

# 2026 SPECIAL NEEDS PLANNING GUIDE

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& STRAUSS, LLC  
*Trusted Counsel*

**OFFICES:** Albany, New York City, Ronkonkoma, Hudson, Garden City, Long Island, Utica , Lake Placid

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**CONTACT US**

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

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# A Letter to Parents, Guardians, and Caregivers

If you are reading this guide, you love someone who depends on you in ways others may not fully understand. You may be a parent, guardian, or family member who has stepped into a caregiving role. You may feel confident and prepared, or overwhelmed and unsure where to begin. All these reactions are normal.

Planning for a loved one with a disability is not simply a legal exercise, it's an emotional process that raises difficult questions about independence, dignity, and what happens when you're no longer able to provide daily care. Many families delay planning not because they don't care, but because the questions feel overwhelming.

This guide will help you take the first steps toward a plan that protects your loved one, preserves essential government benefits, and gives you peace of mind. You do not need all the answers before you begin. Plans can and should evolve as your loved one's needs and your family's circumstances change.

Throughout this guide, when discussing legal documents, we refer to the individual with a disability as the "beneficiary." When speaking directly to you as a caregiver, we use "your loved one." Every individual with a disability is unique, and so is every plan.

## I. Why Special Needs Planning Matters

Millions of Americans serve as caregivers for loved ones with disabilities. While caregiving can be deeply meaningful, it's also demanding and often isolating. Many parents find themselves coordinating medical care, educational services, benefits applications, and daily support often while managing careers, finances, and their own health.

One in five Americans lives with some form of disability, and many individuals with significant disabilities rely on family members well into adulthood. As parents and caregivers age, one pressing concern emerges: \*What will happen to my loved one when I can no longer provide care or advocacy?



## When to Begin Planning

There is no single “right time” to begin special needs planning, but common triggers include:

- Shortly after a diagnosis of a physical, developmental, or mental health disability
- As a child approaches age 18 and legal adulthood
- When applying for or receiving SSI, Medicaid, or other government benefits
- After receiving an inheritance, personal injury settlement, or unexpected funds
- During divorce, remarriage, or family structure changes
- As parents approach retirement or face their own health concerns
- After a health scare or loss involving a primary caregiver

## Government Benefits and Their Limitations

Programs like Supplemental Security Income (SSI) and Medicaid provide essential support, but eligibility rules are strict. Medicaid is “means tested,” meaning beneficiaries must have very limited assets to qualify. Even modest inheritances or improper gifts can disqualify someone from benefits they desperately need.



Without proper planning, families face an impossible choice: spend down assets to qualify for care or preserve savings at the risk of losing benefits. Thoughtful legal and financial planning can help families navigate this tension and build a framework that supports both security and quality of life. A well-structured Special Needs Trust allows you to provide financial support without jeopardizing access to critical programs.

## II. Creating a Future Care Plan

For many caregivers, the question “Who will care for my loved one when I cannot?” is the most difficult to confront. Without a plan, these decisions may be left to courts or agencies unfamiliar with your loved one’s preferences, routines, and needs.

A Future Care Plan provides a comprehensive roadmap coordinating legal protections, financial resources, and personal guidance. The right plan looks different for every family. Some individuals require ongoing supervision and decision-making support, while others live largely independent lives but benefit from advocacy during crises. A well-designed plan adapts as needs, abilities, and laws change.

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 your loved one, efficiently utilizes available resources, and considers not only the needs of the individual with a disability, but also the ongoing financial, personal, and health care needs of the caregivers themselves.

### **III. Understanding Your Loved One's Needs: Starting with a Realistic Assessment**

Before legal documents are drafted or financial strategies discussed, effective planning begins with an honest and compassionate assessment of your loved one's current and future needs. This step is about understanding what support allows your loved one to live their best possible life.

A realistic assessment considers:

- The nature of the disability and how it may change over time
- Medical, therapeutic, and mental health needs
- Ability to manage activities of daily living
- Need for supervision, advocacy, or decision-making support
- Social, recreational, and vocational goals
- The availability of family members or others willing and able to help

#### **The Hidden Value of Family Care**

Families often underestimate the scope of care they provide because it has become routine. Advocacy, transportation, care coordination, financial oversight, emotional support, and supervision are all forms of labor. When provided by a parent or caregiver, they may feel invisible, but they have real value and real cost if they must later be replaced. These services are critical to maintaining your loved one's functioning and quality of life but are only "free" when performed by an unpaid family caregiver.



