

## **SPECIAL NEEDS TRUST HELPS ENSURE SUPPORT, CARE**

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Estate planning for parents with a dependent who has a disability is a complex process. Most parents find it difficult to even contemplate their death and, as a result, planning can be an upsetting experience for families. It is not unusual for parents to feel either too young to consider estate planning or to feel they have so few assets that this type of planning is not applicable to them.

You need not be wealthy or old to begin seriously considering the need to write a will and a supplemental or "special needs" trust if you have a family member who needs government benefits to ensure that he or she receives the care and support necessary over a lifetime. But in order to do this, you must plan carefully.

For most families, planning means having a legal will drafted to ensure that your assets go to people you designate and to name a guardian for a minor or adult child with a disability who needs guardianship. If you die without a will, the state determines how your assets are distributed and the probate court determines who shall serve as guardian of that child, even when there is one surviving parent. The probate court's decision on a guardian may or may not be the same person you would have chosen and your assets may not be distributed in the way you desired.

The process of proper estate planning for a person with a disability is often misunderstood. It is not just a sophisticated method to avoid or reduce estate taxes due when one dies. For most families with a disabled dependent, the primary goal of planning is to ensure that the dependent receives a lifetime of adequate care and support that eligibility for governmental benefits can offer. This requires proper handling of family resources.

You and your attorney need to understand the specific needs of your child with the disability and be familiar with local, state, and federal entitlement, and welfare and sliding scale fee programs upon which your child may depend for lifetime care and support. But most importantly, you need to know about what is commonly referred to as a "special needs" trust. A special needs trust provides that the Trustees distribute funds from the trust for items not provided by the government. Under current law, a properly worded special needs trust is not considered a countable asset of the beneficiary.

As an attorney and volunteer with The Arc of Illinois and Massachusetts, I frequently review wills and trusts for members of The Arc. Nearly 90 percent of the wills and trusts that I review are drafted in such a way that the child can either not receive government benefits or remain eligible for them. Often the wills are not even properly written to avoid a guardianship of the estate. It is unfortunate but most attorneys are not familiar with special needs trusts.

As parents and as your child's advocates, you need to become familiar with the estate planning methods or options often recommended by attorneys and to understand the advantages and disadvantages of each. Which method you choose depends on the size of your estate, your child's needs and the availability of a trusted and responsible family member or friend to manage your child's trust assets. The two most frequently recommended methods are "disinheritance" and "support" trusts.

Lawyers frequently recommend disinheritance to preserve an individual's eligibility for government benefits. However, I never recommend it, even for families with small estates. I believe that disinheritance often offends the individual with a disability and it is often painful for the parent to think about disinheriting the one child who needs their help the most. If a parent or grandparent has a trusted relative or friend who can serve as trustee, there is no reason why a special needs trust should not be used even for small estates.

Frequently parents tell me they have disinherited their child with a disability and plan to rely upon a gift to a sibling, who is then obligated to look out for the child's interests. Such a gift is "morally obligated," not legally enforceable, and there is no guarantee that the funds will continue to be used for that person's care and support. Even when your non-disabled child is extremely conscientious and reliable, many problems could arise that are beyond the ability of the sibling to control. For example, the funds are considered part of the sibling's estate and will go to legal heirs upon the sibling's death, can be claimed by creditors, or by the sibling's spouse in the event of divorce.

The other estate planning method frequently recommended by lawyers is potentially more harmful than disinheritance. Lawyers who are not familiar with eligibility for government benefits and who think of the person with a disability as the "eternal child" often draft a traditional "support" trust. Even if this trust has what is called a discretionary, spendthrift clause that protects the trust assets from the child's creditors, it may not protect the entire trust from being taken by the state.

The reason is that states often claim that their limited resources are only for the care of people with disabilities who are indigent and unable to care for themselves. If a beneficiary of a support trust has a disability and is receiving government benefits, the state may take the position that it should be reimbursed from that trust for the cost of providing care. Therefore, the trustee may be forced to turn over the assets of the support trust to the state if the state is providing services for the person with the disability. If your child requires services from government programs, their trust's assets may be jeopardized in a support trust. Moreover, your child's right to support from such a trust may jeopardize eligibility for certain important government benefits such as Medicaid.

Recent legislation may prevent the loss of an entire estate due to a poorly worded estate plan. Major federal legislation affecting Medicaid benefits was enacted August 10, 1993. This legislation allows a court to order the assets of a person with a disability who is less than age 65 to be placed in trust for the benefit of the individual. At the time of the death of the beneficiary, the state will be entitled to reimbursement from the remainder of the trust for all funds spent on behalf of the individual. However this is far preferable to the beneficiary losing all of one's assets to the point of impoverishment in order to re-qualify for Medicaid, a benefit program which provides residential care among other things.

In summary, a special needs trust remains the only estate planning option that avoids the loss of assets meant to supplement your son or daughter's life. A special needs trust enables your child to receive ongoing goods and services from an adequate share of your estate while still preserving the child's eligibility for

government benefits and the care and support these benefits can provide. If properly drafted, it protects the assets of the trust from liability for services which are available from the state.

If you already have a trust and are not sure if it is a support trust or a special needs trust, look at the language in the trust document which states the primary purpose of the trust. If your trust indicates that the primary purpose is for the "care, support and benefit" of the beneficiary, then you most likely have a support trust. If your trust states that the purpose of the trust is to "supplement and not to supplant" state and federal benefits, then you again most likely have a special needs or supplemental needs trust.

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