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ISSUE #21

Canada's
Down Syndrome
Magazine

3  21

Your Financial
Planning
Questions
Answered

Caring
About The
Numbers:
*A Sibling's
Experience*

Unlocking
Independence:
*Developing Money
Management Skills*

Made in
Canada:
*Federal Financial
Supports for
Canadians with
Down Syndrome*

The
Money
Issue

Plus: Self-advocates Share Their Money Management Practices

Money: it may not be the most fun topic we've ever covered in these pages, but it is surely one of the most essential.

In the economy of 2024, it is becoming more and more difficult for families of all types just to make ends meet on a day-to-day basis, let alone build long-term wealth. And as in many other areas, disability adds a further layer of pressure and complexity. Providing for a loved one with Down syndrome, often for a lifetime, takes hard work, wisdom, and creativity.

In this edition of 3.21, we equip you to make wise financial decisions in both the short and long term. A money math and budgeting instructor provides strategies for helping people with Down syndrome develop their money management skills, while self-advocates let us in on how they make their spending decisions. We also tackle long-term financial planning for Down syndrome families, and dive deep into some made-in-Canada financial supports for disabled citizens, including the Disability Tax Credit, RDSP, and the forthcoming Canada Disability Benefit.

Add it all up, and you're sure to find something in this issue to help you chart your course toward a stable and secure future for your loved one.

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Made in Canada:

Federal Financial Supports for Canadians with Down Syndrome

By Glen Hoos

When a family has a child with Down syndrome, there are many new topics for them to familiarize themselves but few are as complicated as finances.

Financial planning takes on an added dimension when an individual has a disability. It can be a scary, overwhelming endeavour to learn about the various supports on offer, and a great deal of work to put the pieces in place to take full advantage of the available resources.

Here in Canada, our federal government offers several noteworthy forms of financial support to people with disabilities and their families. Below, we attempt to cut through the haze surrounding three of them: the Disability Tax Credit (DTC), the Registered Disability Savings Plan (RDSP), and the forthcoming Canada Disability Benefit (CDB). Although the information included in this article is reliable and accurate, we encourage you to seek advice from a professional to create a financial plan that works for your situation.

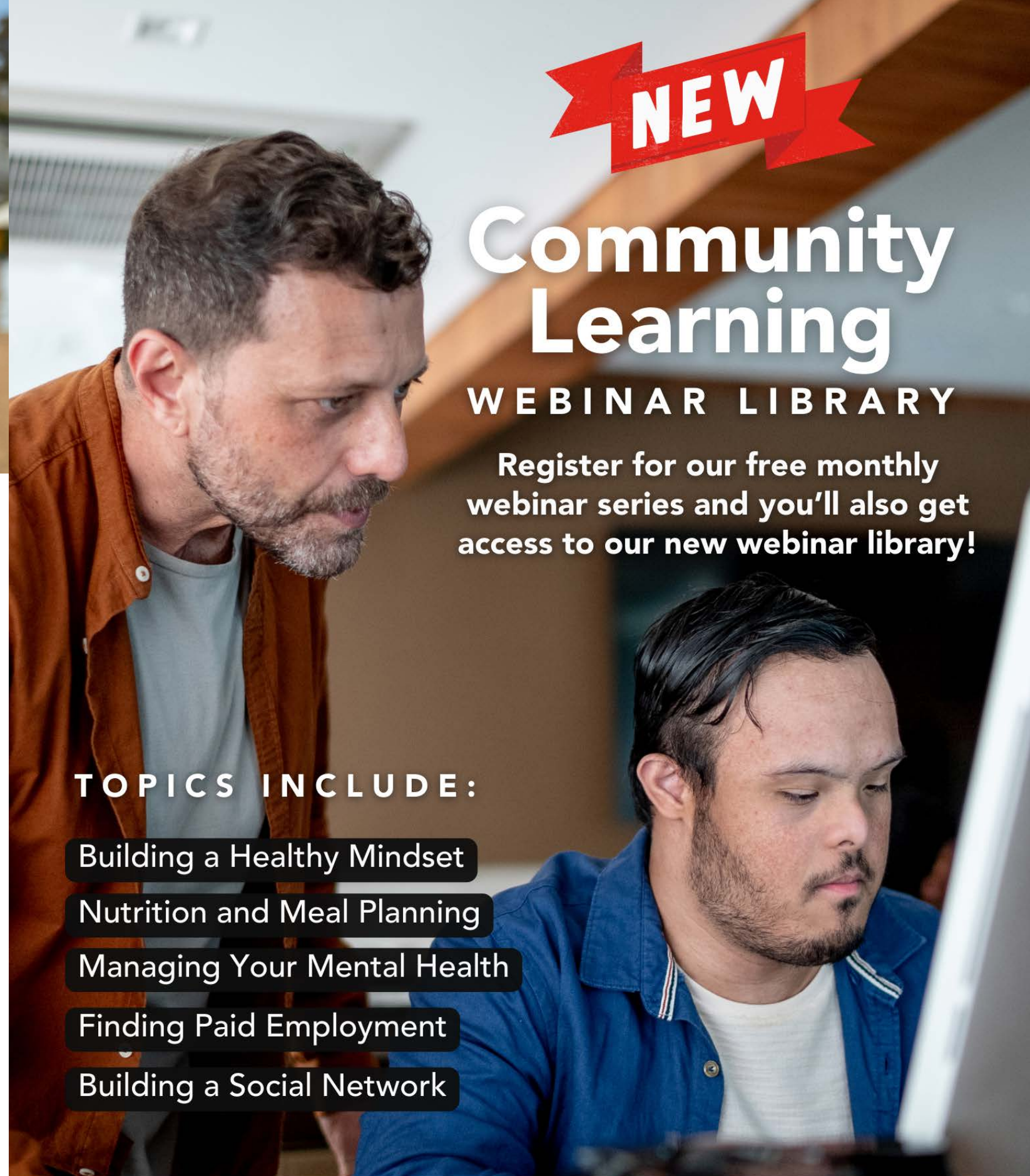
Disability Tax Credit (DTC)¹

When a child with Down syndrome is born in Canada, the first financial step for the family is to apply for the Disability Tax Credit (DTC).

The DTC is a non-refundable tax credit created by the federal government to assist people with disabilities and their families with the costs of having a disability or substantial impairment. It accomplishes this by reducing the amount of income tax the disabled person and/or their caregivers pay. The DTC also provides an extra supplement if the qualifying individual is under 18 years of age at the end of the taxation year.

