PIERRO, CONNOR & STRAUSS, LLC
Trusted Counsel

2020
SPECIAL NEEDS PLANNING GUIDE

www.pierrolaw.com | info@pierrolaw.com
Toll Free: 866-951-PLAN
Albany | New York City | Lake Placid |Hudson, NY | Fort Lee, NJ | Falmouth, MA

TABLE OF CONTENTS

I. Caregiving for Families with a Child with a Disability

Millions of Americans are caregivers. Some provide care for spouses with serious medical problems; some are caregivers for parents or other family members. Our aging population is growing faster than any other population group. It is estimated that by 2050, 20 million Americans will be over the age of 85, nearly 5% of our population.

Most Americans would be surprised to learn that one of every five Americans has a disability; one of ten so severe that they are unable to work. Many of those who are under age 65 live with or are cared for in some way by their parents, who as they age may also have their own health and financial problems.

The United States social support system does little for persons with disabilities, unlike many European nations. Medicare was established in 1965 providing a health care insurance program for persons over age 65 who were entitled to Social Security or Railroad retirement benefits as well as younger persons who have a disability and who have been receiving Social Security Disability benefit payments for two years, but except for some short term benefits for skilled care, Medicare did not – and still does not - provide any long-term care benefits. President Lyndon Johnson was a great politician but not a very good prognosticator when he said at the signing ceremony for the Medicare law he said:

> "Every citizen will be able, in his productive years when he is earning, to insure himself against the ravages of illness in his old age. No longer will illness crush and destroy the savings that they have so carefully put away over a lifetime so that they might enjoy dignity in their later years."

LBJ was terribly wrong. There is no dignity when the costs of long-term care can impoverish patients and caregivers. While Medicaid, adopted along with Medicare in 1965, does cover some long-term care costs (certainly Skilled Nursing Home costs), it is "means tested," so to be entitled to Medicaid benefits (as discussed fully in our **2020 Medicaid Guide**) persons must be "poor," meaning have very limited assets under the program rules. And, except for the State of New York, most states offer very little home care benefits under their Medicaid program.

The needs of older Americans who are incapacitated for social and financial support are significant; so are the needs of younger persons with a disability. In our 2020 Medicaid Guide we discuss the needs of the older cohort, but in this Guide we will focus on the more narrow issue, not just the costs of care or how to pay for necessary care for younger persons with a disability, but how to respond to the concerns of parents who are the primary caregivers and provide life-support for a child with a disability if they become incapacitated in later life or at the time of their death.

II. New in 2020

Many parents who have a child with special needs have a good portion of their wealth in retirement plans. The SECURE Act effective January 1, 2020 makes significant changes in the rules about payout of benefits after the primary beneficiary (the retirement plan owner) dies. Be assured that payments to beneficiaries who are disabled within the meaning of federal law will continue to be able to receive payments over their lifetimes (a STRETCH of the IRA or Retirement Plan) because of an exception through the new rules for disabled and minor beneficiaries. Further, retirement plan benefits for children with disabilities can be placed in SNTs and benefits can be accumulated in the discretion of the SNT trustee when appropriate. We discuss the new rules more fully in our 2020 Estate Planning Guide, including options to convert to a Roth IRA, or to take distributions above the Required Minimum amount and purchase life insurance. Please call us if you have questions on how to integrate your retirement plan funds into your Special Needs Planning.

III. Who Will Care for My Loved One When I am No Longer Able?

One of the greatest fears that parents and other caregivers have is the possibility that they will no longer be able to serve as the caregiver for the care of a child with a disability, parent, relative or friend – we will sometimes refer to the person in need as the PIN – "person in need" - because of death or their own incapacity without having established a care plan for providing the necessary care. Most families only have to be concerned about this issue until their children reach an age when they are self-supporting. However, many individuals with disabilities will never be fully capable of independence and self-support, and their *parents or other caregivers need to plan for the time when they will not be not available to continue to fulfill their caregiving role.* For these caregivers, the failure to properly plan can cause hardship for the person with the disability at precisely the time when they need help the most: when the primary source of support is no longer. **"Future Care Planning"** is the solution to 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 assistance that will be needed will vary according to the nature of the PIN's disability, her or his 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 and sometimes a trustee who is willing to undertake the task of caring for a child with special needs. 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 individuals with disabilities live very independent lives, and need nothing more than some basic assistance in their day to day affairs.

