

Submission to the Standing Senate Committee on Social Affairs, Science and Technology on Bill C-22, the Canada Disability Benefit Act

Recommendations by the Disability Policy Research Program (School of Public Policy, University of Calgary) and Kids Brain Health Network:

Considering the urgency around alleviating poverty for persons with disabilities, we commend the House of Commons on passing Bill C-22, and recommend the Senate **pass this bill as quickly as possible**. We also recommend the Senate consider proposing amendments to the bill in alignment with the recommendations we have outlined below.

Recommendations:

1. Use of appropriate data and metrics of disability poverty for determining Canada Disability Benefit (CDB) amounts;
2. Ensure maximum access to the CDB by adopting a functional needs-based approach to eligibility;
 - a. Lowering the definition of “working-age” from 18 to 15.
 - b. Avoiding tying CDB eligibility to the Disability Tax Credit.
 - c. Adopting a functional needs-based approach to eligibility.
 - d. Adopting a life-span approach to eligibility.
3. Ensure maximum access to the CDB by simplifying the application process;
4. Consider and plan ahead for emergencies;
5. Ensure the supplementary nature of the CDB and avoid clawbacks of other federal or provincial supports; and,
6. Ensure targeted engagement approach when designing the CDB.

Minor **amendments to Bill C-22** could include:

1. A timeframe for the regulatory process (no more than 12 months);
2. Stronger language emphasizing the supplementary nature of the CDB; and,
3. Monitoring of uptake and accessibility with annual data collection linked to population level Statistics Canada data.

Disability policy research findings and recommendations for consideration of Bill C-22 and design of the CDB

Persons with disability in Canada experience disproportionately high poverty rates. Persons with disability experiencing poverty have additional needs and costs to reduce barriers to full participation in society. There are well-known negative health and social consequences of living in poverty, including food and housing insecurity, increased risks of disease, and higher mortality rates.¹

There is currently a patchwork of federal and provincial disability support programs, benefits, and tax credits relating to health, housing, equipment, other supports and income. We propose recommendations to consider for Bill C-22 and the design of the CDB based on research and analysis.

Recommendation 1: Use of appropriate data and metrics of disability poverty for determining CDB amounts

Current poverty measures underestimate poverty among persons with disabilities because the additional cost associated with disability is not fully captured. Adequate income is critical to ensuring full participation in society and meeting the United Nations Convention on Rights of Persons with Disabilities commitments to adequate standard of living and social protection. Unfortunately, persons with disability in Canada experience disproportionately high poverty rates and have a greater likelihood of living with inadequate income.^{2 3}

Analysis of existing standard poverty measures (the Market Basket Measure) have shown disability poverty is underestimated because the additional costs associated with living with a disability are not fully captured.⁴ The Market Basket Measure underestimates the true poverty rate for persons with disabilities as it does not account for all their additional costs and does not represent their average family composition. Importantly, this underestimation is despite the reality that persons with disabilities already experience higher rates of poverty than those without disabilities. This needs to be considered in the implementation of the CDB.

Current population data is inadequate in providing information on disability-related expenses. Consideration of data sources to capture expenses is important. Additional expenses are estimated from tax records or calculated from the Survey of Household Spending. Using tax-based methods 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. For example, the percentage of people with severe, long-

¹ Scott, C.W.M., Berrigan, P., Kneebone, R.D. et al. (2022) Disability Considerations for Measuring Poverty in Canada Using the Market Basket Measure. *Soc Indic Res*, 163, 389–407. <https://doi.org/10.1007/s11205-022-02900-1>

² Berrigan, P., Scott, C. W. M., & Zwicker, J. D. (2023). Employment, Education, and Income for Canadians with Developmental Disability: Analysis from the 2017 Canadian Survey on Disability. *Journal of autism and developmental disorders*, 53(2), 580–592. <https://doi.org/10.1007/s10803-020-04603-3>

