



HIGHTOWER



Protecting Your Special Needs
Child After Your Death

Over the past few decades, life expectancy for individuals with intellectual and developmental disabilities (I/DD) has increased due to medical advances and improved living conditions. The number of adults with I/DD aged 60 and older is expected to nearly double from 641,860 in 2000 to 1.2 million by 2030.¹ Those with both physical disabilities and I/DD often require some sort of support throughout their adult lives to carry out day-to-day tasks. For parents of disabled children, this poses future challenges as their children will likely outlive them and will continue to need assistance after their passing.

To ensure your children are cared for after you pass away, you need to establish a plan that outlines their specific needs and preferences for care, while also providing legal and financial protection. Below, we list three considerations for parents planning a legacy for their special needs children.

Create a Care Plan

Many parents of disabled adults establish daily routines to promote stability and comfort for their children. When creating your estate plan, make sure your child's routine and preferences are documented in a letter of intent so the next caregiver is aware of your wishes. This document can be as detailed as you like, including information about your child's meal preferences, food aversions, hobbies, medications, and a list of medical providers.

After listing their care needs, you should begin the process of determining how decisions will be made for your child. One option to consider is a supported decision-making (SDM) program. This empowers your child with the ability to make their own life decisions with the support of a trusted support team like a family member, friend, mentor, or colleague. In an SDM, the support team helps your child understand, consider, and communicate decisions, providing them with the knowledge to make informed choices independently. This fosters a sense of independence and autonomy. Unlike guardianship or conservatorship, an SDM agreement is not legally binding but is useful for identifying trusted individuals.

Another option for children who are unable to make their own decisions, whether due to being non-verbal or having cognitive challenges, is appointing a durable power of attorney. This legal arrangement allows you to designate someone to make medical and financial decisions for your child when you are no longer able to do so. By appointing a person in your estate plan, you can help prevent the possibility of a judge in probate court assigning a guardian or conservator for your child.

Protect their Government Benefits

In 2022, the U.S. Census Bureau reported that the median income for the U.S. civilian noninstitutionalized population aged 16 and over with a disability was \$30,885.² Some disabled adults supplement their income with Supplemental Security Income (SSI) benefits or Social Security Disability Insurance (SSDI) from the Social Security Administration (SSA). However, if you plan to leave an inheritance for your child, you must be aware of how it will affect their benefits.

As of 2026, SSA requires an SSI-eligible individual's wages to exceed no more than \$2,073 a month and \$3,067 a month for a couple. Income from pensions, gifts, and Social Security may not exceed more than \$1,014 per month for individuals and \$1,511 a month for couples.³ For those receiving SSDI, the income limit is \$1,690 per month (or \$2,830 if you are blind).⁴ Additionally, to qualify for SSI, countable resources (assets) must not exceed \$2,000 for an individual or \$3,000 for a couple.⁵

If your child receives an inheritance from your estate, they will become ineligible for SSA benefits. Even if your child refuses the inheritance to preserve their benefits, the SSA may consider it "constructively received," meaning the income is credited to their account or made available to them, even if they haven't physically received it. For tax purposes, they are considered to have received it.

To prevent your child from losing their government benefits, consider creating a special needs trust.

Set up a Special Needs Trust

A special needs trust (SNT) is a type of trust for individuals with disabilities that allows them to receive assets while remaining eligible for benefits like SSI or Medicaid. The funds in the account can be used for anything your child needs, such as housing, medical bills, home care, education, and food.

SNTs are set up similarly to other trust accounts where the trust includes a grantor (the person who creates the fund), a trustee (the person who manages the account), and a beneficiary (the recipient of the benefits). However, the way the trust is funded can vary depending on the type of special needs trust you select.

The two main types of special needs trusts are third-party special needs trusts and first-party special needs trusts. A third-party trust, one of the most common types, is funded by someone other than the beneficiary. This could be a parent, grandparent, sibling, loved one, or a combination of different donors. In a stand-alone third-party trust, the beneficiary can access the assets while the grantor is alive. In a testamentary trust, the trust is part of the grantor's last will and testament, meaning the beneficiary won't receive the assets until after the grantor's death. To ensure your child continues to receive government benefits with this type of trust, consider making it irrevocable.