The tax credit is broken down into provincial and federal amounts, with the federal portion being the same across the country and the provincial percentage varying. In most cases, qualifying for the disability tax credit can reduce an individual or family's taxes by several thousand dollars per year.

¹ The Disability Tax Credit Resource Guide, <https://disabilitycreditcanada.com/disability-tax-credit-ultimate-resource-guide/>



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Qualification for the Disability Tax Credit is not based on diagnosis. Instead, to be found eligible for the DTC, the individual must experience difficulty performing daily life activities such as:

- Walking
- Mental Functions (Mental Illness & Psychological Impairment)
- Dressing
- Feeding
- Eliminating (bowel or bladder functions)
- Hearing
- Speaking
- Vision
- The cumulative effect of significant limitations
- Life-sustaining Therapy

An eligible medical practitioner must certify that you have a severe and prolonged impairment or marked restricted in one of the above categories, or significant limitations in two or more categories, or that the individual requires life-sustaining therapy to support vital function. The vast majority of people with Down syndrome are ruled eligible for the DTC.

In 2024, the federal government announced that it will begin covering physician fees for completing the DTC application, in conjunction with the forthcoming Canada Disability Benefit.

Once ruled eligible for the tax credit, the individual is eligible for back payment, dated to when the disability

began (to a maximum of ten years). For people with Down syndrome, this is the date of birth.

The Disability Tax Credit is a gateway that leads to other important benefits, such as the Child Disability Benefit (a supplementary payment added to the monthly Child Care Benefit), the Registered Disability Savings Plan (RDSP), and the forthcoming Canada Disability Benefit. As of this writing, the only way to qualify for any of these benefits is by first qualifying for the DTC, so families should apply for the DTC at the earliest possible date.

For more information on applying for the Disability Tax Credit, consult the Canada Revenue Agency (CRA) or visit <https://www.canada.ca/en/revenue-agency/services/forms-publications/forms/t2201.html>.

Registered Disability Savings Plan (RDSP)²

Once an individual has qualified for the Disability Tax Credit, they are also eligible to open a Registered Disability Savings Plan (RDSP). The RDSP is a Canada-wide registered matched savings plan specifically for people with disabilities. It is intended as a long-term savings plan (minimum of ten years).

² The Plan Institute's RDSP Tutorial: <https://www.rdsp.com/rdsp-tutorial/>



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The government of Canada makes generous matching and standalone contributions to an individual's RDSP, allowing money to accumulate quickly. However, there are restrictions around when and how that money can be withdrawn, which are important to understand in order to determine whether the RDSP is the right financial tool for your loved one with Down syndrome. "We recommend consulting your financial professional to determine if the RDSP is right for your loved one."

There are numerous benefits to an RDSP, including:

- Over a lifetime, the government may contribute up to \$90,000 to your RDSP
- If you have a low income and cannot make contributions yourself, the government will still contribute up to \$20,000 on your behalf (see below for more information on the Canada Disability Savings Bond)
- RDSP withdrawals do not impact provincial disability benefits
- Anyone can contribute to the RDSP, including family, friends, neighbours, charities, foundations, and organizations

Government contributions take two forms:

- Canada Disability Savings Grant: Through the savings grant, the government will match contributions made to the RDSP by the individual or anyone who contributes on their behalf. Depending on income, the government will contribute up to \$3 for every \$1 in personal contributions up to \$500, and \$2 for every \$1 in personal contributions for the next \$1,000. This means that if a family is able to contribute \$1,500 per year, the government will contribute \$3,500. (Note: the government contributions are less if the beneficiary's income is over \$111,733.) There is a lifetime government contribution maximum of \$70,000 through the Disability Savings Grant.
- Canada Disability Savings Bond: Through the savings bond, the government will contribute up to \$1,000 per year, regardless of whether any personal contributions are made. If net income is less than or equal to \$36,502 per year, the federal government will contribute the full

\$1,000. If net income is between \$36,503-55,867 the government will make a partial contribution, and if net income is greater than \$55,867, the government will not contribute. For the purposes of the savings bond, when the beneficiary is under the age of 18, it is based on family income, so many children with Down syndrome may not receive the savings bond. However, once they turn 18, it is based on the individual's income, so many adults with Down syndrome will begin receiving the savings bond at that time.

The combination of government contributions, personal contributions, and earned interest make the RDSP a potentially powerful savings tool. Someone saving \$1,500 a year for over 30 years may find their RDSP worth nearly half a million dollars by the time they begin withdrawing from it. However, the rules around withdrawals may impact the amount the beneficiary ultimately receives, and we strongly suggest you familiarize yourself with these restrictions before making the decision to open an account.

As mentioned, the RDSP is a long-term savings plan. In fact, it is primarily designed to create a retirement income for people with disabilities beginning at age 60, providing recurring payments for approximately 23 years. Because most beneficiaries won't receive much or any CPP, the RDSP can be an important safety net for their retirement years.

This complicates things for people with Down syndrome, who currently have a life expectancy of around 65 years. In most cases, these individuals will want to begin withdrawals earlier in life.

The RDSP does allow for earlier withdrawals, but they can come at a price. Early withdrawals are governed by the 10-Year/Proportional Repayment Rule, which stipulates that, if there were any government grants or bonds deposited into the RDSP within the past 10 years, withdrawals will involve having to pay back some of those government contributions.

The proportional repayment rule means that for each \$1 withdrawn from an RDSP, you will lose \$3 of any grants or bonds paid into the plan in the previous 10 years, which is repaid to the government. All personal contributions and interest earned are considered the property of

the beneficiary and will not need to be repaid to the government at any point.

Suppose you wish to begin withdrawals when the beneficiary with Down syndrome is 40 years-old. The RDSP was opened in early childhood, with government contributions being made right up until the age of 40. In this case, all government contributions that were made before the individual turned 30 will remain in the RDSP, but any government contributions made between the ages of 30-40 may need to be repaid according to the above rule (the exact amount of the repayment will depend on the amount of the withdrawal).

This does not mean there is no value in an RDSP for people who intend to start withdrawals at an earlier age. In the above example, the person will still benefit from the first 30 years of government contributions (not to mention personal contributions and interest). But the benefit may not be as great as expected if they have not factored the 10 Year Rule into their planning.

