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Nothing for us without us:

Towards disability-inclusive policy development in Alberta

As a global health crisis, the COVID-19 pandemic has been felt universally. However, not everyone is impacted equally. In the words of BC Chief Medical Officer Bonnie Henry, “We are a global community, and we’re all in the same storm, but we are not all in the same boat.” The COVID-19 pandemic has disproportionately accelerated health and socioeconomic disparities for persons with disabilities in Canada. Persons with disabilities experience activity limitations that impact ability to participate in society, and many COVID-19 policies were developed in a manner that limited inclusion in society. As signatories to the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and with the development of federal and provincial accessibility legislation, we have committed to reducing barriers to participation in society through regulations, policies and programs. This commitment stands even during emergency response situations like the COVID-19 pandemic, however current policy development processes in Alberta have left persons with disability behind.



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Relevant topics

Best practices for citizen engagement in health planning, health and well-being of children with disability in Alberta, access to services.

Lay Summary

This policy brief highlights some core guiding principles – Nothing about us without us; the UN CRPD framework; and accessibility and accommodations, describing the need for COVID-19 policies to incorporate and accommodate the unique needs, challenges and vulnerabilities of persons with disability in an equitable manner. We provide some COVID-19 specific policy examples in Alberta, highlighting approaches to improve disability-inclusive policy responses.

Recommendations focus on health-in-all-policies approaches across government to ensure that recovery efforts in Alberta can move towards a disability-inclusive, evidence- and data-informed mentality to policy development. Specifically, recommendations include:

- Develop provincial accessibility legislation in Alberta and an agency responsible for developing standards to guide accessibility;
- Develop a cross-ministry table to identify and develop policy with consistent and evidence-informed disability-inclusive approaches. Consider approaches for meaningful representation co-design and consultation of persons with disability, as well as with community organizations. For example, re-visit the consultation structure with ministries, and resource the role of Premier's Council on the Status of Persons with Disabilities)
- Develop cross-ministry data linkage across health, education, social services, post-secondary and employment data to better understand service use, and the implications of policy decisions for persons with disabilities and their families.

Recommendations at the provincial level are aimed at achieving a more inclusive, accessible and sustainable policy development process for persons with disabilities, in order to improve health and socioeconomic outcomes.

Issue

COVID-19 policy responses have left persons with disability behind, despite being a population that is disproportionately impacted by the pandemic. This has exacerbated pre-existing disparities for persons with disabilities, disparities that are not being addressed in the Alberta policy development process.

Background Context

Health and socioeconomic disparities for persons with disabilities

Persons with disabilities are 22% of Albertans, but experience significant health disparities relative to the general population as a result of activity limitations and structural barriers to equal participation in society. These realities impact the ability to meet daily living needs [1]. Activity limitations may include implications for mobility, communication, learning, socialization, vocation, self-care and/or independent living. These activity limitations can present barriers to participation in society. Nationally, this has resulted in poorer educational achievement, employment, independent living and physical and mental health, relative to Canadian averages [2].

UN Convention on Rights of Persons with Disabilities Commitments

Through the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) [3], Canada and all provinces have committed to providing services and supports to improve health and socioeconomic outcomes, reduce barriers and enable persons with disability to fully participate in society. While some of the UN CRPD articles are most relevant to federal jurisdiction, several UN CRPD articles are directly relevant to provincial jurisdiction, and the programs and services they offer. These include:

- General obligations (article 4)
- Children with disabilities (article 7)
- Accessibility (article 9)
- Living independently and being included in the community (article 19)
- Personal mobility (article 20)
- Respect for home and family (article 23)
- Health (article 26)
- Work and employment (article 27)
- Adequate standard of living and social protection (article 28)

To more tangibly make the linkage between these UN CRPD articles to existing provincial legislation, programs or representation, relevance to specific articles in each province can be found on this [website](#) [1].

