

When a Loved One Has Special Needs

If you are a parent or a caregiver to a loved one with special needs, you've probably worked hard to develop a network of support systems—health care providers, teachers, therapists, social workers, family and spiritual support. But have you prepared financially for both yourself and your loved one?

It's important to take the right steps financially, legally and administratively to help ensure both you and your loved one have the support you need. By taking care of yourself, you may be in a better position to care for your loved one with special needs.

You know your loved one best. However, the complexity of navigating special care may mean that your own financial necessities are no longer at the top of your priority list, or have shifted. Establishing a financial balance adds another element to the mix.

Special Needs Planning

It's helpful to start with a solid foundation, including Supplemental Security Income (if you qualify) and other forms of basic financial security. Learn more about Supplemental Security Income at ssa.gov. The eligibility rules for needs-based benefits are complex and may require input from someone who specializes in this area.

- › **Government programs** are available that are based on a person's needs and are not tied to your financial situation. Medicare is an example of a program that may pay benefits to people with disabilities under age 65 who have received Social Security for at least two years. Your loved one may be eligible to receive state and local aid as well.
- › **ABLE accounts**, created by the **Achieving a Better Life Experience Act** of December 2014, are available in several states for anyone who has a significant disability that began prior to age 26¹ and is expected to last at least 12 months, and is receiving Social Security Income or Social Security Disability Income. Earnings in the account can



be withdrawn tax-free if used to pay for qualified disability expenses. Anyone can make after-tax contributions to the account, up to a maximum of \$17,000 (2023) in total annual contributions under federal law and \$500,000 in a lifetime under many state laws, but the lifetime limit may vary by state. ABLE accounts are generally not counted as a resource for SSI, Medicaid and other public benefits (up to \$100,000), making ABLE accounts an effective planning tool.

A case worker can also help you understand what state and federal benefits are available, including Social Security, Medicaid and various waiver programs. You may also want to team up with an attorney who specializes in special needs issues.

¹ Effective for 2026, ABLE accounts will be able to be established for individuals who become disabled prior to 46 under the SECURE 2.0 Act of 2022.



Special Needs Trusts

You may want to consider other forms of basic financial security for a child with a disability, especially if your loved one is 100% dependent on you. For example, you may want to consider purchasing a life insurance policy and making the beneficiary a trust.

With this arrangement, your assets are not left to your loved one, who may not be able to manage the money. It is a good way to help assure the child with a disability is taken care of. Funds from a special needs trust can be used to help ensure the child can have the desired quality of life after the caregiver is gone. Other options outside of life insurance to fund a trust can include contributions from your earnings, funding from savings, a retirement plan or investments. Your legal and financial team can suggest options. A properly structured special needs trust can also help protect the child's eligibility for state and federal programs.

Life insurance benefits may also be payable to the beneficiary upon your death and may not be subject to income taxes. However, you should use care when naming your life insurance beneficiary.

When planning financially, be sure to think about costs like therapy, medication, special education, transportation, social outings and respite care. Some of these costs may be covered by government benefits or insurance, but often not completely.

Looking Ahead

Your special needs child's transition into adulthood should also be considered. While independent living options are increasing in popularity, other options may include group living. Independent living means additional costs for transportation, social outings and caregiving. If your child is able to work, then that can help cover some of these expenses.

Stay close to your entire support team. Just as you may meet regularly with your loved one's health care and educational providers, it's important to consult with your legal and financial teams, too. As you age and your loved one matures, both of your needs will change, and it's important to re-evaluate where you stand. Providing a stable life for a special needs child includes establishing financial security for yourself as well as any other family members who depend on you. There is no one size fits all solution for every situation.

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