³ Scott, C.W.M., Berrigan, P., Kneebone, R.D. et al. (2022) Disability Considerations for Measuring Poverty in Canada Using the Market Basket Measure. *Soc Indic Res*, 163, 389–407. <https://doi.org/10.1007/s11205-022-02900-1>

⁴ Scott, C.W.M., Berrigan, P., Kneebone, R.D. et al. (2022) Disability Considerations for Measuring Poverty in Canada Using the Market Basket Measure. *Soc Indic Res*, 163, 389–407. <https://doi.org/10.1007/s11205-022-02900-1>

term disabilities who use the disability tax credit (DTC) is estimated to be around 40 percent,⁵ although more recent data suggest take up is only 25% among those eligible. Those with less severe disabilities are claiming the DTC at even lower rates.

It is necessary to consider functional needs and inequalities within and between households to accurately measure poverty among people with disabilities. The CDB must consider the additional cost of disability when assessing appropriate amounts and eligibility while preventing clawback of existing benefits. Existing surveys could be modified to collect the data necessary for these considerations. For example, the Canada Disability Survey and/or Survey of Household Spending (SHS) could be adapted to include data on additional expenses of persons with different disabilities.⁶ This could help in determining amounts needed to reach a similar standard of living to persons without disabilities.

Recommendation 2: Ensure maximum access to the CDB by adopting a needs-based approach to eligibility

Eligibility is one of the key barriers associated with accessing disability services and income supports. Results from one of our Canada-wide studies showed that 20% of participants (N=499) were not eligible to access federal and/or provincial disability support programs, despite caring for a child/youth with a disability.⁷

- **We recommend lowering the definition of “working-age” from 18 to 15**

The current bill focuses on “working-age” persons with disabilities. Even though there is no age-range specified in the bill, Minister Qualtrough in discussions with the Committee, mentioned a proposed eligibility age range from the years of 18 – 64. It is envisaged to bridge a gap between financial supports for families with disabled children by way of the Child Disability Benefit and for disabled elderly persons through the Guaranteed Income Supplement and/or the Old Age Security pension.

However, the purpose of the Child Disability Benefit is different from the purpose of the CDB proposed by Bill C-22. The Child Disability Benefit is “a tax-free benefit for families who care for a child under age 18 who is eligible for the disability tax credit”.⁸ It is calculated based on, among other factors, parental income and marital status. The purpose of the proposed CDB in Bill C-22 is “to reduce poverty and to support the financial security of working-age persons with disabilities” (s. 3). Whereas the Child Disability Benefit is oriented to supporting the parents of a disabled child and the extra expenses associated with the child’s disability, Bill C-22’s CDB is directed towards the individual with

⁵ Dunn, S., Zwicker, J. (2018). Policy Brief - Why is Uptake of the Disability Tax Credit Low in Canada? Exploring Possible Barriers to Access. *The School of Public Policy Publications*, 11(2). <http://dx.doi.org/10.11575/sppp.v11i0.43187>

⁶ Scott, C.W.M., Berrigan, P., Kneebone, R.D. et al. (2022) Disability Considerations for Measuring Poverty in Canada Using the Market Basket Measure. *Soc Indic Res*, 163, 389–407. <https://doi.org/10.1007/s11205-022-02900-1>

⁷ Finlay, B., Wittevrongel, K., Materula, D., Hébert, M. L., O’Grady, K., Lach, L. M., Nicholas, D., & Zwicker, J. D. (2023). Pan-Canadian caregiver experiences in accessing government disability programs: A mixed methods study. *Research in developmental disabilities*, 134, 104420. <https://doi.org/10.1016/j.ridd.2022.104420>

⁸ <https://www.canada.ca/en/revenue-agency/services/child-family-benefits/child-disability-benefit.html>.

the disability and their financial security. Eligibility for the Child Disability Benefit should not preclude eligibility to the CDB.

