

Special Needs Trusts

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What is a special needs trust?

If you have a child or other loved one with special needs, you may want to establish a special needs trust. A special needs trust (or supplemental needs trust) is an estate planning tool that can help you provide for the needs of a disabled individual without jeopardizing his or her eligibility for government benefits. A qualified attorney can help you establish and administer this type of trust.

Tip: The term "special needs" is used in this discussion to describe any trust that is established to fund the supplemental needs of a disabled individual while maintaining that individual's eligibility for government benefits. The term includes not only trusts funded with a disabled individual's own funds (as governed by the Omnibus Budget Reconciliation Act of 1993 (OBRA '93)), but also trusts funded with assets from a third party (e.g., a parent or grandparent).

Why establish a special needs trust?

Unlike other types of trusts often used in estate planning, the primary goal of a special needs trust is to provide for the needs of a disabled individual throughout his or her life.

Federal and state benefits are generally available to qualifying children and adults who have special needs. If your child qualifies for government benefits, one of your goals may be to ensure that his or her eligibility continues into the future. A special needs trust can help you attain this goal. In addition, this type of trust can provide for supplementary care and services for your loved one.

Tip: Although this discussion focuses on using a special needs trust to benefit a disabled child, some types of special needs trusts may be established for a parent or other individual over age 65 who wants to preserve eligibility for nursing home benefits under Medicaid.

To preserve eligibility for Medicaid

Medicaid, a joint federal–state program, provides medical assistance to those who are disabled and can demonstrate financial need. Children and adults can qualify for Medicaid only if their monthly income and the value of their other assets fall below certain limits, which vary from state to state. (Most states set a \$2,000 asset limit.) For details, see [Eligibility for Medicaid](#).

In determining eligibility for Medicaid, a state may count only the income and assets that are legally available to the applicant. A special needs trust restricts the beneficiary's own direct access to the assets in the trust to such an extent that the assets are not considered legally available to the beneficiary. Thus, a special needs trust can protect Medicaid eligibility because assets in the trust are uncountable.

To preserve eligibility for Supplemental Security Income (SSI)

Children and adults with special needs who have limited income and resources often receive monthly benefits from Supplemental Security Income (SSI). These cash benefits can be used for basic needs such as housing and food. But because SSI benefits are need-based, inheriting money can mean that a child with special needs will lose his or her eligibility for this benefit program. By naming a special needs trust as your beneficiary instead of your child, however, assets can be devoted to the care of your loved one. In addition, since SSI recipients are normally automatically eligible for Medicaid benefits, preserving your child's eligibility for SSI may preserve his or her eligibility for Medicaid as well.

To provide additional care and services

A special needs trust can be especially useful if you want to provide care and services necessary for your child's well-being, without supplanting Medicaid benefits. Although Medicaid pays for a number of medical costs, including hospital bills, physician services, and long-term care, it will not subsidize items and services considered nonessential. These may include health-related expenses such as eyeglasses, dental care, rehabilitation services, and home health aide services, as well as personal expenses such as transportation, computer equipment, and vacations.

Caution: To ensure that trust assets are unavailable to the disabled beneficiary, the trustee must have sole discretion over the distribution of trust income and principal. The beneficiary must have no control over the trust and no right to demand distributions from the trust. The trustee should purchase goods and services directly on the beneficiary's behalf, instead of giving the beneficiary money from the trust to purchase items needed.

What requirements must a special needs trust meet?

If the trust is intended to supplement, rather than replace, government benefits, it must be properly drafted. Although requirements vary according to state law and the type of special needs trust being established, here are some of the rules that apply to special needs trusts in general:

- Generally, only a parent, grandparent, legal guardian, or court can set up a special needs trust. The disabled person, no matter how competent, cannot be the "creator" of the trust (even if the trust is funded by his or her personal assets).
- Funds in the special needs trust may not be available to the disabled beneficiary.
- The beneficiary cannot revoke the trust.
- The individual with special needs must be considered "permanently and totally disabled" under SSI criteria. Different rules apply to adults and children.
- Under the terms of the trust, the trustee may not be permitted to make payments or distributions that might interfere with government benefit eligibility (e.g., distributions cannot

be made directly to the beneficiary).

- Special needs trusts may be established as part of a will (known as a testamentary trust) or during the creator's lifetime (known as a living or inter vivos trust).
- Special needs trusts can hold an unlimited amount of funds and can be added to at any time.