Comprehensive Future Care Planning ensures that the question, *"Who will take care of my loved one when I am no longer able"* 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 the ongoing financial, personal and health care needs of the caregivers themselves.

IV. Start with a Comprehensive and Honest Assessment

Future Care Planning requires a working knowledge of a broad range of issues: **government benefits and eligibility rules, trust and estate law, estate, gift and income tax rules, guardianship law, basic financial planning, and many others**. In all cases, the caregiver and her or his advisor must understand the nature of the particular disability and have a sense of what the future care of the PIN will involve and what the oversight requirements will be. In turn, the care needs of the PIN 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 support they give to the PIN. 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 costs can include serving as advocate, counselor, social service coordinator, companion, guardian, chauffeur, money manager, and recreation director, services that without which the PIN could not function. These services are critical to maintaining the function and quality of the PIN's life. If a parent or caregiver dies or becomes incapacitated without planning for the continuation of such support and services, the functions and quality of life that the person with a disability is likely to be endangered.

Some of these services are available through government funded programs designed for individuals for disabilities. Unfortunately, these programs are generally designed only to provide a basic level of support, and the items and activities that make 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 accessing these programs because of the eligibility thresholds is difficult. As a result, families and caregivers often seek to "supplement" these public benefit programs with their own funds without jeopardizing benefit eligibility. This is where competent planning advice becomes critical.

V. Elements of a Comprehensive Future Care Plan

The needs of every PIN are unique, and so, then, is each Future Care Plan, and it should maximize the formal and informal supports that the PIN receives from government funded programs, family caregivers, community supports provided by not-for-profit organization and others. However, all Future Care Plans must contain three components: **a legal plan, a financial plan, and a life care plan.**

A. Legal Planning

The legal planning component of a Future Care Plan will address many traditional estate and long-term care planning issues.

- Has the caregiver considered how her or his estate will be divided among the estate beneficiaries? Should the PIN share equally with other siblings or will she or he need less because of government benefits? Because of the uncertainty of the future (both the PIN's future needs and the possible change in existing government benefits) should an executor or trustee be given discretion to change current plans?
- What is the caregiver's current estate and income tax exposure? Will the caregiver's current or future needs exhaust funds that may be needed to support the PIN?
- Is there a Will and trust in place, and if so, has it been updated since the onset of the son or daughter's disability if it develops or changes during the caregiver's lifetime?
- Will the appointment of a guardian be necessary, and if so, who will be the guardian? Or does the PIN have the capacity to sign advance directives – a power of attorney, health care proxy and a "living will?" What is the standard of capacity necessary to execute advance directives? If the PIN is capable of executing her or his own power of attorney, health care proxy and living will it may not be necessary to have a court appointed guardian at some future time.
- What if the caregiver needs assistance? Does he or she have a properly drafted power of attorney, health care proxy and living will? 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, particularly a child with disabilities?
- 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 nominated trustee understand how these types of trusts are to be administered, as well as her or his responsibilities and competency to perform the myriad tasks that will be required?
- What federal and state benefit programs that can support the person in the community are available, and have the eligibility requirements for those programs been considered in developing the Future Care Plan? What not-for-profit organization resources and programs exist in the community?

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

B. Financial Planning

A sound financial plan complements the legal component of a Future Care 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 Future Care 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 son or daughter with a disability will be able to continue to reside in the home after the caregiver parents have died. 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 (perhaps because they require moving to an assisted living facility)? 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 pay for their long-term care costs, and may not 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 or life insurance (if they are insurable and the cost is not prohibitive) to replace assets spent on long-term care needs. In the end, the most appropriate planning route may be to restructure assets so that either the caregiver's long-term care costs or the PIN's costs can be paid for through the Medicaid system. Legal and financial professionals participating in the development of a Future Care 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 considerations include planning to ensure that a family will have sufficient funds for a comfortable retirement, investing in assets that will provide for appreciation and minimize income tax liability, and consolidating assets to minimize the cost and effort of overseeing a diverse portfolio and have flexibility to adapt plans in light of changes in family needs and tax laws. These issues are best addressed with a competent and knowledgeable financial professional who understands the importance of proper planning for individuals with disabilities and their families and understands the reality that developing an appropriate future care plan is a team effort.

