Special Families

Planning for your child with a disability

Families with children with disabilities have different needs when it comes to their finances. Here are four things to do now to help ensure your family's security in the future.

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For the past 19 years, Grace has been on a journey with her daughter Julianne. As a baby she knew Julianne was different, and, as she got older she was not able to speak. Around the age of 3, Grace sought a diagnosis, but no one could pinpoint exactly what was affecting Julianne. Four years and many specialists later, Julianne was diagnosed with autism.

"My first reactions were pain and sadness," recalls Grace. "Certainly when you are first told that your child has special needs, your worst imaginings take over. You think you're going to live a life of misery, but actually the opposite was true."

Caring for Julianne was a full-time job, so Grace had to put her professional life as a musician and songwriter aside. As a single mom, there was a definite financial strain on the family. In addition, Grace was actively searching for any information and resources she could get her hands on to help her daughter — and many of those resources were extremely expensive. The community rallied and raised money for the family, but it wasn't enough to keep up with all the expenses. Month after month, debt piled up. With the ongoing demands of a child with autism, Grace had no choice but to declare bankruptcy.

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"Like many families with children with disabilities, we never thought to walk into our bank and ask what might be available to help us," says Grace. Eventually she found an advisor to help her with her finances. Grace learned about grants and savings incentives that she never knew about, and could make a big difference to her finances.

Canada's healthcare system generally covers the medical expenses for families of children with disabilities. However, there are other costs associated with the child that the family must pay out. Parents may have to hire help, reduce work hours, or like Grace, even leave the workforce completely to keep up with the extra demands. There may also be specialized medical equipment or therapy that isn't covered by publicly-funded health care.

"There is a lot of research and hope for children with autism, so parents are doing every possible thing to help their child," Grace reports. "That could be hyperbaric chambers, specialists, and conferences — all things that can cost a lot of money."

Grace worried about Julianne's future as an adult, and with good reason; Statistics Canada reports that only half of Canadians with a disability — physical or intellectual — have a job. The employment rate drops as disabilities become more severe. For Canadians with a severe disability, only 26 per cent are employed.[1] So without a promise of a steady income, families are left to save and plan to ensure a secure financial future for their children.

"It is really important for families with children who have disabilities to pay close attention to creating a solid financial plan," says Ian Lebane, Tax and Estate Planner at TD Wealth. "Any money or assets that the family has now may be used to generate returns long into the future. Even when these families have a plan, it's important to keep it updated because rules change so frequently."

So how do you ensure lifelong financial security for you, your family and your child? These tips may help you along the way:

1) Apply for the Disability Tax Credit Certificate

This certificate is signed by a medical professional and approved by the Canada Revenue Agency. It enables you to obtain tax credits and allowances for someone who has a prolonged or severe intellectual or physical disability, and their caregivers.

With the certificate, you may be eligible to claim the disability tax credit, the child disability benefit for families with children under the age of 18, and certain medical and care expenses. If the disability is intellectual in nature, it may also permit you to create a Lifetime Benefit Trust (LBT), which will allow you to transfer your registered retirement savings over to your child on a tax-deferred basis upon your death. The certificate may also give you access to some provincial tax credits and benefits programs that will provide allowances and income support.

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To be eligible, the applicant's disability must have persisted for at least 12 months. If the disability has been there for some time, but only officially diagnosed recently, you can have your tax returns reassessed as far back as 10 years. If the bearer of the certificate has no income, a spouse, partner or caregiver may be able to use the tax credit.

2) Set up a Registered Disability Savings Plan (RDSP)

The Disability Tax Credit Certificate may also be used to set up a Registered Disability Savings Plan (RDSP) which will allow the beneficiary to receive government grants. An RDSP is an investment program that allows

Canadians with disabilities and their families to save for long-term financial needs. Unlike contributions to a registered retirement savings plan (RRSP), contributions to an RDSP are not tax deductible, but any investment income earned will build tax-free. There is a lifetime maximum contribution of $200,000, so if a family contributes just over $300 monthly, over 50 years of earning an average of 5 per cent per year, that investment could turn into almost a million dollars. Depending on economic conditions, returns may be lower or higher.

Anyone can contribute to the RDSP until the beneficiary reaches age 59. Like a Registered Education Savings Plan (RESP), an RDSP can receive government contributions in the form of the Canada Disability Savings Grant. In addition, if your family income is below a threshold, you may be entitled to the Canada Disability Savings Bond, which is $1,000 per year. Grace now has a financial advisor who is working with her to access these different grants to maximize Julianne's RDSP.

"For adult children, the government matching can be as high as 300 per cent," says Lebane of an RDSP. "Government incentives, tax-deferred growth and a lower tax rate can make an RDSP a good option for families with children with disabilities."

3) Plan for a future that may not include you

When any child is under the age of majority, a parent is a legal guardian of the child and is responsible for making decisions on behalf of them. However, when a child becomes an adult, that all changes. In the case of families with children with disabilities, it's possible that you may need to continue to make decisions for your child — including finances and personal care decisions. This is why it is a good idea to create a sound estate plan for you and your child, in case you are not around or in a position to take care of them. An estate plan could include powers of attorney, which will allow you to designate a person to make both property and personal care decisions on behalf of your child; and the creation of a will for both yourself and your child, so that any assets can be passed on as you direct.

There are many challenges to estate planning when a child with a disability is involved. There must be a plan to provide for the child financially through the course of their lives. It is a common practice for these families to set up a trust in the parent's will. This type of trust, called a "testamentary trust", takes effect upon the death of the person making it. The parent may choose anyone to act as the trustee, but it should be someone the person trusts to act in the best interests of the child; the trustee will be responsible for managing and distributing those assets in the trust.

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About 3.8 million Canadians (13.7%) reported having a disability in 2012. Source: Statistics Canada.

"Along with the will, it may also be useful for families with children with disabilities to create a detailed letter of intent," says Lebane. "It's not a legal document but will be helpful to a caregiver or trustee. List any items, like your child's routines, preferences, medicines, and specialists."

Trusts are complicated animals. Anyone who is thinking about setting up a trust should consult a financial advisor or estate planner who can help you with this task.

4) Get life insurance

Life Insurance is another option that may help ensure that your child can be financially secure when you are gone. An advisor can help you determine how much insurance you will need to make sure that your family is taken care of. While it's tempting to only go with your group plan from your employer or term insurance — which is a policy that may have a short duration of coverage, it's important to build some permanent insurance into your plan in case the term ends, or you change employers.

As Lebane says, it's important to look beyond term insurance. Every time you renew as you get older, it gets more expensive. As you get older, it could become prohibitively expensive or you may even become uninsurable. The insurance proceeds can be placed in a trust, so that the trustee can manage the distribution of the money upon your death.

Lebane says finding the right advisor is especially important for families with children with disabilities. "Not every advisor will know about programs and benefits that can help families with children who have disabilities," he says. "You want to work with an advisor who is knowledgeable about issues particular to your family."

Julianne is now 20, an adult, and Grace is happy to report that she's made huge leaps and bounds. All the trials and tribulations have brought them closer together. "It's been the most challenging time of my life, but having my advisor on board has helped me tremendously. I only wish I had brought her on much earlier in our journey." This is one lesson that Grace has documented in her book, *Children of Autumn: Autism - Here on Purpose*, so that other families who are raising a child with autism can benefit from her experience in bringing up Julianne.

—*Denise O'Connell, MoneyTalk Life*

[1]Statistics Canada. The Daily. "Study: Persons with Disabilities and Employment." December 3, 2014. Accessed April 1, 2016, http://www.statcan.gc.ca/daily-quotidien/141203/dq141203a-eng.htm