



Potential Pitfalls

Creating an effective strategy for families that include a member with special needs requires a thorough understanding of both the individual's unique needs and the family's available resources. Without a carefully coordinated plan, families risk unintentionally jeopardizing access to vital government benefits or failing to secure sufficient support for their loved one's long-term care and quality of life.

To ensure that any estate plan or financial strategy aligns with the family's long-term goals, it is crucial to work with advisors experienced in special needs planning. These professionals can help navigate complex legal, financial, and governmental systems to create a cohesive plan tailored to the family's specific circumstances. Below are several common mistakes that may occur when proper planning is not in place:

- Failure to prepare. Often, caregivers of individuals with special needs spend a significant amount of time, energy, and money managing the day-to-day needs of their family. Considering the additional stress and demands placed upon families with a loved one with special needs, it is understandable that these families often delay developing a formal blueprint until "later." However, without a detailed and thoughtful blueprint, the person with special needs could become disqualified from government benefits or may have insufficient assets to provide for his/her needs.
- Distribution scheme. Even when families implement a well-intentioned estate plan, improper asset distribution can unintentionally disrupt government benefit eligibility. Common missteps include leaving assets outright to the individual with special needs through a will or trust or structuring distributions that can be used for food or shelter, which are considered countable resources under SSI rules. Such provisions can reduce or eliminate eligibility for benefits that are critical to the individual's care, leading to unintended financial strain and disruption in services.
- Improperly drafted special needs trust. To ensure an individual with special needs maintains access to government benefits, it is important that assets are directed to a special needs trust instead of outright to the individual. A special needs trust can provide for a beneficiary's ongoing needs in a manner that will not disqualify him/her from available government benefits. However, if the special needs trust is not drafted properly, assets of the trust could be considered a resource of the person with special needs, frustrating the intended purpose of the trust.
- Funding special needs trust with wrong assets. Since special needs trusts are used to provide a beneficiary with support not otherwise provided through government benefits, funding the trust with the wrong type or amount of assets could impact the beneficiary's ongoing care. For example, when a trust is funded with life insurance, consideration should be given to the type of product used and to the appropriate insured on the policies. Since the beneficiary's need is often permanent, term insurance may not be an appropriate vehicle. Though insurance is often considered for the primary income earning spouse, when the other spouse is the primary caregiver of the beneficiary, insurance on the caregiver spouse should also be seriously considered.
- No letter of intent. Caregivers of individuals with special needs use wills/trusts to provide direction to a fiduciary regarding the individual's assets and financial support. However, a will/trust will not provide fiduciaries and successor caregivers with the necessary information to help maintain the individual's day-to-day needs. A letter of intent is a powerful tool to educate others on the person with special needs' daily routines, behaviors, medical background, ongoing medical needs, and, most importantly, the caregiver's expectations and wishes for the individual. Failing to provide such information often puts the successor caregivers in the impossible position of making decisions regarding every aspect of the individual's life with no direction or background information to guide them.
- Failing to account for finances. Strategizing for a family with a person with special needs often requires a "two generation" blueprint. Failing to consider financial needs may result in the caregivers underestimating the assets and income that will be required for the future support of the person with special needs. Developing a well-contemplated strategy for finances enables the caregivers of a person with special needs to implement tangible actions and objectives to provide for their own retirement income as well as the lifelong support of the individual with special needs.

- Failure to coordinate beneficiary designations with estate plan. An otherwise appropriate estate plan will be ineffective if beneficiary designations are not reviewed and updated to coordinate with the executed documents. If a beneficiary designation leaves assets outright to a person with special needs, the individual's eligibility for government benefits could be affected until those assets are depleted. Beneficiary designations typically control the distribution of qualified plans, IRAs, life insurance, and annuities.
- Wrong fiduciaries. Naming the right team of individuals to manage an individual with special needs' assets and care may be the most important component of the strategy. Designated trustees and advisors should have experience with special needs trusts and should be sympathetic to the circumstances of the person with special needs. Building a team of fiduciaries to support the individual's day-to-day needs will be crucial to protecting his/her lifelong support.
- Failure to coordinate with family. Failure to account for the estate plans of other family members or benefactors can significantly jeopardize a person with special needs eligibility for critical government benefits. If individuals outside the immediate planning process—such as grandparents, siblings, or close relatives—are unaware of the legal and financial implications of leaving assets directly to a beneficiary with special needs, their well-intentioned gifts or inheritances may have unintended consequences. Specifically, outright gifts or bequests to an individual with special needs can result in the reduction or loss of means-tested benefits such as Supplemental Security Income (SSI) or Medicaid. To avoid this, it is essential that all family members involved in the broader estate planning process are informed of the risks and are encouraged to coordinate their planning—such as by directing assets to a properly structured special needs trust—to ensure the continued protection and support of the individual with special needs.
- No guardianship. Upon reaching the age of majority, an individual is legally recognized as an adult and is presumed to have the capacity to make independent decisions regarding personal care, medical treatment, and financial matters. However, individuals with certain types or levels of impairment may lack the cognitive ability or judgment necessary to fully understand legal, financial, or medical concepts, placing them at increased risk of exploitation or uninformed decision-making. In such circumstances, it may be necessary to establish a legal guardianship to ensure appropriate decision-making authority and protection. This legal process appoints a guardian to act in the best interests of the individual with special needs, particularly when they are unable to provide informed consent or manage their own affairs. It is strongly recommended that families and caregivers initiate guardianship proceedings prior to or upon the individual reaching the age of majority. Failure to do so may result in the caregiver losing the legal authority to make decisions related to the individual's health care, financial management, and access to confidential medical information—potentially disrupting the continuity of care and support.

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