



PIERRO, CONNOR  
& STRAUSS, LLC

*Trusted Counsel*

# 2024 SPECIAL NEEDS PLANNING GUIDE

[www.pierrolaw.com](http://www.pierrolaw.com)  
[info@pierrolaw.com](mailto:info@pierrolaw.com)  
Toll Free: 866-951-PLAN

Albany, New York City, Ronkonkoma,  
Hudson, Garden City, Utica, Lake Placid  
Clark, NJ; Falmouth, MA; Clearwater, FL

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# 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. Caregiving often falls on family members. Many people with disabilities under age 65 live with or are cared for by their parents. These caregivers often face their own health and financial problems as they age and worry about who will care for their child with disabilities when they have died.

The United States social support system does little for people with disabilities, unlike many other nations. Medicare, established in 1965, provides a health care insurance program for persons over age 65 as well as younger persons who have a disability and who have been receiving Social Security Disability benefit payments for two years. However, except for good hospital benefits and some short-term benefits for skilled care, Medicare does not provide any long-term care benefits.

Medicaid, adopted along with Medicare in 1965, covers some long-term care costs and is more generous in New York than in most other states. However, even in New York, Medicaid is “means tested,” so to be entitled to Medicaid benefits persons must be legally “poor,” meaning that they have very limited assets under the program rules. Proper trust planning can help people with assets above limited “exempt” amounts shelter excess assets and obtain Medicaid services. Our 2023 Medicaid Guide fully discusses those strategies and focuses on Medicaid planning for seniors and preparing for incapacity.

This Guide focuses how to access care for younger persons with an established disability, as well as how caregivers should plan future care for a child with a disability when they are no longer able to provide that care themselves.



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

One of the greatest fears that parents and other caregivers of a child with a disability have is “Who will take care of that child when I am no longer able?” Some 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 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 available. Establishing a **“Future Care Plan”** is the solution to ensuring that services and support will continue for the life of the person with the disability (the Person in Need or “PIN”), potentially for years after the primary 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, the availability of family willing and capable to assume the caregiver role, their financial 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 by adopting a plan that meets the best interests of the PIN, efficiently utilizes available resources, and in a fashion that considers not only the needs of the disabled individual, but also the ongoing financial, personal and health care needs of the caregivers themselves.

## III. Start with a Comprehensive and Realistic 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 other subjects. In all cases, the caregiver and her or his advisor must understand the nature of the 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.

Identifying the required level and cost of services is often the most difficult task. 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. These services are critical to maintaining the function and quality of the PIN's life but are only "free" when performed by an unpaid family caregiver. If a parent or caregiver dies or becomes incapacitated without planning for the continuation of such support and services, the PIN's functioning and quality of life are likely to decline.

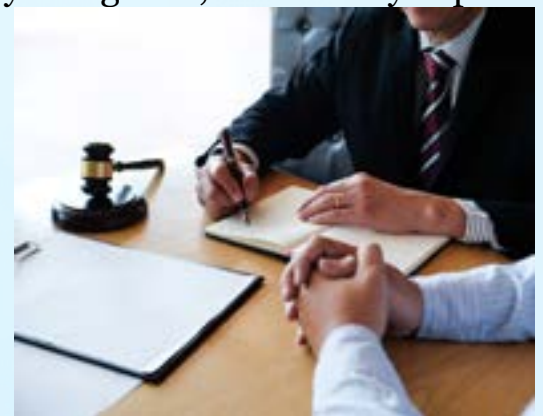
Some of these services are available through government funded programs designed for individuals with disabilities. Unfortunately, these programs are generally designed only to provide a basic level of support, and the items and activities that make lives enjoyable, those that truly provide "quality of life," are simply not offered by these programs. Moreover, the eligibility thresholds for most of these programs are quite low and accessing them because of the financial 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.

## IV. Elements of a Comprehensive Future Care Plan

The needs of every PIN are unique, and so, then, is each Future Care Plan. The Future Care Plan should maximize and coordinate the formal and informal supports that the PIN receives from government funded programs, family caregivers, community supports provided by not-for-profit organizations 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 a smaller share because of available government benefits or more? 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 plan for estate distribution?

- What is the caregiver's current estate and income tax exposure? Will the caregiver's own 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? Does it address possible changes in the PIN's needs during or after 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 or manage some or all activities of daily living himself or herself, 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 so that trust assets will not disqualify the PIN from eligibility for government benefits? Is the nominated trustee capable intellectually and emotionally to understand her or his responsibilities 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? To what extent should the plan be different if the PIN's disability is mental illness? What not-for-profit organizations have appropriate resources and programs for a person with physical or cognitive disabilities?

