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7 Tips for Helping Families with Special Needs

When examining the unique planning requirements of families with children, grandchildren or other family members (such as parents) with special needs, it is important to be aware of numerous misconceptions that can result in costly mistakes. Understanding the pitfalls associated with special needs planning is a must for all of us who assist families who have loved ones with special needs.

Tip #1: Avoid disinheriting the special needs beneficiary. Many disabled persons receive Supplemental Security Income (“SSI”), Medicaid or other government benefits to provide food, shelter and/or medical care. The loved ones of the special needs beneficiaries may have been advised to disinherit them – the beneficiaries who need their help most – to protect those beneficiaries’ public benefits. But these benefits rarely provide more than basic needs. And this solution (which normally involves leaving the inheritance to another sibling) does not allow loved ones to help their special needs beneficiaries after they themselves become incapacitated or die. The best solution is for loved ones to create a special needs trust to hold the inheritance of a special needs beneficiary.

Planning Note: It is unnecessary, and in fact poor planning, to disinherit special needs beneficiaries. Loved ones with special needs beneficiaries should consider a special needs trust to protect public benefits and care for those beneficiaries during their own incapacity or after their death.

Tip #2: Procrastinating can be costly for a special needs beneficiary. None of us know when we may die or become incapacitated. It is important for loved ones with a special needs beneficiary to plan early, just as they should for other dependents such as minor children. However, unlike most other beneficiaries, special needs beneficiaries may never be able to compensate for a failure to plan. Minor beneficiaries without special needs can obtain more resources as they reach adulthood and can work to meet essential needs, but special needs beneficiaries may never have that ability.

Planning Note: Parents, grandparents, or any other loved ones of a special needs beneficiary face unique planning challenges when it comes to that child. This is one area where families simply cannot afford to wait to plan.

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Tip #3: Don't ignore the special needs of the beneficiary when planning. Planning that is not designed with the beneficiary's special needs in mind will probably render the beneficiary ineligible for essential government benefits. A properly designed special needs trust promotes the comfort and happiness of the special needs beneficiary without sacrificing eligibility.

Special needs can include medical and dental expenses, annual independent check-ups, necessary or desirable equipment (for example, a specially equipped van), training and education, insurance, transportation and essential dietary needs. If the trust is sufficiently funded, the disabled person can also receive spending money, electronic equipment and appliances, computers, vacations, movies, payments for a companion, and other self-esteem and quality-of-life enhancing expenses: the sorts of things families now provide to their child or other special needs beneficiary.

Planning Note: When planning for a beneficiary with special needs, it is critical that families utilize a properly drafted special needs trust as the vehicle to pass assets to that beneficiary. Otherwise, those assets may disqualify the beneficiary from public benefits and may be available to repay the state for the assistance provided.

Tip #4: A special needs trust does not have to be inflexible. Some special needs trusts are unnecessarily inflexible and generic. Although an attorney with some knowledge of the area can protect almost any trust from invalidating the beneficiary's public benefits, many trusts are not customized to the particular beneficiary's needs. Thus the beneficiary fails to receive the benefits that the parents or others provided when they were alive.

Another frequent mistake occurs when the special needs trust includes a pay-back provision rather than allowing the remainder of the trust to go to others upon the death of the special needs beneficiary. While these pay-back provisions are necessary in certain types of special needs trusts, an attorney who knows the difference can save family members and loved ones hundreds of thousand of dollars, or more.

Planning Note: A special needs trust should be customized to meet the unique circumstances of the special needs beneficiary and should be drafted by a lawyer familiar with this area of the law.

Tip #5: Use great caution in choosing a trustee. Loved ones or family members can manage the special needs trust while alive and well if they are willing to serve and have proper training and guidance. Once the family member or loved one is no longer able to serve as trustee, they can choose who will serve according to the instructions provided in the trust. Families or loved ones who create a special needs trust may choose a team of advisors and/or a professional trustee to serve. Whomever they choose, it is crucial that the trustee is financially savvy, well-organized and of course, ethical.

Planning Note: The trustee of a special needs trust should understand the trust maker's objectives and be qualified to invest the assets in a manner most likely to meet those objectives.

Tip #6: Invite others to contribute to the special needs trust. A key benefit of creating a special needs trust now is that the beneficiary's extended family and friends can make gifts to the trust or remember the trust as they plan their own estates. For example, these family members and friends can name the special needs trust as the beneficiary of their own assets in their revocable trust or will, and they can also name the special needs trust as a beneficiary of life insurance or retirement benefits. Unfortunately, many extended family members may not be aware that a trust exists, or that they could contribute money to the special needs trust now or as an inheritance later.

Planning Note: Creating a special needs trust now allows others, such as grandparents and other family members, to name the trust as the beneficiary of their own estate planning.

Tip #7: Relying on siblings to use their money for the benefit of a special needs child can have serious adverse effects. Many family members rely on their other children to provide, from their own inheritances, for a child with special needs. This can be a temporary solution for a brief time, such as during a brief incapacity if their other children are financially secure and have money to spare. However, it is not a solution that will protect a child with special needs after the death of the parents or when siblings have their own expenses and financial priorities.

What if an inheriting sibling divorces or loses a lawsuit? His or her spouse (or a judgment creditor) may be entitled to half of an inheritance and will likely not care for the child with special needs. What if the sibling dies or becomes incapacitated while the child with special needs is still living? Will his or her heirs care for the child with special needs as thoughtfully and completely as the sibling did?

Siblings of a child with special needs often feel a great responsibility for that child and have felt so all of their lives. When parents provide clear instructions and a helpful structure, they lessen the burden on all their children and support a loving and involved relationship among them.

Planning Note: Relying on siblings to care for a special needs beneficiary is a short-term solution at best. A special needs trust ensures that the assets are available for the special needs beneficiary (and not a former spouse or judgment creditor of a sibling) in a manner intended by the parents.

Bonus Tip: Stay up to date on changes of the law. The rules applicable to special needs trusts are constantly changing. Most recently, the Social Security Administration changed the rules on special needs trusts that are created using assets of the special needs beneficiary (called a “self-settled special needs trust”). The new Social Security regulations require certain provisions to be present in any self-settled trust drafted after January 1, 2000 that allows for early termination of the trust (termination prior to the death of the special needs beneficiary).

If these required provisions are not in the trust, the special needs beneficiary could lose SSI or Medicaid eligibility. The new regulations went into effect October 1, 2010. Please contact us if you have questions about the new regulations or if you would like more information on the changes.

Planning Note: A recent change in the Social Security Administration regulations governing self-settled special needs trusts could render some existing trusts invalid for SSI or Medicaid purposes. It is imperative to stay up to date on changes in the rules that apply to special needs trusts to ensure the benefits received by a special needs beneficiary are not jeopardized as a result of changes in the law.

Conclusion: Planning for a special needs beneficiary requires particular care and knowledge on the part of the planning team. A properly drafted and funded special needs trust can ensure that a special needs beneficiary has sufficient assets to care for him or her, in a manner intended by loved ones, throughout the beneficiary’s lifetime. Please contact us if you have any questions or would like to discuss any of the above information further.

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