The implication of this for people with Down syndrome is that it pays to start early and save as much as possible in those early years. If a family is able to contribute \$1,500 per year starting when the child is born, by the time that child turns 20, they will already have received the maximum \$70,000 in government matching available through the savings grant. Consequently, by the time the

child turns 30, all that money will be safe from the 10 Year Repayment Rule and will remain available to them if they begin early withdrawals. The earlier you can bank the government funds, the sooner you can begin withdrawals without having to repay it.

There are other considerations surrounding withdrawals that are important to be aware of. It is not necessarily like a bank account that you can withdraw from anytime you want, in any amount.

There are two ways to withdraw money from an RDSP. The first is through Lifetime Disability Assistance Payments (LDAPs), which operate similarly to a pension. The LDAP is a series of recurring withdrawals from an RDSP to the beneficiary. These payments continue at least once/year until there are no funds left in the RDSP or the beneficiary dies. LDAPs generally begin at the age of 60, but in certain circumstances, an LDAP can be requested earlier in life.

The second way to get money out of an RDSP is through one-time withdrawals, known as Disability Assistance Payments (DAPs). The amount that can be withdrawn at one time depends on the composition of the RDSP. If you have more personal contributions than government contributions in the account, you are free to withdraw any amount. You can even withdraw the full value of the RDSP and move it into another investment vehicle.





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However, if the RDSP contains more government contributions than personal contributions, the one-time withdrawal amount will generally be capped at 10% of the fair market value of the plan assets at the beginning of the year.

Because of the complexity of the RDSP, and the special considerations for people with Down syndrome, it is recommended that families seek the advice of a financial planner to determine whether the RDSP is well suited to your circumstances, and how best to maximize the value of this investment vehicle for your loved one.

Canada Disability Benefit (CDB)

In 2020, the federal government of Canada committed to creating the Canada Disability Benefit (CDB), with the stated aim of lifting working-age Canadians with disabilities out of poverty. On June 22, 2023, the Canada Disability Benefit Act received Royal Assent, having been passed with all-party support.

Following an extensive public consultation process in which the Canadian disability community united to advocate for an inclusive benefit that would raise Canadians with disabilities above the poverty line, the proposed Canada Disability Benefit Regulations were published in the spring of 2024.

Unfortunately, the regulations fell short of the expectations of the disability community in almost every respect, including the amount of the benefit, the nature of means testing, eligibility and application requirements, and timeline for implementation.

Nevertheless, payments of the monthly benefit for eligible adults with disabilities, to a maximum of \$200 a month, are scheduled to begin in July 2025. Even as the Canadian disability community continues to advocate for a stronger, more substantial benefit, the CDB will be an important form of support for adults with Down syndrome going forward.

Eligibility for the Canada Disability Benefit is tied to the Disability Tax Credit (see the first section of this article). Those who are eligible for the DTC will automatically qualify for the CDB, dependent on income. Therefore, if you have not yet applied for the Disability Tax Credit, this is another reason to do so soon, particularly if your loved one with Down syndrome is approaching adulthood.

To learn more about the Canada Disability Benefit and to get involved with advocating for improvements to the benefit, we recommend following Disability Without Poverty.

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Unlocking Independence: Developing Money Management Skills

By Andrea Lee, with Glen Hoos

What do having a job, navigating the community, shopping, and going on social outings all have in common?

1. They are all activities that a person with Down syndrome might aspire to do independently.
2. They all involve money.

Virtually every aspect of daily life involves a financial transaction at some point. Consequently, when it comes to unlocking independence for people with Down syndrome, few skills are more valuable than money management.

Adults with Down syndrome want autonomy from their parents. They see their same-age peers managing their own money and making their own purchases, and they naturally want the same for themselves. It makes them feel good to be in control of their money and to have authority over their own spending decisions.

While most parents desire to support their adult child's independence, money can be a sticky topic. It's a chicken and egg situation: the individual needs to be entrusted with money to learn to make good decisions with it, but we fear that poor decisions will be made as part of that learning process. Whether it's income from a job or disability benefits, we want them making wise, informed decisions about where that money goes.

As a teacher, I've found that money math and budgeting can be very challenging concepts for people with Down syndrome to master. That can be frustrating, because they don't want to make outrageous purchases any more than we want them to. The good news is, with the right support, these skills can be developed over time, allowing for a level of self-sufficiency that won't keep parents up at night.



This makes something like budgeting really tricky. If you have \$40 in your bank account and you're looking at the price of an item, and you're not sure whether it's more or less than what you have, how do you make that purchase decision? Without visual aids, concrete strategies, or some other support, it is very difficult. And it affects every purchase, because every purchase involves comparing numbers.

There are also struggles that have nothing to do with math, such as the ability to prioritize needs vs. wants. This is

Common Struggles

First, let's talk about why money management can be so hard. A 2019 study by Monica Cuskelly and Rhonda Faragher suggests that people with Down syndrome may have a higher rate of dyscalculia than the typical population. Dyscalculia is a learning disorder that affects a person's ability to do math. Much like dyslexia disrupts areas of the brain related to reading, dyscalculia affects brain areas that handle math- and number-related skills and understanding.

People with dyscalculia do not have the mental number line that people without dyscalculia possess. This impacts their ability to compare numbers in their mind; for example, knowing intuitively that 12 is less than 15 or even less than 100, or that six is more than zero.

something we talk a lot about in my adult math program. What do you need for your health and well-being, and is that more or less important than something that you just want for fun? We try to teach them to take care of their needs first, and then if there is leftover money, you can get something you want.

Some adults with Down syndrome don't have to worry too much about this. In many cases, their parents take care of their basic needs. They may not pay rent or buy groceries. This gives them more flexibility, but it gives us the opportunity to do some teaching around impulse control. Because, even within the realm of wants, there are still good purchases and bad purchases, and they need support in those decisions.

Many of my students have very little understanding of the importance of saving. If they have the money, they spend it all, every single time. Often, this comes down to a lack of opportunity to exercise responsibility. Those who have been given a little more responsibility, and who have had to live with the consequences of poor spending decisions in the past, exercise a bit more caution. Again, though, it can be tough for parents to let go and allow them to learn from mistakes when there is real money on the line.

There are also some core concepts that are more abstract, like the idea of value. Is this a good deal? Can I get a better deal? Should I pay \$10 for this pair of socks, or am I better off buying that other pair of socks for \$1? It's another question of comparison, but instead of comparing numbers we are comparing items and determining which is more valuable.

And then there are the practical skills. Surprisingly, I find it's usually no longer that necessary to teach students to identify money and count cash, because very few use cash now. But skills like how to read a menu, how to read a price

on a store shelf, how to identify prices online, accounting for taxes and tips, and transactional etiquette all need to be explicitly taught.

