who experiences these?
- Does the timing of policy measures have differential impacts?
- Do the jurisdiction and jurisdictional coordination have differential impacts?
- How does the jurisdictional nature of Canada challenge the navigation of benefits for diverse people with disabilities?

2. How have a) diverse people with disabilities, their knowledges and experiences and b) their families, support/care providers, and disability organizations been included, and accessibility addressed, in

- data gathering?
- communications and information sharing before, during and after an emergency?
- developing policy and program options?
- emergency response plans?

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3. Are there structural and/or systemic barriers to the inclusion of diverse people with disabilities in 2 above? For example, because they

- a. Live in long-term care, prison or other institutions?
- b. Live in group homes?
- c. Live in a shelter?
- d. Experience homelessness?
- e. Attend school?
- f. Are a particular age?
- g. Experience a certain disability or impairment type?
- h. Have a certain family situation?
- i. Have a certain immigration status?
- j. Other?

4. What good practices exist, and what lessons have been learned, in the inclusion of people with disabilities and attention to accessibility in:

- a. communications and information sharing before, during and after an emergency?
- b. data gathering?
- c. developing policy and program options?
- d. emergency response plans?

5. What could be done differently to address the experiences, knowledges and needs of diverse people with disabilities, their families, support/care providers, and disability organizations in emergency planning?

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Appendix 2: Methods

To write this report, we gathered information from numerous sources: policies, surveys, news articles, academic literature, community reports, and interviews with disability experts and people with disabilities. Our goal was to confirm the evidence based on multiple sources, a process called triangulation.

Here, we explain in detail the process we used to gather and analyze the information present in the report.

1. Quantitative Data Collection and Snapshot

The snapshot in Section 2 used data from Statistics Canada and community surveys. To discuss the demographic characteristics of people with disabilities in Canada, we relied on the 2017 Canadian Survey on Disability, as well as 2016 Census data. To discuss the impacts of the COVID-19 pandemic on people with disabilities, we relied on the Statistics Canada crowdsourced initiative "Impacts of COVID-19 on Canadians." Because crowdsourced data is not collected according to probabilistic sampling, we sought to triangulate findings with other sources when available, such as community surveys, with attention to gathering information about multiple social dimensions, including gender, Indigenoussness, disability and impairment types, sexual and gender diversity, geographical area, and living arrangement.

2. Policy Analysis

a. Canadian Policy Scan

We collected and analyzed policy documents related to COVID-19 measures undertaken by the federal, provincial and territorial governments and 5 regional health authorities. We searched for policies related to COVID-19 that directly impact people with disabilities in five provinces (British Columbia, Alberta, Ontario, Québec and New Brunswick) and six health authorities (BC Provincial Health Services, Vancouver Coastal Health, AB Health Services, ON Toronto Central LHIN, Québec Santé Montréal and NB Vitalité).

In our search, we gathered policies related to all ages, such as policies related to school re-entry for children with disabilities, and all living facilities, such as people living in long-term care or other assisted living homes.

Also, we also searched four key areas that we identified from earlier research: income, housing, service provision, and public spaces. We included policies related to institutional living and attending, such as those related to schools, group homes, long-term care, and prisons.

We searched the websites of the federal, provincial and territorial governments and the relevant regional health authorities. We made a list of policies and programs identified for each government and contacted individual health authorities to ask them to supplement the list of policies and programs that we found on their respective websites.

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b. OECD and Transnational Policy Scan

We collected and analyzed policy documents related to COVID-19 measures undertaken in four OECD countries (United States, United Kingdom, Australia and New Zealand) and within the context of the United Nations (UN) system. To do this, we searched relevant websites for reports or other documents related to:

- i. effects of COVID-19 on people with disabilities
- ii. effects of COVID-19 policies on people with disabilities
- iii. particular policies related to Indigenous peoples with disabilities and people living in congregate settings
- iv. disability-related gaps

We explored the government websites of the United States, United Kingdom, Australia and New Zealand, as well as the websites of United Nations Enable, UN Women, UNICEF, UNCRPD, UNDRIP, and the UN Office for Disaster Risk Reduction (UNDRR).

We also considered initiatives related to Article 11 of the UNCRPD on situations of risk and the Sendai Framework for Disaster Risk Reduction.

Finally, we contacted key officials and asked them to identify relevant reports and documents.

3. Literature Review

We reviewed the existing reports, documents, and articles found through social media, academic and community publications.

a. Social Media Scan

We identified key organizations in disability politics and advocacy (see list below), and searched their websites, Facebook pages, and Twitter feeds. We identified the hashtags most used by these organizations, and we searched Twitter to gather what people with disabilities are saying about their experiences during the pandemic, or about the government responses.

We included posts directly about COVID-related experiences of people living with disabilities and about the indirect effects of COVID-19 policy decisions of people with disabilities. We gathered experiences and perspectives for specific groups of people with disabilities, including Indigenous people with disabilities, and people in long-term care and other congregate settings.

b. Academic and Community Literature Review

We searched publications in 2020 written in English or French that were directly about the effects of COVID-19 on people with disabilities, the effects of COVID-19 policies on people with disabilities, and disability-related gaps.

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For the academic literature review, we searched relevant political science and disability sources, including *Canadian Public Policy*, *Canadian Journal of Political Science*, *Canadian Centre for Policy Alternatives*, *Canadian Journal of Disability Studies*, and *Disability & Society*.

