

## Position on Income Security for Families

### POSITION STATEMENT

Some families have children with an intellectual disability. These families need income. They also need resources. Resources and income will give them a good quality of life. Resources and income will let them fully take part in their community. Sometimes a loved one with an intellectual disability needs support from their family. This support should not hurt the family's finances. Families need access to income and disability supports. This would let them focus on being a family. It would let them build an inclusive life.

### POLICY

People with intellectual disabilities need support. In Canada, it is usually their families who support them. They do this for free. They do this out of love. They are committed to supporting their loved one.

Children with an intellectual disability need support from their parents. They need more support than children without a disability. They still need support when they become an adult. Adults with disabilities should have government financial support. This would let them live with dignity. But this usually does not happen. They usually need support and money from their parents. Sometimes one parent does not work so they can support their loved one. This can mean that they do not make enough money for their family.

We know this is a problem for Canadians. We do not know how big it is. There is not enough information or 'data.' We need to know more about children with disabilities. We need to know about their families. This will help make better policy decisions. We need data about certain groups and people. We need to speak to people with different disability types. We need to focus on children and families. We need to collect all this data.

We do have some data. This comes from research. It also comes from our own experiences. Here is what we know.

- Some people support a family member or friend with a disability or illness. They do not get much government support. Over 93% of them get no government help. Over 91% did not get any government tax credits.
- Many people who care for a child with an illness or disability say they have unmet needs. Almost 50% reported this.
- People who support a family member or friend with an illness or disability have unmet needs. They said government aid would help. So would financial support or tax credits.
- Parents of children with an intellectual disability often turn down jobs. Sometimes they work less hours per week. Sometimes they turn down promotions.
- Families of children with disabilities often live in poverty.
- Society expects aging parents to keep giving support to their adult family member.

Families are expected to take care of their loved one with a disability. This can cause them financial problems now. It can also cause problems in the future. It can affect families across generations. Parents may not be able to retire. Siblings may have to take on added responsibilities.

It is hard for families to find inclusive childcare that they can afford. They don't have access to disability supports. This makes it hard for family members to have jobs.

Government programs do not provide enough money to raise a child with a disability. Programs that help families are also hard to access.

## DISCUSSION

### The role of families

We define a family as two or more people. They can live together. They can live apart. They can be related by blood. They can be related by marriage. They can also be related by adoption or a commitment to support each other.

Families of people with disabilities are not all the same. For example:

- They can have different forms.
- They can live anywhere. This can be urban or rural areas. It can be in remote communities. It can be in Indigenous communities.
- They may be part of a marginalized group. These are groups and people that are often left out or forgotten by most of society. This can include newcomers to Canada. It can include racial groups. It can also include gender minorities.

Different families have different financial needs. This paper cannot talk about every type of family. But we understand it is important to do more work to learn about them. Their voices need to be heard. This will help address their needs.

Being part of a family is very important for people with intellectual disabilities. It is the key to inclusion and a sense of belonging. Families are a loving place for people to learn and grow. They help their family members with disabilities to overcome challenges. They help them succeed in life. They foster dreams. They help make a better future for their family member.

It is harder to raise a child with a disability. It is more expensive. It takes more time every day. It can also take a longer time for the child to become an adult. It can be hard for families to include their loved ones in community life. This puts a lot of social stress on families. It also creates financial stress. Families need to know that their loved one's wellbeing is protected. They need to know that they will have enough money to live. They also want these protections in the future.

The make-up of a family can change over time. This means their financial needs change over time. So do the types of support they need. Our [Position on Financial Security and Income Support](#) looks at this. It looks at the specific needs of adults with intellectual disabilities. These two documents can be used together. They explain how to support families throughout their lives.

### Access to the workforce

Being employed is important for families. It gives them financial security. It lets them meet their current needs. It lets them save for the future. In many families with two parents, both work outside the home. This is hard for parents of children with disabilities. They face added barriers when trying to get a job.

Childcare and after school care are expensive. They are usually not inclusive. Parents who cannot find childcare have to stay home. This makes it hard for them to hold a job. Children with disabilities often cannot be left alone. This is different from children without disabilities. Children with disabilities often still need care as they get older. Families of children 13 and older who need support have a tough time. There is not enough help for older kids. They cannot get disability support for adults.

It is hard for people who cannot work to be financially secure. Some families cannot meet their day-to-day expenses. This includes the added expenses that come with raising a child with a disability. It also makes it hard for families to save money. This puts their future at risk. They cannot save to retire. This is hard on single parents. It can also be hard on families with two parents. Sometimes only one of them can work. This can lead to stress. It can be hard on the parent that stays home. They may be left out of the workforce. They may be dependent on their partner who works.

### Access to financial supports

Supporting a family member with an intellectual disability costs a lot. This is true even with improved access to jobs. There are tax credits that can help. There are also financial support programs. But none of these things are enough. They do not offer much help. They are also hard to access.

