

Planning...Just in Case...

(Part 1 of 3)

No. 47, November 2012

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“Let me live one day longer than my child, just one day.” (Parent of a child with ASD)

This series of tip sheets provides suggestions for practical plans and actions that can help ensure the safe and secure future of your child, of any age. The number of steps and the amount of work may seem overwhelming, but it’s important to begin the process and see it through, one step at a time. There is perhaps no other task that will give a parent more peace of mind.

Unfortunately, serious health and other crises that are immediately life-altering can happen at any time. In an instant, family structure and dynamics can change forever. Even if life remains free of major disasters, death is the one event that none of us can avoid. What you can do, however, is to take steps to lessen the impact of such events on your child with ASD.

If you have not yet made plans for the future, you are not alone. In 2008, Easter Seals and the Mass Mutual Insurance Company conducted a survey of more than 2,500 parents of children who have ASD. When it came to planning for the future of a child with ASD on the death of one or both parents, the survey found:

- Only 38% of families had designated a guardian.
- Only 17% had created a trust.
- Only 24% had identified preferences for future living arrangements.

Here are some steps you can take to protect your child’s future without you.

Find a **lawyer** who understands the documents and legal structures involved in protecting persons with disabilities. (You do not want to pay an inexperienced lawyer to gain this knowledge.)

Determine who you want to be the **legal guardian(s)** of your child (or children). This is a role that involves a great deal of responsibility: choosing a guardian will take time and involve many discussions about the process and expectations for the guardian. Ensure that a prospective guardian thoroughly understands the role before accepting it. Be aware that choosing a guardian (typically by naming them in your will) only gives that person temporary guardianship over a child under 18, and no automatic role at all in the care of a child over 18. For children under 18, a court process is required to make the arrangement permanent. For children over 18, who are considered adults regardless of their disability, other processes are involved. (See the separate tip sheet dealing with guardianship of those over 18.)

Write a **will** with the help of a lawyer, ensuring that it includes the types of provisions this tip sheet suggests, and have it notarized and registered.

Determine who should be the **executor** of your will (also referred to as the trustee of your estate). This may or may not be the same person who has agreed to be guardian. Again, be sure the person agrees to, as well as, understands this role: there are several publicly available documents that explain exactly what an executor does.

If your child receives, or will receive, social assistance such as ODSP (Ontario Disability Support Plan), their assets must be managed to make sure those benefits are not put at risk. If your child does not qualify for ODSP, you may still want to put measures in place to protect assets they inherit. This means you need to establish a **trust**. For an inheritance of under \$100,000, a “Disability Expenses Trust” or “Inheritance Trust” where the money is considered an asset of your child but managed by

someone else (a trustee) on their behalf should not affect social assistance benefits. In this type of trust, the child (beneficiary) can also be a trustee, if he or she is capable, so long as there is at least one additional trustee. For a larger inheritance, you need to establish a Henson Trust, a special kind of trust where the money is not considered an asset of your child (and so does not affect social assistance) but is managed at the “absolute” discretion of the trustee. Trusts can be established during your lifetime or based on directions in your will, and should be developed with legal advice. Regardless of the process, establishing any kind of trust means you need to decide who should be trustees. As for guardianship, this is a role that carries a lot of responsibility for the long-term well-being of your child. Expect to spend time and energy finding the people willing to take on this job, and be sure they understand their responsibilities.

While this may not be the best plan for everyone, you may consider establishing an **insurance policy** naming **your estate** as beneficiary, and then direct that the benefit go directly into a trust. Be sure you name your estate, and not your child, as beneficiary to protect social assistance benefits. Consult an insurance broker to see whether term or whole life insurance would be the wiser plan for you. Find out how soon the policy can be paid out and be sure that your executor knows the status of the policy and its worth.

If your child with ASD has **siblings**, don’t forget to make arrangements for them through insurance policies or trusts. Your neurotypical children, or their guardian on their behalf, will need financial support for their education and/or to cover the daily expenses of living until they are able to become independent.

Open a Registered Disability Savings Plan (**RDSP**) for your child. This is a federal plan that allows you (and others) to set aside funds for the long-term financial security of your child. An RDSP will include generous government contributions and does not require any contributions from parents if their income is low. Parents must assist in opening the account. The funds in RDSP’s are tax-free until withdrawal and do not affect your child’s social assistance benefits. See <http://rdsp.com/> or <http://rdspontario.ca/>.

Make annual contributions (even small ones) to a Registered Retirement Savings Plan (**RRSP**), as these also can pay into the Henson Trust or RDSP.

If you are receiving a **work-related pension**, see if it has special inheritance provisions for a surviving child who has a disability.

See part 2 in the series for additional tasks you should perform.

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