The Sibling Collaborative

A GUIDE TO UNDERSTANDING FINANCES for Adults Who Have Siblings with Disabilities

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About this Guide

This guide has been compiled for AIDE Canada by The Sibling Collaborative.

While we have made every effort to ensure the information in this guide is accurate, it should be noted this resource is not a substitute for professional advice. It is intended to provide you with ways you can support the financial security of your siblings with disabilities and, when appropriate, involve other family members in these efforts.

We cannot be held responsible for any actions you take after reading this guide.

Acknowledgments

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The Sibling Collaborative

The Sibling Collaborative is a Canadian network providing social, emotional, and practical support to adult siblings of people with disabilities.

We recognize that while the experiences of siblings are diverse and profound, our stories and needs are often overlooked or even forgotten as families wrestle with the pressing issues that affect our siblings with disabilities. We provide a voice and support to siblings of people with disabilities by connecting them with each other; creating or providing access to helpful and relevant resources; and advocating on behalf of them and their loved ones with disabilities.

Visit sibcollab.ca to learn more.

Introduction

Who is this guide for?

If you're involved in the care or well-being of your sibling* with a disability**—or anticipate that you will be in the future—you're in the right place. This guide is for adults looking to build their awareness and understanding of financial matters related to the long-term financial security of their siblings with disabilities.

Throughout this guide, the term **siblings of people with disabilities refers to siblings, siblings-in-law, cousins, and other second-generation caregivers.*

***The term **disability** refers to a range of disabilities, including intellectual or developmental disabilities, acquired brain injuries, autistic spectrum disorder, cerebral palsy, fetal alcohol spectrum disorder, mental health disabilities, and substance dependence and abuse.*

****When we refer to the term **families**, we follow the Vanier Institute's definition: "Any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following:*

- *Physical maintenance and care of group members*
- *Addition of new members through procreation or adoption*
- *Socialization of children*
- *Social control of members*
- *Production, consumption, distribution of goods and services*
- *Affective nurturance— love*

[The] definition is inclusive of diverse family structures including (but not limited to) single parents, same-sex couples, stepfamilies, married or common-law couples (with or without children), skip-generation families and more."[1]

How will this guide help me?

This guide will help build your understanding of finances as they relate to your siblings with disabilities; this includes the risks of poverty, common sources of income (e.g., government benefits, employment), financial exploitation and safeguarding, and the importance of communicating with your family on money matters.

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[1] The Vanier Institute. Definition of Family.

Poverty and Disability

Having enough money is a concern for most Canadians—but when you have a disability, financial concerns are exacerbated by the poverty trap too many find themselves in.

According to Statistics Canada, people with disabilities (both mental and physical) make up more than 40% of the low-income population and they are twice as likely to live below the poverty line.[2]

What's more, regardless of an individual's financial status, living with a disability is costly. In a recent survey carried out by the Angus Reid Institute, in partnership with PLAN, 85% of the more than 800 Canadians living with disabilities surveyed reported having higher costs of living and additional expenses due to their disabilities, with medical costs and equipment cited as the most common increased expense.[3]

> *"It costs 40% more to live as a disabled person [in Canada]."*
>
> - Michelle Hewitt, Co-Chair of Disability Without Poverty

It's no wonder, then, that you might have worries and questions about the financial security (both for today and the future!) of your siblings with disabilities. You may be especially worried about what will happen when their primary caregiver (often a parent) is no longer able to care for them—and how this might impact your life and finances.

In a survey The Sibling Collaborative carried out in 2021, 83% of respondents agreed they would benefit from resources on managing finances related to their siblings with disabilities (e.g., saving, investing, budgeting).

A 2009 Easter Seals study found that while eight in ten siblings reported being comfortable taking over as their sibling's future caregiver, only about a third felt financially ready. This same study noted that finances are "by far the most worrisome aspect of caring for a sibling with a disability".

Clearly the financial security of our siblings with disabilities is top of mind for many of us. This resource will help guide you on your journey of supporting your sibling's financial security and, in doing so, reduce your own worries and anxieties around finances and the future.

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2 Canada Without Poverty
3 Angus Reid Institute

Common Income Sources

The ways our siblings with disabilities receive income depends on their disabilities and life circumstances. The most common sources of income include government benefits, employment income, or some combination of these and other sources (e.g., investment income, insurance products).

Government benefits

There are multiple federal and provincial benefits, including tax credits, that your siblings may have access to. It's important to be aware of these—and generally understand how they work—as they contribute to their financial security. Prosper Canada recently launched the Benefits wayfinder, an online tool that simplifies the search for government benefits.