The Canadian Survey on Disability (CSD) collects information on people with disabilities ages 15 and older. Analysis of the CSD data shows that young people with disabilities are particularly vulnerable to financial insecurity: *“Age is an important factor for poverty among persons with disabilities as 27.6 percent of individuals age 15–24 with severe disabilities are in poverty compared to 10.4 percent of those age 65 and above with severe disabilities.”*⁹

The Canada Emergency Response Benefit (CERB) was available to Canadians ages 15 and over. Young people between the ages of 15 and 18 were eligible regardless of whether their parents received a Child Disability Benefit. There is no reason that the definition of “working age” for the CDB should differ.

- **We recommend that eligibility criteria for the CDB be distinct from the DTC**

Take up rates of the DTC are very low meaning the majority of people with disabilities are not accessing it. Multiple studies have highlighted barriers to utilizing the DTC. Health providers and the disability community have raised concerns that the DTC eligibility criteria are subjective and the operational definition of what comprises a disability is unclear in terms of which applicants are considered severely disabled and eligible and which applicants are not. This creates barriers in applying for and accessing the DTC, as is evidenced by the relatively low rates of both applying for DTC certificates (recent estimates with population data suggest ~25% of those eligible are applying to the DTC) and utilization of the DTC (after a certificate has been issued) among those with developmental disabilities.

Marginalized groups disproportionately don’t receive the DTC. Recent analysis of Statistics Canada data has shown that the percentage of individuals applying for and accessing the DTC varies widely according to region of residence, family income, disability type, ethnicity and age of applicant. As such, it is imperative that that CDB is designed with distinct eligibility criteria to ensure equitable access across sociodemographic groups.

- **We recommend a needs-based approach to eligibility**

Diagnosis does not equate to functional needs and should not be the gateway. Many participants from the aforementioned study mentioned that it was easier to access programs with a formal disability diagnosis.¹⁰ This is problematic, as there are many barriers to getting a diagnosis, particularly for lower income individuals that cannot afford private assessments and are required to use the backlogged public system. Additionally, many participants reported that receiving access to programs was easier for certain disability diagnoses, which excludes many individuals that require support.

⁹ Scott, C.W.M., Berrigan, P., Kneebone, R.D. et al. (2022) Disability Considerations for Measuring Poverty in Canada Using the Market Basket Measure. *Soc Indic Res*, 163, 389–407. <https://doi.org/10.1007/s11205-022-02900-1>

¹⁰ Finlay, B., Wittevrongel, K., Materula, D., Hébert, M. L., O’Grady, K., Lach, L. M., Nicholas, D., & Zwicker, J. D. (2023). Pan-Canadian caregiver experiences in accessing government disability programs: A mixed methods study. *Research in developmental disabilities*, 134, 104420. <https://doi.org/10.1016/j.ridd.2022.104420>

Functional needs assessments must be evidence based. Participants shared that the level of functioning/intelligence (based on IQ tests and other standard measures) was often used as a reason to exclude individuals from disability programs. This is problematic as there are individuals that score high but still face barriers to employment, therefore requiring support from disability programs.

We recommend a needs-based approach to eligibility to ensure that all individuals requiring support are able to receive it. Some countries have adopted eligibility criteria for disability support programs that use modified forms of the International Classification of Function (ICF). For example Taiwan uses the ICF Chapter code as a basis for the classification of disability and for the application of ICF in their disability eligibility determination system (DEDS).^{11,12,13,14,15} This type of functional needs assessment is to ensure that individuals are able to access support that aligns with their needs rather than their diagnosis.

- **We recommend adopting a life-span approach to eligibility**

Participants of different studies and consultations¹⁶ shared that they were required to reapply for programs over their lifespan. Many disabilities are lifelong conditions, which should negate the need to reapply for programs after originally meeting eligibility criteria. The reapplication process is costly and time-consuming.

We recommend removing the need to requalify for the Disability Benefit on the basis of diagnosis for individuals with lifelong conditions.

