



# Planning for loved ones with **Special Needs**



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Estate planning is a process of not only deciding who is to get what property after death but, most importantly, *implementing the plan* in order to carry out those wishes. For most families, that is a difficult enough task, but for families of children<sup>1</sup> with special needs, the task is much more difficult and even more critical.

There are millions of families in the United States who have family members who have special needs. Those individuals have greater life expectancies today than ever before, often outliving their parents. Today, as families and as a society, we have high expectations for them and for the quality of life they should experience.

## The Importance of Planning

In many cases, a combination of family assets and government programs is not enough to provide the quality of life desired for the child throughout his or her lifetime. That makes special needs planning 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 the child.

There are two broadly stated economic objectives to special needs planning. The first is protecting existing sources of income and medical resources, including those available through government and nonprofit needs-based programs. The second, where applicable, is the creation of additional funding for the future needs of the child, which must be met after the deaths of the parents.

In the context of special needs planning, both the immediate and extended families should be considered as a single unit. Failure to plan by any member of the family, not just the parents, could result in a loss of needs-based benefits that often are vital to the child. Failure to coordinate planning with other family members might cause the receipt of funds that the child is not capable of managing, resulting in the need for a court appointed and supervised guardian. Most critical, however, may be the lost opportunity to provide additional funding as well as guidance that would benefit the child after the deaths of the parents.

Special needs planning is complex, and errors or lack of experience on the part of advisors can be disastrous. It is recommended that all advisors be experienced in special needs planning. 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 a child with special needs should consult an attorney, a licensed financial professional, and other appropriate advisors who are experienced in this area.



<sup>1</sup>Not all persons with special needs are children. Many are adults. While we refer to children throughout this piece, the material is equally applicable to adults.



## General Planning Considerations for Parents of Children with Special Needs

Parents 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 very emotional issues. Predicting the future needs of the child 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 parents' deaths, families who have children with special needs must also:

- ◆ Realistically assess the physical, mental and emotional needs of the child now and in the future.
- ◆ Evaluate not only the current financial needs of the child 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 care givers as well as trustees and guardians where trusts and/or guardianships are involved.
- ◆ Review the above four items on a regular basis.

## Some Specific Questions to Consider

Some of the specific questions parents of children with special needs should objectively consider and answer are as follows:

- ◆ What is the nature of the child's disability, its extent and what is the child's prognosis? To what degree can and will the child be able to care for himself or herself now and in the future?
- ◆ What are the child's specific abilities and disability and how do they impact his or her life?
- ◆ What goals are there for the child to obtain an education or to develop job skills?
- ◆ What is the child's 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 parents, the child, and other family members? Is there a possibility of an inheritance? From whom? Is that person involved in the special needs planning process?



- ◆ Is there a possibility that the child might receive a sum of money from a personal injury claim, life insurance benefit, or from any other source? If so, when?
- ◆ Does the child 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 an specific income that is being targeted?
- ◆ What is the child's legal capacity? Is there a need for a guardianship either now or in the future? Until what age will the guardianship be needed?
- ◆ Does the child need assistance with financial management?
- ◆ Will there be a need for additional funds to provide for the child's needs at the 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 later decides not to for whatever reason?
- ◆ Where will the child live in case he or she is not able, or does not want, to live at home? In that case, what additional costs are involved and what will be the source of that funding?
- ◆ Can the child handle finances in either large or small amounts?
- ◆ How will the child's financial needs following the death of the parents affect the shares of the estate available to other children? How is that to be dealt with and communicated to those children?

## Assessing Current and Future Resources and Express

The financial goal of special needs planning is to provide for the child throughout what is hoped to be a very long life. That takes considerable thought as to what the current costs of caring for the child are and a realistic projection of what they will be in a future impacted by many variables and uncertainties such as: (1) a loss or reduction of funding from the parents or other family members for a variety of reasons, (2) a change in entitlement status of the child, or (3) a change in, or an elimination of, the entitlement program itself. Parents must attempt to make an honest guess (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 the life of the child. That is no easy undertaking.

Determining resources available from family members is a more difficult task than that required of other families. The complication for families with children who have special needs is that well-meaning bequests or gifts from others can disqualify the child 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 very 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 children with special needs. Government benefits fall into two categories: (1) needs-based and (2) non-needs-based. One of the main focuses of special needs planning is the preservation of the needs-based resources such as Social 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, there are also a number of nonprofit organizations that 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

Planning for families with children with special needs is an extremely complex area, and we are living in an age of specialization. While a specialist is not required to prepare a basic will or even a basic trust, special needs planning is quite different. The slightest error in the knowledge of the law or even a misplaced word in a document can have serious ramifications, including the loss of needs-based benefits and family resources. The attorney should not only be a specialist in estate planning but also should be experienced and well versed in special needs planning.

Hiring an attorney who specializes in special needs planning is important for reasons other than simply the complexity of the law. Such attorneys possess an understanding of the broad issues that impact families of children with special needs, including their health, economic, legal, and family issues.

In addition, where a trust is a component of special needs planning, 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, the parents serve as the trustees during their lives. 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 assets as well as determining what distributions should or should not be made for the benefit of the child.

Finally, where a guardian is required, 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 majority. That age varies from state to state but is most commonly eighteen. 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 child.

There are two types of court appointed guardians, (1) a guardian of the property and (2) a guardian of the person.

The guardian of the property, as implied by the name, is responsible for making financial decisions regarding 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 his financial matters. The guardian of the property has jurisdiction over all of the individual's assets other than those held in trust. If a trust is in place, the trustee assumes that function over trust-owned assets.

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 to manage his personal affairs. While the parents are alive, they are responsible for those personal functions so a guardian of the person is not usually needed until the child reaches the age of majority. At that age, most jurisdictions require that the parents be appointed as guardians if the child is found by the court to be incapacitated so as to impair his ability to make financial and/or personal decisions as defined by the particular state law. At the deaths or incapacity of the parents, a successor guardian must be appointed.

## In Summary

For families of children with special needs, planning is absolutely critical. Unfortunately, it is also more difficult to do for these families. The activities of daily life dedicated to the care of the whole family often crowd out the time that might otherwise be available to think about financial matters. That simple fact makes it all the more important for families with children with special needs to be surrounded by the best of advisors to assure that the child receives financial assistance in the same quantities that he receives the love of his family.



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