Teaching Strategies and Supports

Learners with Down syndrome respond well to visual supports, so it's important to incorporate visuals and concrete tools as you work to develop money skills. The number line is a classic tool: a straight horizontal line that represents numbers visually, which students can use to compare numbers.

Some of my students came up with a modern twist on the number line. They'll open their calendar app on their phone and use the days on the calendar, 1-30, as a comparison



tool. I think it's genius, and I didn't teach them that! But it's now become a go-to approach for me. I'll say, "If I have \$15, what price can I afford?" And they know that it's any number that comes before 15 on the calendar.

It can also be helpful to make the comparison concrete. Some students can't tell me whether \$12 is more or less than \$6. But if I ask them who's older, a 12-year-old or a 6-year-old, they can do that. Then I say, "Well, if a 12-year-old older than a 6-year-old, what's more: \$12 or \$6?" Simply reframing it like this can help them get it.

When it comes to teaching budgeting, I will focus on really small budgets at first, such as the budget for purchasing a single item. We have this one goal in mind and we're going to budget towards that before we focus on saving or developing a monthly budget. Earlier in my teaching career with students with Down syndrome, I used to teach monthly budgeting, but I found it to be out of reach for most students. In nine years of instructing over 100 adults in money math, I only found two people who could maintain their monthly budget independently when the class was over – but many more of them can successfully budget for a single purchase. This comes with the caveat – the students who come to see me are the ones who are already having difficulty with money math and budgeting.

I've found our goals need to be extremely tangible. None of my students have ever saved money just to save money, whether for a rainy day fund or a far-off goal like moving out. It has to be more immediate, like, "I need \$800 for an iPad," and then we chip away towards that target. Or, they may need an extra \$50 a month to go toward a date night with their boyfriend or girlfriend. So, we make a chart with a picture of the significant other, and that makes it real. When we get bogged down in numbers, students will often lose focus.

We also make spending lists. If they have a list of things they have to spend money on each month, we'll write that out and they have to check off each item as they pay for it, and track how much money is left. It's highly visual, and they can keep it in their purse or wallet to help them stay on track.



One young woman I worked with, she and her parents would check her bank account together every week, and she would write down how much was in it. Then they would determine how much she could spend that week. And she would just write it on a little post-it note and keep it in her wallet. Little visual reminders like this help because we all know what it's like to check our bank account, and the next time we look it's empty, and we can't remember where the money went!

Teachable Moments

Often the best learning happens on the go, as we go about our daily life. Numbers are everywhere! Developing money management skills need not be merely an academic task; it can take place anytime the opportunity presents itself.

When a child is young, you can begin teaching counting and the concept of one-to-one correspondence (that one item has a value of one). You can demonstrate this as you're setting the table: "One for you, one for me, one for you, one for me." Count things explicitly; slow down and use a lot of comparative language, such as more and less, older and younger, shorter and taller.

With the concept of more and less, I find that many people with Down syndrome have an easier time grasping "more" than "less." A student may be able to tell me that ten is more than six, but when I ask which number is less, they're not so sure.

A practical approach to teaching this lesson may be when you're serving dinner. "You started with six meatballs, but you ate one, so now you have one less (five)." Or, perhaps the individual is interested in sports. We often focus on "Who's the winner?" The Canucks have more goals, so they win. But we don't point out that the Leafs have less goals, so they lose. (Sorry, we're showing our west coast bias here.)

When you're at a restaurant and they're deciding what to order, ask them, "Which item is more expensive? Which one is cheaper?" Modeling your thinking patterns is useful. Compare the prices; read them out loud. Tell the family, "I don't want this family dinner to cost more than \$100. Everybody, let's pick some something less expensive."

Money management is not a skill that will be mastered overnight. This will be a long-term endeavour. But the payoff, in the form of increased independence and self-esteem, is well worth the investment.

- i Cuskelly, Monica and Rhonda Faragher. "Developmental Dyscalculia and Down Syndrome: Indicative Evidence." Feb. 7, 2019. <https://www.tandfonline.com/doi/abs/10.1080/1034912X.2019.1569209>
- ii Cleveland Clinic: <https://my.clevelandclinic.org/health/diseases/23949-dyscalculia>



Below are some fun learn-at-home activities for developing money math skills. Visit [DSRF.org/LearnAtHome](https://www.dsrf.org/learnathome) for more ideas!

Shopping Scavenger Hunt

While shopping, send the child on a scavenger hunt:

- Find something that costs more than \$_____.
- Find something that costs less than \$_____.
- Can you find two items that are equal?
- What can I buy with \$5/\$10/\$20/etc.?

Real World Scenarios

Use story problems involving real world scenarios so that your child gets used to using math for a purpose. For example: "You saw a hat you liked at the store. It cost \$10. Your dad pays you \$6 for raking the leaves. Your mom pays you \$5 for taking out the garbage. Do you have enough money to buy the hat?"

Round Up and Pay

Have your child pick an item from a menu, flyer, or online store, write down the price, round it up to the next dollar, then pay with the smallest bill. Have a number line available to reference.

Flyer or Menu Math

Use flyers or menus from stores that your child is familiar with to work on simple budgeting and purchasing. Give them a set amount of money and ask them to choose some items that they can afford. Use a calculator to figure out how much change they should get back. Discuss which items are more expensive and what the better deals are.



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CARING ABOUT THE NUMBERS: A SIBLING'S EXPERIENCE

By Helen Knoll Ries

A few months ago, my brother Paul, who is a person with Down syndrome, asked me if we could create a budget. I was surprised! He has expensive tastes, so it didn't sound like a bad idea. Paul and I sat down at his computer and started working on putting together his income and expenses. Paul was thrilled by the exercise, collecting receipts, scouring his bank statements, and, with my guidance, entering the numbers into the budget template. It was a lot of work and took a long time but gaining clarity on Paul's finances was enlightening for both of us.

When our parents passed away ten years ago, I stepped into the role of Paul's primary caregiver. Learning this role felt like a roller coaster ride; what started slowly quickly turned into a whirlwind of twists and turns, many of which were challenging. This budgeting experience highlighted that I am still learning the complexities of this responsibility.

Initially, it didn't occur to me that caregiving would be a long-term commitment. My parents and the community set up around Paul have been good to him. He is now 52, and despite difficult health challenges, he is living his best life. Paul will need a solid budget, and I have a duty to preserve and manage his finances so they continue meeting his needs well into the future.

