

POSITION ON INCOME SECURITY FOR FAMILIES



POSITION STATEMENT

Families supporting a family member with an intellectual disability must have the supports and services necessary to assure the full inclusion of their family member. Including a family member with intellectual disabilities within the family unit must not negatively impact a family's economic security and financial well-being. An inclusive and accessible Canada recognizes that families are the fundamental unit of our society and that families provide an essential bridge to the realization of citizenship and the full inclusion of their family members with disabilities.

POLICY CONTEXT

Families are the front line of supports for family members and provide the bulk of supports that a family member with a disability requires. Much of this support is provided without any kind of remuneration or compensation. It has been estimated that the economic value of the contributions of the contributions of family and friends would total more than \$5 billion annually if delivered by a paid workforce. In the absence of appropriate supports and services, the family is expected to play a role well beyond that of typical parents and well beyond the childhood years.

This has significant impact on families. We know that parents of children with intellectual disabilities (27.8%) have to turn down employment opportunities; have to work less hours per week (33.6%); and/or decline promotions (17.1%). In a significant proportion of families with children with intellectual disabilities, one of the parents (usually the mother) remains out of the workforce due to caregiving responsibilities. Children with disabilities are twice as likely as other children to live in households that rely on social assistance as a main source of income, and that families of children with disabilities are more likely to live in poverty than other families. Increasingly, aging parents are expected to continue to provide the bulk of support to their sons and daughters even as adults. It is clearly unacceptable that in Canada today families must be expected to risk their present and future economic security, and often health and well-being, to care for a family member.

DISCUSSION

While a more comprehensive family supportive policy agenda is needed to address the full range of supports that families need, the purpose of this statement is to explore the income needs of families and options for securing a family's economic well-being.

In Canada, there is an expectation and increasing reality that people with intellectual disabilities will be fully included within all aspects of our society. People with intellectual disabilities are no longer routinely shunned to institutions or other segregated living options. This future of inclusion begins with an assumption that children with intellectual disabilities, as is the case for all children, will achieve best possible life long outcomes by growing up and being nurtured within the context of a strong and vibrant family. We know that being a part of a family is key to the current and future inclusion and citizenship of persons with intellectual disabilities.

Evidence of positive outcomes and quality of life for persons with intellectual disabilities who live with family is overwhelming. Yet we know that families often incur a heavy financial burden as they struggle to ensure that their sons and daughters with intellectual disabilities are fully and typically included within their family and family life. This financial cost is for many families well beyond that typically associated with raising a child. All too often these costs, both direct and indirect, place such pressure on the family unit that their family, social and economic well being is jeopardized.

Families do not wish, nor have they asked, to have their financial or caregiving roles replaced or removed. Rather families ask for support – necessary support to ensure that their role can be fulfilled in a manner that ensures the full inclusion of their sons and daughters, in family and community; support that sustains the overall, including financial, well being of the family unit.

Current tax measures, such as the caregiver tax credit, infirm dependent credit, or the transferred disability tax credit, are designed to provide families some tax relief and compensation for the care they provide. Investment mechanisms like the Registered Disability Savings Plan help families plan and invest for future financial security. These existing measures, while valuable, do not go far enough to address the income support needs of families. Refundable measures and more comprehensive measures designed to address caregivers who do not have a taxable income and the long-term economic vulnerability of caregivers who have had to remain permanently out of the labour market are required. Direct benefits should not be subject to provincial/territorial claw-backs.

Governments must provide leadership and take increased action in responding to the diverse needs of family/caregivers in this country. For families to create inclusive lives for their sons and daughters they need to be included in the social and economic fabric of this country.

INCLUSION CANADA'S CALL TO ACTION

1. The Canada Pension Plan be enhanced through expanding the drop-out provisions and allowing for contributions to CPP for those who stay out of the labour market to care for a family member with disability-related needs.
2. A Family Tax Benefit be developed that provides a refundable tax benefit to families providing support to a family member with a disability.
3. The Canada Labour Code be amended to include family leave provisions for those who must leave their job temporarily to care for a family member with disability-related needs.
4. EI Compassionate Care Leave be revised to provide coverage to family members who must leave their job temporarily to care for a family member with disability-related needs.
5. Explore options to ensure that caregivers who, because of their caregiving responsibilities, do not have the fiscal capacity to contribute to CPP or other investment mechanisms and do not benefit from the measures outlines above.