



THE GUIDE TO

Special Needs Planning

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The Guide to Special Needs Planning

*Planning for Your Child
with Special Needs*

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The information in this guide should not be considered legal advice. While we strive to provide as detailed, reliable and understandable legal information as possible in our ASNP Guides, they cannot substitute for an attorney applying the law and 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. Take comfort in knowing you have performed a thorough investigation and have taken steps to preserve both your family's assets and expected government benefits to provide your loved one with special needs the best future you are able.

INTRODUCTION

Estate planning by parents who have children with special needs 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 make sure that the funds are well managed?
- How do you make sure your other children are not over-burdened with caring for the sibling with special needs?
- What is fair for 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 child with a disability.**

They have several reasons for this approach: The special needs child shouldn't receive anything because she can't manage money and would lose her benefits. She needs no 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 several reasons:

- **Public benefits programs are often inadequate.** They need to be supplemented with other resources.
- Both public benefits programs and individual circumstances change. **What's working today may not work tomorrow.** Other resources must be available, just in case.
- 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: to manage funds for someone who may not do so himself due to disability, and 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 about how to spend the trust funds on the beneficiary's behalf – whether and when to distribute the trust income and principal.

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 is appropriate for an individual who is disabled coming into an inheritance or receiving proceeds from a personal injury or medical malpractice claim; a third-party trust is best for a family member planning for a loved one with special needs, 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. You cannot create a trust for your own benefit and have the funds uncountable for 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

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.

Matters get more complicated when the trust income and assets are 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. While the existence of a properly-drafted trust will not affect eligibility for benefits, using the trust funds could if care is not taken.

Some supplemental needs trusts are written to restrict the trustee's discretion to make payments so 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.

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 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 several possible solutions available to choosing a trustee. Often parents appoint co-trustees – a bank or law firm as a professional trustee, with a family member. Working together, they can provide the resources and experience to meet the needs of the child with special needs. Often such a combination is not possible. Professional trustees may not be available if the trust assets are below a certain level or there may not be an appropriate family member to serve as a co-trustee.

Where the size of the trust does not justify hiring a professional trustee, two solutions are possible. The first has a **family member trustee who would hire attorneys,** accountants and investment advisors to help with administering the trust. The second uses a **third-party pooled trust,** which may provide the professional trust administration and financial management for more modest estates, or 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 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: 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

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 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 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's better to err on the side of more money rather than less.** You can't be certain 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 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 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 TRUST

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 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 available to the disabled beneficiary and render him **ineligible for Medicaid or SSI benefits**.

Fortunately, both Medicaid and SSI recognize two "**Exempt 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 into two categories: single-beneficiary and pooled trusts. The single-beneficiary trusts are "(d)(4)(A)" trusts, referring to the enabling statute, or "payback" trusts, referring to their primary feature that any funds remaining in the trusts upon the beneficiary's death be used to reimburse the state 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 “(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 non-profit organizations**.

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

“Payback Trusts” - also referred to as “Self-Settled Special Needs Trusts” - 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 reimburse the state for Medicaid benefits paid on the beneficiary’s behalf.



“Pooled Disability Trusts” - also referred to as “Pooled Trusts” - must be **administered by a nonprofit organization**. Unlike a payback trust, there is no choice of trustee. Another difference between a pooled and 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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