



SPECIALIZED ESTATE PLANNING

STRATEGIES TO SUPPORT A LOVED ONE WITH SPECIAL NEEDS

An estate plan allows you to control what happens to your property and possessions if you become incapacitated or die, makes your wishes clear to avoid family disputes, preserves assets, and provides for loved ones. It's especially important and necessary if you want to provide your special needs loved one with ongoing financial support that creates a rich quality of life led as independently as possible without jeopardizing income received from governmental support programs.

You're not alone in your challenges to support your loved one:

- More than 44 million Americans have either physical or cognitive disabilities.¹
- More than 12 Americans with disabilities have challenges with self care.²
- More than 7 million Americans with disabilities have trouble living independently.³

Beginning estate planning early can help contribute to the independence, financial security, and peace of mind of all of your children, not just the child with special needs. Planning now can also help alleviate questions and concerns regarding a sibling's role in the future care of a loved one. If you are a sibling caring for someone with special needs, estate planning is also necessary to ensure the individual's ongoing care in case you experience a life-changing event too.

Children and adults with special needs often rely on government programs such as Supplemental Security Income or Social Security Disability Insurance to provide a limited income for their basic needs and Medicaid to cover health care. Since these programs are needs-based, inheriting a financial windfall like a standard inheritance could affect their eligibility.

Three common estate planning tools offer ongoing financial support without compromising other assistance:

- 1 Special Needs Trusts
- 2 Pooled Trusts
- 3 ABLE Accounts

¹ 2023 American Community Survey [Census.gov/programs-surveys/acs](https://www.census.gov/programs-surveys/acs)

² [CDC.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#:~:text=3.6%20percent%20of%20U.S.%20adults,with%20difficulty%20dressing%20or%20bathing.](https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#:~:text=3.6%20percent%20of%20U.S.%20adults,with%20difficulty%20dressing%20or%20bathing.)

³ [Urban.org/sites/default/files/2022-10/People%20with%20Disabilities%20Living%20in%20the%20US%20Face%20Urgent%20Barriers%20to%20Housing_0.pdf](https://www.urban.org/sites/default/files/2022-10/People%20with%20Disabilities%20Living%20in%20the%20US%20Face%20Urgent%20Barriers%20to%20Housing_0.pdf)

1 Special Needs Trusts

Creating a special needs trust (and using it properly) protects your child's income while securing supplemental financial support. There are two general categories for special needs trusts:

- First-party trust funded by the person with a disability (most commonly funded by assets from a personal injury settlement)
- Third-party trust funded by someone other than the beneficiary

A special needs trust can be used for things that can improve quality of life:

Common Uses

- ✓ Health care
- ✓ Therapies
- ✓ Assistive technology services not covered by Medicaid
- ✓ Travel and entertainment
- ✓ Hobbies
- ✓ Pets
- ✓ Furnishings

Excluded Items

- ✗ Housing
- ✗ Food or restaurant meals
- ✗ Utilities

You can establish a special needs trust and then fund it with assets from your estate:

- Life insurance
- Investments
- Property
- Cash
- Retirement plan benefits

Having a special needs trust can also protect your other children financially as they will be less likely to be burdened with expenses on behalf of the child with special needs. If you're funding the special needs trust with life insurance, you can allocate the remainder of your estate to your other children. Regardless of how you fund a special needs trust, communicate your intentions to your other children to avoid misunderstandings.

How does a special needs trust work?

You must assign a trustee who understands the rules to approve requests. Options include:

- You or your spouse
- Another family member
- A professional or institution
- A professional and a family member serving as co-trustees

Your loved one (or the caregiver) requests money from the trust and the trustee decides whether the expense falls within the rules and how it will be spent. While not a legal document, you can also consider creating a “Letter of Intent” to provide additional guidance to your trustee (and future caregivers) on how you want your child, sibling, or other loved one to be cared for in the event you can no longer do so.

Family relationships can be complicated and even if a sibling is willing to serve as a trustee upon your death, he or she may not have the skills to make investment decisions, pay taxes, or take care of reporting requirements. Career, marriage, parenting, and other life changes could impact their ability to fulfill their role. They may also feel uncomfortable denying requests for trust distribution. Selecting a corporate trustee with sibling oversight of performance in the role of a trust protector could be an option.

2 Pooled Trusts

A pooled trust (also known as community or master trust) is a type of special needs trust managed by a nonprofit organization:

- The nonprofit becomes the trustee.
- Assets are pooled for the purposes of investment.

Operating and managing a special needs trust is complicated so having access to professional trustees through a pooled trust can be appealing for families.

Why consider a pooled trust?

- ✓ The nonprofit is experienced in state and federal rules regarding the usage of funds.
- ✓ You may not have enough assets to warrant a special needs trust but want to provide the benefits of one to your child, sibling, or loved one.
- ✓ Establishing a trustee avoids strain on any family members or friends.
- ✓ Because administration is centralized, there may be lower fees to establish and maintain the trust.
- ✓ Pooled trusts operate differently in every state and expertise varies among providers.

Here are some tips:

- Ask for references from other families when selecting an agency.
- Understand the reporting provided to account holders.
- Request details for enrollment and maintenance fees.
- Ask how earnings from investments are shared among account holders.
- Determine how requests and distributions are handled.
- Ask whether the nonprofit offers care coordination.

3 ABLÉ Accounts

Individuals with disability onset before the age of 26 who receive benefits under SSI and/or SSDI are eligible for an ABLÉ (Achieving a Better Life Experience) account, which can be used as a stand-alone financial support tool or as a supplement to a special needs trust without jeopardizing eligibility for SSI, SSDI, and Medicaid benefits, as well as other programs they may qualify for such as low-income housing support or food stamps.

An ABLÉ account is managed by your special needs child, sibling, or loved one. The individual decides how to spend the money and must understand the rules. The individual can seek advice from family members and professionals they trust.

An ABLÉ account can be used for “qualified disability expenses” that improve your loved one’s health, quality of life, and ability to live independently:

- ✓ Costs of living such as rent, mortgage, and utilities
- ✓ Education
- ✓ Food
- ✓ Transportation
- ✓ Support services
- ✓ Technology

Total annual contributions to an ABLÉ account cannot exceed \$18,000/year, and the total limit over time varies by state (\$235,000 - \$550,000). It’s important to note that if you exceed \$100,000 total in an ABLÉ account, you may inadvertently suspend your child’s ability to receive SSI benefits.

Resources

Life is uncertain. Establishing an estate plan can provide you and your loved ones with peace of mind and alleviate the burden of making decisions in the midst of a crisis. Assessing your goals and implementing a plan with input from a financial professional and/or special needs attorney can be one of the best things you can do for your overall financial, physical, and emotional well-being.

The following resources may be helpful:

- ✓ The Arc of the United States
- ✓ ABLÉ National Resource Center
- ✓ Special Needs Alliance
- ✓ The American College of Trust and Estate Counsel

Talk to your financial professional to learn more or contact us at 800.888.2461.

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