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, while preserving benefit eligibility, 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 financial 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 own long-term care costs and may not be available for child with the disability.

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 their 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. New in 2023 – Retirement Plans**

Many parents who have a child with special needs have a good portion of their wealth in retirement plans. The SECURE Act 2.0 signed into law in late 2022, altered rules for money that is saved and withdrawn from retirement accounts. Effective in 2023, the age when required minimum distributions (RMDs) increased to 73 from 72. This is an update to the SECURE ACT first enacted in 2020, which made significant changes to the rules about payout of benefits after the primary beneficiary (the retirement plan

owner) dies; the most significant being that beneficiaries are required to take benefits over a 10-year period, not their lifetime.

Fortunately, an exception applies to disabled and minor beneficiaries. Individuals with disabilities can continue to receive payments over their lifetimes (also called a ‘STRETCH’ of the IRA or Retirement Plan payout period). This is an advantage to parents and guardians who want to provide for loved ones with a disability. Further, retirement plan benefits for children with disabilities can be placed in Supplemental Needs Trusts – discussed later in this Guide - and benefits can be accumulated at the discretion of the trustee when appropriate.

SECURE Act 2.0 also has an impact on money in college savings plans, which will be covered later in this Guide under VIII. ABLE Accounts.

#### **D. 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 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 the trustee, look to for advice and counseling? How does the trustee make critical decisions when the person with the disability cannot speak on his or her own behalf?

Should the trustee be making decisions based on her or his wishes or the choices of the PIN? If the trustee does not know the PIN’s wishes and cannot ascertain them, does the trustee act based on what he or she thinks is in the PIN’s 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 include medical information, history, 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 in-





formation 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 becomes incapacitated or dies, perhaps unexpectedly.

It is impossible to overemphasize the importance of this part of the Future Care Plan development 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?

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? Have you established the necessary trust for your child and named this person as trustee?

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, experienced counsel will be able to help you preserve resources for the person with the disability. The caregivers may not create and adopt a Future Care Plan for several reasons. They may not understand the need to do so, or may find some of the decisions to be made beyond their capacity or understanding, are unable to decide on the appropriate person to assume all or some of their responsibilities, or may not have the means to afford the costs of developing the plan.

In such case, someone will need to institute a guardianship proceeding, which should be the plan of last resort for many reasons. A court appointed guardian could be a stranger to you and your child with the disability and may not have knowledge of the necessary facts, history or preferences of your child, or have the expertise and be the caring person you would have chosen.

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 coor-

dinator 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.

## V. Supplemental Needs Trusts

The core of almost all Future Care Plans will be a Supplemental Needs Trust (also known as a “Special Needs Trust” referred to as an “SNT”). Supplemental Needs Trusts provide financial resources for persons with disabilities that allow for obtaining needs-based government benefits such as Supplemental Security Income (“S.S.I.”) and Medicaid, when appropriate.



If properly drafted, SNTs do not disqualify otherwise eligible persons 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). Perhaps, even more importantly, 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.

## VI. 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, or if the care provided by Medicaid is insufficient:

- 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 in determining 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 goods 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 or a third party SNT) 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 SNT beneficiary for Medicaid purposes.

## VII. Basic Types of SNTs

There are three basic types 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<sup>1</sup> 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.
- 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).

Keep in mind that Medicaid, title 19 of the Social Security Act, enacted in 1965 at the



same time as Medicare, is a joint program of the federal government and the states. States are required to provide certain benefits required by Title 19 and cannot be “more restrictive.” But states can provide additional benefits (be more “generous”) than required. For example, New York has a fairly generous “Community Medicaid” (home care) program; a few other states have some home care benefits, but eligibility rules are more restrictive.

## A. Third Party Trusts

As noted above, these trusts are called “third party trusts” because they are created by a third party – i.e., by someone other than the beneficiary. Historically in most situations, parents would establish an SNT for their child in their wills, which take effect upon the death of the surviving parent and are funded by estate assets, life insurance, or other “non-probate” assets 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 usually to become effective upon the death of the parents. The advantages of estate planning via the use of a revocable living trust are fully discussed in our **2024 Estate Planning Guide**. Caring relatives or friends may also want to set up a trust to ensure that their money is being used to improve the PIN’s quality of life. In such an event, we may recommend setting up a “free-standing” third-party SNT so that each benefactor could “pour over” funds they wish to set aside for the child with a disability into a common trust for management and investment efficiency. A third-party SNT should be drafted properly so that it does not jeopardize problems with eligibility for government benefits.

