

Special Needs Trusts

The Problem

- For families with a special needs child, life is filled with unexpected questions and ongoing challenges. A child with special needs adds unique joys and lifetime difficulties, along with complex financial and emotional concerns for parents, siblings and guardians.
- Everyday needs like healthcare, therapy and education can quickly take precedence over long-term planning.
- Medicaid and Supplemental Security Income (SSI) are critical to a special needs child's financial support, but they are limited—hardly enough to provide for a lifetime of security and comfort.
- Because eligibility for Medicaid and SSI is based on available assets, a gift or inheritance meant to supplement this basic support can instead rob a special needs child of essential benefits by rendering the child ineligible when assets no longer meet the “means” test.
- Special needs planning can seem overwhelming, but it is essential to identify what your child will need in the future and think about the “what-ifs” that are likely to occur when you are no longer able to provide support.

The Solution

- Congress created the Section 529A ABLE account for special needs families. The 529A ABLE account provides tax-deferred growth on after-tax contributions, similar to a college savings 529 plan. Individuals are free to enroll in any state's program (although not all programs may be open to out-of-state residents). It is important to keep in mind that the allowable annual and total savings amounts are limited.
- To qualify for an ABLE account, the individual's disability or blindness must begin at age 26 or younger. Under the SECURE 2.0 legislation, starting in 2026, that age will increase to 46.
- A special needs trust continues to be an essential financial tool for ensuring adequate resources to provide a special needs child with a lifetime of security and comfort.
- When fully compliant with state and federal law and administered by a trustee, a special needs trust will not disqualify the beneficiary from Medicaid and SSI benefits.

How a Special Needs Trust Works

- A special needs trust is created for the sole benefit of a special needs child.
- The trustee has sole discretion over distributions. Often, a parent and a professional (such as an attorney or financial institution) will serve as co-trustees.
- Distributions are meant to supplement what the child receives through government programs and must be used discretely. For example, since SSI provides a small income for food and shelter, money paid out of the trust for food and shelter could significantly reduce SSI benefits.

- Distributions must be paid directly to service providers. Distributions that go to the beneficiary will be considered taxable income and could reduce government benefits.
- As a result of the SECURE 2.0 Act, special needs trusts that receive IRA assets may now list a charity as a designated beneficiary, and the charity may receive payments over the expected life span of the special needs beneficiary.

Three Types of Trusts

- There are two types of private special needs trusts—the first-party or self-settled trust and the third-party or estate planning trust.
- **The first-party trust** is an irrevocable trust funded with the child's own assets (usually from a legal settlement or an inheritance). It is a stand-alone document available to beneficiaries under age 65.
- **The third-party trust** is funded with contributions from family members, money directed to the trust from a will, or life insurance proceeds directed to the trust. It can be irrevocable or revocable, a stand-alone document or part of a will, and it has no age limit.
- Distributions from a first-party trust are limited to basic needs only. Distributions from a third-party trust do not have this limitation, so the trustee has much more flexibility.
- When the child dies, a first-party trust may pay funeral expenses, but remaining funds must be used to pay back the state agencies that provided the child with assistance during life, up to the total amount of benefits provided. With a third-party trust, after funeral expenses are paid, remaining funds go to named beneficiaries.
- Third-party trusts are highly preferable due to their flexibility in making distributions and the ability to pass on the remainder of the trust to other beneficiaries.
- **The pooled trust** is the third type of special needs trust—a good option for parents who don't feel they have enough money to justify creating a private trust. Pooled trusts are available through nonprofits that combine the assets of many individual beneficiaries. They offer expert administration and management but very little flexibility.

Funding Options

- Most parents fund a third-party special needs trust minimally during their lifetimes. Instead, they plan to fund the trust with money that becomes available when either parent dies—typically from life insurance proceeds or an inheritance or both.
- Historically, life insurance has proven to be the single most effective funding choice. The benefits of cash value life insurance as a funding vehicle are numerous. Proceeds are payable immediately in a lump sum at the death of the insured. Knowing the funding will be there provides peace of mind for all parties by ensuring that the special needs trust will be executed precisely as it was envisioned.
- Other funding options have drawbacks. Retirement plan assets incur taxes and, depending on the beneficiary, may have to be paid out within five or ten years after the owner's death. The value of securities and real estate fluctuates, and real estate can be difficult to sell in a timely manner.
- The cost of life insurance can be minimal compared to other accumulation methods. The policy owner buys future funds by making scheduled premium payments, and the amount of the death benefit is usually significantly greater than the premiums paid.

- Using life insurance to fund the special needs trust allows surviving siblings or other family members to inherit the other estate assets.

The Bottom Line

The best way to start is to prepare a future needs assessment specific to your child's needs and anticipated resources, including both public benefits (Medicaid and Supplemental Security Income) and private funds. You will want to keep "quality of life" issues in mind as you envision what your loved one will need—medical expenses beyond what is covered by government benefits, extra education expenses, housing and transportation costs, enrichment activities, caregiver and custodial expenses, and funds to meet personal needs.