C. Life Care Planning

The final step in developing a Future Care Plan is often the most overlooked. In theory, people appreciate the need to address the legal and financial issues discussed above. But once the parents and caregivers have died and assets have been protected, probably in a well-drafted supplemental needs trust ("SNT") for the benefit of the individual with the disability, many questions still remain. How should the funds in the SNT be used to enhance the life of the trust beneficiary – the person with the disability? To whom should I, as Trustee, look to for advice and counseling? How do I make critical decisions when the person with the disability cannot speak on his or her own behalf when I am old? Should I be making decisions based on her or his wishes? If I do not know her or his wishes and cannot ascertain them, can I act based on what I think is in her or his best interest? How is that determined?

"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 no longer available. It begins with ensuring that as much personal, financial and other pertinent information concerning the PIN is obtained and recorded during the planning process so it is available for guidance in the future. Many advocates use workbooks designed specifically for this purpose. The workbooks will 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 impossible to overemphasize the importance of this part of the Future Care Planning process. Consider this: if you were to suffer a stroke unexpectedly who would be able to step in and handle your personal and financial affairs? Would 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? Your computer passwords? Who breaks the news to the person with the disability? Who will step in to perform the caregiving role 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 you or the PIN in days, and who will they call? And if you have someone in mind, have you provided this person with the information and legal authority 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 family member or friend with a disability when you are no longer able to do so, a well-written Life Care Plan tailored to her or his needs will be worth its weight in gold. And as uncomfortable as it is for many parents and other caregivers to face the topic, completing this piece of the process often provides great satisfaction and relief. Even if advance planning has not been done, competent counsel will be able to preserve some of the family's funds for the person with the disability. But **such "crisis intervention planning" is always more expensive, time consuming, may not be as effective and may need to have undesirable court intervention and supervision** (possibly as a matter of public record), but it can be done.

Once the parents or primary caregivers have died or are incapacitated, however, the ability to prepare a comprehensive and detailed Life Care Plan becomes 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 her or his life.

VI. Supplemental Needs Trusts

Almost all Future Care Plans will incorporate the use of a Supplemental Needs Trust (also known as a "Special Needs Trust"). Supplemental Needs Trusts (SNTs) provide supplemental a source of funds for persons with disabilities that supplement need based government benefits such as Supplemental Security Income ("S.S.I.") and Medicaid. Because of certain legal limitations on these trusts, individuals can remain eligible for such government benefits. SNTs enhance the quality of life of the person with the disability (who is referred to as the "beneficiary" because the trust is set up for her or his benefit). The trust can purchase additional support services, therapy and care that are not covered expenses or are not covered adequately by the Medicaid program, but which are vital to her or his well-being. The SNT is the lifeblood of a Future Care Plan which includes management of property and arrangements for personal care, vocational services, housing and care management.

VII. SNTs and Government Benefits

S.S.I. and Medicaid provide a basic level of support for food, clothing, shelter, medical care and long-term chronic care. The SNT can pay for the gaps. Based on the beneficiary's particular needs, the trust can pay for, but is not limited to, the following, to the extent they are not covered by Medicaid:

- Additional medical treatment or health insurance
- Individualized therapy
- Special medical equipment
- Care management
- Recreational activities
- Other goods, services and activities

A supplemental needs trust created by a person other than the beneficiary with her or his own funds - usually referred to as a "third party" SNT - is not counted as a resource for the beneficiary's eligibility for S.S.I. and Medicaid. For those programs, the trust is not "actually available" to the beneficiary because she or he has no right to demand that the trust pay for any good or services or distribute money to her or him. All distributions or payments from the trust are made at the sole discretion of the trustee, and they are usually made directly to providers of goods and services to the beneficiary. Any money paid directly to the beneficiary will be counted for purposes of eligibility for S.S.I. and Medicaid.

In-kind donations of food or shelter – that is, when someone (including a parent) gives the disabled individual food, or a place to live for free or at a reduced rate- will generally reduce SSI payments by up to one-third, but in some states, including New York, are not counted as income or a resource to the trust beneficiary.

VIII. Basic Types of SNTs

There are three basic forms of SNTs. The appropriate type of trust for a disabled individual depends on whose money or assets will be funding the trust. The amount of money available to fund the trust and whether there is someone who can act as trustee (i.e. administer the trust) are other factors.

