

# Special Needs Planning



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*The best interest of all family members is served when you secure the counsel of an experienced attorney who practices Special Needs Planning. Take comfort in knowing that you have performed a thorough investigation and planted measures to preserve your family assets and expected benefits in order to provide your special needs child with the best future that you are able.*



# Introduction



Estate planning by parents who have children with special needs include many 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 sibling with special needs?
- What is fair in terms of distributing your estate between your child with special needs and your other children?
- How do you make sure there is enough money to sustain your special needs child over time?



# Special Needs Trusts

Often, parents of children with special needs try to resolve these issues by leaving their estates to their other children and disinheriting the disabled child. They have a number of reasons for this approach: The special needs child shouldn't receive anything because she can't manage money and would lose her benefits. She doesn't 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 unsound 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 sibling places an undue burden on them and can strain relations between them. It makes it unclear whether inherited money belongs to the child to spend as he pleases, or





whether he must set it aside for his sister with special needs. If one child sets money aside, and the other doesn't, resentments can build that may split the family forever.

The better answer for many of these questions is the Supplemental Needs Trust, also often called a "Third Party Special Needs Trust." Such trusts fulfill two primary functions: The first, to manage funds for someone who may not be able to do so himself due to disability. The second, to preserve the beneficiary's eligibility for public benefits, whether that be SSI, Medicaid, public housing, or any other program.



# How Trusts Work

A trust is a form of ownership of property, whether real estate or investments, where one person – the trustee – manages the 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*** sometimes referred to as a “First Party Special Needs Trust” 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. A self-settled trust for an individual, who is disabled, coming into an inheritance or proceeds from a personal injury or medical malpractice claim; A third-party trust for a parent planning for a special needs child, or one spouse planning for a spouse with a disability.

Each situation and each benefit program has its own rules that affect the drafting, funding and administration of special needs trusts. Generally, you cannot create a trust for your own benefit and have the funds uncountable for purposes of Medicaid, SSI and other public benefit programs. However, Medicaid and SSI have provided for “safe harbors” that permit the creation of self-settled special needs trusts in certain circumstances.



# Accessing and Preserving Public Benefits

*I*n general, if one person creates a trust for the benefit of someone else, and the trustee has complete discretion about 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 income and assets are actually used for the beneficiary. For instance, trust funds distributed directly to the beneficiary will reduce his SSI dollar for dollar. Trust funds used for food and shelter 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. Since the future cannot be predicted with any certainty, flexibility permits the trustee to adjust to whatever may happen.



# 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 includes 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 a family member. 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 may not be available if the trust assets are below a certain level. There may not be an appropriate family member to act as a co-trustee.

Where the size of the trust is insufficient to justify hiring a professional trustee, two solutions are possible. The first is to have a family member trustee who would hire attorneys, accountants and investment advisors to help with administering





the trust. The second is to use a *pooled trust*. Medicaid and SSI laws permit “(d)(4)(C)” trusts or “pooled trusts” for beneficiaries with special needs. Such trusts pool the resources of many beneficiaries, and those resources are managed by a non-profit organization.

To find a listing of pooled trusts in your state, refer to the Special Needs Answers Web site: [www.specialneedsanswers.com](http://www.specialneedsanswers.com) where you will find a listing of pooled trusts around the country.

Where no appropriate family member is available to serve as co-trustee, the parent may appoint a professional trustee and 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 trust described above provides a solution. Both trusts have professionals on staff who 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 money 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. The answer 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. But in all cases it's better to err on the side of more money rather than less. You can't be certain current public benefits programs will continue. And you have to factor in paying for services, such as case management if you are not available.

If these assumptions mean that your child with special needs will require a large percentage of your estate, how will you provide for your other children, as you desire?

One solution to the challenge of assuring that there are enough funds is **life insurance**. You could





divide your estate equally among your children, but use life insurance to supplement the amount going to the supplemental needs trust for your child with special needs. The younger you are when you start, the more affordable the premiums will be. And if you are married, the premiums can often be lower if you purchase a policy that pays out only when the second parent dies.



# Safe Harbor Trusts

So far, we've primarily been discussing estate planning by parents and the money they plan to leave for their child 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 should never hold funds belonging to the disabled individual. As a general rule, the funds held by such a *self-settled* trust would be considered available to the disabled beneficiary and render him ineligible for Medicaid or SSI benefits.

Fortunately, both Medicaid 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 "pay-back" trusts, referring to their primary feature that any fund remaining in the trusts upon the beneficiary's death be used to reimburse the state for any Medicaid expenditures it made on the beneficiary's behalf. Only funds that remain after such reimbursement may pass 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, these are established by non-profit organizations.





Each of these safe-harbor trusts has its own rules, which must be strictly followed to qualify for Medicaid and SSI exceptions.

***“Payback Trusts”*** -- also referred to as a “Self-Settled Special Needs Trust” -- must be created while the special needs individual is under age 65 and they must be established by her parent, grandparent or legal guardian or by a court. They must provide for the sole benefit of the beneficiary and at the beneficiary’s death any remaining trust funds will first be used to reimburse the state for Medicaid paid on the beneficiary’s behalf.

***“Pooled Disability Trusts”*** -- also referred to as a “Pooled Trust” -- must be managed by a non-profit association. Unlike Payback Trusts, upon the beneficiary’s death the state does not have to be repaid for its Medicaid expenses on her behalf as long as the funds are retained in the trust for the benefit of other special needs beneficiaries. (At least, that’s what the federal law states; some states, Massachusetts for example, are known to require reimbursement under all circumstances.)



# It's Up to You

Planning today and for the future can ensure the highest quality of life for your child with special needs. Trusts can help families manage funds while also preserving a child's eligibility for public benefits. An experienced Special Needs Planner can help you devise the best solution for your child.





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