



THE SCHOOL
OF PUBLIC POLICY



Disability Policy
Research Program



Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

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University of Calgary) in collaboration with other researchers at the
University of Calgary and Kids Brain Health Network**



Recommendations

Recommendation 1: Commit to integrating child health and wellbeing in all policies and budgets.

Recommendation 2: Invest in COVID-19 recovery efforts to ensure that persons with disabilities and their families are adequately supported, and that their needs are recognized in future emergency planning.

Recommendation 3: Allocate sufficient funds to the inclusive development of the CDB.

Context

A recent UNICEF report showed that Canada ranks among the countries with the best economic, environmental and social conditions for growing up, but is **among the countries with lower than average health and wellbeing outcomes for children** compared with other high-income countries (30th out of 38 countries).¹

Children with neurodevelopmental disabilities (NDD) and their families face barriers and challenges in everyday activities. **Children with NDD and their families face a higher risk of adverse mental health issues and poor health and socio-economic outcomes.** This has been exacerbated by the COVID-19 pandemic, which exposed deep cracks in access to services for the more than 400,000 children under 14 years old across Canada living with NDDs and their families.

Children with medical complexity comprise 1% of the pediatric population, but are responsible for 33% of all pediatric healthcare expenditures. Children with complex medical needs as well as NDD require extensive support from health and social services sectors to achieve their potential. Many experience barriers to accessing these services, due in part to lack of consistent policies, inconsistent standards for information sharing, and an absence of a clear communication plan across the continuum of care.

Parents and families often experience financial hardship, and live with the stress and isolation of finding, navigating, and accessing services for themselves and their children. Our research and other reports² indicates that caregivers receive insufficient support in navigating services and lack access to clear information about available services, creating additional stress in their lives. Further, in one of our studies, we found that most caregivers of persons with NDDs incur large out of pocket costs (up to \$60,000) to support their children.

OECD data suggests that countries with higher financial investments in child and family policies, showed better child wellbeing outcomes on UNICEF measures.³ James Heckman's work shows that the highest rate of economic returns comes from the earliest investments in children, which leads to greater success to more children and reduces social spending for society.⁴

We recognize and commend the steps taken by the Federal Government to mainstream health and wellbeing in all policies, improve outcomes for children, and reduce barriers to full participation in society for children and youth with disabilities. We highlight these steps and provide recommendations to build on these steps in the sections to follow.

Child Health and Wellbeing

¹ <https://www.unicef-irc.org/child-well-being-report-card-16>

² https://canadiancaregiving.org/wp-content/uploads/2022/11/Giving-Care_Executive-Summary.pdf

³ <https://www.unicef-irc.org/child-well-being-report-card-16>

⁴ <https://heckmanequation.org/the-heckman-equation/>

We observed:

- a) Investments in early childhood have long lasting impacts

There is significant evidence that demonstrates how childhood experiences and wellbeing influence child development with lasting implications for lifelong health, relationships and opportunity. Investments made in the early years of a child's life have substantial impact on future health outcomes and skills, which ultimately benefits economies and leads to high levels of return on investments for governments.

- b) Consideration of all determinants of health

In February 2023, the Office of the Prime Minister announced it will increase health funding to provinces/territories by \$196.1 billion over 10 years.⁵ We commend the efforts to protect Canada's publicly funded health care system and collaborative efforts with the provinces/territories. However, a reactive strategy to address health is not a sustainable solution. In finding upstream approaches to prevent and manage an overwhelmed health care system, governments need to consider all determinants of health and wellbeing, with focus on the early years of life. Responsibilities of caregivers and families also need to be taken into consideration, as caregivers of children with complex needs encounter multiple barriers in accessing services.

