Estate Planning for the Exceptional Parent

By Timothy E. Williams

Estate planning is one of those tasks that we all know we need to do but can never seem to find the time for. Besides the natural discomfort we all feel when we think about end of life issues, most of us have some sense of "it is not going to happen to me, at least not anytime soon." Intellectually, we all know we will die eventually but thinking about it is just not on our agenda today!

On any given Sunday, in the business section or supplement of the local newspaper you can probably find someone reminding us to get our affairs in order. Or someone like Terri Schiavo makes the national news, and we all start talking about what we want done at the end of life. Soon, however, our daily lives take over again, and that estate planning can be put on the back burner. "I'll get around to it."

While estate planning is important for everyone, it is especially important for you if you have a loved one, particularly a child, who has special needs and will either likely qualify for government benefits because of their disability or have difficulty managing a significant amount of money they might receive as an inheritance—or both.

So what is estate planning? At its most basic, it is having a will that will specify where you want your stuff to go when you die. Also in a will, you can usually designate who you want to raise your children if you and your spouse should die while they are still minors. "Usually," wills and most estate planning documents are specific for each state, and the rules vary considerably from state to state. This is one reason why you should see an attorney in the state in which you are a resident and why form documents found on the internet tend to be inadequate. If your will is valid in your state of residence at the time you sign it, it remains valid in any state to which you move.

Usually included when we discuss estate planning are Powers-of-Attorney and Health Care Directives (also known as "Living Wills"), an issue made prominent again by the Terri Schiavo case. A Revocable Living Trust (RLT) or a Special Needs Trust (SNT) may also be advised.

So what is a trust? A trust is a legal right in property, real or personal, that is held by one party (the trustee) for the benefit of another (the beneficiary). It is a separate entity, like a person, but which never "dies", although many states do place limits on how long a trust may remain in effect. All trusts have at least three components:

- the settlor, the person who places money or other assets into the trust;
- the trustee, the person who manages the trust; and
- the beneficiary, the person who benefits from the trust.

These three can all be the same person, or they can all be different.

Trusts can either be set up in a will to take effect when you die. Or they can be set up while you are still living, hence the term "living trust." A revocable living trust is often established in order to avoid probate. Probate is the legal process of transferring your assets to your heirs. Probate laws, and the cost and trouble of probate, vary considerably from state to

state. Consequently, avoiding probate through a trust is important in some states and not important in others.

Of more importance to the person with a child or grandchild with special needs is the idea of a Special Needs Trust. A Special Needs Trust accomplishes two important things for your child.

- Since the assets never "belong" to the child, they won't disqualify him or her for needs based governmental benefits such as Medicaid or Supplemental Security Income (SSI).
- Assets are also protected from mismanagement by your child and from being stolen, either directly or through coercion or undue influence

If your child has no assets now and will likely only receive significant money when you and your spouse die, setting this trust up in your will may make the most sense. Otherwise, you can set one up immediately and add money or other assets to it either now or later.

One of the most important aspects of setting up a Special Needs Trust is selecting the Trustee. If you are setting it up in your will, you, of course, cannot be the trustee. You should select someone who is both trustworthy and financially astute, and someone who knows your child and is willing to work with them. There are also professionals who will do this for a fee. Many banks have trust companies for this purpose, and there are other professionals who do this for a business. Be careful, as regulation of these professionals varies significantly from state to state.

The trustee will have discretion to distribute assets, or not, depending on circumstances. Normally they will not be giving money directly to the beneficiary or providing food or housing. The trustee will have broad authority to buy other things, however, including furniture and electronics, vacations to Disneyland, Graceland, or the Taj Majal (This is not an exhaustive list. You get the idea.) In addition, when the beneficiary dies, you will have selected another beneficiary for any remaining funds, often your other children or your grandchildren, or perhaps a charity.

What happens if you delay, and you and your spouse end up dying without wills? We call this dying "intestate," and your estate will be distributed equally to your children; whether they are disabled and need government assistance will not be a factor. If you are in a "blended" family, the distribution may depend on which spouse dies first, and some children may be disinherited.

Most importantly, if you have a child receiving SSI or Medicaid benefits, this inheritance will immediately disqualify them from continuing to receive these benefits. The inheritance will need to be used to pay for whatever services they have been receiving. If your child's guardian or advocate does nothing (remember, you are not there to help), this will continue until the inheritance is gone. Only then will your child again be eligible for benefits. This is the functional equivalent of giving your child's share of the inheritance to the state.

It is usually not quite that dire, however. Your child's guardian or advocate can petition the court to set up a different kind of Special Needs Trust. This trust will be similar to one in your will, except that you don't get to name the trustee, and when your child dies, any remaining assets will go to reimburse the state for any benefits received, rather than going to other family

members or charity. This also takes time and money, often prolonging probate and making life more stressful for your loved ones at a time that they are already upset because of your death.

Special Needs Trusts do require care in drafting and are most efficiently done in conjunction with the other estate planning documents listed above. They should be drafted by attorneys experienced in estate planning and who are familiar with special needs trusts. You can check with your local or state bar associations for referrals to estate planning attorneys in your area, or check with the Special Needs Alliance or the National Academy of Elder Law Attorneys (NAELA).

This article is meant as a brief introduction into estate planning and special needs trusts and their importance for parents with children with special needs. It is a complex area of the law, but with the assistance of a qualified attorney can be done relatively painlessly.

Do your estate planning now. You will be amazed at the load it will take off your mind.

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Reprinted with the expressed consent and approval of ***Exceptional Parent***, a monthly magazine for parents and families of children with disabilities and special health care needs. Subscription cost is $39.95 per year for 12 issues; Call (877) 372-7368. Offices at 416 Main Street, Johnstown, PA 15901.