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Welcome!

You are reading *The Voice*, a newsletter published by The Special Needs Alliance. Our purpose is to provide information--and answers--about special needs planning for family members and professionals. We hope this newsletter helps you. We would love to hear your questions, suggestions and comments; please feel free to [e-mail us](#). We also encourage you to forward our newsletter to others who might benefit from the information here, or who might have similar questions.

Estate Planning for Families With Special Needs Children



Introduction: Families with special needs children must exercise extra care in making their estate plans. This is true whether their special needs child is still a minor or now an adult, and particularly so when the child is – or in the foreseeable future will be -- receiving needs-based public benefits such as SSI or Medicaid. While planning considerations for such a child will vary depending upon the child’s age, competency, and other family considerations, the goal is always the same: parents want their estates utilized to enhance and enrich the life of their special needs child while maintaining the child’s enrollment in essential public benefits programs. These goals can be met through the use of a properly prepared special needs trust.

The essence of all special needs estate planning is to ensure that the portion of the parents’ estate which passes to their special needs child at the time of their death is not considered an “available asset,” as defined by public benefit agencies. Parents must be mindful of both income and principal, as too much monthly income, as well as too much “cash,” can negatively impact their child’s future eligibility for benefits.

Purpose: Special needs planning works to preserve public

benefits for the disabled child while supplementing and enhancing the quality of the child's life. This type of planning is useful for many different purposes, including

—lifetime money management for the benefit of the disabled child;

—protecting the child's eligibility for public benefits; and

—ensuring a pool of funds available for future use in the event public funding should cease or be restricted.

Planning Options: The options available to families in making an estate plan for a special needs child who is receiving needs-based public benefits include the following:

—Disinherit the child. This is the simplest option, but it does nothing to accomplish the essential purpose of enriching the life of the special needs child.

—Give the estate to the brothers and sisters. At the parents' death the entirety of the estate is distributed to the child's siblings, with the understanding that they will "take care of" their disabled brother or sister. There are inherent risks with such an approach, including claims by the siblings' creditors, bankruptcy, divorce, mismanagement of funds, etc. This may be appropriate when the child's potential inheritance is modest.

—Leave an inheritance to the disabled child. The outcome of this planning option will be the almost certain negative impact on the child's continued eligibility for publicly funded benefits. At the least, benefits may be reduced. In the worst case scenario, the child may be rendered ineligible for SSI and Medicaid, and with this ineligibility for assisted housing, supported employment, vocational rehabilitation, group housing, job coaching, attendant personal care aides, and transportation assistance. The key benefit is Medicaid, as this program represents the child's ability to access not only essential health care but many other public assistance programs.

—Leave any inheritance in a Special Needs Trust. This last option will be preferred by most families in their efforts to provide and ensure a positive outcome for a special needs child. By using a properly drafted – and properly administered – Special Needs Trust, the child will continue to qualify for public assistance programs that would otherwise be unavailable to the child, especially the "means tested" programs that require the child to meet

strict financial eligibility criteria. A Special Needs Trust works because the assets held in the trust are not “available” to the child. These types of trusts must be discretionary spendthrift trusts, with strict limits on the trustee’s ability to give money to the child. Under no circumstances can the special needs child force the trustee to make trust money available to the child. An additional benefit of the Special Needs Trust is that because the child is often unable to manage his or her own finances, the parents, in creating the trust, will appoint a trustee to act as the child’s money manager, and in so doing, ensure proper financial management after their death.

During Life or at Death? Families have the option of creating a Special Needs Trust at their death by incorporating a trust within a Last Will and Testament – this is called a “testamentary trust.”

The other option is for the parents to create a Special Needs Trust while alive -- not surprisingly, this is often referred to as a “living trust” (or inter vivos trust). The advantages of the living trust include:

- the avoidance of a probate;
- the creation of a trust to which other family members can make contributions, most usually the grandparents; and
- an opportunity for a co-trustee to gain “hands on” experience in administering the trust.

Revocable or Irrevocable? Tax considerations come into play in the decision to make the Special Needs Trust either revocable or irrevocable. Generally speaking, the family will make the trust revocable whenever:

- the goals include maintaining maximum control over the trust; and
- the family is not concerned with income tax considerations.

Correspondingly, the use of an irrevocable trust may be appropriate when the family is concerned with:

- income tax considerations; and
- if more than a million dollars will be going into the trust, possible federal estate and gift taxes.

Tax planning is beyond this beyond the scope of this article, so be sure to consult with your attorney, CPA or financial advisor if there are any special tax considerations in the creation of your Special Needs Trust.

Selecting Your Trustee: The Trustee will be responsible for administering your Special Needs Trust. So selecting your Trustee is one of the most important decisions your family will make in ensuring the long-term success of your Special Needs Trust. Given the natural pressures inherent in all families, someone in your family may consider the funds in the Special Needs Trust as “their” money, rather than the money of your special needs child. This can be a dangerous situation, especially as to your child’s continued eligibility for public benefits. In most families, it is best to consider selecting an independent, non-family member to serve as your Special Needs Trustee. The range of options includes:

- a parent, sibling or another “distant” relative;
- your attorney;
- a Trust company or a financial institution;
- a non-profit organization -- especially one with experience in special needs; or
- co-Trustees, usually a family member acting with a trust company.

The selection of any of these potential Trustees has both advantages and disadvantages. You should closely counsel with your attorney or financial advisor before making your Trustee selection.

Conclusion: This brief summary is just the start of your enquiry as you begin your special needs estate plan. By working closely with your attorney, your CPA, and your financial planner, you will develop a much greater understanding of the options available to you and your family in making an appropriate estate plan for your special needs child. After making your wishes known and getting the appropriate documents in place, you will have taken crucial steps in assuring that this child will receive proper care when you are no longer able to provide that care yourself.

About the Author: James M. O’Reilly is a Certified Elder Law Attorney in Las Vegas, Nevada, whose practice focuses on special needs planning, elder law and estate planning. Mr. O’Reilly is a member of the Special Needs Alliance, a non-profit organization dedicated to serving the legal planning needs of people with disabilities and their families. Contact information for a member in your state may be obtained by calling toll-free (877) 572-8472, or by

visiting www.specialneedsalliance.com.