The second type of special needs trust is a first-party trust. This trust is more suited for beneficiaries who are mentally able to manage their finances since they will be funding it themselves. It is common for individuals to choose this type of trust if they had assets before becoming disabled (e.g., someone who developed Long COVID, blindness, or amyotrophic lateral sclerosis (ALS)). Under the Special Needs Trust Fairness Act, the beneficiary can fund the trust themselves or allow a parent, grandparent, or legal guardian to fund it using the beneficiary's assets.⁶ Beneficiaries should know that if they select this type of trust, any remaining assets in the trust will be used to repay Medicaid before being distributed to their contingent beneficiaries.⁷



Consider Opening an ABLE Account

The ABLE Account, a tax-advantaged savings program for eligible people with disabilities, was established by the Achieving a Better Life Experience Act of 2014. Under this Act, individuals whose disability began before the age of 26 can save money in an ABLE account without losing their government benefits. Starting January 1, 2026, the onset age will increase to 46 years old.⁸ The funds in an ABLE account must be used for qualified disability expenses, such as education, legal fees, funeral expenses, and assistive technology, and are tax-free. This provides a significant tax and savings benefit as out-of-pocket expenses continue to rise for disabled Americans.

To be eligible for this program, you must already be receiving SSI payments or SSDI benefits or have a signed disability certificate from a licensed physician stating your diagnosis and showing that you have/had severe functional limitations that began before age 26. As of 2026, the contribution limit for an ABLE account is \$20,000. The balance limit varies by state and matches the respective state's education-related 529 savings account balance limit.⁹

conclusion

We hope these resources help you understand your options for the legacy you leave behind for your child. It's important to discuss your wishes for your child's future with your financial advisor to integrate them into your estate plan effectively. With a well-crafted plan, you can take comfort in knowing your child will be well taken care of when you are no longer around.





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¹ Impact | Volume 23, Number 1 | People with Intellectual and Developmental Disabilities Growing Old: An Overview. (n.d.). Institute on Community Integration Publications. Retrieved March 14, 2025, from <https://publications.ici.umn.edu/impact/23-1/people-with-intellectual-and-developmental-disabilities-growing-old-an-overview>

² US Census Bureau. (2024, August 14). Anniversary of Americans With Disabilities Act: July 26, 2024. Census.gov. <https://www.census.gov/newsroom/facts-for-features/2024/disabilities-act.html>

³ Social Security Administration. (2026, January). Are you eligible for supplemental Security income (SSI)? (Publication No. 05-11003). U.S. taxpayer expense. Retrieved July 8, 2026, from <https://www.ssa.gov/pubs/EN-05-11003.pdf>

⁴ Substantial gainful activity. (n.d.). Retrieved July 8, 2026, from <https://www.ssa.gov/oact/cola/sga.html>

⁵ SSI Spotlight on Resources | Supplemental Security Income (SSI) | SSA. (n.d.). Social Security. Retrieved March 17, 2025, from <https://www.ssa.gov/ssi/spotlights/spot-resources.htm>

⁶ U.S. Congress. (2015). Special Needs Trust Fairness Act of 2015. Retrieved March 18, 2025, from <https://www.finance.senate.gov/imo/media/doc/S%20349%20Mark.pdf>

⁷ Estate Recovery | Medicaid. (n.d.). Retrieved March 18, 2025, from <https://www.medicaid.gov/medicaid/eligibility/estate-recovery/index.html>

⁸ What are ABLE Accounts? – ABLE National Resource Center. (2025, February 6). ABLE National Resource Center. <https://www.ablenrc.org/what-is-able/what-are-able-accounts/>

⁹ Howard, J. (2025, March 4). ABLE Account Contribution Limits (2025) – ABLE National Resource Center. ABLE National Resource Center. <https://www.ablenrc.org/able-account-contribution-limits-2025/>

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