Planning for a Special Needs Child in Your Estate Plan

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Learn about ABLE accounts, Special Needs Trusts (SNTs), government benefits (SSI, Medicaid), and other essential tools for your child's future.

By Anne Mank

When you become a parent or guardian of a special needs child, your world can turn upside down. You are learning medical terms, navigating the insurance industry and trying to thrive in a world that is different from anyone's around you. You spend extra time thinking about and planning for an unknown future for your child.

You might also enter the world of government benefits, which can be a blessing but also very confusing. Terms like Medicaid, Medicare, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), waiver program and others become standard terms around the dinner table.

You realize that having a strong financial future is an integral part of the equation, but you don't know where to start. And, regardless of your income, these benefits could open doors and create opportunities for your child that you could not ordinarily provide. Don't make the mistake of losing them because you don't understand the rules.

The overwhelm is real and might be stopping you from sitting down and taking a look at both your financial future and your child's. Here are a few key tools and resources you should consider as you navigate your child's future:

Achieving a Better Life Experience (ABLE) Accounts

These tax-advantaged accounts allow eligible individuals to save money without jeopardizing their eligibility for government benefits, like Medicaid and Supplemental Security Income (SSI). Your contributions are after-tax, and the earnings grow tax-free within the account. And, if you use the money in the account for qualified expenses, the distributions are also tax-free.

As of 2025, the annual contribution limit to the account is $19,000 and individuals can only have one account in their name. You can have a balance of up to $100,000 without impacting your SSI. If you don't receive SSI, you can save even more in these accounts, up to the state's limit for education-related 529 savings accounts, or on average, about $450,000.

You'll find quite a few rules surrounding this, so consider working with a trusted professional to set these up and determine the appropriate savings and distribution plan. This might be a good solution for an individual with special needs who is independent enough to work but also needs to retain those government benefits.

Special Needs Trusts (SNT)

These trusts hold assets for the beneficiary's benefit while ensuring they don't own them directly. This allows the beneficiary to still qualify for government benefits, but the trust will pay for qualified expenses like medical care, education and personal needs.

Two main types of SNTs include first- and third-party trusts. The beneficiary's own assets fund first-party trusts. Any remaining assets after the individual's death could be subject to a Medicaid clawback provision. Medicaid could use those assets to pay for services provided while the individual was still alive. Assets from other individuals, such as family members or friends, fund a third-party trust. Since other individuals fund this trust, any remaining assets can be left for beneficiaries and would not be subject to the Medicaid clawback provision.

The investable assets in these trusts could be managed by a financial adviser. However, a little more work is needed with these trusts because it is up to the trustee to prove that assets were used for qualified expenses. Another option is a pooled SNT. These are typically managed by a non-profit organization, and the assets are pooled together for investment purposes. The organization will then make financial decisions based on the individuals within the pool.

The documents for these trusts take into account both current law and future anticipated needs, and can be complicated. It is important to work with a legal professional who understands how to draft a trust and is familiar with the idiosyncrasies of the world of special needs.

Decision Making Documents for Adults

Individuals could use three legal tools to help them manage their personal, financial and medical affairs.

Power of Attorney

A Power of Attorney (POA) is a legal document that allows others to make decisions on behalf of the individual. This ability could be in effect immediately and for the individual's life or set for a specific period or after an event such as incapacitation. It typically covers financial or medical decisions.

Guardianship

The next tool is Guardianship. If the court determines that the individual cannot make their own decisions, they will appoint a guardian for the individual. This guardian will then make all financial, medical and personal decisions. This is the most restrictive path because it removes the individual's legal decision-making ability.

Supported Decision Making

A third tool is called a Supported Decision Making (SDM) document. This less formal approach allows a representative to help support the individual in their decision making; it does not remove any rights or decision-making abilities from the individual. An example would be helping your adult child while they are at a doctor's appointment. You could explain what was said, discuss directly with the doctor, talk with your child about the options but your child would make the final decision.

Beneficiaries

As a family is coming together to set up their financial affairs, there is usually a lot of consideration about how assets will pass at the death of a parent. Many of the tools mentioned above will be used to pass assets from one generation to another successfully. But what about relatives outside your immediate bubble, like a single uncle or your loving grandmother? For example, if Grandma has your child listed as a beneficiary and her assets are passed to your child, your child might lose government benefits because now their assets are over the limit. Even though Grandma was trying to be fair and provide a gift, it could reduce the level of care your child receives.

So, how do you navigate this situation? One strategy would be to have any assets your child inherits titled in the name of the trusts you have established. These trusts should be listed as the beneficiaries on others' accounts, not the child. As noted above, consulting legal professionals for advice is very important.

Letter of Intent

You know everything about your child, whether they are two or 30 years old, but what happens when you are no longer around to care for them? How will anyone know that loud sirens upset them or that they need help administering their medication? This is where a letter of intent becomes valuable. This letter is used to pass on everything you have learned about your child so their next caregiver can provide the same level of care. This letter would include personal details, daily schedules, medical information or anything you feel is essential. It is not a legal document but a vital part of a transition plan for your child.

When caring for a child with special needs, there is no right or perfect way to do it. The same will go for financial planning. With your support and the guidance of your trusted professionals, you will be better able to provide the future that is just right for him or her. You are doing a great job!

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