Absence of data collection to monitor commitments

Article 31 of the UN CRPD outlines the need to systematically collect and report disability data to monitor the implementation of UN CRPD commitments (UN General Assembly 2007, 19). At present, centralized data and information on provincial disability programs are lacking or are completely absent, which prevents appropriate monitoring and accountability mechanisms. In the concluding observations of their initial report on Canada, the UN Committee on the Rights of Persons with Disabilities (2017, 12) highlights the concern that Canada “does not have up-to-date quantitative and qualitative data on the situation of persons with disabilities”. Without accessible program data across provinces, it is difficult to determine whether Canada is meeting its commitments to the UN CRPD. It is also difficult to determine whether the current design of provincial programs is meeting the diverse needs of Canadians with disabilities in an effective, efficient, and responsive manner, or whether the reach of current disability programs is adequate. This is particularly concerning when one looks at socio-economic factors for Canadians with disabilities, as they indicate that these individuals are more likely to experience poverty, are less likely to be employed, and report lower educational achievements relative to Canadians without disabilities (Morris et al. 2018, 4).

Federal and provincial accessibility regulations

Accessibility standards have been implemented across the country through various sub-national bylaws, policies, and guidelines that aim to create barrier-free access to communities, workplaces, and services for people with disabilities. To better enforce these rights-based commitments, we have the Accessibility Act, and individual and family rights for care under the Canada Health Act. Federal legislation on accessibility standards came into force in July 2019 through the Accessible Canada Act. The act identified seven priority areas federally regulated entities should focus on, so to identify, remove, and prevent barriers, and to improve access and opportunities for persons with disabilities. This includes the design and delivery of programs, services and communication among other domains that affect daily life for people with disabilities. Proposed regulations for the Act are currently under review (Employment and Social Development Canada, 2021).

Facilities and services that fall under provincial jurisdiction and the private sector in Alberta will not be governed by this federal act. Four provinces have passed, or are finalizing, accessibility legislation that aims to remove barriers that prevent full participation of individuals with disabilities. Current provincial accessibility legislation includes Ontario’s Accessibility for Ontarians with Disabilities Act passed in 2005, Manitoba’s Accessibility for Manitobans Act passed in 2013, Nova Scotia’s Accessibility Act passed in 2017, while British Columbia passed the Accessible British Columbia Act in 2022.

The COVID-19 pandemic has exacerbated health and socioeconomic disparities

The COVID-19 pandemic – and the resultant policy responses to it – has exacerbated pre-existing challenges around accessibility and access to services for individuals with disabilities and their caregivers.

Throughout the pandemic, a number of approaches have been used federally and provincially to ‘flatten the curve’ and reduce the spread of the novel coronavirus. The policy approaches included public announcements, social distancing and self-isolation policies, nonessential workplace closures, health facility restrictions, such as triage policies, and medical visitation policies [4]. The impact of these policies on persons with disability, and their caregivers, is greater than the impact on the general public. The reasons for this is detailed in a recent Royal Society [report](#) [5] and are highlighted below:

Individuals with disability often have co-occurring health conditions and multiple complex health care and community-based needs;

A greater proportion of adults with disability live in congregate settings

COVID-19 pandemic practices and policies, such as designation and cessation of non-essential in-person supports and ongoing health services; vaccine prioritization; restrictions in access for family members, friends and volunteers; school regulations; and regulations and provision around Personal Protective Equipment (PPE) have had particularly difficult implications for persons with disability and their families;

Ongoing risk of discriminatory practices in the care and treatment for persons with disability who develop COVID-19

Lower socio-economic status is disproportionately represented in persons with disability and their families. Persons with disabilities (broadly defined) are two times more likely than the general population to be living in poverty, which is an additional risk factor for increased infection rates.

Despite being disproportionately impacted by the COVID-19 pandemic, rapid policy responses have left persons with disabilities behind. This is a trend that has been seen in other public health and humanitarian crises [6, 7]. A disability-inclusive approach to policy development and pandemic response planning is important to meet the commitments of the UN Convention on the Rights of Persons with Disability to ensure that persons with disability have access to essential services. The benefits of this approach would also extend to society as a whole. The UN describes how “adopting a disability inclusive response will provide for more inclusive, accessible and agile systems capable of responding to complex situations, reaching the furthest behind first. It will pave the way for a better future for all.”[8]

Key considerations

Core guiding principles must guide the development of recommendations, as recommended by a recent Royal Society report [5]:

- **Following the principle of “Nothing about us without us”** – adopted by the UN Convention on the Rights of Persons with Disability – disability inclusion requires accessible, accountable approaches to be taken when developing population-level responses across ministries, incorporating meaningful consultation in all stages of response and recovery.