What types of special needs trusts are available?

Although there are many types of special needs trusts, they fall into two general categories: the third-party special needs trust (funded with assets belonging to someone other than the beneficiary) and the self-settled trust (funded with assets belonging to the beneficiary).

Third-party special needs trust

The third-party special needs trust is established with funds that belong to someone other than the disabled beneficiary. For instance, a parent or grandparent may create such a trust under a will and fund it with a gift of cash, life insurance, or another asset. Upon the death of the disabled individual, any assets that remain in the trust can be distributed to whomever has been designated; if the third-party trust is properly drafted, the state will not have to be "paid back" for long-term care services when the disabled individual dies.

Self-settled trust

A self-settled special needs trust is established with funds owned by the disabled person. For instance, a self-settled trust might be established using a personal injury award or inheritance.

One type of self-settled trust is the qualified self-funded special needs trust. This kind of trust is created for the sole benefit of a disabled individual who is under age 65 at the time the trust is established. Upon the beneficiary's death, Medicaid must be "paid back" from the trust assets for any long-term care provided. This type of trust is also known as a (d)(4)(A) trust.

Another common type of self-settled trust is the qualified pooled trust, also known as a (d)(4)(C) trust. This kind of trust is established and managed by a nonprofit organization. Separate accounts are maintained for each trust beneficiary, but funds are pooled for investment and management purposes. Upon the beneficiary's death, the nonprofit organization receives assets remaining in the trust, and will reimburse Medicaid for benefits paid to the beneficiary. In some cases, surviving family members may be entitled to receive some or all of the remaining funds.

Caution: Self-settled trusts are complex and must comply with the requirements of OBRA '93 that govern them.

Caution: A parent can preserve his or her own eligibility for nursing home benefits under Medicaid by transferring his or her funds into a special needs trust established to benefit a disabled child, as long as the trust has a Medicaid payback provision.

How is a special needs trust typically funded?

In many cases, a special needs trust is established, but not funded, while the parent or other creator is alive. Upon the parent's death, his or her will transfers the disabled child's portion of an inheritance to the special needs trust. The trust (instead of the disabled child) can also be designated as the beneficiary of various assets, such as employee benefits and life insurance policies.

Typically, a special needs trust is funded using:

- Life insurance
- Cash (including gifts from relatives)
- Investments (e.g., stocks, bonds)
- Retirement plan benefits (e.g., pension benefits, IRA funds, 401(k) assets)
- Personal and real property
- Proceeds from a personal injury settlement (applies to self-settled trusts)

Although life insurance is one of the most popular funding methods (in particular, lower-cost survivorship life insurance), each method has advantages and disadvantages. To ensure that the trust is adequately funded, you'll need to estimate how much income your child is likely to need over the course of his or her lifetime.

What else should you consider?

If you're thinking about setting up a special needs trust, there are a few other points you should consider.

Selecting a trustee

A trustee is a person or institution selected to administer a trust and manage its assets. The trustee's role is to adhere to the terms of the trust document and fulfill its objectives. You may wish to name yourself or another family member as trustee of the special needs trust, or you may wish to name an attorney, bank, or other professional trustee. There are advantages and disadvantages to each. Another option is to name a family member and a professional trustee as co-trustees. For more information, see [Selecting a Trustee](#) .

Providing a letter of intent

If you set up a special needs trust through your will, you might also want to draft a letter of intent to describe how you want your child to be cared for after you're gone. Although it's not a legal document, it can provide important information to guardians, trustees, family members, and others involved in the care of your child. The letter may address such issues as your child's medical needs, daily routine, interests, likes and dislikes, religious practices, living arrangements, social activities, behavior management, and degree of self-sufficiency. Such a letter can prove invaluable to your child's caregivers and can also make the transition to a new living situation as smooth as possible for your child.

Informing family members

Explain to siblings or other family members why you're setting up the special needs trust. Although siblings might expect to receive equal inheritances, more resources will probably need to be set aside for the benefit of your child with special needs. Explanations and clear directions now may help avoid family conflicts later.

Working with a qualified attorney or financial professional

Special needs planning is complex and technical, and the laws that govern special needs trusts differ from state to state. To properly plan for your child's future, work with a qualified attorney or financial professional who has experience with the planning needs of families of disabled individuals. This person should also have a thorough understanding of the income, gift, and estate tax consequences that must be considered when funding and administering a special needs trust.

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