Some of these services are available through government-funded programs designed for individuals with disabilities. Unfortunately, these programs generally provide only a basic level of support. The items and activities that make life enjoyable are those that truly provide "quality of life" and are simply not offered by these programs. Moreover, eligibility thresholds are quite low, making access difficult.

As a result, families and caregivers often seek to "supplement" public benefit programs with their own funds without jeopardizing benefit eligibility. This is where competent planning advice becomes critical.

## IV. The Three Pillars of a Comprehensive Future Care Plan

Every individual with a disability has unique needs, and every Future Care Plan is unique. However, all comprehensive plans contain three essential components: legal planning, financial planning, and life care planning. Together, these ensure that authority, resources, and personal knowledge are preserved and coordinated.

### A. Legal Planning: Ensuring Authority and Benefit Preservation

Legal planning ensures the right people have authority to act, government benefits are preserved, and your intentions are honored.

**Key considerations include:**

**Estate Distribution:** How will your estate be divided among beneficiaries? Should your loved one with a disability receive an equal share, or does access to government benefits suggest a different allocation? Because of the uncertainty of the future for both your loved one's needs and possible changes in government benefits, should your executor or trustee have discretion to adjust the plan? What is your current estate and income tax exposure? Will your own current or future needs exhaust funds needed to support your loved one? Has your Will or trust been updated since the onset of your loved one's disability?

**Decision-Making Authority:** The appropriate decision-making structure depends on your loved one's capacity. For individuals who can understand and execute legal documents, advance directives (power of attorney, health care proxy, and living will) should be completed immediately upon turning 18. These documents provide necessary authority while preserving your loved one's autonomy. For individuals who lack capacity to execute these documents, guardianship provides essential legal protection and ensures someone has authority to make critical decisions on their behalf. In either case, identifying who will serve in these roles is a critical planning decision..

**Caregiver Planning:** What if you need assistance? Do you have properly drafted advance directives? If you're serving as primary caregiver, have you considered how to pay for your own long-term care needs without jeopardizing your children's inheritance, particularly a child with a disability?

**Trust Structure:** Does your Will or revocable trust include a properly drafted Supplemental Needs Trust? Who will serve as trustee, and are they capable intellectually and emotionally of understanding their responsibilities and performing the myriad tasks required?



**Benefits Coordination:** What federal and state benefit programs are available to support your loved one in the community? Have eligibility requirements been considered in developing your Future Care Plan? What nonprofit organizations have appropriate resources and programs for individuals with physical or cognitive disabilities?

Thoughtful legal planning reduces the risk that courts or unfamiliar agencies will make decisions about your loved one's care and ensures continuity of advocacy. A sound legal plan addresses these issues and is best developed early and comprehensively, with consideration of the needs and intentions of all members of your loved one's circle of support.

## **B. Financial Planning: Aligning Resources with Goals**

Financial planning focuses on ensuring resources are available for both your loved one and for you as a caregiver. Many parents worry about preserving assets for their child while also protecting their own retirement and long-term care needs. Legal and financial planning must work together because even a strategy that appears sound, financially, may undermine benefit eligibility if not properly structured.

### **Asset Protection Strategies**

Consider a family whose primary asset is the family home. Many families hope this asset will be available as an inheritance and that their loved one with a disability will be able to continue residing there. But what happens if the parents need assisted living care and must sell the home to pay for it?

Strategic planning, through using other assets to generate income, purchasing long-term care or life insurance, or restructuring assets for Medicaid eligibility, can help protect the home for your loved one while ensuring your own care needs are met. Legal and financial professionals should collaborate to evaluate the pros and cons of each strategy and arrive at the most appropriate solution for your family.



### **Retirement Account Considerations**

Many parents hold a good portion of their wealth in retirement plans. The SECURE Act 2.0, signed into law in late 2022, altered rules for retirement account withdrawals. The SECURE Act (2020) made significant changes to payout rules after the account owner dies so that most designated beneficiaries must now take distributions over a 10-year period, rather than their lifetime.