For the community literature review, we searched the websites of relevant disability organizations in Canada for publications related to the COVID-19 pandemic. Some of the organizations included DAWN Canada, Inclusion Canada, Council of Canadians with Disabilities, Canadian Association of the Deaf, Alliance for Equality of Blind Canadians, National Educational Association of Disabled Students, People First of Canada, National Network for Mental Health, ARCH Disability Law, Disability Justice Network of Ontario, BC Aboriginal Network on Disability Society (BCANDS), Confédération des organismes de personnes handicapées du Québec, Voice of Albertans with Disabilities, and Citizens with Disabilities Ontario. We also reviewed publications by the Canadian Human Rights Commission, Amnesty International, FAFIA, and other human rights organizations.

4. Qualitative Data Analysis

We conducted interviews and focus groups with key informants (disability leaders and policy experts) and people with disabilities to get a deeper understanding of the impacts of COVID-19 on the lives of people with disabilities and whether the current policies addressed these impacts.

This research received research ethics approval from the Research Ethics Board of the University of Guelph (REB #20-09-019).

All participants were given an Information Letter and Consent Form, and the interview questions before the interview. Each participant gave their written or oral consent before the beginning of the interview. The audio-recordings of the interviews were transcribed verbatim and then destroyed.

a. Key informant interviews

Our goal was to interview 10 –15 key informants from the federal, provincial and territorial governments and five regional health authorities to supplement the policy scan. We also sought to interview 5 –10 disability leaders in Canada to identify key impacts of COVID-19 measures on people with disabilities, as well as lessons learned and good practices about the government response from a disability perspective.

Due to the challenges described in Section 1.3, we were not able to talk to many key informants in government and regional health authorities, as they were focused on managing the COVID-19 pandemic. An additional barrier was that it was difficult to identify officials who could speak of the COVID-19 policy response for people with disabilities.

Although we invited 12 policy experts (five federal policy makers, five provincial government officials from QC, ON, BC, and AB, and two regional health officials), to participate we had limited success in obtaining these interviews. In total, we interviewed one federal policy-maker, two provincial government officials

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(both from Québec), and no one representing regional health authorities, for a total of three policy experts.

We invited 12 disability leaders to identify key impacts of COVID-19 measures on people with disabilities. We interviewed nine disability leaders, and conducted a focus group of 15 disability leaders, representing regional, provincial, and federal organizations. These disability leaders also represented diverse groups of people with disabilities, including people with intellectual and developmental disabilities, people who are Deaf or hard of hearing, women with disabilities, Indigenous people with disabilities, and children with disabilities.

All the interviews took place on the videoconferencing platform Zoom and lasted between 30 and 90 minutes.

b. Focus groups and interviews with diverse people with disabilities

To recruit participants, we posted information about the study on the social media pages of DAWN Canada and the Live Work Well Research Centre.

Once a person expressed interest in the project, we sent them the Information Letter and Consent Form, as well as the interview questions.

We also invited the interested individuals to fill out a survey about their participation preference, accessibility needs, and demographic information, including their gender, age range, race, Indigenous status, and caregiving responsibilities. With this information, we created a recruitment grid to select participants that would represent a wide variety of social groups.

In total, we conducted 21 interviews with people with disabilities and two focus groups, gathering the experiences of 30 people with disabilities. People represented the provinces of Ontario (n=20), Québec (n=3), Alberta (n=3), and British Columbia (n=4). Participants (n=27) reported physical (n=14), mental (n=8), sensory (n=5), learning (n=4), episodic or chronic (n=3), age-related (n=3), or other (n=3) disabilities. Demographic information for participants is provided in Tables 1 and 2.

The interviews took place by telephone or via Zoom and lasted between 30 minutes and two hours.

5. Collaborative Data Analysis

The research team met for two collaborative data analysis sessions. In these sessions, we reviewed the data and the analysis to discuss important themes, key findings, and gaps. The team members bring diverse perspectives and experiences that contributed to the analysis of the data gathered.

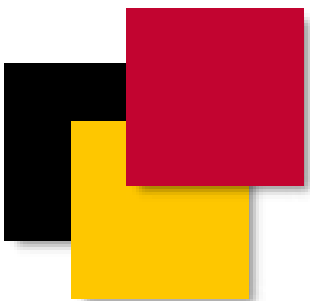
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Tables 1 and 2: Summary of participant demographics

Age in years (n=30)	Gender (n=30)	Disability (n=27)*	Racialized (n=20)	Indigenous (n=30)	LGBTQ2+ (n=30)
18-29	4 Woman	20 Mental	18 Racialized	5 Indigenous	0 LGBTQ2+
30-49	8 Man	7 Physical	14 Non-racialized	12 Métis	1 No
50-64	3 Non-binary	2 Sensory	5 Unknown	13 Non-Indigenous	17 Unknown
65 and older	3 Unknown	1 Learning	4	Unknown	12
Unknown**	12	Age-related	3		
		Episodic/chronic	3		
		Other	3		
		Unknown	3		

Region (n=30)	Immigration status (n=30)	Caregiving responsibilities (n=30)	Congregate settings (n=30)	Living arrangements (n=30)
Urban	17 Citizen, not born in Canada	2 No	17 No	9 Lives with at least one family member with a disability
Suburban	4 Non-citizen	0 Yes	3 Yes	5 Lives with other family members
Rural	3 Born in Canada	18 Unknown	10 Unknown	16 Does not live with children or other family members
Unknown	6 Unknown	10		4 Unknown

*Six participants had two or more disabilities. **Unknown numbers include those who selected "I prefer not to say" and those who did not answer that question.



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