Federal benefits

The federal government also has an online tool to help determine what benefits your siblings may be eligible for, including the following most common ones:

Disability Tax Credit

The DTC is a non-refundable tax credit that helps people with disabilities (or their caregivers) reduce their income tax payable. It's meant to create greater tax equity by allowing some relief for disability costs. Gaining access to the DTC can be challenging—and not all adults with disabilities are eligible. Nonetheless, if your sibling can access it, it can open the door to other government programs like the Registered Disability Savings Plan (RDSP). To learn more about the DTC and its eligibility, visit the Government of Canada's website.

Registered Disability Savings Plan

The RDSP is a Canada-wide registered matched savings plan designed for people with disabilities. It can be a valuable savings vehicle for your sibling for many reasons, including that 1) it unlocks additional federal government benefits (i.e., Canada Disability Savings Benefit and Canada Disability Savings Grant) and 2) it is exempt from most provincial disability and income assistance programs.

RDSPs have several restrictions, including around when and how the money can be withdrawn. Additionally, to qualify, your siblings must be approved for the DTC.

There are many great resources outlining the ins and outs of RDSPs available online. We recommend starting with PLAN Institute's rdsp.com.

Canada Caregiver Credit

If you are the primary caregiver for your sibling with a disability, you may be eligible for the Canada Caregiver Credit (CCC), a non-refundable tax credit.

Canadian Disability Benefit

While the Canadian Disability Benefit does not exist (yet!), many people and organizations across Canada are working hard to make it a reality. In the September 2020 Throne Speech, the federal government promised to establish a monthly Canada Disability Benefit, intended to "reduce poverty and support the financial security of persons with disabilities." While the promise was short on details, the main idea is that the guaranteed-income policy would be modelled after the Guaranteed Income Supplement (GIS) for seniors—meaning payments would be stacked on top of the existing benefits people with disabilities are already receiving from their province or territory.

Those pushing the benefit forward are optimistic it will soon be a reality. To stay informed on the Canadian Disability Benefit, visit disability without poverty.

Provincial and territorial benefits

Like the federal government, provincial and territorial governments in Canada provide income support benefits to people with disabilities.

Benefit rates

Not surprisingly, there is wide variation in benefit rates across Canada, depending on the particular jurisdiction. Unfortunately, one feature that is consistent is that no province or territory reaches a level of financial support that enables those receiving assistance to live above the poverty line. Additionally, virtually all jurisdictions have different rates depending on your sibling's circumstances. For example, there are different rates for those who are single versus in a couple; this typically means couples who are both disabled will receive less than if they both received the rate for a single person.

Eligibility

Though eligibility criteria also vary by jurisdiction, most assessments include the following areas: reside in the jurisdiction; are between 18-65 years old; are in financial need; and have a severe, permanent, or enduring significant disability that limits or impedes an ability to work. If your sibling is not currently receiving provincial or territorial income support, be aware that most applications involve an assessment by a health care practitioner and detailed financial disclosures. Finally, as your sibling's disability can change over time, we recommend periodically reviewing their needs and eligibility for disability benefits.

Additional benefits

Income support programs are not only made up of monthly payments. Depending on where your sibling lives, they can also include additional benefits:

- health benefits such as prescription drugs, essential medical supplies, optical, dental, and emergency ambulance services
- employment- and education-related expenses such as work-related support, assistive technology, criminal record checks, training wage subsidies
- additional benefits such as childcare, addictions treatment, funeral benefits, and transportation supplements

As these benefits can have significant value (e.g., covering the cost of prescription drugs), it makes sense to learn about those offered in your sibling's particular jurisdiction. Nonetheless, in most cases these benefits—even when combined with monthly payments—will not cover all the additional expenses related to your sibling's disability.

Individualized funding

Some jurisdictions like Ontario and British Columbia offer individualized funding, money that goes directly to people with developmental disabilities and their families that can be used to direct their own services and support. Because individualized funding supports the self-determination of people with disabilities, it is worth looking into whether it is available to your sibling.

Asset limits

Asset limits refer to the amount of money (or equivalent value) of things like savings, houses, and cars that your sibling can have before impacting their eligibility for income assistance or benefit amounts. It is generally broken out into liquid assets (e.g., cash in a savings account) and non-liquid assets (e.g., car).

While there is once again significant disparity across jurisdictions, there are also some commonalities. Liquid assets limits are typically in the $3,000 to $5,000 range with variations for single and family assets. All jurisdictions now fully exempt RDSP assets prior to withdrawal. Trusts are usually exempt but sometimes with a maximum asset limit (e.g., $100,000 in Ontario). Similarly, principal residence and vehicles are commonly exempt.