From the age of 18, I lived away from my family and was not involved in Paul's day-to-day life. I didn't have insight into many aspects of his life, including his finances. I remember seeing my exasperated mother with provincial disability benefit papers scattered all over her desk. Thankfully, reporting for provincial benefits is no longer as complicated. Provincial benefits were the first place I started when learning how to navigate Paul's finances.

Disability benefits are crucial, not just for the monthly dollar amount but also for the health benefits. Depending on where you live in Canada, benefits typically include

medical supplies such as mobility devices, CPAP machines (often used by people with Down syndrome), and dental care. If you had to pay for those things out of pocket, the costs would add up quickly. Because the overall value of provincial benefits is high, it is essential to know the regulations that accompany them. For example, our siblings with Down syndrome cannot have a substantial amount of money accumulated in their bank account or receive large monetary gifts, which can happen when someone leaves money in a will or this could also apply to earnings from a job. It's vital to respect these limits to avoid the complicated process of reapplying for benefits. Just as important as the provincial and territorial gift and asset limits is the information about where money can be held without jeopardizing those benefits.

Disability benefits are meager, and the bleak truth is that they can confine our siblings to poverty. Some may question the point of filing taxes when the income is so low. However, there can be some relief from other federal and provincial programs available through filed taxes, such as the GST rebate or, in Ontario, the Trillium Benefit Fund. It may not be much, but it is something, which means that filing your sibling's taxes is important. When Paul and I were working on his budget, I was surprised at how much additional revenue came from tax programs. Don't get me wrong; it does not alleviate his poverty status, but every little bit helps.

My parents saved a small amount for Paul, which was bequeathed to him in their will and intended to be held in an Absolute Discretionary Trust, also known as a "Henson Trust." Since individuals receiving provincial benefits cannot hold many assets or receive large gifts, it's crucial that a will includes the Henson Trust clause. As the sibling, you may be appointed as the trustee of the Henson Trust. If your parents are still alive, take the opportunity to ask if they have included the Henson Trust clause in their will and ensure that it was done correctly by a knowledgeable lawyer. It would also be beneficial to know who the trustees will be. Discussing death is emotional and challenging, but if you can manage only one conversation with your parents about life after they pass, this should be it.

Henson Trusts can only be used for specific expenses related to your sibling's support and services. As a trustee, you must manage the trust, which includes investing it

wisely, filing taxes, keeping track of the money flow, reporting and more. It is yet another steep learning curve!

My parents had been proud to be among the first in Canada to open a Registered Disability Savings Plan (RDSP) for Paul. I had the impression that the RDSP would be a significant contribution to my brother's usable financial assets; however, I was wrong! In the first few years after my parents died, I diligently contributed to the RDSP, only to discover that I had inadvertently pushed back the vesting period, meaning we wouldn't be able to access those funds for many years. Paul would need to wait for the vesting period to pass or until he turned 65 to access this money. If neither of these are met, most of the money will go back to the government. RDSPs are long-term investments and may not be immediately, if ever, useful to our siblings with Down syndrome. Parents can open and invest in an RDSP, but siblings need to understand the details, to have realistic expectations and to avoid making the same mistake I did.

As we put the final touches on Paul's budget, we discussed his expenses and the importance of safeguarding his bank account. Rather than randomly taking money out at the ATM, we established a "payday." Every Friday, he goes to the ATM and withdraws his "pay," which is a predetermined amount for his weekly expenses. I also talked to him about who can accompany him to the ATM. I had been alarmed to learn that, on one occasion, when I had made a mistake paying one of his support workers, she took him to the ATM and had him withdraw money for her. This experience highlighted Paul's potential vulnerability and the need to cap withdrawal amounts, set up notifications of withdrawals to my phone, and educate him about keeping his money safe.

When Paul's budget was complete, he wisely noted that he had many expenses, and to my surprise, he elected to cut down on some of his favourite more costly activities. His diligence was admirable and helpful.

We now revisit the budget regularly to ensure it is current and that his expenses align as much as possible with his income. The exercise is not just about the numbers on a spreadsheet. Paul's enthusiasm and diligence around drawing up his own budget helped him take ownership of his financial choices. It also helps me gain some clarity and better plan for the years to come.



Your Financial Planning Questions Answered

By Plan Institute

Financial planning can often feel overwhelming and complicated, especially when you add having a disability into the mix. Navigating funds available, helping your loved one manage their budget, planning for future care and retirement - there is no one way to approach these challenges. To help demystify the topic, we have addressed 8 of the most commonly asked questions about financial planning for people with disabilities.

1. What are the financial plans and programs available to me as somebody with a disability?

One you may already be familiar with is your provincial/territorial income assistance program. While they have different names and eligibility criteria depending on where you live, they all provide some sort of funding for your daily living and housing expenses, medical plan, as well as associated benefits like a discounted transportation pass.

It is also a good idea to try applying for the Disability Tax Credit (DTC), also known as the [T2201 form](#). While this is a non-refundable tax credit, meaning it reduces the amount of taxes you need to pay rather than putting money directly in your pocket, it also gives you access to a lot of other programs like the [Registered Disability Savings Plan \(RDSP\)](#), the [Canada Worker's Benefit Disability Supplement](#), and the [Child Disability Benefit](#).

If you have contributed to the Canada Pension Plan (CPP) through your work in Canada but become disabled and are no longer able to work, you can apply to receive [CPP-Disability \(CPP-D\) benefits](#) at any age. The [average monthly amount](#) somebody could receive on CPP-D is \$1,177.20.

Additionally, depending on where you live, there may also be local programs that offer disability-specific

support, extra funding for medical expenses and accessibility devices, or discounts on services.

2. What are the steps to creating a simple and effective budget?

When creating a budget, the two most important things are that it is easy for you to follow and update. You can feel free to customize these suggestions to create a budget that works for you:

1. Decide how you want to track your budget. This could be written down on paper or electronically.
2. Make a list of all your monthly expenses and when those expenses are due. It is important to include expenses that you know won't change, like rent and phone plan payments, as well as expenses that do change, like groceries and utilities. Budget for expenses at the highest potential cost so that you know you will have enough money to pay for them.
3. Make a list of all your income and when you will receive it. It is good to separate out guaranteed income like your salary paycheck and changing income like money from odd jobs or gifts.
4. Once you have all of this information, calculate your total expenses and total income. If your total expenses are higher than your total income, you will want to sit down on your own or with



somebody you trust to decide what expenses you can reduce or change. If your total income is the same or higher than your total expenses, you may want to consider putting the extra money into a savings account.

