ADVANCED PLANNING





Preparing for the Future of Your Loved One with Special Needs



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Preparing for the future of your loved one with special needs

Millions of families in the United States have loved ones with special needs. Those individuals have greater life expectancies today than ever before, often outliving their parents, grandparents, siblings, and other familial caregivers. Today, as families and as a society, we have high expectations for them and for the quality of life they should experience. Their future will depend on the actions families take now, while they're still able to provide care.

WEALTH TRANSFER

Wealth transfer is a process of not only deciding who is to get what property after death but, most importantly, also considering transfer strategies to carry out those wishes. For many families, that is a difficult enough task. But for families of loved ones with special needs, the task is much more difficult and even more critical.





The emotional impact to you and your family would be life-changing.

IMPORTANCE OF PREPARING FOR YOUR LOVED ONE'S FUTURE FINANCIAL WELLNESS

In many cases, a combination of family assets and government programs is not enough to provide the quality of life desired for loved ones with special needs. That makes preparing for the future of paramount importance so that existing family resources are not over-taxed, or even dissipated, in an effort to provide for the care and comfort of a family member with special needs.

When preparing for the future of a family member with special needs, two broad economic objectives need to be accomplished. First, protect existing sources of income and medical resources, including those available through the government and also nonprofit needs-based programs. Second, create additional funding sources to help meet the individual's needs, both during the caregivers' lifetimes and after their deaths.

When preparing for the future of loved ones with special needs, both the immediate and extended families should be considered potential sources for financial and personal support of these individuals. Care must be taken by all family members to avoid giving the individual money or other assets that could result in their loss of needs-based benefits. For example, eligibility for Supplemental Security Income can be lost if the individual with special needs has personal assets in excess of \$2,000 and income more than certain levels.

Preparing for loved ones with special needs is complex, and errors or lack of experience on the part of tax and legal advisors can be disastrous. The material that follows is intended to be only a general discussion of the subject and is in no way meant to suggest a course of action or to be legal advice applicable to any specific situation. It cannot be emphasized enough that those families with loved ones with special needs should consult an attorney, a financial professional, and other appropriate advisors who are experienced in this area.

ELIGIBILITY

Supplemental Security Income eligibility can be lost if the individual with special needs has personal assets in excess of **\$2,000** and income more than certain levels.

General considerations for caregivers of individuals with special needs

Caregivers, whether parents or others, of individuals with special needs must consider both personal and financial issues with great care. Both of these aspects come together in a complex way, often melding into emotional issues. Predicting the future needs of the individual and protecting needs-based resources, all in coordination with both the immediate and extended family members, presents a challenge for all involved.

In addition to the already difficult decisions of what goes to whom at the caregivers' deaths, families who have loved ones with special needs must also:

- Realistically assess the physical, cognitive, and emotional needs of the individual now and in the future
- Evaluate not only the current financial needs of the individual, but also those needs after the deaths of the parents or other care providers
- Consider what needs-based benefits are available now and factor in the possibility that those programs may change or be eliminated in the future
- Carefully choose caregivers, as well as trustees and guardians, where trusts and/or guardianships are involved
- Review the above four items on a regular basis

Questions to consider

Some of the specific questions caregivers of loved ones with special needs should objectively consider and answer:

- What is the nature and extent of the individual's disability, and what is their prognosis? To what degree can they care for themselves, both now and in the future?
- What are their educational and vocational goals?
- What is their current educational and/or employment status? Will it continue or might there be significant changes in the near future?
- What is the current financial status of the caregivers, the loved one with special needs, and other family members? Is there a possibility of an inheritance? From whom? Is that person involved in the planning process?
- Is there a possibility that the individual with special needs might receive a sum of money from a personal injury claim, a life insurance benefit, or any other source? If so, when? If so, have appropriate trust arrangements been made so these assets are not owned directly by the individual?
- Do they qualify for government benefits? If so, is that need thought to be permanent? If not, for how long is the qualification expected to continue?
- Is there a specific income that is being targeted?
- What is their legal capacity? Is there a need for a guardianship either now or in the future? Until what age will the guardianship be needed?
- Do they need assistance with financial management? Can they handle finances in either large or small amounts?
- Will there be a need for additional funds to provide for their needs at the death or disability of the parents?
- At the death or disability of the parents, who can substitute for them? What if no family member is able to do so, or one is but later decides not to for whatever reason?
- Where will they live in case they are not able, or do not want, to live at home? In that case, what additional costs are involved, and what will be the source of that funding?
- How will their financial needs following the death of the parents affect the shares of the estate available to other children? How will that be dealt with and communicated to those children?



