

Special Needs Planning

Introduction

Estate planning by parents who have children with disabilities includes the following challenges:

How do you leave funds for the benefit of the child without causing the child to lose important public benefits?

How do you make sure that the funds are well managed?

How do you make sure that your other children are not over-burdened with caring for the disabled sibling, and that any burdens fall relatively evenly among the siblings?

What is fair in terms of distributing your estate between your disabled child and your other children?

How do you make sure there is enough money to meet your disabled child's needs?

Often, parents of children with special needs try to resolve these issues by leaving their estates to their other children, leaving nothing to the disabled children. They have a number of reasons for this approach: The disabled child should not receive anything because she can't manage money and would lose her benefits. She does not need any

inheritance because she will be taken care of by the public benefits she receives. The other children will take care of their sister.

This approach is to be discouraged for a number of reasons. First, public benefits programs are often inadequate. They need to be supplemented with other resources. Second, both public benefits programs and individual circumstances change over time. What's working today, may not work tomorrow. Other resources need to be available, just in case. Third, relying on one's other children to take care of their siblings places an undue burden on them and can strain relations between them. It makes it unclear whether inherited money belongs to the healthy child to spend as he pleases, or whether he must set it aside for his disabled sister. If one child sets money aside, and another does not, resentments can build that may split the family forever.

The better answer to many of these questions is the Supplemental Needs Trust, also often called a "Special Needs Trust." Such trusts fulfill two primary functions: The first is to manage funds for someone who may not be able to do so himself or herself due to disability. The second is to preserve the beneficiary's eligibility for public benefits, whether that is MassHealth, Supplemental Security Income, public housing, or any other program. They come into play in a multitude of situations, including parents planning for a disabled child, a disabled individual coming into an inheritance, winning or settling a personal injury claim, or one spouse planning for a disabled spouse.

First, a short explanation of what trusts are and how they work: A trust is a form of ownership of property, whether real estate or investments, where one person—the trustee—manages such property for the benefit of someone else—the beneficiary. The trustee must follow the instructions laid out in the trust agreement as to how to spend the trust funds on the beneficiary's behalf—whether and when to distribute the trust income

and principal. In general, trusts fall into two main categories: self-settled trusts that the beneficiary creates for himself with his own money and third-party trusts that one person creates and funds for the benefit of someone else.

Each situation and each benefit program has its own rules which affect the drafting, funding, and administration of special needs trusts. The public benefit programs in many ways track the treatment of trusts in terms of creditor protection. Just as you cannot create a trust for your own benefit and protect the trust funds from creditors (the new Delaware and Alaska trusts being an exception to this long-accepted rule), you generally cannot create a trust for your own benefit and have the funds uncountable for purposes of MassHealth, SSI, and other public benefits programs. However, MassHealth and SSI have provided for “safe harbors” that permit the creation of self-settled supplemental needs trusts in certain circumstances.

Preserving Public Benefits

In general, if one person creates a trust for the benefit of someone else, and the trust is drafted to give the trustee complete discretion whether and when to make distributions to the beneficiary, the trust funds will not be considered as available when considering the trust beneficiary’s eligibility for public benefits. Unfortunately, matters get more complicated when the trust funds are actually used for the beneficiary. For instance, trust funds distributed to the beneficiary will reduce his SSI dollar for dollar. In many circumstances, trust funds used on the beneficiary’s behalf will also cause a reduction in SSI benefits. In other words, while the existence of a properly-drafted trust will not affect eligibility for benefits, the use of the trust funds could if care is not taken.

As a result, some supplemental needs trusts are written to restrict the trustee's discretion to make payments so that only those payments from the trust that will not affect eligibility for public benefits are permitted. Other trusts are written to give the trustee complete discretion, but the trustee receives instruction on how to make distributions to minimize their impact on eligibility for benefits. In most cases, the second approach is preferred because it allows for more flexibility. Since the future cannot be predicted with any certainty, flexibility permits the trustee to adjust to whatever takes place.

Choice of Trustee

Choosing a trustee is one of the most difficult parts of planning for a child with special needs. The trustee of a supplemental needs trust must be able to fulfill all of the normal functions of a trustee—accounting, investments, tax returns, and distributions—and also be able to meet the needs of the special beneficiary. The latter can include an understanding of various public benefits programs, sensitivity to the needs of the beneficiary, and knowledge of services that may be available.

There are a number of possible solutions available. Often parents choose to appoint co-trustees—a bank or law firm as a professional trustee along with another child as a family trustee. Working together, they can provide the necessary resources and experience to meet the needs of the child with special needs. Unfortunately, in many cases such a combination is not available. Professional trustees generally require a minimum amount of funds in the trust, usually at least \$500,000. Otherwise, their fees become unreasonable in relation to the size of the trust. In other situations, there is no appropriate family member to appoint as co-trustee.

