

TORONTO STAR

Providing for a disabled child's future needs

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Dennis Mullins has a doctorate in chemistry. He was working in research at Ontario Hydro when his son Scott was born in 1987.

Scott has cerebral palsy and is developmentally delayed. He also suffers from depression and general anxiety.

"My personal experience with a child with special needs highlighted a system that is fragmented and difficult to navigate," his father says.

Parents of disabled children have so much day-to-day work finding the right schools and caregivers, they often neglect the most important job.

That involves planning for a day when they're no longer around — and providing long-term income for family members who may never be able to support themselves.

Caring for Scott, now 18, has changed Mullins' life and his career.

When he was downsized from Ontario Hydro in 1996, he decided to switch gears.

Today, he's a financial adviser with Y.I.S. Financial Inc. in Burlington. He uses his own experience to help other families battle the system.

(The medium-sized chain, whose initials stand for Your Investment Shoppers, has its headquarters in St. Catharines.)

Here's an example of the tips he provides for those trying to understand the complex world of benefits and tax credits.

Suppose you have a disabled child or grandchild. To provide for future needs, you put \$10,000 into a guaranteed investment certificate in the child's name.

But this generous gift will come back to haunt you.

The Ontario Disability Support Program disqualifies applicants who have more than \$5,000 in cash, investments, RRSPs or insurance policies.

However, there's an exception to the rules. Families of disabled children may not know about it, unless they have good advice.

Segregated funds are similar to mutual funds. But they're a life insurance product and excluded from the \$5,000 cap on financial assets.

So, you can invest what you like in segregated funds for disabled children or grandchildren — without having to worry about them missing out on government benefits when they turn 18.

You may set up a trust in your will to provide for a disabled child or grandchild after you die. Again, you need good advice.

Otherwise, the income from the trust could interfere with the child's qualifying for disability benefits in later life.

Families of disabled children learn about the Henson trust, named after Leonard Henson of Guelph. He provided for his disabled daughter with a trust whose assets would be paid at the discretion of a trustee. This meant she didn't own the assets.

The Ontario social services ministry challenged the will and lost. Its appeal was dismissed in 1989. This established the principle that an absolute discretionary trust preserves the right of a child with disabilities to receive benefits.

Trustees must be picked carefully. They will wield power over a disabled child's standard of living many years into the future.

"If you can find a family member who will do it for free, that's ideal," says Mullins.

It may not be worthwhile to set up a Henson trust if you have an asset in the \$50,000 range. There's too much cost and paperwork, he tells clients.

Parents with special-needs children may not have much to leave in their estates. One spouse often quits the workforce and stays home full-time as a caregiver.

"I recommend they buy a life insurance policy, a joint last-to-die policy that's cheaper than buying life insurance for either spouse," he says.

"They need a policy that's paid up by the time they retire, so they're not paying premiums forever."

Mullins knows from his own experience how hard it is to work while caring for a disabled child.

His son, a happy-go-lucky child until recently, is now severely depressed.

"During the past two years, he has been hospitalized in an adolescent psychiatric unit four times," the father says.

His depression can't be treated with drugs, the family was told.

"Upon his last discharge from the psychiatric unit, which he can't go back to since he's now 18, the recommendation was that he needs intensive behaviour modification therapy in a controlled setting, and ultimately placement in a residential group home.

"It has been made painfully obvious to us that such a setting doesn't exist in Ontario and the best we can expect is some in-home support, with us left to shoulder the majority of the care."

He's been trying to reach his provincial Member of Parliament, so far without success.

"I'm not able to spend as much time as I would like helping other families with disabled members," he says, "as a great amount of time is spent trying to solve the problems of my own."

Graeme Treeby is in a similar position. His daughter Jennifer, 18, has cerebral palsy and developmental delays, as well as seizures and sleep disorders.

"I was a certified general accountant, but I gave it up in 1993," Treeby says. "I started planning solely for Jenny's needs."

Today, he runs his own firm, the Special Needs Planning Group in Stouffville, and makes his living as a life insurance broker.

He also travels around Ontario to give seminars on how to plan for disabled children — all without charging a fee.

"I'm doing five this month," he says. "I speak mostly to families of people who are disabled, but also to lawyers and financial advisers."

At his website, <http://www.specialneedsplanning.ca>, Treeby provides free information on financial issues and strategies.

He covers the Succession Law Reform Act, advising parents it's unwise to cut off a disabled child over 18 in their wills.

"If we did disinherit the person with a disability, our will could be challenged in the courts and the end result could be a redistribution of our estate assets."

As well, parents should try not to burden the siblings of a disabled child with too much responsibility after they die.

Brothers and sisters have their own lives to live. They may feel they've been deprived of attention by the parents' focus on the disabled child.

So, it's important to make a plan that is clear, well thought out and fully supported, if necessary, by outside assistance.

Treeby says he's seen many wills that have something resembling a Henson trust. But the lawyers haven't drafted them properly.

"For example, I saw a family in Welland whose wills were prepared by a lawyer in the area. He had added the words: 'These funds are available for the maintenance of the child.'

"This doesn't work for a Henson trust, where money is dispensed only at the absolute discretion of the trustee."

Treeby's estate planning guide for families with disabled children, *Removing the Mystery*, sells for \$29.95 at the Ontario Federation for Cerebral Palsy's website.

There's also a \$9.95 CD-ROM version with two hours of video (<http://www.ofcp.on.ca>).

Jennifer's disabilities are so significant that she won't be able to work. She can stay in school only until she's 21.

"Then, I don't know what will happen to her," her father says with some trepidation.

However, it's not all bad news.

When Jennifer was younger, she was treated at the Bloorview MacMillan Children's Centre, which is affiliated with the University of Toronto

The doctors said she needed a special brace just to sit in a chair.
"Today, she's walking and running," Treeby says.

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