- **Disability-specific policies** are an important requirement of a disability-inclusive policy response. Persons with disability require consideration during the pandemic response and during any policy development, as they experience additional barriers to participation in society and are disproportionately impacted by the COVID-19 outbreak.

Current context in Alberta

Examples of Alberta COVID-19-related policy responses that illustrate the need for disability-inclusive policy response and the need to ensure that decision tables developing these COVID-19-specific policies have a disability perspective:

1. **Mandatory mask policy:** Alberta instituted a mandatory mask policy as an approach to prevent the spread of COVID-19. For persons with disabilities who required an exemption due to their medical condition, a letter from a medical professional was required. One must remember that there are some unique challenges to mask regulation compliance for persons with disabilities [9].
 - **Disability inclusive and accessible policy:** Provision of public information to reduce stigma, improve accessibility of affordable mask distribution and reduce the cost of procurement considerations for supplying regular support workers. *Accessibility considerations and intergovernmental collaboration are required.*
2. **Vaccination prioritization:** Persons with disability who are not seniors, such as some persons with intellectual/developmental disabilities, have been shown in large-scale studies to be more susceptible to COVID-19 infection than the general population, and to suffer more severe outcomes, including death from infection. Protection of persons with developmental disabilities from COVID-19 will also require protection of their paid and unpaid caregivers and families. These groups were not adequately prioritized for vaccinations.
 - **Disability inclusive and accessible policy** Prioritization and protection of younger persons with disabilities and their caregivers in the same manner as other vulnerable groups such as seniors. *Provision of vaccines and information surrounding them in an accessible manner is required.*
3. **Essential service worker policies:** Persons with disability have faced significant disruption of their usual essential supports and services due to the COVID-19 pandemic. Access to supports and services across ministries (such as rehab, primary care, acute care, community and home care services, as well as informal supports and mental health supports) was often (and inconsistently) cancelled, decreased or realized differently (such as through telehealth). Some examples include diagnostic evaluations and necessary specialized disability-related medical care and rehabilitation services, home and school-based therapies, outpatient care in specialized clinics related to associated health conditions, personal care assistance, and preventative “non-essential” care. Furthermore, support persons and caregivers,

or family members, were often not permitted to attend in-person health care appointments and hospital stays, despite being essential supports for some persons with disability.

- **Disability inclusive and accessible policy:** Focus on designating services, supports, therapy and support workers for persons with disability as essential in health and social care sectors. Telehealth and mental health services need to be accessible and adapted to meet the unique needs of persons with disability. *Inter-ministry collaboration and data collection to understand service use and needs of population is required.*

4. **Emergency COVID-19 related funding for persons with disabilities:** The COVID-19 pandemic has exacerbated pre-existing inequalities in social determinants of health for persons with disabilities. Persons with disabilities have experienced greater financial hardships and disproportionate job loss and employment impacts, particularly among young workers. Disability income assistance recipients face higher risk of hospitalization and mortality [10]. Provision of the Canada Emergency Response Benefit (\$2,000/month temporary cash benefit) was provided to Canadians in response to severe economic circumstances, however those on income or disability assistance (disability assistance programs are all less than \$2,000 a month), experienced a 75% clawback rate on CERB-related income in Alberta [11]. Furthermore, many caregivers of persons with disability were ineligible for the emergency caregiver benefit, due to eligibility limitations requiring previous paid work.

- **Disability inclusive policy:** Develop pandemic income supports for persons with disability in line with extra costs experienced during the pandemic. Recognize that persons with disability and their families experience additional costs, such as PPE for support staff and technology needs. Concurrently develop an emergency benefit provision for caregivers of persons with disability. *Inter-ministry and inter-governmental collaboration, and adequate data collection on income and needs for population is required.*

5. **Sustainable community support:** Private sector, not-for-profit and community organizations provide critical supports and services to persons with disabilities and their families [12]. During the pandemic these organizations experienced reduced revenue streams, rapid transition to online services, and inadequate communication and collaboration with government, often competing for small, short-term funding [12].

