



Long-Term Care Planning for Children with Disabilities

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Welcoming a child into the world is a profound and life-changing experience, and when that child has a disability, the journey takes on unique challenges and considerations. As parents of a disabled child, planning for their long-term care becomes a crucial aspect of ensuring their well-being and quality of life. In this article, we will explore key considerations for parents embarking on the path of long-term care planning for their beloved child.

Getting Started

Understand Your Child's Needs

Before diving into long-term care planning, it is essential to have a comprehensive understanding of your child's current and potential future needs. Consult with healthcare professionals, therapists, and educators to create a detailed profile of your child's abilities, limitations, and medical requirements. This foundation will serve as a guide for tailoring a care plan that addresses your child's unique circumstances.

Legal and Financial Planning

Long-term care involves intricate legal and financial considerations. Establishing legal guardianship, setting up trusts, and exploring government assistance programs are crucial steps. Consult with a qualified attorney who specializes in special needs planning to navigate the complexities of estate planning and ensure the financial security of your child.

It may be necessary to establish a [guardianship](#) and/or conservatorship upon your child reaching the age of eighteen. The following gives an overview of the legal and financial considerations that may be necessary:

- [Guardianships](#)

Although some states have different terms for the court-appointed positions of guardian and conservator, generally, a guardian is a court appointed position that oversees the health and well-being of a disabled individual. Guardianship serves as a protective



measure for those unable to make decisions for themselves, ensuring they receive fundamental necessities such as food, shelter, and healthcare. Guardians also play a crucial role in ensuring the safety of adults with disabilities, making medical decisions, and arranging necessary treatments. They also address the individual's social, educational, recreational, and future needs.

- **Conservatorships**

A conservator is someone who is court-appointed to oversee the finances of a disabled person who may lack the capacity to do so themselves. This can help safeguard them from financial exploitation and mismanagement.

A [Special Needs Trust \(SNT\)](#) is a common legal tool used by both parents of children with disabilities as well as disabled persons themselves to protect their assets while also allowing them to receive needs-based government benefits like Medicaid and SSI. There are three general categories of special needs trusts: first-party special needs trusts, pooled trusts, and third-party special needs trusts.

- **First-party special needs trusts (or Medicaid payback trusts or self-settled SNTs)**

Funded with the disabled person's own assets and can only be used for their benefit. After their death, Medicaid must be reimbursed for amounts paid by the program on behalf of the disabled individual, ensuring funds go back to the program.

- **Pooled trusts**

Another form of a first-party trust is managed by a non-profit corporation, which pools the assets of its trust beneficiaries for investment purposes. Pooled trusts can be an attractive alternative to other first-party trusts because they provide professional management for lower fees.

- **Third-party special needs trusts**

Formed with funds not belonging to the individual; they can be established either as a living or testamentary trust (meaning it was created by a will). These trusts can also receive gifts from family members who don't want to create special needs trusts in their own wills. Parents can contribute either during their lifetime or through a bequest in their will or trust, and the money can help fund long-term care costs.



Public benefit programs play a crucial role in determining the quality and availability of long-term care for individuals with disabilities. The following public benefit programs are commonly part of the financial considerations involving payment for long term care:

- **Medicaid**

A medical public benefit funded by both the federal government in combination with individual states, which can help pay for long-term care (LTC). Medicaid's long-term care coverage has traditionally been limited to institutional Medicaid or nursing home Medicaid, covering room and board, assistance with daily activities, skilled nursing, and medication administration. Meeting the financial qualification criteria for Medicaid is essential for LTC coverage. The process to obtain this funding will vary based on the state where the individual with disabilities resides. To find out more about the process in your state, go to <https://www.medicaid.gov/state-overviews/index.html>.

- **SSI (Supplemental Security Income)**

A cash assistance program funded by the federal government and administered by the Social Security Administration that assists financially eligible individuals 65 or older (without enough quarters of work to qualify for social security retirement), blind or disabled. In many states, qualification for SSI will also allow for Medicaid qualification. If eligible for Medicaid nursing home care, most of the monthly SSI income must be used to cover room and service costs.

- **Home and Community Support Waivers (HCBS) or 1915(c) Waivers**

Programs authorized by the federal government that grant states flexibility in using Medicaid funds to provide long-term care services and support to individuals in their homes or communities. Almost all states offer LTC services through HCBS Medicaid Waivers and should be explored as they are frequently more cost effective and align with individuals' preferences.

- **Achieving a Better Life Experience (“ABLE”) Accounts**

They provide individuals with disabilities and their families a tax-deferred savings tool, similar to 529 college savings plans, to save funds for future needs. They can be used for “qualified disability expenses,” which include contributions toward LTC. In 2023, these accounts allow up to \$17,000 per year to be contributed while preserving Medicaid eligibility. In 2024, the contribution amount will go up to \$18,000.



Diving Deeper

- **Transition Planning**

As your child approaches adulthood, it's essential to plan for the transition from pediatric to adult care services. Investigate vocational training programs, educational opportunities, and employment options that align with your child's abilities and interests. A smooth transition can contribute significantly to your child's independence and fulfillment.

- **Explore Housing Options**

Investigate suitable housing options that align with your child's needs and abilities. Depending on the level of support required, parents may consider group homes, assisted living facilities, or even modifications to their own home to accommodate their child's specific needs. Each option has its own set of considerations, so weigh the pros and cons carefully.

- **Create a Support Network**

Building a robust support network is vital for both you and your child. Connect with other parents of disabled children, join support groups, and engage with organizations that specialize in the care of individuals with similar conditions. These connections can provide valuable insights, emotional support, and a sense of community.

- **Healthcare Coordination**

Collaborate with healthcare providers to create a comprehensive healthcare plan. This includes regular check-ups, therapies, medications, and emergency protocols. Keeping detailed medical records and ensuring open communication with healthcare professionals is crucial for maintaining your child's health and well-being.

- **Emotional Well-Being**

Consider the emotional well-being of both you and your child. Seek counseling or therapy to navigate the emotional challenges that come with LTC planning. Taking care of your own mental health ensures you are better equipped to support your child in their journey.

Conclusion

Long-term nursing care planning for individuals with developmental disabilities is a multifaceted process. By understanding the financial options, Medicaid qualification, and



legal considerations such as guardianship, you are taking significant steps toward securing a stable future for your loved one. To get assistance navigating the various programs and processes related to funding and securing long-term care for your loved one, check out the [Special Needs Alliance network](#) to find legal help within your state.

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