

Part 2

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

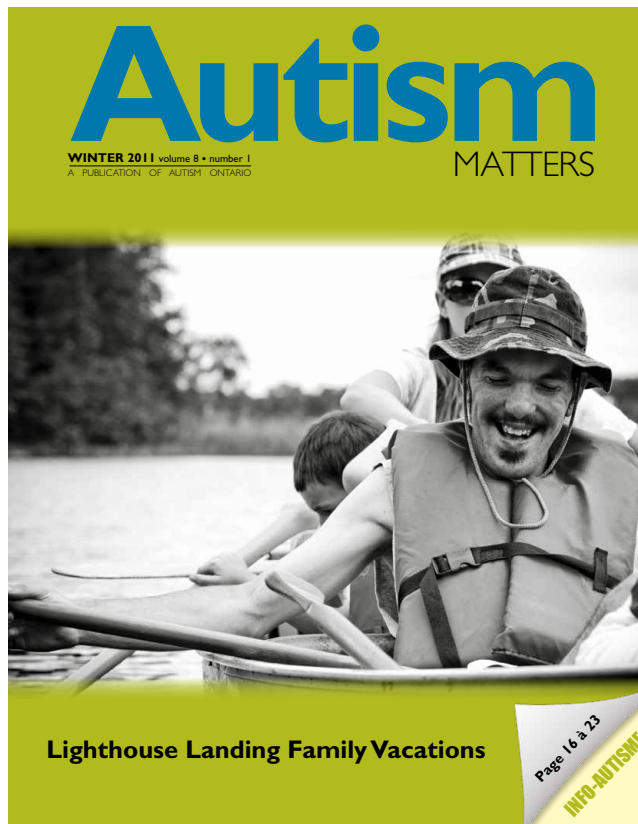
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A Cautionary Tale

If I got hit by a bus tomorrow . . .

by Leslie Broun

In this second installment of “A Cautionary Tale,” Leslie Broun discusses the process of learning to be the executor of an estate, the trustee of a Henson Trust and guardian of an adult with an Autism Spectrum Disorder.

IN THE ROLES OF EXECUTOR AND TRUSTEE, I knew that I would have much to do, but initially understood very little of what was expected of me. Fortunately, I am retired and had time available to work on all the business, legal and “Megan matters.” For weeks, I spent days and nights sorting through papers, studying and filling out the many forms involved in closing someone’s estate, as well as seeking funding for Megan. Some sources of funding had to be re-applied for (including child support payments) as the Estate would now be the recipient, not Gertrude. There was the sad duty of sorting through my dear friend’s belongings and disposing of them, only guessing and hoping that I was making decisions of which she would have approved.

There were some things that Gertrude could have done that would have made my job much easier:

1 She had never really talked to me or to her brother about the responsibilities of the executor, nor had she gone over her will with me, explaining what everything meant, particularly the Henson Trust. As it happened, her brother very quickly resigned from the role of executor leaving me to do it alone. Several years ago, he had told Gertrude that he did not want to be an executor. He did not know the world of ASD, agencies and services and knew that he could not fulfill this role. Gertrude didn’t make the change to her will. She always planned to remove his name, but never got around to it.

It is critical to ensure that the executor of your will and the intended guardian of your child have a complete understanding of the nature of the child’s disability. Prepare a profile of your child and update it at least once a year. Collect and copy critical documents such as psychological assessments, medical reports and adaptive functioning assessments. Also, it is helpful to include several key articles about the disability and discuss its implications for relationships and independent living.

Never take someone’s name off a waiting list.

Ensure that the names and contact information for the child’s doctors is included, as well as any other medical concerns beyond the primary area of disability, such as diabetes, skin conditions, medications, etc., as well as a list of the agencies with which the child is associated.

The selected executor, trustee and/or guardian must have a full understanding of the expectations of the role. You must accept that with this understanding, they may choose to opt out. Better that than they find themselves, after the fact, in a role for which they are not prepared and cannot continue.



2 Gertrude did not have crucial financial information prepared and centrally located to be accessed in the event that something happened to her. Although her brother was able to find her will, her financial information was spread throughout the house in baskets, drawers and files through which I had to search meticulously for information about bills, accounts, debts and insurance policies. Knowing where to find the documents, would have significantly simplified things and saved me many days of work. While this does not sound directly pertinent to Megan, it is critical. As her guardian, I needed a picture of what money was going to be available to support her as quickly as possible.

We usually think about our financial affairs as being private – for our eyes only; however, when we have a child who has a disability, it is critical that we keep the intended guardian and trustee fully apprised of our finances and where the information is kept.

Ideally, an envelope or box with copies of all information, including the will and information about the child, should be kept in a safe place that is known to the family and particularly to the executor.

3 After two difficult experiences of having Megan live away from home, Gertrude created an apartment for her in the basement of her house. She took Megan’s name off the waiting lists for other housing arrangements.

Never take someone’s name off a waiting list. When you put your child’s name on a registry, you may be asked to give a timeline of when you think your child will be ready to access a more independent living situation – two years, three years? There are no guarantees, but this information helps agencies determine their placement schedule. If your child’s name comes up, you are not obligated to accept a placement. You can say no and their name can still remain on the list.

In Toronto alone, there are thousands of individuals with disabilities waiting for housing and there are thousands of aging parents who are less and less able to care for their adult children with disabilities. Putting your child’s name on a list does not mean that you don’t love them. You want them to have independent living skills, as well as activities and people in their lives to fill the void when you are gone.

The ultimate goal is to ensure, as much as possible, the future security of your child who has a disability by the creation of a will, a Henson Trust and a plan.

Once a year, meet with those people who would be instrumental in the execution of the plan to discuss any changes to your situation. Let them know your hopes, dreams and wishes for the ongoing development of your child. And, on a practical note, make sure that they know where to find your documents.

You may never need this plan. Chances are that you won’t, but is it worth the risk? For my part, because of this experience, I have created a document that thoroughly outlines my own final wishes, my financial picture, where everything is and how I want my property dispersed. In those hours and days when, in grief, we do not always think clearly, my preferences and instructions will be clear to my husband and children. This is a gift, both to me for my peace of mind, and to them, for the hours of work and worry it will save them.

In Part 3, Leslie discusses the role of siblings, the issue of guardianship and shares the resolution of Megan’s story. ■

NOT FORGOTTEN

If you care about someone with Autism, please help us to help them!

In order to successfully advocate for adults with Autism and Aspergers we need you to add your voice.

Go to our website www.autismontario.com/adults and fill out the “Count Me In” registration form. This registry consists of adults living with ASD in Ontario, their family members, their supporters and their service providers.

Numbers are powerful tools to take to Ontario Government leaders. Please don’t wait, complete the form today.

Those who need services and supports are counting on you!



COUNT ME IN!

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