

10 Estate Planning Tips for Families with Beneficiaries with Special Needs

Thursday, May 3, 2018

Life is more complicated for families who have a loved one with a disability. From finding the right medical professionals and the right schools or other programs, to obtaining necessary therapies and services, people with disabilities face additional steps, extra time, and a need for specialized knowledge at every stage of life. In addition to facing these stresses, families may receive misinformation, which makes decision-making more difficult.

While the development of an estate plan can be difficult for any family, for a family of a person with a disability, the planning, as with all things, has added complexity. Primary caretakers of a loved one with a disability routinely wonder who will care for, love, and financially support their family member when they are gone. They ask themselves questions like the following:

- Where will my loved one live?
- Who will make sure my loved one is happy and well cared for?
- What services will be available for my loved one?
- How will these services be paid for?

Needless to say, we recommend that all families engage with an estate planning attorney, but for families with a loved one with special needs, the process of developing an estate plan requires more than document drafting skills. It also requires the ability to navigate the confusing and often counter-intuitive rules of government benefit eligibility, and being intimately familiar with the circle of doctors, diagnoses, therapies, and services that will be available to provide special needs support over the course of a lifetime.

If your family includes a person with special needs, here are 10 tips to get you started on the right track to developing an estate plan that works for your family.

1. Prepare a Letter of Intent. This letter informs trustees, guardians, advocates, and others involved in the care for the family member with a disability about the family member's functional abilities, routines, interests, and likes and dislikes. This is not a legal document but a practical one. It should be drafted using a conversational voice and should grow with the family member and be updated regularly. We have provided a guide to drafting a Letter of Intent, which can be found [here](#).

2. Set up a Special Needs Trust for the beneficiary with a disability. Sometimes called a "Supplemental Needs Trust," and often referred to simply as a "SNT," this specialized trust allows assets that family members and friends contribute to it to pay for goods or services that are in the beneficiary's best interest, while also maintaining the beneficiary's eligibility for means-tested government assistance programs. In planning for an individual with special needs, money is not everything - there may be residences or programs that require the person with special needs to be eligible for benefits such as Medicaid or SSI and do not accept private payment. A SNT allows the beneficiary to have the best of both worlds.

3. Provide guidance on the use of government benefits or trust assets. The Letter of Intent provides

The logo for Schiff Hardin, featuring the word "Schiff" in a blue, cursive-style font and the word "Hardin" in a black, serif font below it.

Article By
[Robert M. Freedman](#)
[Alexis R. Gruttadauria](#)
[Schiff Hardin LLP](#)
[Publications](#)
[Estates & Trusts](#)
[All Federal](#)

some guidance to the Trustee concerning how you envision supplementing your family member's care, but you may also want to include specific language in the SNT to inform distributions. Specifically, you may want to authorize the trustee to hire care managers, advocates, and other professionals who can guide the trustee on the expenditure trust funds.

4. Set up the plan so it does not require court intervention. When you prepare the plan, it is ideal to avoid or minimize the role of court-appointed guardians or trustees. Typically, once the matter goes to court, the court will have a say in your family member's care, and litigation of course is time consuming and financially burdensome for all involved. Set up the SNT during your lifetime, not in your will, as trusts created by will are typically subject to a court's interventions.

5. Calculate how much should be left to the SNT for the beneficiary with a disability. You should consider the beneficiary's current lifestyle and how much money will be ideal to support it. Keep in mind that because of a variety of factors, you may choose to allot more or less to the person with a disability than to similar beneficiaries who do not have a disability. Once you have decided how much money is the right amount:

- Do not underfund the trust; if you do not have sufficient assets to fund the SNT immediately, consider life insurance that will fund the trust, which is often a good solution for a young family; and
- Do not overfund the trust; if your family is wealthy, consider capping the amount left to the SNT or using a "Pot Trust" or a "sprinkle provision" to allow the trustee to use trust assets in excess of a certain amount for other family members.

6. Fund the SNT from non-retirement assets, if possible, and leave the retirement accounts to other beneficiaries. Retirement accounts have their own set of specific planning considerations which make them a less-than-ideal method of funding a SNT; for this reason, this should be avoided where possible. If you need to fund the SNT with retirement assets, it is essential that the SNT be set up to qualify as a designated beneficiary and that care is taken in designating remainder beneficiaries. The best course of action is to allow your estate planning attorney to fill out the designation of beneficiary forms for the asset to ensure smooth funding.

7. Select the trustee. This is probably the most important and most difficult decision you will make in setting up a SNT. In selecting your trustee, the most important qualifications are loyalty and competency in administering the trust. The trustee is the quarterback of the plan who can hire financial advisors, attorneys, accountants, bookkeepers, social workers, and care managers. The trustee can delegate, but must oversee everything. Corporate trustees are an option if the trust is large enough. Look for a bank with special needs experience and a willingness to administer an SNT. If you use a corporate trustee, consider adding an individual family member or friend as a co-trustee to work with the corporate trustee who has expertise in SNTs.

8. Do not forget to include special needs considerations in all of your estate planning documents. The special needs estate plan goes beyond just ensuring that the SNT is properly set-up. You must also make sure that your other estate planning documents, like Powers of Attorney and Trusts, are set-up to take the SNT into account. For example, your Power of Attorney should give someone the power to fund the SNT with your assets and your will or any other trusts from which there is even a remote possibility that your loved one with a disability will inherit. It should reflect that any distributions that would otherwise go to the person with a disability instead be diverted to the SNT.

9. Avoid having the beneficiary receive gifts, bequest, or inheritances outright from other family members. It is advisable to be candid with other family members about the planning being done for your family member. If you plan far in advance, and ensure that other family members make similar adjustments made in their own planning, you can see to it that the beneficiary does not inherit assets outright. If you determine anyone wants to leave something to the disabled beneficiary, your estate planning attorney should provide language that you can pass on to those family members that will allow them to divert their bequests to the SNT. This will avoid the need for a guardian, a loss of eligibility for needed benefits, or other complications. Additionally, you may need to review any existing family trusts, especially life insurance trusts or gifting trusts that would distribute directly to the beneficiary with a disability. Look for provisions where your family member with a disability is a contingent beneficiary and determine if they have rights of withdrawal, as either of these circumstances could interfere with their eligibility for needed benefits. In the case of an irrevocable trust, consult with an attorney about decanting or other methods to address the issue.

10. Consider setting up an exempt trust to protect any assets the disabled beneficiary may have from prior work, accumulated benefits, inheritances, gifts, or lawsuits. If your family member with a disability already has money in their name, there is another type of SNT, commonly referred to as a "d4a" or "d4c" trust, and allowed under federal law that can be funded from funds belonging to an eligible person. ABLE accounts may also be an option for preserving a person with a disability's assets for their use while maintaining

their eligibility for government benefits. Your estate planning attorney will be able to assist in determining which type of exempt trust would be best suited for your loved one's circumstances.

Bonus tip: Please note that funds belonging to the person with a disability should be kept strictly separate from any third-party funds, as the rules requiring payback to the state for the cost of benefits when a beneficiary dies, if properly managed, will attach only to funds owned by the individual, or "first-party" funds.

© 2019 Schiff Hardin LLP

Source URL: <https://www.natlawreview.com/article/10-estate-planning-tips-families-beneficiaries-special-needs>