A third-party trust provides the parents with the comfort of knowing that their child will be appropriately provided for during her or his lifetime and will still allow them to 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.

**Important:** the parents of a child with a disability must be careful that such child is not named as beneficiary of any non-probate asset (such as a life insurance policy, retirement plan or joint account) which would vest in the child when the parent - other other benefactor – dies.

## B. 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” – the statutory obligation to reimburse the state its outlays for the beneficiary when the beneficiary dies to the extent of Medicaid’s expenditures. 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 SNT will include the payback requirement.

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 have the SNT as beneficiary. <sup>4</sup> 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 SSI and Medicaid.

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

<sup>3</sup> 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.

<sup>4</sup> 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

A pooled SNT is established and administered by a not-for-profit organization, which “pools each beneficiary’s “separate” trust account for investment and management purposes.

Individual trust accounts are established by the beneficiary if she or he has capacity or 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 a 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, as well as a duly appointed agent of

the PIN under a Power of Attorney. 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-profit 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.

## VIII. ABLE Accounts

*The Achieve a Better Life Experience (ABLE) Act*, allows people with qualifying disabilities to save funds for future needs, including higher education, into a tax-advantaged account. Other permissible uses for ABLE funds are medical costs, housing, transportation, employment training and support, financial management and more.

ABLE accounts do not replace traditional trust planning but can provide a useful supplement with a great advantage: money in the account is not calculated in benefits like Medicaid and Supplemental Security Income (SSI).

ABLE Accounts are currently for individuals whose disability arose at or before age 26; however, the SECURE Act 2.0 will raise that age to 46 beginning in the year 2026. This change opens the door to a broad range of people who are diagnosed when older.

Some other ABLE account rules:

- Earnings in account are not subject to income tax
- A donor may use the annual gift tax exclusion of \$17,000 per beneficiary
- The first \$100,000 in the ABLE account is excluded for S.S.I. eligibility 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

## IX. Legal Advocacy

PCS staff are experienced in advocating for clients to access various community-based services and benefits. This includes:

- Supplemental Security Income (SSI);



- Social Security Disability Insurance (SSDI);
- Medicaid
- Special Education;
- Children’s HCBS Services Waiver;
- OPWDD Comprehensive Waiver;
- N.Y. Long Term Health Care Program;
- N.Y. Nursing Home Transition and Diversion Waiver; and
- N.Y. TBI Waiver.

We recommend that families with children with disabilities seek a comprehensive evaluation early in their loved one’s life. Such information will facilitate timely access to special education, SSI, and a wide spectrum of Medicaid-funded services.

## 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 in five Americans has a disability), including a person who has suffered a traumatic brain injury, has an appropriate system of financial support, personal care management and advocacy, beyond basic government entitlements. This benefit exists even after the 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 the disabled person’s parents or caregivers. The SNT must be drafted carefully so that it will not be treated as “available” to the PIN and cause program ineligibility.



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 cautionary advice 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 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; and complete and implement the plan. After the plan is adopted and implemented, necessary modifications can be made. Legal documents can be modified, assets can be restructured, and new information can be added to the Life Care Planning workbook. But if a plan is not effectuated the caregiver will have missed 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 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 the family. And, we will be here if there is a need to modify the plan, or if there are problems, we can 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.

The information in this guide is provided for informational purposes only. While every effort has been made to ensure accuracy, it cannot be relied upon as legal advice and laws can change at any time. Applicability of the legal principles discussed may differ substantially in individual situations, and you should always consult with your legal advisor.

The divorce law in New York has been amended to extend the obligation of support for a child with a disability when there is a divorce proceeding until age 26. It is not clear as of the date of this Guide how Medicaid will deal with this change in New York law.

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.

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# **LifeHappens RADIO**

**BY PIERRO, CONNOR & STRAUSS**

**LOU PIERRO**



**AARON CONNOR**



**FRANK HEMMING**



**“Life Happens” is a weekly radio program with our attorneys and guests which explores the unprecedented challenges confronting individuals and their families through the stages of life.**

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A smiling man with a beard, wearing a white t-shirt and a green apron, is holding a small potted plant. He is standing in front of a large window with a green plant hanging from above. The background is bright and airy.

# LOCATIONS

## **CAPITAL REGION**

43 British American Boulevard  
Latham, NY 12110  
Phone: 518-459-2100

## **NEW YORK CITY**

260 Madison Avenue, 16th Fl.  
New York, NY 10016  
Phone: 212-661-2480

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