

The Roles of Friends, Family and Siblings

(Part 3 of 3)

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November 2012



Because family structures and dynamics differ from family to family, choosing who will be involved in the care and support of your child upon your death (or if you are no longer able to care for your child) is important, but different for different families.

Choosing those to involve as guardian, executor, and/or trustee is difficult. People need to be able to care for your child, supervise their living arrangements, manage their finances, advise on their medical care, oversee their community engagement, and always act in the best interests of the child. It is possible for one person to play all the roles, but that puts a lot of pressure and responsibility on just one person.

Because life is unpredictable, remember that you may need to change your list of involved people over the years: friends relocate, siblings marry, and other changes in life occur.

Parents often look to other family members to take responsibility for their children if the parents are no longer able to provide care. It's best not to just assume that everyone will be ready and willing to carry out your wishes. You

need to discuss the issues, reach some sort of agreement, and set out a planned financial structure for the ongoing care of your children, particularly the child (of any age) with ASD.

In the case of parents who are divorced, separated, or who are single parents with or without a partner, it is critical to discuss what would happen to your children and make a plan to which all parties can agree. If differences exist, they must be set aside in order to make decisions that are best for the children.

Adult children may be called upon to make decisions about the life of their sibling with ASD. Again, do not just assume that this will be acceptable: discuss the siblings' role openly and repeatedly over time. This is not something to be put on someone in a moment of tragedy, when siblings have suffered their own loss.

Here are some questions to help focus your thinking:

- What are your expectations for your neurotypical children with regard to assuming responsibility for your child with ASD?

- How old are your children? How old would a sibling have to be for you to think he or she would be ready to take responsibility?
- Do the siblings have a good relationship? Does a sibling want to assume the role of caretaker or to take on financial and legal responsibility?
- What are the professional aspirations of your neurotypical children? Would their lifestyles or educational pursuits be able to accommodate the responsibilities of supporting your child with ASD?
- Have you talked to siblings about matters of finance, trust, and property?

It's best to make sure that siblings grow up with the understanding and assurance that their own lives will not be negatively affected by their relationship with the child with ASD. Ensure that you have, as much as possible, made financial arrangements for your neurotypical children so that they can receive an education and be able to make a good start in life. If their life is progressing well, then they will be more able and willing to have an active role in making wise and effective decisions to support your child with ASD.

Looking Beyond the Family

In the absence of siblings or other

family members, or if family would not be able to fulfill any of the necessary roles, you may need to look to friends or a professional such as a lawyer to assume the role of guardian, executor, and/or trustee.

Where no arrangements have been made, or if the designated persons are not able to fulfill their role, the Office of the Public Guardian and Trustee takes on responsibility. Take the time to research the role of this public office and perhaps make an appointment to discuss how the Office would carry out that responsibility for your child. For a list of offices in Ontario, visit: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/locations.asp>.

You can find other information about the office at: <http://www.ontario.ca/en/communities/law> - select Guardianship

The most important thing is to take the first step. Open the discussion. Make a plan. Avoiding the discomfort of the process now is not in your best interest, or the best interest of your family.

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