

POSITION ON INCOME SECURITY FOR FAMILIES

POSITION STATEMENT

Families who have children with an intellectual disability must have the income and resources they need to secure a good quality of life and fully participate in all aspects of their community. Supporting a loved one with an intellectual disability should not negatively impact a family's economic security and financial well-being. Families need access to income and disability supports that enable them to focus on being a family and building an inclusive life.

POLICY CONTEXT

In Canada, families provide most of the support for their loved ones with an intellectual disability. This support is provided freely out of love and commitment.

Parents of children with an intellectual disability have to provide much more support than parents of children without a disability. This expectation continues even when their loved one is an adult. Although adults with disabilities should have access to sufficient support and income to live a life with dignity, this is usually not the reality. Often, one parent stays out of the workforce to meet the support needs of their family member. This has a significant financial impact on families.

The extent of this impact is not well documented. Lack of recent data collection focused on children with disabilities and their families has created a significant information gap. To best inform future policy decisions, it is crucial that disaggregated data, speaking to specific disability type and focused on children and families, be collected.

Based on available data and qualitative experience, we know that:

- 93.2% of people providing support to a family member or friend with a long-term health condition or disability did not receive any financial support from government programs.ⁱ 91.6% did not receive any federal tax credits.ⁱⁱ
- Almost 50% of people providing care to their child with a long-term health condition or disability reported they had unmet support needs.ⁱⁱⁱ
- Financial support, government assistance or tax credits are the most common unmet need among people providing support to a family member or friend with a long-term health condition or disability.^{iv}
- Parents of children with an intellectual disability often have to turn down employment opportunities, work less hours per week, and decline promotions.
- Families of children with disabilities often live in poverty.
- Aging parents are typically expected to continue providing support to their adult family member.

Families are expected to risk their current and future financial security to care for their loved one with a disability. This has an intergenerational impact on financial security, as parents struggle to afford retirement and adult siblings take on added responsibilities.

Lack of access to inclusive, affordable childcare and appropriate disability supports keeps families out of the

workforce or limits their involvement.

Financial programs that help families are difficult to access. Some of these programs don't offer enough money to balance out the cost of raising children with a disability.

DISCUSSION

The role of families

We understand family to consist of two or more people, living together or apart, related by blood, marriage, adoption, or a commitment to support one another.

Families of people with disabilities are not a homogeneous group. Their financial needs may differ depending on where they live (urban, rural, remote northern, or indigenous community), their family structure, or experience as part of a marginalized group (newcomers, indigenous and racialized people, gender minorities, etc.). While this position paper cannot address the unique realities of all families across Canada, we acknowledge that more work is required to ensure the needs of these families are heard and addressed.

Being part of a family is key to the inclusion and belonging of people with an intellectual disability. Families provide a loving, nurturing space to learn and grow. They help their family members with disabilities to overcome challenges and achieve success. They foster dreams and the means to realize a promising future.

Raising children with disabilities is more expensive, time-consuming, and lasts longer. Families often have to struggle to have their loved ones fully included in community life. This places significant social and financial pressure on families. They simply want the assurance that their financial and social wellbeing will be protected, now and in the future.

The financial and support needs of families change and evolve over the life cycle and as family composition changes. Our [Position on Financial Security and Income Support](#) explores the specific needs of adults with an intellectual disability. These two documents can be used together to best understand how to support families throughout the lifespan.

Access to the workforce

Connection to the workforce is key to the financial security of many families. It allows them to meet their current needs and save for the future. For many two-parent households, this means both adults work outside the home. However, families of children with an intellectual disability experience added barriers to participating in the workforce.

Lack of inclusive, affordable childcare prevents single-parent, and two-parent households from fully participating in the workforce. Parents of children with an intellectual disability who are unable to secure childcare must often stay home as their child cannot be left alone, unlike pre-teens and teens without disabilities. This may begin during pre-school, and extend through to adulthood if inclusive, affordable before and after-school childcare is not available. For families of children 13+ who continue to require support, a significant gap exists in before and after-school care and access to disability supports.

The financial security of families is significantly impacted by this limited participation or absence from the workforce. Some families may struggle to meet day-to-day costs of living. This includes added out-of-pocket expenses associated with their child's disability. Extended absences from the workforce also puts the long-term financial security of families in jeopardy, making saving for retirement almost impossible, particularly among single-parent households. In

situations where one parent remains at home to provide support while the other is employed, economic vulnerability and financial dependency may also occur.

Access to financial supports

Even with improved access to the workforce, it's clear that supporting a family member with an intellectual disability comes with added financial costs. While some tax relief measures and financial programs exist to help offset these costs, they are often difficult to access and limited in scope.

The Child Disability Benefit (CDB) is a tax-free monthly payment for families supporting a child aged 18 and under with a disability. To access the CDB, a child must be approved for the Disability Tax Credit (DTC). This process is often long and difficult and requires proof of a 'severe and prolonged impairment'. The 2018 report, *Breaking Down Barriers: A critical analysis of the Disability Tax Credit and Registered Disability Savings Plan*, explains the many problems with accessing the DTC. It is often difficult for people with an intellectual disability to get approved for the DTC based on their 'limitations in mental functioning'. People with lifelong disabilities often have to reapply. For young children, the program often assesses their disability by comparing their development with that of other children instead of looking at the impact of their disability on their daily activities. Because children all develop at different rates, this comparison can make it difficult to establish eligibility. As the gateway to the Child Disability Benefit and other financial benefits, ensuring access to the DTC is critically important for the financial wellbeing of people with an intellectual disability and their families.

