

## **Protecting Those You Love: Estate Planning When a Family Member Has a Disability**

Many famous figures have argued that how a society treats its most vulnerable members is a measure of its humanity and moral character. As Mahatma Gandhi famously observed, a society is ultimately judged not by its wealth or power but by how it uplifts those who need help the most.

Government programs such as Social Security, Medicare, and Medicaid support the needs of millions of disabled Americans. However, many of the day-to-day responsibilities and costs of caring for an individual with special needs fall on families, who are often left to navigate complex rules while trying to do the right thing for someone they love.

For families with disabled loved ones, estate planning must address proactive, coordinated decisions that protect benefits, support quality of life, and consider long-term financial planning alongside long-term care needs.

### **The Public Benefits Versus Private Wealth Conundrum in Special Needs Planning**

The term *disability paradox* refers to a well-documented pattern in which many people living with serious disabilities report a high quality of life and strong life satisfaction even when they face substantial limitations shaped by healthcare gaps, social stigma, daily restrictions, and inadequate support systems.<sup>1</sup> Outside observers often interpret these same circumstances as inherently undesirable and assume that disability and the struggles these individuals face must correspond to reduced well-being and overall satisfaction with life.

A related paradox shows up in how our system supports people with disabilities. Public programs that are designed to provide critical assistance such as income support, housing assistance, medical care, and long-term support are typically available only if an individual has very limited financial resources of their own. Qualifying for these benefits therefore requires severe financial constraints, even when family members want to provide financial assistance. Access to essential support, in other words, often depends on maintaining what can feel like voluntary poverty layered on top of an existing disability.

Programs such as Supplemental Security Income (SSI) and Medicaid generally require individuals to have limited income and assets—often no more than \$2,000 in countable resources.

At the same time, families caring for a child with a disability face nearly double the risk of financial hardship compared with families with nondisabled children.<sup>2</sup> Research shows that these families are more likely to rely on a single income, work lower-paying or less flexible jobs, live in poorer-quality housing, and experience long-term financial strain.<sup>3</sup> And yet, the help that family members try to provide is still closely scrutinized. Giving money directly to a disabled

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<sup>1</sup> Gary L. Albrecht & Patrick J. Devlieger, *The Disability Paradox: High Quality of Life Against All Odds*, ScienceDirect (Apr. 8, 1999), <https://www.sciencedirect.com/science/article/abs/pii/S0277953698004110>.

<sup>2</sup> Amy J. Houtrow et al., *Health Care Cost Concerns and Hardships for Families of Children With Disabilities*, Nat'l Libr. Med., Apr. 24, 2025, <https://pmc.ncbi.nlm.nih.gov/articles/PMC12022804>.

<sup>3</sup> Donna Anderson et al., *The Personal Costs of Caring for a Child with a Disability: A Review of the Literature*, Nat'l Libr. Med., Jan.–Feb. 2007, <https://pmc.ncbi.nlm.nih.gov/articles/PMC1802121>.

loved one—or leaving assets to them outright through an estate plan—can unintentionally cause them to lose the very benefits they depend on.

**This is the challenge at the heart of special needs planning: how to provide necessary support without putting essential benefits at risk.**

### **Special Needs Trusts and Other Disability Benefit Work-arounds**

Because leaving money directly to a disabled loved one can jeopardize their public benefits, families need a way to provide financial support that promotes stability and protects eligibility.

One common approach is a *special (or supplemental) needs trust (SNT)*. SNTs hold funds for a disabled beneficiary and allow money to be used for approved expenses that improve quality of life but do not affect eligibility for programs such as SSI or Medicaid. These trusts are designed to **supplement** public benefits, not replace them.

SNTs are central to disability planning but are not the only option families may consider. The following planning tools can play a supporting role:

- **ABLE accounts.** Achieving a Better Life Experience (ABLE) accounts allow eligible individuals with disabilities to save a limited amount of money each year for qualified expenses such as housing, education, transportation, and healthcare while keeping public benefits intact. These accounts can offer flexibility for smaller day-to-day needs.
- **Pooled trusts.** Pooled trusts are sometimes used when creating a standalone SNT is impractical. Funds are pooled for investment purposes but tracked separately for each beneficiary and are professionally managed, reducing any administrative burden on the individual and their loved ones.
- **Life insurance.** A life insurance policy can be used to fund future care needs, particularly for parents or caregivers who want to ensure that resources will be available for their disabled loved one after they are gone. In many cases, insurance proceeds are directed into a trust rather than paid outright to avoid jeopardizing any needs-based benefits the disabled individual currently relies on.

The right approach often involves a combination of tools, carefully coordinated to reflect a family's resources, goals, and the specific needs of the disabled individual.

The size of the support matters, but so does **how** it is structured. Each approach should be judged not only individually but collectively, based on how it fits into the bigger planning picture.

### **Matching People with Plans**

The right planning strategies can empower disabled individuals to live more independently and securely, often with a higher quality of life. But a plan is only as strong as the people designated to carry it out. Guardians, caregivers, and trustees play a pivotal role in maintaining continuity of care within a special needs estate plan.

### **Naming Guardians, Caregivers, and Trustees**

A strong plan does not rely on a single person to do everything. It clearly defines roles so that responsibilities are shared, understood, and sustainable over time. In most plans benefiting

people with special needs, that means thoughtfully naming and coordinating the following individuals:

- **Guardians or primary caregivers.** These are the people responsible for day-to-day care and major personal decisions. They ensure that the individual's living situation, healthcare, routines, and personal needs are met consistently and compassionately.
- **Trustees or financial decision-makers.** Trustees manage funds set aside for the disabled individual. They make decisions about when and how money is used to support quality of life while also preserving eligibility for public benefits. Their role is financial oversight, not daily caregiving.
- **Advocates or backup decision-makers.** In some families, a trusted person serves as an extra set of eyes. This person understands the plan, the benefits rules, and the individual's preferences and can step in if needed.

In addition to these key individuals, the plan may require support from outside professionals such as life care planners, social workers, financial advisors, and a corporate or professional trustee to serve as either the primary or backup fiduciary.

Clearly separating these roles helps avoid confusion, reduces conflict, and prevents any one person from becoming overwhelmed. Everyone involved should understand the disabled person's needs and preferences and the role public benefits play in their care. When caregivers and decision-makers are on the same page, care is more consistent, benefits are better protected, and transitions—expected and unexpected—are easier to manage.

An estate planning attorney can serve as the hub in the special needs planning structure, helping to identify areas of concern, suggest options, and connect families with disability professionals, resources, and solutions.