The Child Disability Benefit (CDB) is a monthly payment that is not taxed. It is for families who support a child under 18 years old with a disability. To get this benefit, a child must first be approved for the Disability Tax Credit (DTC). The process to get the Disability Tax Credit is long and difficult. It requires proof of a 'severe and prolonged impairment.' A report from 2018 explains many of the problems people have when trying to get the Disability Tax Credit. Here are some of these issues.

- People with an intellectual disability find it difficult to get approved. This is based on their 'limitations in mental functioning.'
- People with lifelong disabilities often have to reapply.
- Young children with disabilities are compared to other children. The impact of their disability on their daily lives is not taken into account. This can make it difficult for them to get the Disability Tax Credit.

Access to the Disability Tax Credit is critical. It is the gateway to other benefits. When approved for the Disability Tax Credit, families have access to the Child Disability Benefit.

The Child Disability Benefit is important to families. It gives money to parents raising a child with a disability. It puts money in the pockets of families. There are ways to make the benefit better. It should not be taxed. It should not be 'clawed back' by provinces or territories. The benefit is especially useful for low-income families. But other families can also benefit from it. It should be improved to help a wider range of families.

Social assistance is the main income for some families. This comes from provincial or territorial governments. These are programs of last resort. They are not made to help families raising children with a disability. These programs are also hard to get. They have strict rules about how people can get help. They limit how much money somebody can earn. They have policies that do not help families. They trap families of children with a disability in poverty. These programs need big changes. But there are some small changes that could happen now. For example, child support payments should not be taxed. Another example is changing the policy on who can live together and still get support.

Adults with intellectual disabilities need access to good jobs. They need a federal income program. These would help their financial wellbeing. They must also have access to safe and affordable housing. They need access to disability supports. These things would also help families. Families need to know that their loved ones have financial help if they need it. This lets them take care of their own needs. This lets them save for the future.

## Saving for the future

Family members who cannot work are not able to save so they can retire. Parents who stay home to support their child cannot get the Canada Pension Plan (CPP) or similar programs. These parents provide needed support. Their efforts should be recognized and valued. Caring for a child should not mean being poor and unable to retire. Parent care takers need a way to retire. They need access to the Canada Pension Plan. There have been other groups who have been allowed to contribute to the plan. This should also be explored for family members who support somebody with a disability.

## INCLUSION CANADA'S CALLS TO ACTION

The federal government has a responsibility to the families of people with a disability. They need to make sure they are financially secure. Here are some ways they can do this.

### Top Priorities

- 1) **Provide access to childcare for parents of children with an intellectual disability. Make it inclusive. Make it affordable. Provide before and after school support for children over 12 years old.**
- 2) **Rename and improve the Child Disability Benefit.**
  - Do not tax the Child Disability Benefit. It should also not result in a 'clawing back' of other benefits. This applies at the provincial and territorial or federal level.
  - Double the current benefit amount (\$242.91 per month) for every eligible child.
  - Let working people get the benefit. Allow an income of \$98,040 before taxing the benefit. This will help low and middle-income families.
  - Extend coverage to include youth with disabilities above the age of 18. The benefit should go to at least age 21. Going to age 30 would be even better. This would reflect the reality of the support families provide to loved ones with a disability. Rename this extended benefit the *Child & Youth Disability Benefit*.
- 3) **Make it easy to get the Disability Tax Credit.** Access to the DTC is important. It allows access to other programs. Getting the DTC is hard. It is even harder for some people. This includes young children, people with an intellectual disability, and people on the autism spectrum. Make this process easier. People with lifelong disabilities should not have to reapply.
- 4) **Help parents save for retirement.** It is hard to care for somebody and work. This makes it hard to save money. We need to find a way to make sure caregivers can save money. They need to be able to retire. We need solutions to address this.

## Systemic Priorities

- 5) **Do a full review of federal government programs. Here are some things this should include.**
  - Study the Disability Tax Credit as it controls access to the Registered Disability Savings Plan (RDSP) and the Child Disability Benefit (CDB).
  - Review the eligibility criteria for the Home Buyers' Plan. Look at how it is used by families of people with disabilities.
  - Review eligibility for the Canada Student Grant. Look at how it is used by people with disabilities.
  - Review the way funds can move between Registered Disability Savings Plans (RDSPs) and Registered Education Savings Plans (RESPs) without affecting grants and bonds.
  
- 6) **Make the RDSP better. Make it help support families to save for the future. Provide grants and bonds. Let people get funds earlier.** More ideas to improve the RDSP can be found in [\*Designing a RDSP Homeownership Plan: Exploring the Canada Disability Savings Program for Homeownership\*](#).
  
- 7) **Collect more detailed data about children with disabilities and their families.** Break it down by type of disability. This may reveal new data. It will also allow data to be studied based on the type of disability.