- c) Continued need to align budgeting with quality of life/wellbeing measures and data

In taking into consideration determinants of health, we recognize the Government's efforts with the "Measure What Matters: Toward a quality of life strategy for Canada", which sets the stage for the development of a Quality of Life Framework to define and measure success and make better use of data and evidence to improve public decision-making.⁶ Whereas the 2021 and 2022 Budget Impacts Reports include additional information to align budgets and expenditures with the different domains under the Canadian Quality of Life Framework, there is little information on how the framework is used for actual budgeting decisions or how much was spent in relation to each domain. It is therefore difficult to see how the government tracks progress to ensure that priorities and decision-making are based on evidence of what will most improve current and future Canadians' quality of life and wellbeing.⁷ Moreover, the framework does not sufficiently take into consideration the importance of early childhood experiences on an individual's health and wellbeing throughout the life course.

We recommend: A commitment to integrating child health and wellbeing in all policies and budgets. Specifically, we request:

- a) **Greater investment in research and the application of evidence-based solutions** focused on improving outcomes for children and youth with disabilities and their families.

⁵ <https://pm.gc.ca/en/news/news-releases/2023/02/07/working-together-improve-health-care-canadians>

⁶ <https://www.canada.ca/en/department-finance/services/publications/measuring-what-matters-toward-quality-life-strategy-canada.html#Toc6196827>

⁷ <https://www.budget.gc.ca/2021/report-rapport/anx5-en.html#5>

- b) **Mainstream health and wellbeing in all policies, budget allocations and reporting.** For example, the Canadian Gender Budgeting Act enshrines the government’s commitment to decision-making taking into account the impacts of policies on specific population groups. Wellbeing (particularly of children) should be similarly mainstreamed by requiring their consideration in policies, budgeting and reporting across sectors, allowing for **upstream and preventive spending in line with determinants of health.**
- c) Collection of key health related data on a regular basis for improved governance, decision-making and budgeting,
 - o The Federal Government should **increase data collection and monitoring on child wellbeing outcomes and system performance** in collaboration with provinces/territories.
 - o In line with the “Get Well Canada” initiative,⁸ we request the Federal Government **monitor the ratio of social spending relative to medical spending** by tasking the Canadian Institute for Health Information to feature this ratio as part of its annual reporting.
- d) **Increased investments in early childhood education and care, housing, and a basic income guarantee** in line with Canadian Public Health Association proposals.⁹
- e) Considering caregivers and their additional burden of navigating services. **The Federal Government needs to allocate funds and hold discussions on how to ensure effective care coordination for caregivers of children with complex needs.**
- f) **Increased investments in culturally appropriate mental health resources** in line with the Public Health Approach to Population Mental Wellness.¹⁰

COVID-19 Recovery and Future Emergency Planning

We found:

Youth with disabilities and their families experienced significant challenges during the COVID-19 pandemic due to COVID-19 policies that did not sufficiently take their needs into consideration.¹¹ This population experienced various denials, delays, and disruptions in relation to their access to services and activities of daily living. This resulted in changes to mental and physical health, impacts on youths’ developmental progress and academic success, deconstruction of social networks and support systems, impacts on caregiving capacity, and financial strains on families.

“Things shut down overnight and supports literally evaporated. For families like ours you saw the difference immediately. We went from being reasonably okay, to crisis.”

– Parent of multiple children with neurodevelopmental disabilities

⁸ https://www.gensqueeze.ca/new_get_well_canada_alliance_launches

⁹ <https://www.cpha.ca/poverty-reduction-strategy-consultation-response>

¹⁰ <https://www.cpha.ca/public-health-approach-population-mental-wellness>

¹¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9629071/>; <https://pubmed.ncbi.nlm.nih.gov/36639341/>

We recognize the Federal Government's efforts in supporting individuals with disabilities during the COVID-19 pandemic through the implementation of the one-time payment in 2021. While this was an important step in recognizing the extraordinary expenses of persons with disabilities during the COVID-19 pandemic, we believe there is room to build and expand upon this initiative in recovery efforts, in recognition of the continued impact of the pandemic on the lives of persons with disabilities and their families.