5. Regularly update your budget and keep track of all income and expenses. If you aren't sure where to start, we recommend reviewing Prosper Canada's free [Budgeting and Saving Toolkit](#).

3. What are some common financial mistakes young people make, and how can I avoid them?

One of the biggest mistakes is not incorporating savings into your monthly plan. The future can often feel far away but starting to save money early is key to long-term financial security. The Registered Disability Savings Plan (RDSP) and a Tax-Free Savings Account (TFSA) are two examples of savings tools to consider.

Another common mistake is relying on memory alone to budget and keep track of your income and expenses, which can lead to forgetting important expenses and suddenly throwing off your entire monthly budget. See steps in the previous question response to avoid this. Follow the steps in the previous question for monitoring your expenses and income.

A third common mistake is relying on credit cards, payday loans, or other high-interest options that can't be paid back in a reasonable timeframe. It's good practice to only borrow money you can pay off relatively quickly and explore other options for saving and spending.

4. What are the best resources to use for learning how to manage my finances?

There are lots of resources to help you increase your financial literacy, but here are some excellent free ones to start with:

- Prosper Canada's Centre for Financial Literacy: <https://prospercanada.org/Resources/Overview.aspx>
- Momentum Money Management online 15-60 minute courses: <https://courses.momentum.org/>

- Prosper Canada's Benefit WayFinder Tool: <https://benefitswayfinder.org/>
- Non-profit Credit Counselling Society's Financial Education: <https://nomoredebts.org/financial-education>

5. What is the difference between a discretionary and non-discretionary trust?

A trust is a relationship in which one person, known as the settlor, gives money to a second person, known as the trustee, for the benefit of a third person who is the beneficiary. The assets in the trust can only be used for the benefit of the beneficiary.

In a discretionary trust, the trustee has complete discretion, or control, over how the money is used for the benefit of the beneficiary. These types of trusts are usually protected from any clawbacks of disability or income assistance benefits and can typically hold any amount of money.

In a non-discretionary trust, the trustee does not have complete control on how the money is spent. For a beneficiary on disability benefits, these types of trusts are usually restricted to a certain amount of money unless they are given special permission.

6. I am about to take over as the primary caregiver for my sibling; what financial factors should I be thinking about and preparing for?

The most important is to make sure that you have the correct legal authority to be able to help your sibling with their finances as their primary caregiver. Options available to grant this legal authority change depending on what [province or territory you live in](#).

Often this permission is given by getting a [power of attorney or enduring power of attorney](#) agreement created, but in situations where your sibling doesn't have the legal capacity to sign those agreements, you may need to explore guardianship/committeeship.



In BC, there is also the option of a [representation agreement](#) for people who do not have legal capacity, which is much less restrictive than guardianship.

Once you have the legal authority in place, you will need to understand your sibling's monthly expenses and income, as well as what financial accounts they currently have. You may need help to make the best financial decisions and prepare for fluctuations in expenses that can come from changes to income and costs, particularly as your sibling ages.

7. What financial support is available for new parents of a child with Down syndrome?

Down syndrome is one of the only disabilities that allows somebody to automatically qualify for the DTC, so it would be a good idea to apply for this tax credit as soon as your child has the diagnosis confirmed. The DTC will reduce the taxes you owe (up to \$14,928 per year), as well as give you access to other benefits.

You may also consider the Canada Child Benefit, which is a tax-free monthly payment made to eligible families to help with the cost of raising children under 18 years of age. You can [apply for this benefit](#) as soon as your child is born and the amount you receive will [depend on your family income](#). You can also receive a top-up amount for each child who is approved for the DTC.

Depending on where you live in Canada, there is additional funding available to help with medical expenses, caregiving needs, and education and other support needs. We encourage you to review our Plan Institute [resource page](#) that includes federal and provincial/territorial supports.

8. How can we set our child up for a safe and secure future when we are no longer around?

You are already on the right track by thinking about this now. Planning ahead is the best thing that you can do, and know that you don't have to make the perfect plan for it to be a good plan.

Plan Institute provides a free disability planning helpline service to people across Canada. You can contact them directly at 1-844-311-7526/info@rdsp.com or browse their website and resources at planinstitute.ca.

There are lots of other resources you can access to help navigate planning ahead. Some have been mentioned already in this article, but here are a few others that focus on this topic more specifically:

- Safe and Secure: Seven Steps on the Path to a Good Life for People with Disabilities: <https://planinstitute.ca/learning-centre/publications/safe-and-secure/>
- Future Planning Tool: <https://futureplanningtool.ca/>
- A Good Life – for you and your loved one with a disability: <https://planinstitute.ca/learning-centre/publications/a-good-life/>
- Health Canada's Advance Care Planning Resources: <https://www.advancecareplanning.ca/>
- Plan Institute's Wills, Trusts, and Estate Planning webinar: <https://planinstitute.ca/learning-centre/wills-trusts-and-estate-planning/>
- Canadian Down Syndrome Society's Today and Tomorrow: A Guide to Aging with Down Syndrome: <https://cdss.ca/resources/healthy-aging/>

Remember, no matter where you are with your financial planning journey, you are not alone.

Self-Advocate Q&A



Sam
Calgary Alberta

How do you decide how to spend your money?

I look at what I need and what I want.

How do you save your money?

I don't take my bank card to school so I won't spend money at the vending machine. I think about something special I want to save for.

Do you have any financial goals?

This year I saved for a paddle board and had enough to buy it this summer. Now I want to save for an iPad.

Do you have any challenges with managing your money?

Not spending money on candy, pop and bags or purses.

Does anyone help you manage your money?

Yes my mom and dad help me.



Jacob
Whitby, Ontario

How do you decide how to spend your money?

I figure out what my schedule is for the month and what I have to pay for. My mom helps me to make a list of my events and my bills. We figure the amount I have to pay. With the money left over, half goes into savings and the other half is for me to spend on things like eating out, going to the movies or buying new clothes.

How do you save your money?

Each month I put a certain amount in my savings account to save money. If there is something big I want to do like go to a concert or on a trip, my mom helps to figure out the cost and with the extra money I have to spend each month, I take a little bit of that and keep it in the bank until I have enough money for the concert or trip or whatever it is I am saving for.

Do you have any financial goals?

I would like to learn more about my money and how to do banking. I would like to have enough money so that I never have to worry about money.

Do you have any challenges with managing your money?