While asset limits and their criteria are complex, they are worth understanding. We recommend spending time researching and learning as much as you can about asset limits in your sibling's jurisdiction.

Municipal disability benefits

Each municipality has their own disability benefit programs. Like provincial and territorial income support programs, these benefits will vary widely depending on where your sibling lives. Two municipal benefits that are worth investigating are housing and transportation.

Employment

Unfortunately, our siblings with disabilities are less likely to be employed than Canadians without disabilities. And when they are working, they are often underemployed, in low-paying and insecure positions.[4]

Despite this reality, the income of those with jobs tends to be higher than those without and the employment income of those working generally makes up a large share of their total income. Additionally, employment may come with access to occupational benefits such as extended health care or insurance plans.

> In 2011, the employment rate of Canadians aged 25-64 with disabilities was 49%, compared with 79% for those without.
>
> \- Statistics Canada

For these reasons and more, employment may be a good avenue for your sibling to pursue if they are not working already. As the interest in creating inclusive workplaces grows, there are more resources available to help your siblings find and maintain employment. (If your sibling is interested in employment, Ready, Willing & Able has good resources on this topic.)

Keep in mind that if your sibling is earning employment income *and* receiving provincial or territorial disability benefits, you will need to consider earning exemptions; these are limits on what people with disabilities can earn before their benefits are impacted. As the limits vary quite a bit by jurisdiction, you will want to check with the provincial or territorial disability benefits office in your sibling's region.

Other income sources

In addition to government benefits and employment earnings, other sources of income for your sibling may include savings and investments, insurance products (e.g., annuities), and discretionary trusts, among other vehicles.

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[4] Statistics Canada. Persons with disabilities and employment.

Financial Safety and Security

As we touched on earlier in this guide, people with disabilities are more vulnerable to financial instability and poverty. Unfortunately, they are also more vulnerable to abuse, which includes financial exploitation. According to the Government of Alberta, people with disabilities are 50% more likely to be victims of some form of abuse in their lives (with the type of disability, presence of a support network, and degree of social isolation all influencing the level of risk).[5]

Financial stewardship

It's possible that at some point you might find yourself acting as a financial steward for your sibling with a disability. Financial stewardship involves ensuring that financial resources are spent wisely and can include financial planning, managing, and decision making. It can be a major responsibility impacted by a variety of factors, including your sibling's wishes, your understanding of financial topics, your financial position and habits, and your relationships with your siblings or other family members.

When it comes to financial stewardship, it can be helpful to have support and input from people you and your sibling trust. If your family hasn't already done so, consider setting up a microboard or personal support network for and with your sibling with a disability as well as consulting with an experienced, credible, and trustworthy financial advisor.

Financial exploitation

Financial exploitation occurs when a person misuses or takes the assets of a vulnerable adult for their own personal benefit. In the case of people with disabilities, this can often occur without their explicit knowledge or consent, depriving them of vital financial resources for their personal needs.[6]

If your sibling agrees, your role as a sibling, especially when your parents are no longer the primary caregivers, could include helping to safeguard them from both poverty and financial exploitation. This might involve different activities or strategies: getting emails from the bank for your sibling's account transactions; keeping an eye on your sibling's credit; keeping their personal information off social media and other online networks; setting up two-factor authentication; managing their passwords; and setting withdrawal limits.

[5] Disability Credit Canada

[6] National Adult Protective Services Association

Communicating with Family

Talking about finances and significant life changes (which sometimes involves the aging and death of our loved ones) can bring up a wide range of emotions. Some families can talk about these things easily, while others can only talk about certain topics or would rather not have these discussions at all. But for siblings, not knowing the plan—or not being included or considered when it comes to finances and the future—can be emotional too.

Recognizing these challenges, The Sibling Collaborative developed a resource entitled "A Guide to Communicating with Family for Adults Who Have Siblings with Disabilities" (found on the AIDE Canada website). This guide will help you start or continue conversations with your family about financial and other sensitive matters.

Building on the major items covered in this guide, the following table includes some questions you might want to raise with your families:

Government benefits	• What government benefits does your sibling currently access (e.g., RDSP, provincial income support, tax credits)? • What has your family's experience been in accessing these benefits? • What is the gap between what your sibling receives in benefits and what they require to live comfortably? • Who are the key contacts for the different benefits?
Other income sources	• What are your sibling's other main sources of income (both today and in the future)? And how might these impact the government benefits they receive (e.g., asset limits)? • What are your sibling's expenses and how are these expected to change over time?
Financial safety	• What financial safety and security measures are currently in place, and which are missing? • What financial safety and security risks are possible? • How and where are important financial records kept? • Who else can help ensure financial safety and security for your sibling (e.g., support networks, other family members)?