We recommend: An Investment in COVID-19 recovery efforts to ensure that persons with disabilities and their families are adequately supported, and that their needs are recognized in future emergency planning. Specifically, we request:

a) Funding allocated specifically towards the following:

- A targeted investment in accessible mental health support for persons with disabilities and their families within current mental health investments.
- Financial support and employment support (including job protection policies) for caregivers of youth with disabilities, to address the unique situation they often faced during the pandemic (for example, time off work to provide support to their children that is normally provided by education assistants in an in-person school setting)
- Special care coordination support for caregivers of children with complex needs to navigate changing policies.

b) Allocation of funding to co-designing emergency preparedness planning with relevant stakeholders, including individuals with disabilities and their caregivers, disability service providers, and community organizations, to ensure that policies for future emergencies do not infringe on the rights of persons with disabilities.

- **This should include an investment in future emergency planning at the provincial and territorial level** to enable provinces/territories to create equitable future emergency strategies that are cross-ministerial in nature, and include plans that ensure continuous access to services, recreation, and inclusive education, as well as equitable job protection and income support policies.

Canada Disability Benefit (CDB)

We applaud the government on the recent Royal Assent of Bill C-22. We think the CDB has great potential to support persons with disabilities across Canada.

We recommend: That sufficient funds are allocated to the inclusive development of the CDB. Specifically, we request:

- a) Sufficient funding to ensure inclusive engagement when designing the CDB.** We encourage the government to utilize a co-design approach in designing the CDB, which gives people with lived experience an equal seat at the table. We recommend the government utilize previous consultations and engagements in relation to Bill C-22, the Accessible Canada Act, and the Disability Inclusion Action Plan, in addition to a targeted engagement process that focuses on co-creation through working groups and task forces.

- b) **Allocation of funding to roll out the CDB as soon as possible.**
- c) **Utilization of appropriate metrics of disability poverty to determine CDB amounts.** Analysis of existing standard poverty measures (Market Basket Measure) have demonstrated that disability poverty is underestimated because the additional costs associated with living with a disability are not fully captured.¹² To address this concern, we suggest modifying existing surveys, such as the Canadian Survey on Disability and/or Survey of Household Spending, could be adapted to include data on additional expenses of persons with different disabilities. This could help in determining CDB amounts needed to reach a similar standard of living to persons without disabilities.
- d) **Careful consideration of CDB eligibility criteria.** Using tax-based methods (such as the Disability Tax Credit (DTC)) as a gateway is problematic as both low-income individuals and persons with disabilities are less likely to use tax credits and may have lower tax filing rates. The percentage of persons with disabilities who access the DTC is estimated to be around 40 percent. Innovation in eligibility criteria will be critical as utilization of the DTC on its own would be insufficient in reaching the Canadians with disability that the CDB is intended to support.
- e) **Allocation of funding for equitable design of the CDB with provinces/territories.** Cooperation and extensive discussions between the Federal Government and provincial/territorial governments is required to consider how the CDB will interact with existing supports to ensure persons with disabilities do not lose or experience clawbacks of supports they already access. Lessons learnt from the differential treatments of CERB by provincial/territorial social and disability assistance programs¹³ is a great starting point for discussions.

Disclaimer: The information in this submission reflects the views and opinions of a selected group of individuals and does not represent the views and opinions of the University of Calgary as a whole. For more information about the Disability Policy Research Program, please visit our website:

<https://www.dipo.ca/>

¹² [https://link.springer.com/article/10.1007/s11205-022-02900-1#:~:text=The%20Market%20Basket%20Measure%20\(MBM,differences%20in%20daily%20living%20costs.](https://link.springer.com/article/10.1007/s11205-022-02900-1#:~:text=The%20Market%20Basket%20Measure%20(MBM,differences%20in%20daily%20living%20costs.)

¹³ <https://www.jstor.org/stable/26974721>