Yes, my mom helps me figure out how to spend my money so all my bills get paid. Sometimes I run out of money because I spend too much. It's easier for me to have cash than just using my debit card because cash shows me what I have and my debit makes it harder.

Does anyone help you manage your money?

My mom helps me to keep track of my money and to pay my bills.



David Shuttleworth
Surrey, BC

What are you saving your money for?

Calgary Flames merchandise.

How do you decide what to spend your money on?

If I have the money with me.

Who helps you manage your money?

My mom.



Aaron Waddingham
Burnaby, BC

What are you saving your money for?

A Lamborghini and hurricane roaster.

How do you decide what to spend your money on?

Ask parents when going on a date. Find places that are on our budget.

Who helps you manage your money?

My father, but mostly me.

Harold Yeo

Burnaby, BC

What are you saving your money for?

To eat at restaurants with my friends.

How do you decide what to spend your money on?

Yes to clothes.

Who helps you manage your money?

Myself. If I have questions I ask my friends.



Zamaan Jivraj

North Vancouver, BC

What are you saving your money for?

For a trip to Toronto and champagne.

How do you decide what to spend your money on?

If I really need it I'll buy it.

Who helps you manage your money?

My mom and my dad.



Emma Neville

North Vancouver, BC

What are you saving your money for?

I'm saving for a laptop.

How do you decide what to spend your money on?

To try out new things, my mom thinks it will be helpful.

Who helps you manage your money?

Myself. My dad helps with my bank account.



Darryl Andaya

Vancouver, BC

What are you saving your money for?

Superman costume and doing things with my friends.

How do you decide what to spend your money on?

I'll buy any Marvel superhero things.

Who helps you manage your money?

My teacher Andrea helps me.



Sid Lalwani

North Vancouver, BC

What are you saving your money for?

Going to the movies and ice cream.

How do you decide what to spend your money on?

I spend it on my family. Not if my mom tells me not to buy it. Don't buy the wrong things.

Who helps you manage your money?

Myself, and the teachers help me if I have questions.



Jason Lee

Richmond, BC

What are you saving your money for?

Movie fan store: posters.

How do you decide what to spend your money on?

I have a money journal. I write the things that I want and the ones I already got.

Who helps you manage your money?

My dad.



CDSS SPOTLIGHT



'Assume That I Can' reached hundreds of millions of people around the world, becoming one of the most viewed messages in our community's history



Families and leaders in our community hosted Down Syndrome Walk events across the country, raising awareness and reaching thousands of people



Our community-selected Daymaker coffee blend, 21 Reasons, celebrated its one-year anniversary and 100's of bags sold



After many years of advocacy work, the Canada Disability Benefit was created



Thousands of Canadians were challenged to overcome their misconceptions about the social skills of people with Down syndrome and make a new friend during Canadian Down Syndrome Week



We celebrated 10 years of improving representation for our community with photographer Hilary Gauld



Mismatched sock sales from Friday Sock Co. reached a milestone of \$40,000 raised for CDSS programs

A Look Back at 2024

Our community took some historic strides towards our goals of inclusion and authentic representation this year! We want to take a moment to acknowledge and celebrate some of these milestones with you all. The Down syndrome community has some truly dedicated leaders showing the world that we are capable, we are valued, and we deserve respect.

Gifts That Give Back

The CDSS Gift Shop is a great way you can show your support for our work! Proceeds from each item sold go right back into programs and initiatives for the Down syndrome community. From coffee selected by our community members to postcards designed by a Canadian artist, give a gift they will love that also gives back!



Limited edition postcards, totes, mugs, and shirts designed for the Down syndrome community by Canadian artist J Positive



Celebrate the 1 year anniversary of 21 Reasons, our community-selected blend with a cup of delicious Daymaker coffee



Grab a pair of our new 2024 CDSS mismatched socks from Friday Sock Co.

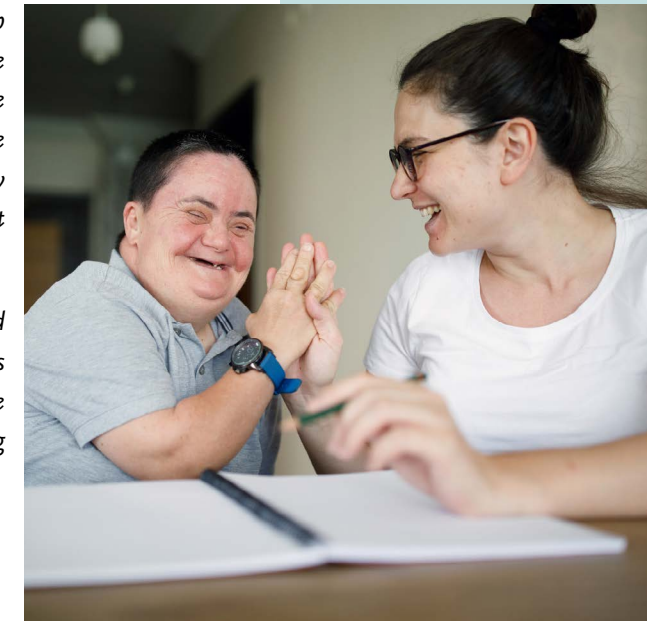
CDSS Has A New Address!

"In recent years, our CDSS team has transitioned from our long-time office in Calgary to a fully remote work model in an effort to keep costs down and ensure your donations are being used as effectively as possible. As part of this change, we've moved our official mailing address to Ontario.

We want to emphasize that this change in address was an administrative decision and will in no way cause a disruption to our work in Alberta. CDSS was founded in Calgary by a small group of incredibly dedicated Down syndrome community members and parents and we would not be the national organization we are today without the decades of advocacy work, volunteer hours, and loyal support we have received from them.

CDSS greatly appreciates the passion and time of all of our community members from coast-to-coast and we will continue to look for new ways to connect and bring us closer together."

Laura LaChance
Executive Director, Canadian Down Syndrome Society



ADVOCATING FOR IMPROVED FINANCIAL SUPPORTS

Financial supports like the RDSP and the Canada Disability Benefit are meant to aid Canadians with Down syndrome and their families with the additional costs that come with living with a disability and help to provide security for the future. Unfortunately, without proper accessibility and adequate funding, these supports make very little impact on daily life challenges and expenses.

At CDSS, we are actively working with many organizations, parties, and individuals across Canada to improve some of the most critical resources our community relies on

for financial support. Along with the other members of the National Disability Network, we are advocating for an increase to the Canada Disability Benefit to truly meet the needs of people with disabilities living in poverty. We are also working with members of the government to affect changes that will make the RSDP more favorable for Canadians with Down syndrome, such as allowing earlier withdrawal.

