ESTATE PLANNING FOR SPECIAL PEOPLE: WHAT YOU NEED TO KNOW ABOUT SPECIAL NEEDS TRUSTS

Parents of children with disabilities and special needs face unique challenges in providing for the day-to-day needs of their loved ones. When their thoughts turn to the issues that would arise if the parents were no longer around, the challenges become perhaps even more daunting. Consequently, estate planning for parents of special needs children requires much thought and preparation.

Essentially, there are two components to the estate planning that parents of special needs children need to cover:

1. Making sure that there would be sufficient financial assets available to provide for the necessary support and maintenance of the special needs child and any other children they may have;

2. Providing an organized structure that would be in place for the management of the assets in a way that would ensure that the beneficiaries would be taken care of, which would include:

   a. A Last Will and Testament, which includes the designation of a guardian for the child – i.e., the person who would be charged with the day-to-day care of the child;

   b. A properly structured trust, specifically designed to provide the framework for how the trust assets would be expended for the benefit of the child. (See the discussion which follows, describing how Special Needs Trusts or Supplemental Needs Trusts can be structured in such a way that the trust assets – no matter how extensive, will not disqualify the beneficiary from receiving “needs-based” benefits.)

Since I am an estate planning attorney, not a financial advisor or life insurance salesman, I will leave it up to others to provide you with advice as to how to ensure that there are sufficient financial resources. What I can offer is guidance as to how to properly create an estate plan that provides the framework for accomplishing all of your
goals in making sure your special loved one is protected in the event of your death or disability.

For parents with special needs children, any good estate plan will include provisions for one or more kinds of Special Needs Trust or Supplemental Needs Trust.

The terms “Special Needs Trust” and “Supplemental Needs Trust” are often (and properly) used interchangeably. Essentially, they refer to trusts the assets of which will not be considered to be resources of the disabled person, so that such person will still be able to qualify for needs-based benefits, such as Medicaid and Supplemental Security Income (SSI). The terms of such trusts generally direct that distributions from the trust shall be made to supplement, but not supplant, any government benefits the disabled person is receiving. Such government-provided benefits are basically limited to medical costs, food and shelter. The assets in a Special Needs Trust can be used to provide for additional or supplemental support, including additional health benefits, computers and other electronic equipment, educational materials, special equipment, recreational opportunities, travel costs for vacations or other trips, gifts to family members, etc.

When speaking about Special Needs or Supplemental trusts, it is important to distinguish between “self-settled” trusts and “third party” trusts.

Self-settled trusts are trusts that contain assets that once rightfully belonged to the disabled person. This may be because the disabled person was awarded money in a lawsuit or other legal proceeding, or inherited the money, or money was distributed to the disabled person from a custodial account when he or she reached the age of 21. When the disabled person’s own money is placed in a special needs/supplemental trust, there must be specific “payback” provisions in the trust that provide that, upon the disabled person’s death, any amounts paid out from government needs-based benefits (such as Medicaid or SSI) must be paid back to the government from the funds remaining in the trust.

So-called “third party” special needs/supplemental trusts are funded by someone other than the disabled person with funds that the disabled person never owned or was entitled to. With third party trusts, there need not be any “payback” provisions. Thus, all assets remaining in the trust when the disabled person dies can be distributed to other beneficiaries that the person who set up the trust wants to receive them, without any amounts being paid to the government.

This points out the reason why it is especially important that parents of special needs children have a proper estate plan. If such parents die without having made provision for a special needs trust, the inheritance the child receives will disqualify the child from government benefits. The most that could then be done would be to have a self-settled trust created. However, such a trust would have to have “payback” provisions that would ultimately deplete the trust of some or all of the assets.
That is why, in this author’s view, the first step that should be taken by parents with children with special needs is to complete their basic “foundational” estate plan. This will include wills, powers of attorney, medical directives and an appropriate trust, including special needs provisions for the disabled child. If life insurance is needed to provide a source of funds necessary to support the disabled child and any other children, then such life insurance needs to be coordinated with the estate planning documents (i.e., the trust should be made the designated beneficiary on the insurance company’s forms). A proper estate plan will give the parents the peace of mind in knowing that if something should happen to them, their special one will be taken care of. In many cases, this is all the planning these parents require. There is no need to set up separate trusts and fund them with cash or investments. After all, as long as the parents are alive and well, they know that the child will be taken care of. And, if things change in the future (i.e., changes in the law, changes in the condition of the special needs child or other family members) the parents have the comfort of knowing that all of these documents can be amended to accommodate those changes.

In some case, however, it is appropriate to establish separate irrevocable Special Needs Trusts in addition to the essential estate planning documents. Frequently, these trusts are established so that if the grandparents or other family members wish to leave some part of their estate to the special needs child, those bequests can be made to the trust instead of the child him/herself, so that the inheritance will not disqualify the child from government benefits and that there will be no “payback” required.

This article is not intended to provide a detailed explanation of all relevant elements of the various types of special needs trusts. In our view, what is important for parents of special needs children to know is that there are many planning strategies and opportunities available to them, and that it is especially important for them to do proper estate planning, utilizing the services of an experienced attorney who practices extensively in this area of the law.