Assessing current and future resources and expenses

The financial goal of preparing for the future of loved ones with special needs is to provide for them throughout what is hoped to be a long life. That takes considerable thought as to what the current costs of caring for the individual are, and a realistic projection of what they will be in the future, impacted by many variables and uncertainties such as:

- **A loss or reduction of funding** from the parents or other family members for a variety of reasons.
- **A change in entitlement status** of the individual or a change in, or an elimination of, the entitlement program itself.

Parents or others must attempt to make a realistic assessment (and that is all that it can be) of the family economics, the current economic needs, and the present value of the financial needs for the rest of their life. That is no easy undertaking.

A complicating factor for families with loved ones who have special needs is that wellmeaning bequests or gifts from others can disqualify them from government needs-based benefits. On the other hand, family members who would like to assist financially may be reluctant to do so because of a lack of knowledge of how it may be done without impairing those benefits. Extended family members can be a willing source of financial assistance once they understand the options that are available to assist.

Government resources can be a vital component of the financial structure of families of loved ones with special needs. Government benefits generally fall into two categories: (1) **needs-based** and (2) **non-needs-based**. One of the main focuses of preparing is the preservation of the needs-based resources such as Supplemental Security Income and Medicaid. Those programs that involve state oversight will vary from state to state. The family and its advisors must be familiar with the specific programs in their state.

In addition to governmental programs, a number of nonprofit organizations also provide significant assistance that cannot be given due attention here. The family would be wise to become familiar with such organizations.



Assembling the advisory and support team

Preparing for the future of families who have loved ones with special needs is a complex undertaking, and we are living in an age of specialization.

Consequently, families should take care to work with attorneys who have expertise not only in estate planning, but also in special needs law. For example, such attorneys can provide Special Needs Trust documents for the benefit of the individual with special needs that will help ensure that trust assets are to be used to provide supplemental and extra care over and above government benefits—not in place of government benefits—thereby preserving eligibility for government benefits.

TRUSTS

With respect to trusts, careful consideration must be given to the selection of the person or institution that will serve as the initial trustee and those who will serve as successors. Typically, for an inter vivos trust, established by the parents or other caretaker while they are alive, they serve as the trustees. The issue of who will succeed them as trustee(s) at their deaths is a vital one because the trustee is responsible for the custody and management of the trust assets, as well as determining what distributions should or should not be made from the trust for the benefit of the individual.

GUARDIANSHIPS

The selection of a guardian must be made with great care. From a legal standpoint, the relationship between a parent and a child changes when the child reaches the age of majority. That age varies from state to state, but is most commonly age 18. If, at that age, the child does not have the capacity to make personal or financial decisions, a guardian (usually a parent) must be appointed by the court so that someone has the legal authority to make those decisions on behalf of the individual.

The most common types of court-appointed guardians are guardians of the property and guardians of the person. One person may be appointed to perform both responsibilities.



GUARDIAN OF THE PROPERTY

The **guardian of the property**, as implied by the name, is responsible for the real estate, personal property, money, and similar property that is owned on behalf of a minor or an individual of any age who has been determined by a court to be incapable of caring for their property. Note that if a trust has been established for the individual's benefit, the trustee oversees assets that are owned by the trust.

GUARDIAN OF THE PERSON



The **guardian of the person** is responsible for making health care and other personal decisions on behalf of a minor or an adult adjudicated by a court to be incapable of managing their personal affairs. While the parents are alive, they are generally the natural guardians for their children, so a guardian of the person is not usually needed until the child reaches the age of majority. At that age, the law presumes the individual to be an adult, so parents generally apply to the court to be appointed general guardians for their adult children with special needs. At the deaths or incapacity of the parents, a successor guardian must be appointed.

In Summary

For families of loved ones with special needs, preparing for the future is critical. Unfortunately, it is also more difficult. Time spent caring for the whole family can reduce the time that might otherwise be available to think about financial matters. That simple fact makes it all the more important for families with loved ones with special needs to seek out qualified and experienced financial professionals and legal advisors to plan for the future of their loved ones with special needs.



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