- A "Third Party" SNT is a trust set up and funded by a parent or other person who has no legal duty to support the PIN (parents have a duty to support their children only until they reach age 21).
- An "OBRA-93" Payback SNT (usually referred to as a "First Party" trust) is a trust established by the PIN herself or himself, a parent, grandparent, legal guardian or a court[1] but which is funded with the assets of a beneficiary who is disabled and is under age 65. When the person with a disability dies, the State has a right to be "paid back" for medical assistance (Medicaid) it gave to the beneficiary if there are any assets left in the trust.

---

[1] Under OBRA '93 the PIN was not allowed to create the "First Party" trust for herself or himself. It could be created only by a parent, grandparent, guardian or a court. In many cases this required filing a court proceeding and convincing a judge who often was not familiar with S.S.I. and Medicaid law, that the trust was in the best interests of the PIN and should be established. After years of advocacy by elder law attorneys and the National Academy of Elder Law Attorneys the law was amended in 2018 to permit the PIN who had capacity to create a SNT for herself or himself.

- An “OBRA-93” Pooled Trust is a trust that can only be established and managed by a not-for profit organization. A separate trust account is funded with the assets of the PIN. With this type of trust, the state does not have to be paid back for Medicaid benefits as long as the remaining assets in the beneficiary’s account stay in the pooled trust after the beneficiary dies (for the use of other pooled trust beneficiaries).[2]

A. Third Party

These trusts are called “third party trusts” because they are created by a third party – i.e., by someone who is not the beneficiary. In the most common situation, parents will establish a SNT for their child in their wills, which will take effect upon the death of the surviving parent and are funded at that time. It is becoming more common, particularly in New York, for parents to utilize revocable living trusts as the primary vehicle for their estate planning and in such case the SNT for their child with a disability will be established under the revocable living trust. The advantages of estate planning via the use of a revocable living trust is fully discussed in our **2020 Estate Planning Guide.** Caring relatives or friends may also want to set up a trust to be assured that their money is being used to improve the PIN’s quality of life, and that it is drafted properly so that it does not jeopardize problems with eligibility for government benefits.

One advantage of a third-party trust is that the parents can have the comfort of knowing that their child will be appropriately provided for during her or his lifetime and will still be able to direct how any remaining assets in the SNT will be distributed after the child’s death.

As long as the SNT was established when the parent had no duty to support the child and the trust was not funded with any property of the child, there is no “payback” – the state has no right of recovery and no right to place a lien against the trust property. Any remaining funds in the SNT can be distributed in accordance with the parents’ testamentary plan.

B. OBRA-93 Payback Trusts – the “First Party Trust”

As noted above, this form of SNT can be established by the person with a disability, a parent, grandparent, legal guardian, or court and is funded with the assets of a beneficiary who is under the age of 65. The trust must direct a “payback.” In other words, a right to receive the assets in the trust when the beneficiary dies to the extent of Medicaid’s expenditures for the beneficiary during her or his lifetime. A person with a disability is permitted to transfer his or her own assets into a qualifying SNT and still receive S.S.I. and Medicaid, as long as the state will be paid back after the beneficiary dies and other formalities are followed.

Payback trusts are often set up when an individual receives an inheritance or the proceeds from a judgment or settlement in a lawsuit, either a lump sum or more commonly with a lifetime annuity, which can be added into the SNT.[3] As we have noted, if the PIN anticipates large medical bills, the need for lifetime care, or is severely disabled, she or he can use the settlement fund or annuity to fund a “payback trust” and still qualify for Medicaid and S.S.I.

The county Department of Social Services (Human Resources Administration in New York City) must be notified when the Third Party SNT is created or funded, before the trust makes certain transactions, and when the beneficiary dies.

---

[2] Depending on the remaining balance in the account, if Medicaid is repaid and there are some funds remaining after the pay-back, depending on the bylaws and rules of the not-for-profit organization’s trust agreement, a distribution may be allowed to family.

[3] Judges who approve settlements for persons with disabilities in a lawsuit are sometimes not familiar with the eligibility rules for S.S.I. and Medicaid and it is usually advisable to have the litigation lawyer consult with an experienced elder law attorney. The SNT can be established in the court’s lawsuit compromise order.

