The Guide to Special Needs Planning

Planning for Your Child with Special Needs

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MEMBER OF ACADEMY OF SPECIAL NEEDS PLANNERS

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Planning for Your Child with Special Needs

specialneedsplanners.com

The information in this guide should not be considered legal advice. While we strive to provide legal information in our ASNP Guides that is as detailed, reliable, and understandable as possible, the Guides are not a substitute for an attorney's application of the law and their years of experience to a particular client situation. We urge readers to use the Guides as background material and to consult with one of our members before taking action.

The best interest of all family members is served when you secure the counsel of an experienced professional who practices special needs planning. Then you can take comfort in knowing that you have done all you can to preserve both your family's assets and expected government benefits to provide your loved one who has special needs the best future possible.

Introduction

For parents who have children with special needs, estate planning includes 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 ensure that the funds are managed well?
- How do you ensure that your other children are not overburdened with caring for their sibling with special needs?
- What is fair for distributing your estate between your child with special needs and your other children?
- How do you ensure that 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 child with a disability.**

Parents have several justifications for this approach: First, the special needs child should not receive anything because they cannot manage money and would lose their benefits. Second, their child with special needs does not need an inheritance because they will be fully taken care of by public benefits. Finally, the other children will take care of their sibling with special needs. This approach is unsound for several reasons:

- **Public benefits programs are often inadequate to fully care for individuals with special needs.** Such programs need to be supplemented with other resources.
- Both public benefits programs and an individual's circumstances can change. **What is working today may not work tomorrow.** Other resources must be available, just in case.
- Relying on a parent's other children to take care of their sibling places **an undue burden on the other children and can strain relations** between them and their sibling with special needs. It also makes it unclear whether inherited money belongs to the child to spend as they please or if it must be set aside for their sibling with special needs. If one child sets money aside and another does

not, resentments can build that may divide the family forever.

The better solution for many of these issues is to create a third-party supplemental needs trust, also called a *third-party special needs trust*. This type of trust fulfills two primary functions: (i) managing funds for someone who may not be able to do so themselves due to disability and (ii) preserving the special needs beneficiary's eligibility for public benefits, whether that be SSI, Medicaid, public housing, or another program.

How Trusts Work

A trust is a form of property ownership in which 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 about how to spend the trust funds on the beneficiary's behalf—that is, whether and when to distribute the trust income and principal.

Special needs trusts fall into two main categories: *self-settled trusts*, sometimes referred to as a *first-party special needs trusts*, which the beneficiary creates for themselves with their own money, and *third-party trusts*, which one person creates and funds for the benefit of someone else. A self-settled trust is appropriate for an individual who is disabled and comes into an inheritance or receives proceeds from a personal injury or medical malpractice claim; a third-party trust is best for a family member who is planning for a loved one with special needs or one spouse who is planning for their spouse with a disability.

Each situation and each benefit program have their own rules that affect the drafting, funding, and administration of special needs trusts. You cannot create a trust for your own benefit, have the funds available to you, and have them uncountable for Medicaid, SSI, and other need-based public benefit programs. However, **Medicaid and SSI provide safe harbors** that permit the creation of self-settled special needs trusts in certain circumstances.

Accessing and Preserving Public Benefits

If a third-party special needs trust for the benefit of someone else is properly drafted and the trustee has complete discretion about whether and when to make distributions to the beneficiary, the trust funds will not be considered to be an available resource when evaluating the trust beneficiary's eligibility for public benefits.

Matters get more complicated when the trust's income and assets are used for the beneficiary. For instance, trust funds distributed directly to the beneficiary will reduce their SSI dollar for dollar. Trust funds used for shelter will also cause a reduction in SSI benefits. While the existence of a properly drafted special needs trust will not affect eligibility for benefits, using the trust funds for certain purposes could affect eligibility if care is not taken.

Some supplemental needs trusts restrict the trustee's discretion to make payments such that only payments from the trust that will not affect eligibility for public benefits are permitted. Other trusts give the trustee complete discretion, but the trustee receives instructions 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.