Recommendation 3: Ensure maximum access to the CDB by simplifying the application process

Our Canada-wide study revealed that the majority of participants (78%) had some level of difficulty applying for disability programs, with 47% finding the process very difficult and challenging.¹⁷

¹¹ Liao, H. F., Yen, C. F., Chiu, T. Y., Chi, W. C., Liou, T. H., Chang, B. S., Wu, T. F., & Lu, S. J. (2022). Factor Structure of an ICF-Based Measure of Activity and Participations for Adults in Taiwan's Disability Eligibility Determination System. *Frontiers in rehabilitation sciences*, 3, 879898. <https://doi.org/10.3389/fresc.2022.879898>

¹² Liao HF, Hwang AW. Introduction to international classification of functioning, disability and health (ICF) and recommendations for its application in disability evaluations in Taiwan. *FJPT*. (2009) 34:310–8. <https://doi.org/10.1007/s00113-010-1742-7>

¹³ Liao HF, Yen CF, Hwang AW, Liou TH, Chang BS, Wu TF, et al.. Introduction to the application of the functioning scale of the disability evaluation system. *Formosan J Med*. (2013) 17:368–80.

¹⁴ Chiu WT, Yen CF, Teng SW, Liao HF, Chang KH, Chi WC, et al.. Implementing disability evaluation and welfare services based on the framework of the international classification of functioning, disability and health: experiences in Taiwan. *BMC Health Serv Res*. (2013) 13:416. <https://doi.org/10.1186/1472-6963-13-416>.

¹⁵ Teng SW, Yen CF, Liao HF, Chang KH, Chi WC, Wang YH, et al.. Evolution of system for disability assessment based on the international classification of functioning, disability, and health: a Taiwanese study. *J Formos Med Assoc*. (2013) 112:691–8. <https://doi.org/10.1016/j.jfma.2013.09.007>

¹⁶ CASDA (2020) “Policy Compendium: The Development of a National Autism Strategy through Community and Stakeholder Engagement” at: https://www.autismalliance.ca/wp-content/uploads/2020/08/CASDA-KBHN-Briefs-Compendium-_28102020-.docx.pdf

¹⁷ Finlay, B., Wittevrongel, K., Materula, D., Hébert, M. L., O'Grady, K., Lach, L. M., Nicholas, D., & Zwicker, J. D. (2023). Pan-Canadian caregiver experiences in accessing government disability programs: A mixed methods study. *Research in developmental disabilities*, 134, 104420. <https://doi.org/10.1016/j.ridd.2022.104420>

Elements of the application that made the application process challenging for participants, as delineated from interviews include the following:

- Difficulties finding out about programs due to lack of widespread information
- Large amounts of paperwork, which often required seeing multiple different professionals
- Lack of clarity and plain language in application instructions
- Lack of transparency regarding reasons for rejections
- Lack of support for applications from professionals that are required to help support applications (e.g. not all physicians/accountants have knowledge of the various programs)

We recommend designing a simple application processes for the CDB that:

- Avoids large amounts of paperwork needing multiple professionals to review;
- Provides simple and plain-language instructions;
- Establishes a transparent process regarding rejection reasons and appeal procedures
- Provides support for applications through:
 - o Encouraging “social prescribing,” which involves physicians connecting their patients to programs outside of the health system
 - o Access to service navigators

Recommendation 4: Consider and plan ahead for emergencies

As part of our work, we examined disability focused COVID-19 policy responses across Canada and matched these with the experiences of youth with neurodevelopmental disabilities and their caregivers during the pandemic.^{18,19} The overall findings were that relief policies often did not consider people with disabilities, which led to many supports and services suddenly halting. This had notable impacts on the health and well-being people with disabilities and their families. Moreover, the pandemic had significant implications for persons with disabilities and their caretakers in relation to livelihood, employment, income, and additional expenses.

Many people with disabilities could no longer work due to the increased risks associated with contracting the virus, and caregivers could often not continue working full-time due to increased caregiving needs. Combined with having to incur additional costs because of specific needs (e.g. PPE), the pandemic pushed many people with disabilities and their families into poverty. A powerful way to see and hear these impacts is through these [Digital Stories - How Covid-19 affected our lives](#).

