



Special Needs Estate Planning for Families with Special Needs: Top 10 Action Steps

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Disabilities affect families at all income levels. Everyone knows someone who is challenged by a disabling condition—whether it is a physical, mental or intellectual disability. Some disabilities are no one’s fault (such as Down Syndrome or Autism). Others have been caused by the actions or inactions of third parties (such as damage from a personal injury). Addressing the “special needs” that result from such disabilities can be a tremendous challenge. Families trying to secure the future of loved ones with disabilities often become fierce advocates for them and assemble teams of professionals with special expertise to address all aspects of their current and future care.

An essential member of the team is a special needs planning attorney. Such an attorney is able to recognize the many issues that should be addressed [when a family’s estate plan names a person with a disability as a beneficiary](#). In most cases, one or more Special Needs Trusts (SNTs) should form the core of the planning for a person with a disability. However, many other issues must be addressed beyond this planning technique.

Many traditional estate planning attorneys are unaware of the special expertise required to plan for people with disabilities, arising in part because of their traditional focus on tax minimization rather than on public benefit programs. All members of the Special Needs Alliance possess the necessary expertise to practice competently in this area of the law. The following ten unique issues should be considered by every family that is planning for a person with a disability.

1. Do not disinherit the beneficiary with special needs. *In a misguided attempt to avoid prejudicing eligibility for public benefits, many traditional estate planners still recommend disinheriting a family member with a disability. However, SNTs are designed to supplement, not supplant, means-tested government benefits for which the beneficiary is otherwise eligible as a result of his or her disability. Attorneys who still recommend disinheriting the beneficiary with special needs are now being held liable for rendering this incompetent advice to unsuspecting families.*

2. Know the difference between government benefits that are “means-tested” and those that are based on a worker’s employment history. “Means-tested” government benefits (such as Medicaid and Supplemental Security Income) are available for persons with qualified disabilities who have limited income and resources. Other government benefits (such as Medicare and Social Security Disability Insurance) are forms of insurance that are based on someone’s work record (typically that of a retired, disabled, or deceased parent). Many traditional estate planning attorneys do not appreciate these distinctions. Although a SNT is designed primarily to preserve means-tested government benefits for which the beneficiary is eligible as a result of his disability, SNTs must also be coordinated with employment-based benefits. Furthermore, even if the SNT beneficiary does not need to rely on Medicaid for health insurance coverage, there are many programs for which a person must be “Medicaid eligible” to participate, e.g. “life skills” programs designed to maximize the beneficiary’s independence, and community-based housing arrangements.

3. Know the difference between a “first-party” and a “third-party” SNT. A “first-party” SNT is funded with assets that belong to the beneficiary with special needs, e.g. an unexpected inheritance or a personal injury award. A “third-party” SNT is funded with assets that belong to someone else, e.g., a parent or sibling. The rules that apply to a first-party or “self-settled” SNT are much more stringent than those that apply to a third-party SNT. Many families establish a network of several SNTs, e.g., one first-party SNT and multiple third-party SNTs designed to receive funding from different sources at different times. There is no such thing as a one-size-fits-all SNT that effectively accommodates all funding sources.

4. Select an appropriate Trustee for SNTs. Serving as the trustee of a SNT is not an easy job. It can be time-consuming and exacting. Further, whether the SNT is established under a will or during life, there are numerous traps for the unwary in administering a SNT. Professional trustees are strongly recommended, either to serve as the sole trustee or as a co-trustee with a family member or other individual. Required reading for any person who may consider serving as the trustee of a SNT may be found in the SNA’s publication database or here <https://specialneedsalliance.org/special-needs-101/free-trustee-handbook/>

5. Determine an appropriate distribution of estate assets to fund a SNT. Although many parents want to treat each of their children equally, an equal division of assets among a family’s beneficiary with a disability and those without disabling conditions may not necessarily be fair or appropriate. Although it is easy to recognize that a beneficiary with special needs will likely require a larger share of the family’s resources, it is often a difficult decision for a family to augment that beneficiary’s share at the expense of his or her

siblings or other beneficiaries without disabilities. However, since most families have numerous asset pools and sources of funding for the ultimate benefit of all of their beneficiaries, there are often creative options to resolve concerns about fairness.

6. Coordinate beneficiary designations with the rest of the planning. It can be easy to forget that some valuable assets are distributed neither by will nor by living trust. Instead, these assets are governed by separate “beneficiary designations,” e.g., life insurance, IRAs and other retirement plans, and certain transfer-on-death and jointly-held assets. Failure to coordinate these assets with those subject to the will or living trust can completely destroy a special needs plan!

7. Coordinate the estate plans of more distant family members who may wish to benefit the beneficiary with special needs. Once the parents and other close family members of a person with a disability have decided to maintain his or her eligibility for means-tested public benefits, they must work closely with other well-intentioned relatives. Using a “receptacle” third-party SNT to receive pour-over bequests or lifetime gifts from multiple donors can be an elegant solution. This can avoid the establishment of multiple SNTs by more distant family members and also helps avoid direct inheritances or gifts that threaten the beneficiary’s public benefits.

8. Assemble a team of “allied professionals” to help secure the future of a beneficiary with special needs. In addition to an estate planning attorney who is familiar with the legal requirements for SNT planning, [the following allied professionals](#) are often valuable members of the beneficiary’s team: (i) a life care planner; (ii) a care manager; (iii) a life insurance professional who is familiar with the distinct SNT funding challenges faced by family members with special needs; (iv) an investment advisor who knows how to manage funds for beneficiaries with special needs, taking into account their generally lower investment risk tolerance; (v) a government benefits application specialist and claims processor; (vi) a special needs advocate; (vii) a special education expert to assist in developing and enforcing an “individualized education plan” for school-aged beneficiaries with special needs; (viii) a home accessibility specialist; and (ix) an accountant who is familiar with the deductions to which families may be entitled as a consequence of special needs expenditures, and who is proficient in preparing income tax returns for SNTs. The estate planning attorney often serves as the initial “quarterback” of this team of allied professionals, and makes recommendations and referrals for team members.

9. Appoint an appropriate legal guardian for the beneficiary with special needs. Many parents do not realize that providing financially for their child with a disability is not enough, and that they should also secure the appointment of a legal guardian for their adult child with disabilities who cannot make his or her own personal health and safety decisions.

Once a child attains 18 years of age, his or her parents no longer have the legal right to make health care decisions for their child unless and until they qualify as court-appointed guardians. Parents should seek their own appointment as legal guardians during their lifetime and nominate a successor guardian to serve when they are no longer directly involved with their adult child's care.

10. Consider encouraging estate planning by the adult child with disabilities. Many adult children with disabilities remain legally competent to sign their own wills and disability documents, [including a financial power of attorney and a health care directive](#). The appointment of a guardian for an adult with a disability does not necessarily remove his or her right to make a will.

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