The Child Disability Benefit itself offers important financial support to parents raising a child with a disability. This payment puts money directly into the pockets of families. To be effective, the CDB must be considered as exempt income, and not taxed or clawed-back at the provincial or territorial levels. While the CDB is most impactful for low-income families, it should be enhanced to offer greater financial security to a wider range of families.

For some families, provincial or territorial social assistance is their primary source of income. These programs of last resort are not designed to address the financial needs of families raising children with a disability. Strict eligibility rules, earning restrictions, and household policies mean that families of children with disabilities remain trapped in poverty. While these programs require significant reform, small steps like exempting child support payments or cohabitation policies should be implemented now.

Having access to adequate income through employment, and programs like a targeted federal income program, contribute to the financial wellbeing of adults with an intellectual disability. This must be supplemented with access to safe, affordable housing and appropriate disability supports. Although not focused on the family unit, the positive impacts of these programs are often felt by the family as a whole. Knowing that the financial security of their loved one is assured, families can focus their resources on meeting their own needs and saving for the future.

Saving for the future

Family members who are absent from the workforce for long periods of time may find it particularly difficult to save for retirement. Parents who stay at home to support their child do not have access to government savings programs like the Canada Pension Plan (CPP). These parents provide essential support, and their contributions should be recognized and valued. Caring for your child should not mean compromising your future financial security. It's clear that family members who provide support for their loved ones need a solution to save for retirement while continuing to provide this essential support. Innovative solutions have been developed to allow other groups (like self-employed individuals) to contribute to CPP. Similar options should be explored and tested for family members supporting a loved one with a disability.

The federal government has a responsibility to improve the income security of families who support a loved one with an intellectual disability. We recommend they:

Maximum Impact Priorities

- 1) **Provide access to inclusive, affordable childcare for parents of children with an intellectual disability. This must include appropriate before and after school support for children age 12+.**
- 2) **Enhance and rename the Child Disability Benefit.**
 - The Child Disability Benefit should be considered as exempt income for the purposes of provincial or territorial income assistance. The Child Disability Benefit and other child or family tax credits should not result in a 'clawing back' of other financial benefits for families at the provincial/territorial or federal level.
 - Double the current benefit amount (\$242.91 per month) for every eligible child.
 - Increase the threshold at which the benefit starts being reduced to align with the upper limit of the second federal personal income tax bracket (\$98,040 in 2021). The current threshold for this benefit is a net family income of \$69,395). This will provide the greatest level of support to low and middle-income families who need it most.
 - Extend coverage to include youth with disabilities above the age of 18. The Child Disability Benefit should extend to at minimum age 21. However, access up to age 30 would most appropriately reflect the ongoing support families provide to loved ones with a disability. This extended benefit could be renamed the *Child & Youth Disability Benefit*.
- 3) **Simplify approval for the Disability Tax Credit.** As the gateway to the Child Disability Benefit and other financial programs, access to the DTC is crucial. Getting approved for the DTC is particularly difficult for young children, people with an intellectual disability, and people on the autism spectrum. A simplified approval process, without the requirement to reapply, should be introduced for people with disabilities that are lifelong and stable in nature.
- 4) **Support parents to save for retirement.** When a parent is out of the workforce for an extended period of time to care for their child, it has a significant impact on their future financial security. We know a gap exists in retirement savings and investment mechanisms for these families. This gap must be recognized, and a commitment made to explore and test solutions.

Systemic Priorities

- 5) **Undertake a comprehensive review of federal government programs, including:**
 - An analysis of the Disability Tax Credit as the gatekeeper to the Registered Disability Savings Plan (RDSP) and the Child Disability Benefit (CDB).
 - A review of the eligibility criteria for the Home Buyers' Plan and its use by families of people with disabilities.
 - A review of eligibility for the Canada Student Grant and its use by people with disabilities.
 - A review of the way in which funds can be moved between Registered Disability Savings Plans (RDSPs) and Registered Education Savings Plans (RESPs) without compromising grants and bonds.

- 6) **Explore enhancements to the RDSP to support families to save for the future (through grants and bonds) and unlock funds earlier.** Detailed recommendations for these enhancements can be found in [Designing a RDSP Homeownership Plan: Exploring the Canada Disability Savings Program for Homeownership.](#)

- 7) **Reinstate a mechanism to collect disaggregated data about children with disabilities and their families.** This data should allow for analysis based on type of disability.

ⁱ Statistics Canada. [Table 44-10-0012-01 Caregivers receiving financial support from government programs for providing care to family members or friends with a long-term health condition, physical or mental disability or problems related to aging](#)

ⁱⁱ Statistics Canada. [Table 44-10-0013-01 Caregivers receiving federal tax credits for providing care to family members or friends with a long-term health condition, physical or mental disability or problems related to aging](#)

ⁱⁱⁱ Hango, Darcy. 2020. "Support received by caregivers in Canada". *Insights on Canadian Society*. January. Statistics Canada Catalogue no. 75-006-X.

^{iv} Hango, Darcy. 2020. "Support received by caregivers in Canada". *Insights on Canadian Society*. January. Statistics Canada Catalogue no. 75-006-X.