C. Pooled Trusts

By law, pooled SNTs are established and administered by a not-for-profit organization. Individual trust accounts are established by a "sponsor" who signs a "sponsor agreement." As with individual SNTs, there are two basic forms of pooled SNTs. Third party pooled trusts are funded with the assets of parents, relatives and/or friends and "OBRA-93" pooled trusts (in effect a "First Party" pooled trust) are funded with the assets of the person with a disability.

The sponsor of a trust account funded with the beneficiary's assets can be the person with a disability, a parent, legal guardian, or court. Pooled trusts usually require a minimum amount to set up an account.

The provisions of the pooled trust agreement will determine whether any portion of remaining funds in the beneficiary's pooled trust account may be paid over to a designated beneficiary. There are many pooled trusts in New York. Each not-for-profits organization that has established a pooled trust has a different policy regarding distributions to individuals when the pooled trust beneficiary dies. Keep in mind, as we have noted, that there will be a "payback" to the state before a distribution to an individual even if the pooled trust agreement permits distributions.

IX. ABLE Accounts

The Achieve a Better Life Experience (ABLE) Act, a federal law enacted in 2014, included a new Internal Revenue Code section 529A allowing the establishment of accounts for individuals with disabilities to cover disability related expenses. ABLE accounts do not replace traditional trust planning, but provide a useful supplement to an existing plan for a child with a disability. Permissible uses for ABLE funds include more than just medical costs, and include education, housing, transportation, employment training and support, financial management and more.

Some other ABLE account rules:

- They are for individuals who had a disability before age 26
- Earnings in account are not subject to income tax
- A donor may use the annual gift tax exclusion of $15,000 per beneficiary
- The first $100,000 in the ABLE account is excluded for S.S.I. purposes
- In some states, the Medicaid resource limit in the plan matches the state's 529 Plan amount ($375,000 in New York)
- Roll-over of 529 Plan assets into ABLE Plan accounts, subject to the annual contribution limit, is permitted
- There is a payback provision for Medicaid recipients

X. Conclusion

Future Care Planning is by necessity a dynamic process and needs to be flexible. It is a unique combination of **legal, financial, and personal care planning** designed to ensure that a family member or friend who has a disability (remember one of five Americans), including a person who has suffered a traumatic brain injury, has an appropriate system of financial support and personal management and advocacy, beyond basic government entitlements. This applies even after the disabled individual's parents or other caregivers become unable to provide care and supervision. Effective Future Care Planning involves consideration of the needs of both the caregiver and the individual with the disability. A properly drafted Supplemental Needs Trust often serves as the foundation of a comprehensive Future Care Plan. Like any legal document, the Supplemental Needs Trust should be designed to meet the needs of the individual with the disability and should be part of a comprehensive estate and long-term care plan for the disabled person's parents or caregivers.

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 a disability, as many individuals with disabilities are unable to actively advocate on their own behalf, particularly without the help of their parents – their primary caregivers - when they are no longer available to act as loving and effective advocates. 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; the second is to complete and implement the plan. Then, once the plan - the foundation for the future - is adopted and implemented, 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 the process is not begun, you may never have the opportunity to answer the question, *"Who will take care of my loved one when I am unable to do so?"*

At Pierro, Connor & Strauss, LLC, we have the experience, experience and resources to be a part of, and perhaps the leader, of the team that can assist in developing an appropriate Future Care Plan that meets the needs of your family. And, we will be here if there is a need to modify the plan or, if there are problems, to advocate aggressively before the state and federal agencies that administer government benefit programs. To accomplish the goal of meeting your needs, we have developed a network of government, private, and non-profit professionals who provide advice and support when a comprehensive "future care plan" is being developed and to assist in implementing the plan both while our initial client is involved or at a later time. If you are an individual with a disability or, a family member of an individual with a disability, we are confident we can assist in improving important aspects of life.

CIRCULAR 230 DISCLOSURE: To comply with the U.S. Treasury regulations, we must inform you that (i) any U.S. federal or state tax advice contained in this resource guide was not intended or written to be used, and cannot be used, by any person for the purpose of avoiding U.S. tax penalties that may be imposed on such person and (ii) each taxpayer should seek advice from their tax advisor based on the taxpayer's particular circumstances. If you would like an opinion on the one or more tax issues addressed in this guide, please contact Pierro, Connor & Strauss , LLC.