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SPECIAL NEEDS ESTATE PLANNING FOR PERSONS WITH DISABILITIES

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One of the greatest fears that parents and other caregivers have is the possibility that they will die without having arranged for the care of a disabled son, daughter, relative or friend. Most families only have to be concerned about this issue until a child reaches an age when he or she is self-supporting. However, many individuals with disabilities will never be fully capable of self-support, and their parents and caregivers will have to plan for the day when they will not be available to provide assistance and oversight. For these families, the failure to properly plan can cause tremendous hardship for the person with the disability at precisely the time when he or she most needs help: when the primary source of support, often a family member or close friend, is no longer available for companionship, assistance, and help. "Special Needs Estate Planning" is the practice of ensuring that services and support will continue for the life of the person with the disability when the caregivers are no longer able to help.

The type and level of assistance that will be needed vary according to the nature of the disability, the disabled person's age and family circumstances, and many other factors. For example, parents of a minor with a severe developmental disability are often most concerned with identifying a Guardian who is willing to undertake the task of caring for a special needs child. Caregivers dealing with mental illness understand that the illness can bring loneliness and isolation, and they want to ensure that there will always be an advocate willing to step in and assist in a time of crisis. On the other hand, many people with disabilities live very independent lives, and need nothing more than some basic assistance in their day to day affairs.

Comprehensive Special Needs Estate Planning ensures that the question, "Who will take care of my loved one when I am gone" is answered in the most cost-effective and efficient manner possible, and in a fashion that considers not only the needs of the disabled individual, but also the ongoing financial and health care needs of the caregivers themselves.

Begin With a Comprehensive and Honest Assessment

Special Needs Estate Planning requires a working knowledge of a broad range of issues: government benefit eligibility, trust and estate law, estate and income tax rules, guardianship, and others. In all cases, the planner must understand the nature of the particular disability and must have a sense of what the future care and oversight requirements will be. In turn, the care needs will determine the resources that will be required to support a comprehensive care plan.

This last consideration, identifying the level and cost of the services that will be required to provide support to a loved one, is often the most difficult. Indeed, families and caregivers seldom add up the costs of the various forms of support they give to an individual with a disability. Those who contend that a disabled individual's financial needs are minimal often forget to add up the cash value of the many services they provide. These can include serving as advocate, social service coordinator, companion, guardian, chauffeur, money manager, and recreation director. These services enhance the quality of the disabled individual's life. If a parent or caregiver dies without planning for the continuation of these services, the quality of life that the person with a disability previously enjoyed is likely to be reduced substantially.

Some of these "quality of life" services are available through government funded programs designed for individuals with disabilities. These programs are generally designed to provide only a basic level of support, and the items and activities that make our lives enjoyable, those that truly provide "quality of life," are simply unavailable. Moreover, the eligibility thresholds for most of these programs are quite low, and living within these thresholds can be quite difficult. As a result, families and caregivers often seek to "supplement" the goods and services available through these public benefit programs with their own funds, but without jeopardizing benefit eligibility. This is where competent Special Needs Estate Planning becomes critical.

The Elements of a Comprehensive Special Needs Estate Plan

Each Special Needs Estate Plan is unique, and it should maximize the formal and informal supports that the individual with the disability receives from government funded programs, family caregivers, community supports, and others. However, all Special Needs Estate Plans contain three basic components: a legal plan, a financial plan, and a life care plan.

Legal Planning

The legal planning component of a Special Needs Estate Plan will address many traditional Estate and Long Term Care Planning issues. Has the client considered how the estate will be divided among his or her intended heirs? What is the family's current estate and income tax exposure? Is there a Will in place, and if so, has it been updated since the onset of the son's or daughter's disability? Will the appointment of a Guardian be necessary, and if so, who will be the Guardian?

What if the *caregiver* needs assistance? Does he or she have a properly drafted Power of Attorney and Health Care Proxy? If aging parents are serving as the primary caregivers for the person with the disability, have they considered how they will pay for *their own* long term care needs without jeopardizing the inheritance of their children? Does the parent's Will or Living Trust include a properly drafted Supplemental Needs Trust, which is a trust instrument designed especially for individuals with disabilities? Who will serve as Trustee of the Supplemental Needs Trust? Does the Trustee understand how these types of trusts are to be administered?

What is the functional level of the individual with the disability? Is he or she capable of executing his or her own Power of Attorney and Health Care Proxy so as to preclude the need for a formal

guardianship at some future time? What are the federal and state benefit programs that support the person in the community, and have the eligibility requirements for those programs been factored into the Special Needs Estate Plan?

A sound legal plan will address these and other issues, and as with any type of planning, it is best developed early and comprehensively, considering the needs and intentions of all members of the disabled individual's circle of support.

Financial Planning

A sound financial plan complements the legal component of a Special Needs Estate Plan. Whereas legal planning primarily involves the preservation and transmission of wealth, financial planning is primarily concerned with the enhancement of wealth and the selection of assets to ensure growth, diversification, liquidity and availability to meet a client's goals and objectives. The two areas are closely intertwined, and a comprehensive Special Needs Estate Plan will contain components of both disciplines.

