
KEY HEALTH CONSIDERATIONS FOR CHILDREN WITH DISABILITIES IN CANADA

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The Issue

Over 800,000 children in Canada have a disability impacting their everyday life. The Social Determinants of Health (SDOH) such as social inclusion, education, and income disproportionately affect these children and their families. They are also often overlooked by mainstream health promotion strategies. Neglecting the needs of these children in policies can result in poor health-related outcomes such as higher risk for cardiovascular diseases and mental health challenges, decreased social participation, higher use of the healthcare system, and increased caregiver burden. The COVID-19 pandemic dramatically increased these risks and exposed further vulnerabilities to these families, such as the reliance on the education system for health services, and the lack of social protections to maintain and promote health for these children and families during a public health emergency and beyond.

The United Nations committees on the Rights of Persons with Disabilities and the Committee on the Rights of the Child have recently produced reports to Canada indicating areas, such as health promotion, that could benefit from a better use of human rights frameworks.

Key Issues for children with disabilities during the COVID-19 pandemic	Recommendations for the health promotion of children with disabilities
<ul style="list-style-type: none"> • Distanced learning challenges (inaccessible online education, loss of routine, mental health strain) • Loss of services (therapeutic/medical care, home support) • Social isolation • Post-pandemic delayed recover (safety of public spaces) 	<ul style="list-style-type: none"> • Adopt inclusive strategies for the engagement of children with disabilities and families in policymaking. • Support research and services that is done in close collaboration with diverse groups and addresses intersectionality and across-jurisdictions and systems of care. • Inclusion of childhood disability lenses in ongoing policy development emphasizing multi-sectorial approaches across the lifespan (e.g., The National Autism Strategy, the Accessible Canada Act, tax benefits). • Allocation of budgetary resources for communities to capitalize on inclusive public play spaces. • The expansion of current data collection instruments to include disaggregated data on children with disabilities.

Studies conducted during the pandemic by our group shed light on healthcare concerns for children with disabilities and their families in Canada during the COVID-19 pandemic, including the *UNICEF-World Health Organization Global Report on Developmental Delays, Disorders, and Disabilities*. Among 883 participants, **35.5% reported mental health complications for their child**, and many spoke to their own mental health challenges in coping with multiple personal demands and the care of their child, including **managing complex healthcare needs in the absence of health and community supports**. One parent from Ontario said:

- “I was at a loss [at] what to do with my life.”

Another caregiver from Quebec noted:

- “All services were stopped. We have been abandoned by the state. No help whatsoever.” (Translated from French).

Caregivers felt that services were insufficient during the pandemic, citing a **significant lack of respite services, in-home services, mental health therapy, access to medical services, and limits on their prescription medication allowance**. Caregivers pointed priorities for the health of children with NDDs:

1. Inclusive education services and alternatives (e.g., health and rehabilitation services received through the school service were discontinued or resumed much later than services provided to other children),
2. Increased financial supports (funding essential equipment, specialized at-home care, and formal and informal caregivers, particularly for children with complex healthcare needs), and
3. Improved mental health services.

Another study examined resilience from COVID-19 among children with disabilities and their families using the same data. Findings indicated that **a child's diagnosis type, parenting self-efficacy, and access to schooling were predictors of resilience**. The study also indicated that **adapting support programs for different diagnoses enhances caregiver empowerment** and contributes to overall better perception of health and social service access, mitigating social disadvantage disparities.

A different study asked caregivers' input about their perceptions of policies and supports available during COVID-19 and analyzed provincial policies addressing mental health concerns of children with disabilities during the pandemic in relation to the UN Convention on the Rights of Persons with Disabilities' obligations. We found that children with disabilities were **vulnerable to mental health risks resulting from public health measures, reporting exacerbated behavioral challenges, sleep problems, distress, and anxiety**. Another study indicated that children with intellectual disabilities were distressed due to confusing information, hygiene measures like frequent hand washing and mask use, and altered routines. Nevertheless, **few policies addressed mental health impacts of the pandemic for these children**. For instance, policies supporting the creation of mental health services for youth in schools did not consider accessibility and inclusion of children with communication, visual, sensory, or physical health complexities preventing them from online education. The absence of policies supporting community- and home-based supports for families exposes gaps in the types of health services available for children in their communities. The lack of inclusive health promotion strategies delayed the return to activities and impeded children with complex care needs to return to their communities. Programs for these children are offered in specialized and tertiary care and not part of mainstream health promotion.

All these studies indicated that COVID-19 intensified existing inequities and that the health of children with disabilities depends largely on intersectoral collaborations with education, communities, and families.