Where the size of the trust is insufficient to justify hiring a professional trustee, two solutions are possible. The first is simply to have a family member trustee who would hire accountants, attorneys, and investment advisors to help with administering the trust. The second is to use a pooled trust. In Massachusetts, two non-profit agencies provide pooled trusts—the CJP Disabilities Trust and the Plan of Massachusetts Trust—through which they manage funds left for individuals with disabilities. These are “third-party” pooled trusts, not to be confused with “(d)(4)(C)” trusts that are described below.

Where no appropriate family member is available to serve as co-trustee, the parent may direct the professional trustee to consult with named individuals who know and care for the child with special needs. These could be family members who are not appropriate trustees, but who can serve in an advisory role. Or they may be social workers or others who have both personal and professional knowledge of the beneficiary and the resources available for her care. This role may be formalized in the trust document as a “Care Committee.” Again, where no such individuals exist, the pooled trusts described above provide a solution. Both trusts have professionals on staff that can provide the care component of a special needs trust.

Funding the Trust

A number of issues arise with respect to the question of how much to put into the trust. First, how much will your child with special needs require over her life? Second, should you leave the same portion of your estate to all of your children, no matter their need? Third, how will you assure that there is enough money?

The first question is a difficult one. It depends on what assumptions you make about your child's needs and the availability of other resources to fulfill those needs. A financial planner with experience in this area can help make projections to assist with this determination. However, it is better to err on the side of more money rather than less. You cannot be certain current programs will continue. In addition, you have to factor in paying for services, such as case management, that you provide free-of-charge today.

If these assumptions mean that your child with special needs will require a large percentage of your estate, how will your other children feel if they receive less than their pro rata share? After all, your estate may already be smaller than it would be otherwise due to the time and money spent providing for the child with special needs. Moreover, your other children may have received less of your attention growing up than they would have otherwise had they not had a sibling with special needs.

One solution to the question of fairness and to the challenge of assuring that there are enough funds is life insurance. You could divide your estate equally among your children, but supplement the amount going to the supplemental needs trust for your child with special needs with life insurance. The younger you are when you start, the more affordable the premiums will be. In addition, if you are married, the premiums can often be lower if you purchase a policy that pays out only when the second of you dies.

Safe Harbor Trusts

The above discussion primarily involves estate planning by parents for money they plan to leave for their children with special needs. A supplemental needs trust can also serve to hold any inheritance that may come from a grandparent or other family

member. However, it cannot hold funds belonging to the disabled individual himself. Generally, the funds held by such a self-settled trust would be considered available to the disabled beneficiary and render him ineligible for MassHealth or SSI benefits.

Fortunately, both MassHealth and SSI share two “safe harbor” trusts that permit a beneficiary to shelter his own funds, qualify for public benefits, and remain a continuing beneficiary of the trusts. These trusts fall in two categories: single-beneficiary and pooled trusts. The single-beneficiary trusts are generally referred to as “(d)(4)(A)” trusts, referring to the enabling statute, or “payback” trusts, referring to their primary feature that any fund remaining in the trusts upon the beneficiary’s death be used to reimburse the Commonwealth for any MassHealth expenditures it has made on the beneficiary’s behalf. Only if funds remain after such reimbursement may they be passed on to the beneficiary’s family.

The pooled trusts are generally referred to as “(d)(4)(C)” trusts, again referring to the enabling statute, or “pooled disability” trusts. Like the third-party pooled trusts described above, these are operated by non-profit organizations. Two exist in Massachusetts: the MARC Trust and the Berkshire ARC Trust.

Each of these safe-harbor trusts has its own rules that must be strictly followed to qualify for the MassHealth and SSI exceptions. “Payback” trusts must be created while the disabled individual is under age 65 and they must be established by his or her parent, grandparent, or legal guardian or by a court. They also must provide that at the beneficiary’s death any remaining trust funds will first be used to reimburse the state for MassHealth paid on the beneficiary’s behalf.

A non-profit association must manage pooled disability trusts. Unlike individual disability trusts, which may be created only for those under age 65, pooled trusts may

be for beneficiaries of any age and may be created by the beneficiary herself. In addition, at the beneficiary's death the state does not have to be repaid for its MassHealth expenses on her behalf as long as the funds are retained in the trust for the benefit of other disabled beneficiaries. (At least, that's what the federal law says; Massachusetts requires reimbursement under all circumstances.) Although a pooled trust is an option for a disabled individual over age 65 who is receiving Medicaid or SSI, those over age 65 who make transfers to the trust will incur a transfer penalty.