



Parents may wonder how they will be able to pay for their child's care as they grow, especially when a child has complex health needs. While each family's situation is very different, there are certain common threads that can make planning a child's care easier.

First, it's important to know that individuals with disabilities are often eligible for government assistance programs. However, the guidelines for eligibility are often very specific, so it is crucial to know when a child is or isn't eligible. Programs like SSI or Medicaid have income limits - if a child's income exceeds those limits, they are no longer eligible for those programs. Eligibility for certain programs can also depend on a parent's income - moderate-to-high-earning parents can disqualify a child from benefits.

Because of these financial limitations, there are strategies available for ensuring that income the child earns is not counted as assets towards the prescribed limit - these strategies include setting up a special-needs trust and getting help from a financial planner or attorney who can make sure that estate planning and wills do not negatively impact a child's benefits. Typically these attorneys will be certified in estate planning and will have expertise in working with individuals with disabilities. In many cases, birth injury attorneys will have access to these resources and can assist families with setting up a trust for funds successfully recovered from a lawsuit.



To make sure a child is eligible for SSI, the child cannot have more than \$2,000 in assets or earn more than \$500/month. The federal government pays about \$470 a month in S.S.I., and subsidies (in some states) can bring sums closer to \$600. Attorneys can help set up special needs trusts and help prepare parental wills, while financial planners can help ensure that the



funds in the special needs trusts are preserved and available to cover the costs of the child's care.

Tips for Financial Planning:

- Choose a good team of financial advisers and attorneys to help you plan your child's future care. In many cases, one highly recommended option is setting up a 'special-needs trust.' These trusts are set up in such a way that they can help fund care that is not covered by government benefits. There are some options available for setting up trusts without an attorney, but these are strongly discouraged because of the complexity of these arrangements, and the negative impact that an improperly settled trust can have on government benefits.
- Plan for the lifetime of your child. It can be difficult to confront aging, but parents will not always be around to care for their children; plans must be put in place to ensure the child's care after parents have passed away.
 - If a grandparent or parent leaves something to the child, those assets should be funneled through the special needs trust, not gifted directly to the child, in order to preserve the child's benefits.
 - Life insurance policies should be crafted so that funds paid out to the child upon the parent's death should be funneled through the trust, not given directly to the child. There are many kinds of life insurance policies used by the parents of individuals with disabilities. These include:
 - Joint-life (first-to-die) policies: These pay out when the first of the two spouses dies, and costs about $\frac{1}{3}$ of buying term insurance for both parents.
 - Survivorship-life (second-to-die) policies: These pay out when the second spouse dies, and cost about half of buying term insurance for both spouses.
- Create a [letter of intent](#). This document helps signal to future guardians or caretakers how to care for the child. This is not a legal document but still provides valuable information, including the child's medical history, doctors and personal information



(such as their preferences and habits).

- Establish legal guardianship to help the child make financial decisions. Although a person is an adult when they turn 18, individuals with special needs may need additional assistance well into their adult years. Generally, parents are the legal guardians of their children, but it is important to designate in a will who will assume legal guardianship of the child when the parents die.
- Parents who do not have enough money for a special needs trust can research other options. Sometimes parents of children with disabilities can enter into an arrangement called a 'pooled trust' or 'master cooperative trust,' where multiple families pool together assets that are paid out to those families' children, and the assets are managed by a non-profit organization. How much each child receives can be determined on a percentage basis, depending on how much the initial investment in the trust was.

Practical Financial Resources for Disability Care:

- [Kids' Waivers](#): This tool helps you navigate the waivers available to you based on your state, needs, income level, and more.
- [The Pacer Center: Possibilities](#): Provides a comprehensive, step-by-step plain language financial planning guide for parents of children with disabilities. Covers topics ranging from taxes to credit to long-term care payment.
- [The Arc](#): This organization publishes a planning handbook for parents of individuals with disabilities.
- [Financial-Planning.com](#): Special Needs Clients: 'Retirement for 3'
- [The Special Needs Alliance](#): Attorneys who work specifically to plan care for special needs individuals.
- [Vermont Family Network](#): Six Ways to Access Medicaid Benefits
- [Financing Strategies](#): Sources of Government Funding for Children and Youth with Special Needs
- [Medical Home Portal](#): Breakdown of Available State and/or Federal Assistance Programs
- [Kiplinger](#): Planning for a Special Needs Child
- [KidsHealth](#) [Video Library]: Financial Planning



- [Financial Planning 101](#): What Kind of Experts are Available for Special Needs Planning Help?
- [Disability.gov](#): Disability Public Assistance Programs
- [Legal Resources](#): Funding a Special Needs Trust
- [SingleMothersGrants.org](#): Free and Low-Cost Financial Aid and Grants

Academic Financial Resources for Disability Care:

- [Journal of Financial Planning](#): A Team Approach to Financial Planning for Families with Special-Needs Dependents
- [Recent Trends and Developments in Long-Term Care in the United States](#)
- [Journal of Accountancy](#): Potential Tax Breaks for Families of Special Needs Children

Parent Stories:

- [Forbes](#): Planning for Multiple Generations
- [Time](#): Financial Planning for Special Needs Such as Autism

Disability Cost Guide:

We partnered with Kacy Seitz, a special needs financial adviser and HIE mom, to break down the lifetime costs associated with neonatal brain injuries like HIE and cerebral palsy. Check out the video below and [view the full guide here](#).