As you explore options, you'll find that the special needs trust is unique in its ability to cover the additional expenses of your special needs child. Other options have serious drawbacks:

- Distributing assets directly to a special needs child will likely disqualify the child from government benefits.
- Disinheriting a child keeps the child's assets low but doesn't leave anything beyond minimal government benefits.
- Giving assets to another family member for the child's care raises a host of potential problems.
- 529A accounts, when available, provide tax benefits but limit savings.

Proper planning is essential. Special needs trusts fill an important role in the equation, and life insurance is the ideal funding vehicle.

A Special Needs Planning Profile

While other parents worry about how they'll pay for their kids' orthodontia and education, parents of special needs children have additional considerations that extend far beyond the first 18 to 22 years. These concerns range from current and future therapies to a lifetime of expenses for those extras that can positively impact quality of life. Special needs families have to think about how they will pay these expenses while still meeting the needs of other children and saving for retirement. Furthermore, they have to think about how a special needs child will live after they're gone.

These are daunting questions that often stop parents in their tracks. While creating a plan may feel overwhelming, it can actually ease financial and emotional concerns by addressing issues ranging from simple to challenging. Families who begin to tackle these issues now will find they have peace of mind down the road, so let's look at the various items to consider during this planning process.

Create a Special Needs Trust Funded With Life Insurance

A special needs trust is the most important element in a comprehensive financial plan designed to benefit a special needs child. Parents, grandparents or others can set aside money now by making gifts to the trust without worrying that the money will affect the child's eligibility for government benefits.

Most parents fund a third-party special needs trust minimally during their lifetimes.

Major funding takes place when either parent dies—typically from life insurance proceeds, an inheritance, or both. Even if no one contributes to the trust now, make the creation of a special needs trust a priority.

Historically, life insurance has proven to be the single most effective funding choice. The biggest benefit: proceeds are payable immediately at death in a lump sum. Knowing that funding will be there when it's needed provides peace of mind for all parties by ensuring that the special needs trust will be executed precisely as it was envisioned.

Review Beneficiary Designations

If you plan to leave money from retirement plans, IRAs or life insurance policies to your special needs child, make sure to designate the special needs trust as the beneficiary. Money going directly to the child will likely result in a loss or reduction of state and federal benefits. This applies to anything with a beneficiary designation, including annuities, savings bonds, UTMA accounts, etc. It's important to remember that beneficiary designations—not your will—determine these distributions.

Draft a Will

Your will specifies what will be done with your assets after your death. Without a will, a probate court judge could name your special needs child as a beneficiary of your estate, which could make your child ineligible for government benefits. By drafting a will, you make certain that assets are distributed properly to your heirs and to the special needs trust you create.

Name an Executor, Trustee and Guardian

Selecting an executor for your estate, a trustee for the special needs trust and a guardian for your special needs child is an important and often challenging task. In selecting these important people, keep in mind that the family member who may be best at handling administrative and financial matters after your death may not

be the right person to supervise the care of your special needs child. Give careful consideration to whether or not there is a family member who is willing and capable of caring for your child after you are gone. If need be, consider naming an agency that specializes in providing the services your child will need.

Apply for Guardianship or Power of Attorney

When children turn 18, they're considered adults in the eyes of the law. This gives your special needs child the right to make medical and financial decisions. If your special needs child needs guidance or is not capable of making these decisions, consider assuming legal guardianship. A less restrictive alternative is to have a power of attorney and health care proxy for the child's financial, legal and medical affairs.

Write a Letter of Intent

A letter of intent lets you express your personal concerns about how your child's everyday needs will be met when you are not around. Include a list of contact information for your child's physicians, therapists and other medical support people, as well as current medications with their dosages and schedules. When your child's daily routine is very important, write it down and be as detailed as possible. The same goes for activities you want your child to maintain, travel or enrichment you want to be sure continues, your child's likes and dislikes. Write everything down. Since this is an informal document that lets you express your personal concerns, it's easy to keep it up to date. Keep a copy wherever you have your will, and make certain your child's appointed guardian has a copy.

Educate and Communicate

Communicating with family members can avoid costly misunderstandings. Grandparents and other loved ones may want to make gifts to your special needs child. If they are not aware of the existence of your special needs trust and the importance of making the gift to the trust and not the child, well-intentioned gifts can have adverse consequences. Explain to everyone the importance of not putting anything in your child's name—not even in a will or as a named beneficiary.

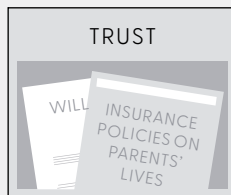
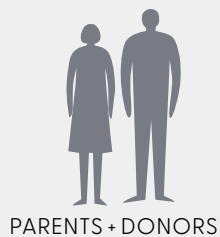
SPECIAL NEEDS TRUSTS

1

Parents establish a third-party special needs trust to leave money to a special needs child without disqualifying the child for Medicaid and Supplemental Security Income (both means-tested programs).

2

Parents and others may put money into the trust at any time. However, the majority of funding comes at the parents' deaths from life insurance or an inheritance or both.



3

A carefully selected trustee makes distributions to service providers on behalf of the special needs child to supplement government benefits and enhance quality of life.



4

When the person with special needs dies, the trust pays funeral expenses, then distributes remaining assets to named beneficiaries.



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