Choosing a 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 (or delegate) 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 needs beneficiary.

Meeting the beneficiary's needs includes having an understanding of various public benefits programs, a sensitivity to the needs of the beneficiary, and knowledge of services that may be available.

There are several possible trustee options available. Parents often appoint co-trustees—a bank or law firm as a professional trustee, along with a family member. Working together, they can provide the resources and experience to meet the needs of the child with special needs. Often, however, this co-trustee combination is not possible. Professional corporate trustees (such as large financial institutions with in-house trust departments) may not be available if the trust assets are below a certain monetary amount, or there may not be an appropriate family member to serve as a co-trustee.

When the size of the trust does not justify hiring a professional corporate trustee, other solutions are possible. The family can look to private fiduciaries, who require lower asset thresholds for management and charge hourly for services. Many families want to keep the fiduciary close to home and seek to use **a family member as trustee**. This trustee would then **hire attorneys**, accountants, and investment advisors to help administer the trust. Lastly, a family may choose to utilize a third-party pooled trust, which may provide professional trust administration and financial management for more modest estates or serve as a viable alternative to a corporate or family trustee.

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 the pooled resources are **managed by a nonprofit organization**.

To find a listing of pooled trusts in your state, refer to the Special Needs Answers website **(specialneedsanswers.com)**.

If 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 individuals 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 the beneficiary's care. This role may be formalized in the trust document as a care *committee*. Again, where no such individuals exist, a pooled trust as described above provides a solution. Pooled trusts have professionals on staff who can provide the care component of a special needs trust.

Funding The Trust

Several 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 their lifetime? Second, should you leave the same portion of your estate to all of your children, no matter their need? Third, how will you ensure 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 can help make projections to assist with this determination. But in all cases, it is better to err on the side of leaving more money rather than less. You cannot be certain that current public benefits programs will continue. Also, consider the cost of services, such as case management, if you are not available. If these assumptions mean that your child with special needs will require a larger percentage of your estate, how will you provide for your other children as you desire?

One solution to the challenge of ensuring 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.

Exempt Trusts

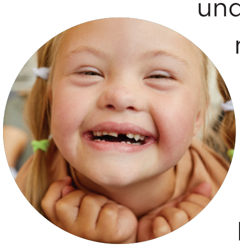
So far, we have primarily been discussing estate planning by parents and the money they plan to leave for their child with special needs. A supplemental needs trust can also hold any inheritance that may come from a grandparent or other family member. However, it should never hold funds belonging to the disabled individual. As a general rule, the funds held by a self-settled trust would be available to the disabled beneficiary and render the beneficiary **ineligible for Medicaid or SSI benefits**.

Fortunately, both Medicaid and SSI recognize two types of exempt trusts that permit a beneficiary to shelter their own funds, qualify for public benefits, and remain a continuing beneficiary of the trusts. These trusts fall into two categories: single-beneficiary and pooled trusts.

The single-beneficiary trusts are self-settled special needs trusts often called (d)(4)(A) trusts, referring to the enabling statute, or payback trusts, because any funds remaining in this type of trust must be used to reimburse the state upon the beneficiary's death for any Medicaid expenditures 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 called (d)(4)(C) trusts, again referring to the enabling statute, or pooled *disability trusts*. Like the third-party pooled trusts described above, these trusts are **established by nonprofit organizations**.

Each of these exempt trusts has its own rules, which must be strictly followed to qualify for Medicaid and SSI exceptions. Payback trusts/self-settled special needs trusts: Must be created while the individual with special needs is under age 65, and they must be established by the disabled individual; their 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 reimburse the state for Medicaid benefits paid on the beneficiary's behalf.



Pooled disability trusts: Must be administered by a nonprofit organization. Unlike a payback trust, there is no choice of trustee. Another difference between a pooled and a payback trust is what happens upon the beneficiary's death. Any remaining assets in the pooled trust do not have to be used to repay the state for Medicaid expenses as long as the funds are retained by the trust. The retained funds are used for other people with disabilities.

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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