¹⁸ Seth, A., Finlay, B., Currie, G., Roth, C., Lach, L., Hudon, A., Lencucha, R., Hunt, M., Nicholas, D., Shikako-Thomas, K., & Zwicker, J. (2023). Impacts of the COVID-19 Pandemic: Pan-Canadian Perspectives From Parents and Caregivers of Youth With Neurodevelopmental Disabilities. *Journal of pediatric health care : official publication of National Association of Pediatric Nurse Associates & Practitioners*, 37(2), 122–132. <https://doi.org/10.1016/j.pedhc.2022.11.011>

¹⁹ Currie, G., Finlay, B., Seth, A., Roth, C., Elsabbagh, M., Hudon, A., Hunt, M., Jodoin, S., Lach, L., Lencucha, R., Nicholas, D. B., Shakako, K., & Zwicker, J. (2022). Mental health challenges during COVID-19: perspectives from parents with children with neurodevelopmental disabilities. *International journal of qualitative studies on health and well-being*, 17(1), 2136090. <https://doi.org/10.1080/17482631.2022.2136090>

We recommend that lessons are drawn from the experiences with the pandemic and stakeholders take into consideration how the benefit may interact with future emergency response support payments (e.g. CERB).

Recommendation 5: Ensure the supplementary nature of the CDB and avoid clawbacks of other federal or provincial supports

Lessons learnt from the CERB need to be taken into account when entering into negotiations with the Provinces/Territories.²⁰ We recognize that clarifying the CDB's interaction with existing provincial/territorial disability support programs will be complex. We urge all parties involved to continue negotiating in a non-partisan spirit to ensure that people with disabilities do not lose access to or experience clawbacks of existing supports or benefits.

Recommendation 6: Ensure targeted engagement approach when designing the CDB

We encourage the Government to continue working with the disability community in the regulatory process by co-designing, i.e. giving people with lived experience an equal seat at the table.

In the interest of time, we recommend that previous consultations and engagement in relation to Bill C-22, the Accessible Canada Act, and the Disability Inclusion Action Plan are utilized. The Government should have a targeted engagement and focus on co-creation through working groups and task forces, instead of broad repeated consultations.

Who We Are

The Disability Policy Research Program (DiPo) at the School of Public Policy, University of Calgary aims to understand the experiences of people with disabilities and their families in accessing services and recommending improved policies for care coordination and service provision with the overall objective of ensuring participation in society for persons with disabilities. DiPo's research utilizes qualitative methods, economic evaluation and policy analysis to capture experiences and measure access to disability programs and services. The group fosters strong collaborations with community partners, people with lived experience and interdisciplinary researchers, which are all critical in the translation of peer-reviewed publications to policy papers, op-eds and briefing notes, utilized by both federal and provincial government. More information on the group's work can be found at www.dipo.ca. DiPo is led by Dr. Jennifer Zwicker, Director of Health Policy at the School of Public Policy, Associate Professor at the Faculty of Kinesiology at the University of Calgary and Deputy Scientific Director at Kids Brain Health Network.

Kids Brain Health Network (KBHN), is a national network that develops and harnesses scientific advances in technologies, interventions and supports with the goal of helping children with neurodevelopmental disabilities and their families live the best lives. The science of children's brain

²⁰ Petit, G., & Tedds, L. (2020) The Effect of Differences in Treatment of the Canada Emergency Response Benefit across Provincial and Territorial Income Assistance Programs. *Canadian Public Policy*, 46(S1). <https://doi.org/10.3138/cpp.2020-054>



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health is making advancements and KBHN is bridging the gaps between these scientific advances and implementing solutions that directly address the needs of children and families. Through catalyzing collective action across sectors, KBHN's mission is working to ensure optimal care and better outcomes for children with neurodevelopmental disabilities and their families. In delivering on its mission, KBHN is advancing federal responsibilities and priorities aimed at building a healthier future for children and families, building a barrier-free country and accelerating the pace of implementation, scale and spread of research innovations to unleash their full potential for healthier kids, healthier families, and social and economic benefits to Canada. More information is available at:

<https://kidsbrainhealth.ca/>