- **Disability inclusive policy:** Development of person-centered policies and programs to sustainably and predictably support frontline community organizations. Pandemic preparedness includes coordination with central government frameworks to create a plan for service continuity with organizations. *Reciprocal partnerships, data collection and inter-ministry and governmental collaboration are required.*

Policy recommendations

The following recommendations focus on applying the core principles of Nothing About Us Without Us, and a disability-inclusive approach to policy development, with the aim of preventing the propagation of the current pandemic experience in the future, which has seen policies increasing health and socioeconomic disparities for persons with disabilities. To that end there are three overarching recommendations necessary to align with core principles, UN CRPD commitments, and federal accessibility legislation.

1. Alberta accessibility legislation development

As seen during the COVID-19 pandemic, there is a need for guidance around accessibility health and social service provision as rapid pandemic specific policy is developed. The *Accessible Canada Act* (ACA) highlights areas in which the federal government guides unifying standards of accessibility. However, there are many health, social supports and services that the Alberta government provides directly. The five Alberta policy examples provided show that there is a need for accessibility considerations in each of the policy approaches taken. Alberta needs to follow the lead of Ontario, Manitoba, Nova Scotia and B.C., and develop and enforce provincial accessibility legislation to guide disability inclusive policy development.

RECOMMENDATION: Develop provincial accessibility legislation in Alberta and establish an agency responsible for developing standards to guide accessibility.

2. Mechanisms for cross ministry consultation, and inclusion of persons with disability in disability-inclusive policy development/decision tables, and for pandemic response and recovery efforts

Currently there is a “patchwork” of health services, education, social housing and family, disability, unemployment, welfare, and early childhood benefits and services[13, 14]. Despite repeated emphasis on issues of fragmented access and long waits for many critical support services for children, youth and their families, ministries still have different priorities, mandates and approaches, inconsistent policies, distinct eligibility criteria, and a lack of data on service use [15]. In addition, spending on social services and community programs aligns with many social determinants of health and their impact on health outcomes, but is not included in health spending allocations[16]. Social policy impacts health in a number of complementary ways: by reducing poverty and homelessness (e.g., universal basic income for families, National Housing Strategy, disability supports), reducing social inequalities (e.g. public education, accessible child care, affordable university tuition), increasing labour force participation (e.g. subsidized quality daycare) and ensuring good physical health (e.g. free and accessible medical care, tax credits for physical activity and fitness). However, as the COVID-19 pandemic has highlighted there is a lack of coordination and collaboration across these policies and services.

RECOMMENDATION: Develop a cross ministry table to identify and develop policy with consistent and evidence-informed disability inclusive approaches. Consider approaches for meaningful representation co-design and consultation of persons with disability and community organizations (re-visiting consultation structure with ministries/resourcing the role of Premier's Council on the Status of Persons with Disabilities)

3. Develop a cross ministry disability-inclusive data strategy for data collection and monitoring

Alberta has some assets in the one health system approach with Alberta Health Services data. However, there are some major data gaps, as it pertains to understanding access to services for persons with disability across ministries (health, education, social services, employment). As such, Alberta is falling alarmingly behind other provinces in its capacity to understand service utilization across ministries for all Albertans, but particularly for Albertans with disability and their families. This impacts the ability to make evidence-informed program and policy decisions. Administrative data across some health and social service programs have been linked in four other provinces, enabling researchers and policymakers to ask and address critical questions related to cross ministry service use. These provinces are B.C. (Data Innovation Program in BC), Manitoba (Manitoba Center for Health Policy), Ontario (ICES data) and New Brunswick (NB-IRDT). All these provinces have successfully navigated health legislation privacy concerns, which are often cited as a limitation in Alberta. Currently, with data refreshes ongoing, these provinces can look at the impact of the pandemic on service use for persons with disabilities beyond simply health service use data. Alberta has been left behind. In Alberta, the lack of cross ministry access to services results in inefficient and expensive service delivery with a lack of ability to conduct necessary analysis to understand cross ministry service use.

RECOMMENDATION: Develop cross ministry data linkage across health, education, social services, post-secondary and employment data to better understand service use and implications of policy decisions for persons with disabilities and their families.

Conclusion

Effective and accessible disability programs are essential to supporting Albertans with disabilities, and to achieving Canada's commitment to the United Nations Convention on the Rights of Persons with Disabilities. The pandemic has highlighted growing gaps in Alberta's policy development processes, which have resulted in widening socioeconomic and health disparities for persons with disability. Cross-ministry approaches are required to address these disparities and shift towards more disability-inclusive policy development to help Albertans with disabilities, and their families, thrive.

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