Consider, for example, a family whose primary asset is the family home. Many families hope that the value of the home will be available as an inheritance for a disabled son or daughter and other heirs. Indeed, many parents and other caregivers contemplate that the disabled son or daughter will be able to continue to reside in the home after they are gone. But have they considered what will happen if *they themselves* reach an age when they will no longer be able to reside in the home and need assistance with their own health care needs? If the caregivers have not considered how *their own* long term care costs will be met, there is a risk that the home would need to be sold to satisfy these obligations, and may never be available for the son or daughter. One solution may be to use other assets to generate the income that would be necessary to pay these costs. Another possibility may be the purchase of a long term care insurance policy. In the end, the most appropriate planning route may be to restructure assets so that long term care costs would be paid for through the Medicaid system. Legal and financial professionals participating in the development of a Special Needs Estate Plan should expect to share their ideas on the pros and cons of each strategy, and arrive at the most appropriate solution for the family.

More traditional financial planning considerations include planning to ensure that a family will have sufficient funds for a comfortable retirement, investing in assets that will minimize income tax liability, and consolidating assets to minimize the cost and effort of overseeing a diverse portfolio. These issues are best addressed with a competent and knowledgeable financial professional who understands the heightened importance of proper planning for individuals with disabilities and their families.

Life Care Planning

The final step in developing a Special Needs Estate Plan is often the most overlooked. At least in theory, people appreciate the need to address the legal and financial issues discussed above. But once the parents and caregivers are gone and the assets have been protected for the benefit of the individual with the disability, many questions still remain. "How should the funds that the family has worked so hard to protect be used to truly enhance the life of the person with the disability?" "To whom

should I, as Trustee or Guardian, look to for advice and suggestion when the person with the disability cannot speak on his or her own behalf?"

"Life Care" planning is the process of providing answers to these and similar questions for the family members, friends and advocates who will provide assistance and oversight after the primary caregivers are gone. It begins with ensuring that as much personal, financial, and other pertinent information concerning the person with the disability is stored in a single place and accessible for future reference. Many advocates use workbooks designed specifically for this purpose. The workbooks usually request background medical information, financial information, family history, community contacts, and recreational preferences of the person with the disability. The workbooks also often request that the caregivers provide similar information about *their own* finances and family supports.

This information can prove to be especially crucial for those who must step in and assist when the caregiver is seriously injured or dies unexpectedly.

It is difficult to overemphasize the importance of this step in the Special Needs Estate Planning process. Consider this. If you were to get up and leave town today, right this minute, completely unexpectedly and without advance notice to *anyone*, including your disabled family member or friend, who would step in to handle your affairs? Does this person know where all of your pertinent financial information is stored? Have you provided him or her with the legal authority to access your funds and act on your behalf? Who breaks the news to the person with the disability? Who will step in to do what *you* have been doing all these years? Who stays in contact with the service coordinator or social worker? Who double checks to be sure that medication is being taken as prescribed? Who will make those calls when no one has heard from your son or daughter in days, and who will they call? And if you have someone in mind, have you provided this person with the information he or she needs to carry out your wishes? Does this person know what you know about your son or daughter's needs, preferences and dislikes?

To those people who will step in and assist your disabled family member or friend when you are no longer able to do so, a well written Life Care Plan will be worth its weight in gold. And as uncomfortable as it is for many parents and other caregivers to face the subject, completing this piece of the Special Needs Estate Planning process often provides the most satisfaction and relief. Certainly the legal and financial components are equally as critical, but in most circumstances, competent counsel will be able to preserve some of the family's funds for the person with the disability, even if no planning whatsoever has been completed prior to the disability or death of the caregiver. This "crisis intervention planning" is always more expensive, time consuming, and will be conducted before a court as a matter of public record, but it can be done.

Once the parents or primary caregivers are gone, however, the ability to prepare a comprehensive and detailed Life Care Plan becomes quite limited. There may be an Individualized Service Plan to use as a reference, a dedicated service coordinator who might have some additional personal information, or some other family member or friend who could assist in compiling pertinent information, but none of these fallback references will ever replace the Life Care Plan prepared by the person who has taken care of the person with the disability all of his or her life.

Conclusion

"Special Needs Estate Planning" is by necessity a dynamic process. It is common to hear financial professionals talk about the need to periodically "review a plan" to be sure that it still meets a family's needs. This admonition is equally as important, if not more so, in the context of planning for an individual with the disability, as many people with disabilities are unable to actively advocate on their own behalf once their primary caregivers are gone. Laws governing taxes, property rights, and government benefit programs that support a disabled individual in the community are changing constantly. And the resources, needs and preferences of the person with the disability as documented in the Life Care Plan will change with time.

The most important thing is to *begin the process*. Once you have built the foundation, small changes are easy to accommodate. Legal documents can be modified, assets can be restructured, and new information can be added to the Life Care Planning workbook with minimal effort. But if you wait too long to begin the process, you may never have the opportunity to answer the question, "Who will take care of my loved one when I am gone?"

At Wilcenski & Pleat PLLC, we have assisted hundreds of families and friends of the disabled develop comprehensive estate and long term care plans that integrate traditional estate and long term care planning with the use of supplemental needs trusts. We have the experience and resources to aggressively advocate before the state and federal agencies that administer government benefit programs, and have developed a network of government, private, and non-profit professionals who provide advice and support when a comprehensive "Special Needs Estate Plan" is being developed. If you have a family member or friend with a disability and would like to discuss what you can do to help secure a stable future for that person's benefit, please do not hesitate to contact us.