



Expert View

10 Tips For Parents Of Special Needs Children

Bernard A. Krooks, 06.10.10, 12:00 PM ET

Providing for children in an estate plan is not a simple task. For parents of children with special needs, the concerns and difficulties are magnified since, in many cases, the child will not be able to care for himself after the parents pass away. With recent advances in modern medicine, people with disabilities are living longer; meaning aging parents need to address this issue. However, since estate planning involves facing many difficult issues, many parents put it off--especially when they are already stretched thin navigating the special needs maze, obtaining services for and caring for their child.

There is more to estate planning--particularly when special needs children are involved--than signing some documents and putting them in a strong box or filing cabinet, never to be found again. As a general rule, we should keep our estate planning documents in a safe place that is readily accessible in the event they are needed. Parents of children with special needs should also use a binder that contains all the information that future caregivers will need to carry on after the parents are gone. The information in the binder should be updated periodically to reflect changes in family circumstances, changes in the needs or desires of your child, and other issues that may assist your child's future caregivers in carrying out their duties. Here are 10 things to put in that binder:

1. Important legal papers for any children with special needs (for example, birth certificates, Social Security cards and health-insurance cards).
 2. A "Letter of Intent," which parents should update at least once per year. This is a nonbinding document that passes vital information about a person with a disability to future caregivers. It can include such things as your child's sleeping preferences, eating habits and other important aspects of your child's daily routine. While these items may be second nature to you, it is important not to take them for granted. After all, in many cases the future caregivers assume their role in caring for your child without having actually walked a single day in your shoes.
 3. Written instructions spelling out any wishes regarding final arrangements (burial, cremation or religious services or other ceremonies that may be desired).
 4. Your own advance health care and financial directives such as powers of attorney, living wills and health care proxies. By having these documents in a binder that can be accessed when needed, you can save your family the heartache and expense of a guardianship proceeding should you yourself become incapacitated. This is important for any family, but if you have special needs children it is crucial; the last thing you want is confusion over your own wishes to distract from the needs of your child.
 5. Copies of any trusts--special needs trusts, living trusts, or insurance trusts--that may have been prepared. Remember, signed copies or originals may be needed to complete property transfers. Thus, you should also provide information about where the original documents are kept, whether that's at an attorney's office or in a safety deposit box.
 6. A list of major assets and information about where they are kept (for example, a list of insurance policies, stocks, mutual funds, bank accounts, with policy and account numbers and the names of any brokers, insurance agents and investment advisors).
 7. Guardianship papers for your special needs child, if any, and a list of advocacy organizations that may be helpful. Also, write down any personal reflections or thoughts you may have about these organizations.
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8. The names of government agencies or case workers that you may have dealt with in obtaining services for your child.
 9. A list of government benefits your child may receive, as well as copies of any filled-out application forms. (These application

forms will help the future caregivers the next time they apply for benefits on behalf of your child; especially since the caregivers may not understand the complexity of these applications.)

10. Other miscellaneous papers, such as tax returns filed for your child, information about housing options, schooling and photographs of the family.

The estate planning process, especially when parents are planning for the future security of a child with special needs, can often seem overwhelming. But when you have taken the steps necessary to accomplish these objectives, it is a great sense of relief.

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