We have made history this year with the creation of the benefit and we will continue to push our government officials and organizations to improve the supports available. Everyone deserves financial security and independence, and we will not be left behind!

Please use our new address for mailing us your donations and forms:

Canadian Down Syndrome Society
220-1 First St, Collingwood, ON L9Y 1A1

JOIN OUR COMMUNITY

FIND US / TAG US

@CdnDownSyndrome on all our platforms



CDSS.ca



Canadian Down Syndrome Society

Société canadienne de la trisomie 21

Tiana Kirkegaard Awarded 2024 George Klukas Achievement Award

Her mantra is, "I am graceful, poised, and fearless!" Considering all that she has achieved just a few years into adulthood, it is clear that Tiana Kirkegaard embodies all three of these qualities.

A veteran of the Down Syndrome Resource Foundation's Speech-Language Therapy service, Reading and Communications Plus program, and Sharp Shooters Photography Club, Tiana's light shines brightest at Let's InterACT, our Integrated Improv Ensemble. There, her confidence and self-expression have bloomed. She takes risks in class, stepping into leadership roles and advocating for herself and others with grace. Tiana communicates powerful messages while perfectly balancing professionalism and humour to connect with others.

Desiring to embark upon an acting career, Tiana has worked with DSRF staff to prepare for auditions and presentations. As her storytelling and writing skills have grown, doors have begun to open for her to make her mark.

In 2022, Tiana landed a supporting role in the Hallmark movie *Color My World with Love*. Her film debut was the feature presentation at DSRF's 2024 Down Syndrome Film Festival, where Tiana has served as a speaker for the past two years.

Tiana has also been a featured speaker at Down Syndrome



Tiana Kirkegaard
2024 George Klukas Achievement Award

BC's Three Twenty-One Summit, and has given presentations to Canada's federal government.

Most notably, in early 2024, Tiana was invited to emcee the 3rd Annual Canadian Health and Wellbeing in Developmental Disabilities Conference. Tiana wrote all her own scripts and pre-recorded all her segments – nailing each one of them on the first take. Tiana's motivation and drive is contagious, and many conference goers shared how inspiring it was to see Tiana thriving in the emcee role.

Tiana recently completed a leadership learning course through L'Arche Canada. Through her advocacy work, she has put these skills into practice and is paving the way for others with disabilities. She has strong core values and is proud of her Chinese heritage. Tiana loves to express herself through many different mediums, which has allowed her to touch the hearts of a diverse set of people through the years – not least of all, those of us who have the privilege of working with her at DSRF.

In recognition of all her incredible achievements, Tiana has been awarded the 2024 George Klukas Achievement Award. Congratulations Tiana, we are so proud of you!

Making an Impact

Earlier this year, we surveyed DSRF families to find out how our clients with Down syndrome and their families have been impacted by DSRF's programs, services, and resources. The feedback we received warmed our hearts. This quote from one parent conveys the overwhelming sentiment:

"My daughter loves coming to DSRF. The skills she's developed with the help of her therapy team impact all areas of her life – from eating to playing with her family and friends, to communicating with peers, teachers and support staff in the classroom. DSRF has been fundamental in setting her up to reach her full potential across all areas of her life."



Among our findings:

98% would recommend **DSRF** to other families

93% say DSRF **provides support** they cannot receive anywhere else

91% say DSRF has contributed to their **child flourishing** in their daily life

91% say DSRF has helped their child **become more independent**

We are grateful for the privilege of coming alongside our students and families to support them in their Down syndrome journey. If you haven't yet connected with DSRF, we would love to support you, too!

MCFD Pilot Project Underway with 43 Families

43 children and youth with Down syndrome are currently receiving up to one year of free speech and/or occupational therapy thanks to a grant from the Province of BC's Ministry of Children and Family Development. This pilot project is part of DSRF's engagement with MCFD to inform the development of a new provincial system for supporting children and youth with developmental disabilities.

Each child will receive 10-12 sessions of therapy this fall. None of the families engaging in this project were previously receiving funding for speech or occupational therapy, and 12 of the families are new to DSRF. One of the objectives of this project is to improve service delivery to rural and remote families, and eight of the families are from rural and remote locations.

In addition to the free therapy sessions, these families will also benefit from a free family information series covering the basics of Down syndrome including health and medical issues, development, behaviour, and more. There is still room in this program for families who meet the criteria for participation. Learn more at [DSRF.org/MCFD](https://www.dsrff.org/MCFD).

Down Syndrome
Resource Foundation



FRIENDS OF DSRF

This fall, over \$400,000 was invested in people with Down syndrome through DSRF's annual Up the Down Market Dinners in Vancouver, Calgary, and Toronto. Thank you to each and every sponsor, donor, guest, and volunteer for your overwhelming generosity. Special thanks to presenting sponsor, The Answer Company, and to National Chair Maili Wong. All funds raised through Up the Down Market support DSRF's pre-employment programs for young adults with Down syndrome.

Thank you to DSRF Board member Mike Watson and to Mike Boehm, who hosted a Suds 'n Slices fundraiser in early October, raising over \$41,000 for essential Down syndrome educational programs and therapy services. Thank you also to featured speaker, DSRF Board member Tamara Taggart, whose story inspired all the guests.

Longtime supporter the Loyal Protestant Association has granted DSRF \$7,500 for our reading and math programs for learners with Down syndrome. We are grateful for their ongoing investment.

The Lohn Foundation has donated \$3,000 towards DSRF's educational programs and services for students with Down syndrome. Thank you!

Special thank you to Bordon Ladner Gervais LLP (BLG) on their longstanding support of DSRF as our law firm, providing many hours of pro bono legal assistance. As well, we are honoured to receive donations from the BLG Foundation and the annual Martin Donnor Charity Volleyball tournaments, and also have BLG participate in and sponsor DSRF's Magical Morning Breakfast.

UPCOMING AT DSRF

Flourish for Life Giving Campaign: *throughout Dec*

DSRF presents... A Magical Morning: *Dec 13, 2024*

World Down Syndrome Day: *March 21, 2025*

FIND US / TAG US

@DSRFCanada on all our platforms



[DSRF.org](https://www.dsrff.org)

Donate now to help
children with Down syndrome

Flourish for Life

Down
Syndrome
Resource Foundation



DSRF.org/flourish