Recommendations

Recommendations from the multi-sectorial consultation on the future of children in Canada: [*"Inspiring Healthy Futures"*](#) highlighted the importance of "engag[ing] children and youth" and "build[ing] child, youth and family capacity to initiate and participate in change leadership." **Children with disabilities and their families must be included in consultations and strategies when elaborating health policy and service**. Facilitating their participation includes covering expenses related to childcare and attendance, disseminating child-friendly information before consultation processes, maintaining "safe spaces" for children to speak and participate, and providing accommodations for overcoming language barriers.

Another priority highlighted in this report was **supporting impactful research**. One participant stated:

- “We need to reflect on what we learned from COVID.”

This includes understanding the experience of disability of those at the intersection of multiple avenues of vulnerability, such as persons with disabilities with LGBTQIA+ identities or experiencing homelessness. Additionally, underrepresented groups considered “hard to reach” are often not included in research initiatives, such as: fathers of children with disabilities, parents of children who identify as LGBTQI, as well as low-income, racialized, immigrant, and Indigenous children with disabilities and their families.

The third priority was the **adoption of child-centric policies**. Several ongoing policy initiatives adopt rights-based approaches for child health across federal-provincial jurisdiction need a childhood disability consideration. Examples are: the Canada Youth Guarantee (a program ensuring youth access to education, training, and employment to mitigate disruptions caused by the COVID-19 pandemic), the Canada Child Benefit (to eradicate child poverty entirely in Canada in addition to empowering vulnerable families such as those supporting children with disabilities and children with complex medical needs), and the Bill S-203, *An Act respecting a federal framework on autism spectrum disorder* (mandating the federal Minister of Health to develop a national framework for autism). Research and public consultation done by the Canadian Academy of Health Sciences have presented [recommendations](#) for drafting a National Autism Strategy, with clear suggestions for coordinating care for early access to diagnosis and interventions between community, education, and health, and strengthening the services across the lifespan, understanding the developing capacities and needs of children with developmental conditions and complex healthcare needs. The [Accessible Canada Act](#) is currently being implemented, and the development of standards for accessibility should consider the unique needs of children. These are current policy opportunities to implement a broader understanding of health for children with disabilities, considering multiple SDOH as key for a healthy development.

The fourth priority encourages **leveraging ongoing health promotion strategies to include children with disabilities**. Communities should be seen as health and wellbeing hubs. Availability of play spaces is one mean for children attaining healthy physical activity levels, avoid deconditioning, maintain cardiovascular health and practice social and communication skills essential for their development. The [WHO Urban Health Agenda](#) highlighted the impact public policies have on public health by determining spaces for play, active transportation, and green areas. Yet, play spaces are often inaccessible or unwelcoming for children with disabilities. When they are excluded from the development of these spaces, their needs are not considered resulting in lack of accessible changing stations, play equipment, drinking fountains, etc. Supporting inclusive community development includes creating new public play spaces and updating existing play spaces currently inaccessible for children with multiple developmental disabilities. We also recommend the adoption of inclusion and accessibility lenses for all public funded programs. The CHILD-Community Health Inclusion Index is one such lenses that can be applied to determine how policies, programs, and facilities are inclusive of children with disabilities and help promoting their health.

The last priority is **the creation of accessible, adaptable, and integrated health and wellbeing systems**. Participants noted the relevance of this priority for the childhood disability community:

- “Families with children with medical complexities, disabilities or developmental issues have lost so much ground because of the pandemic. We need to rally behind supporting the most fragile children in our community”.

A consistent and comprehensive data collection strategy, integrating administrative data from health, education, social services and across jurisdictions, to measure children’s health, healthcare and health

outcomes. This strategy is reflected in other priorities as well, such as the call for a “comprehensive open, accessible data strategy” to facilitate impactful research or the call to “improve data and outcomes monitoring of child and youth wellbeing, including disaggregated data to track inequities”. A strategic and comprehensive data collection is one of the articles of both UN Conventions that can support the creation and implementation of child-centered policies and structures. The UN Office for the High Commissioner on Human Rights developed a set of indicators for the UNCRPD to support implementation and monitoring of the convention. Specifically, the convention suggests data to be collected for children with disabilities to include: school enrollment, nutrition, and funds allocated for their care. Existing data strategy frameworks, such as the Canadian Quality of Life Index, support the collection of data across sectors to inform health policies and programs, however, children with disabilities are not included in the data collection strategies. Expanding this strategy to address the quality of life and wellbeing indicators for children with disabilities will make possible the creation of targeted strategies for the promotion of health for these children.

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