



How to Assess Future Life Needs for a Loved One with a Disability

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The first months, or even years, after receiving the diagnosis are filled with unexpected questions and challenges when you have a loved one with special needs. “Here-and-now” needs like healthcare, therapy, education and other immediate needs can quickly take priority over future planning, which is understandable. You’re likely to ask yourself, “How do I go about assessing my child’s future needs, let alone begin thinking of how to pay for them?”

Although special needs planning can seem overwhelming, it is important to begin identifying what your son or daughter will need throughout his or her life and the what-ifs for when you are no longer there.

What will be needed?

The best way to start is by preparing a future needs assessment specific to your child’s disability and anticipated resources, either public benefits, such as Medicaid and Supplemental Security Income (SSI), and/or your own private funds. You will want to consider the quality of life that you envision for your loved one, along with the following categories:

- Medical
- Educational
- Housing/Living
- Transportation
- Assistive Equipment or Technology
- Caregiver Needs
- Personal Needs
- Other Expenses

You may find it useful to create a spreadsheet or folder to organize information and record expenses and funding resources. Some expenses may recur monthly, such as rent or health insurance premiums, while others, such as the purchase of a car, may happen only

once in a while. As such, it is good to track the costs associated with these needs over a period of time, such as six months, to give you a baseline that includes frequent and intermittent expenses.

Contacting organizations specific to your child's disability, such as the National Down Syndrome Society, Autism Speaks, Brain Injury Association of America and NAMI (National Alliance on Mental Illness), can help complete the future needs assessment. These organizations offer support, education and an opportunity for parents to connect with one another to share insight from their own planning experiences and provide tips on additional expenses you may need to include in your own planning.

As you start tallying these figures, you quickly might be wondering, "How much do I need to save for all this?" Some financial service providers have created online calculators that can help estimate how much will be needed to cover the necessary expenses that you identify.

Protecting your child's needs into adulthood

Once you've calculated how much you'll need to save, remember that a special needs trust (SNT) is an effective tool to provide financial support to someone with disabilities into adulthood, largely because it protects eligibility for Medicaid and SSI, which prohibit recipients from possessing more than \$2,000 in countable personal assets. As you go farther down the special needs planning road and establish an SNT, there are several additional things to keep in mind:

- **Naming a trustee:** A trustee is responsible with administering funds from the SNT should your son or daughter not be able to manage his or her own money. Choosing a trustee with the knowledge, skills and experience needed is a major decision. Common choices include:
 - Trust or estate planning attorneys
 - Bank or investment institutions
 - Family members
 - Nonprofit pooled special needs trust organizations
- **Guardianship:** When your child turns 18, he or she becomes an adult, and unless you've set up a guardianship, you will no longer have control over his or her affairs. It's critical to decide if your child needs a guardian before he or she becomes an adult, and if so, who's best suited for this responsibility.
- **Will and estate planning:** Establishing a will that includes SNT language is important because it mandates how your assets should be dispersed in the event of

your death. The consequence of not planning could be that the government decides how your assets will be disbursed.

By taking the time to think about future needs and related expenses, you can better plan for how much will be needed for your loved one. Don't despair. You are not alone. There are many professionals, including special needs planning attorneys such as SNA members, as well as financial planners, medical specialists, nonprofit organizations and public agencies that serve people with disabilities, who can assist you with special needs planning.

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