

Part I

A Cautionary Tale: If I got hit by a bus tomorrow...

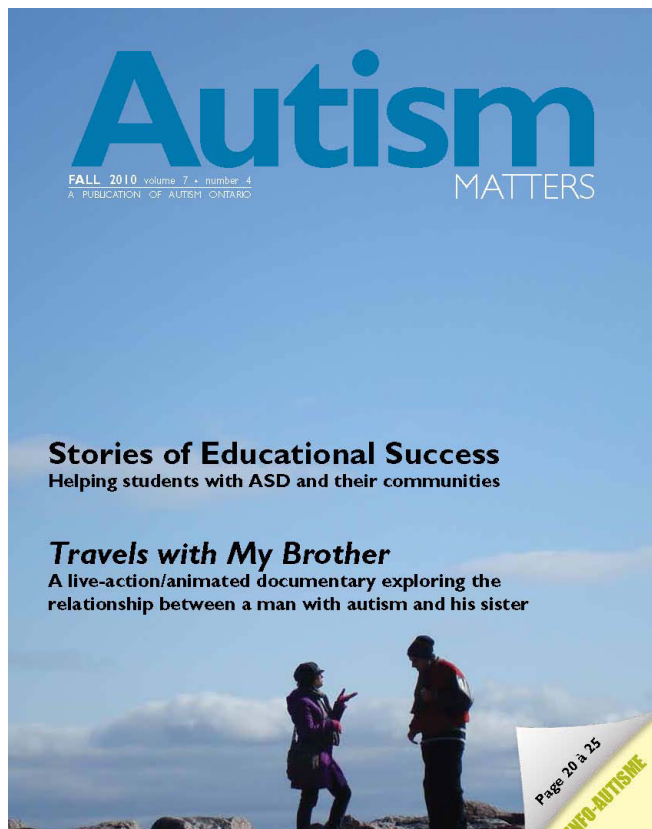
by Leslie Broun

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by Leslie Broun



One Sunday morning in March, I received a phone call. My best friend, Gertrude, had died in the night. Although Gertrude had had several serious health concerns over the years, her death was nevertheless unexpected and all of her friends and family were stunned by the news. When I arrived at the house, her brother had found a copy of Gertrude's will in a drawer. We read it together, the words barely making sense in our grief. We were named as joint executors. I remembered Gertrude asking me if I would be an executor, but it had been nine years ago. We hadn't really talked about it much.

During the initial hours of sorrow and confusion, Gertrude's daughter, Megan was waging her own war with grief. Megan has Aspergers Syndrome and at the age of 27, her adaptive functioning levels place her in the eight to 11-year-old range. Megan had found Gertrude's body that morning. She did everything right: She got the neighbour, called 911 and her respite worker. When the police arrived, she was in an hysterical state, threatening to kill herself. She was restrained, an ambulance was called and she was taken to the Brampton Civic Hospital. Her worker went with her. That evening, she was finally seen by a psychiatrist who, after a five-minute interview, deemed her fit to go home.

Over the next 24 hours, Megan tried to kill herself with any tool or substance she could find. Staying alone at the house with her, I literally had to chase her from room to room either to clean up vomit or to hide anything that could be used as a tool with which she could hurt herself. Finally, when she had found a knife in a storage room, I confronted her. Firmly and steadily, I held out my hand for the knife. I knew I was taking a huge risk, but was too tired and desperate to think of anything else. Fortunately, she surrendered it. I knew then that I couldn't handle this alone anymore. Megan's respite worker arrived a little later and, under the pretext of going out for a coffee, took Megan to a different hospital where she was admitted and put under suicide watch.

AFTER TWO WEEKS in the hospital, it was arranged that Megan would go to a "safe house" where she would have 24-hour supervision. This was a time-limited arrangement (up to two months) and the clock was ticking: What would happen to Megan? Where would she live? How would we work this out?

Indeed, what *would* happen to Megan? This truly is a cautionary tale that I write in order to warn and advise parents of the utter and uncompromising necessity for preparation in the event of their death.

"Well, I suppose I could get hit by a bus tomorrow, but this won't happen to me, I'm a careful person, I do things right."

Sadly, serious health and other crises that are immediately life-altering do happen – not often – but they do. We hate to confront death, but I know that parents of children who have disabilities are tormented by wondering what will happen to their child if they die. It is uncomfortable to confront it, to talk about it and to make a plan. Yet it is this confrontation, discussion and planning that can save your child from the possibility

of an unpleasant and deprived life experience.

Gertrude had taken good steps to ensure that, should anything happen to her, there would be financial resources available for her daughter's ongoing care:

1. She had composed a will and had it legally written and registered with a lawyer.
2. The will included provision for the creation of a Henson Trust for Megan. A Henson Trust is a legal and financial construct that ensures that an individual with a disability can receive an inheritance without it interfering with the receipt of their government-issued disability pension. While the appointed trustee has sole discretionary power over the trust, the money is to be used only for the benefit of the individual with the disability. There is a wealth of information on Henson Trusts on the internet (see list below) and when you are ready, find a legal professional who is familiar with this kind of estate planning.
3. Years ago, Gertrude had taken out a large insurance policy naming the Estate of Gertrude Horthy as beneficiary, which enabled the amount to go directly into the Henson Trust. It is critical that the estate be named beneficiary and not the child. Consult an insurance broker for whether term or whole life insurance would be the wiser plan. Check to see if the policy can be released before probate of your will and make sure that your executor knows the status of the policy and its worth.
4. Gertrude had taken out RRSPs* every year, which have also gone into the Henson Trust.

In Part 2 of this series, critical factors in the preparation of information for trustees and executors will be outlined. In Part 3, the roles of siblings and guardians are discussed, as well as the resolution of what happened to Megan. ■

Author's Note: We will be forever grateful to Deb Pyper of the Peel Crisis Capacity Network and Margarete Guerra of Brampton Caledon Community Living for their invaluable help and advice throughout this difficult period.

Where to Start

Beginning in 2009, the federal government has given citizens the option of saving money through a Registered Disability Savings Plan (RDSP*), intended to help parents and others save for the long-term financial security of a person who is eligible for the Disability Tax Credit. (Visit <http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/rdsp-reei/menu-eng.html>)

**It is important to check the tax implications for all of the financial provisions, including the Henson Trust.*

Across Canada, provinces have different arrangements for persons who have disabilities and how inheritance affects the ongoing receipt of their provincial disability pension. Ontario is the only province that has the Henson Trust. It is critical to check into one's provincial laws regarding inheritance and, whenever possible, to work with a lawyer who is familiar with the execution of inheritance laws as they pertain to persons with disabilities. There are many parents of individuals with disabilities who are not literate in English, who are not affiliated with organizations and who may not know anything about making a life plan for their child in the event of their death. Whenever possible, share this information with persons who need to know.

Informative websites:

www.kpopelaw.ca
www.specialneedsplanning.ca
www.siskinds.com
www.estatelaw.ca/resources/henson.html