Fortunately, an exception applies to disabled beneficiaries. Individuals with disabilities can continue to receive payments over their lifetimes (a “stretch” distribution). Further, retirement plan benefits can be placed in Supplemental Needs Trusts and benefits can be accumulated at the trustee’s discretion when appropriate.

As of 2023, required minimum distributions (RMDs) begin at age 73, with the age scheduled to increase to 75 in 2033. SECURE Act 2.0 also impacts college savings plans, which will be covered later under ABLE Accounts.

## Comprehensive Financial Coordination

Traditional financial considerations include ensuring sufficient funds for comfortable retirement, investing for appreciation while minimizing income tax liability, and consolidating assets to minimize oversight costs while maintaining flexibility. These issues are best addressed with competent financial professionals who understand the importance of proper planning for individuals with disabilities and recognize that developing an appropriate Future Care Plan is a team effort.

## C. Life Care Planning: Documenting What Matters Most



Once legal documents are drafted and assets protected, critical questions remain: How should trust funds be used to enhance your loved one’s life? To whom should the trustee look for guidance? How does a trustee make decisions when your loved one cannot advocate for themselves?

Life care planning is the process of providing answers to these questions for the family members, friends, and advocates who will

provide assistance and oversight after you’re no longer available. It begins with ensuring that personal, financial, and other pertinent information is obtained and recorded during the planning process so it’s available for future guidance.

Many advocates use workbooks designed specifically for this purpose. These typically include:

- Medical history, current providers, and treatment preferences
- Daily routines, communication methods, and behavioral patterns
- Relationships, social connections, and recreational interests
- Crisis management approaches and coping strategies
- Educational and vocational history
- Financial account information and important contacts
- Caregivers’ own financial information and family supports

## The Stakes Are High

Consider this: if you suffered a stroke unexpectedly, who would step in to manage your loved one's care? Would they know where financial documents are stored? Would they have legal authority to access accounts? Who would explain the situation to your loved one? Who would coordinate with service providers, manage medications, and maintain the routines that provide stability?

To those who will step in when you're no longer able, a well-written Life Care Plan will be invaluable. And as uncomfortable as it is for many caregivers to face this topic, completing this piece often provides great satisfaction and relief.



## The Risks of Delaying

Even without advance planning, experienced counsel can help preserve resources.

However, caregivers may delay creating a Future Care Plan because they don't understand the need, find the decisions overwhelming, can't identify the right person to assume responsibilities, or lack the means to afford the planning costs.

Without a plan, someone may need to institute guardianship proceedings which should be a last resort. A court-appointed guardian could be a stranger unfamiliar with your loved one's history, preferences, or needs, and may not be the caring person you would have chosen.

Once you are incapacitated or have passed away, the ability to prepare a comprehensive Life Care Plan becomes severely limited. There may be service coordinators or family members who can help, but none of these fallback options will ever replace the Life Care Plan prepared by the person who has cared for your loved one all their life.

## V. Supplemental Needs Trusts - The Foundation of Your Plan

A Special Needs Trust (SNT) is the legal tool that makes comprehensive planning possible. For many families, the SNT is what allows all other planning to work effectively.

### How SNTs Work

If properly drafted, SNTs do not disqualify otherwise eligible individuals from government benefits. The trust is managed by a trustee who has discretion to make payments directly to service providers for the beneficiary's benefit. Because the beneficiary has no right to demand distributions, the trust is not considered an "available resource" for benefit eligibility purposes.

SNTs enhance the quality of life of the beneficiary by purchasing additional support services, therapy, and care that are not covered adequately by government programs or not covered at all, but which are vital to wellbeing. The SNT is the lifeblood of a Future Care Plan, enabling management of property and arrangements for personal care, vocational services, housing, and care management.

## **What SNTs Can Pay For**

Government benefits like SSI and Medicaid provide basic support for food, clothing, shelter, medical care, and long-term chronic care. However, strict eligibility rules mean even modest assets or improper distributions can jeopardize benefits.

The SNT fills the gaps. Based on the beneficiary's particular needs, the trust can pay for, but is not limited to:

- Additional medical treatment or health insurance
- Individualized therapy
- Special medical equipment and adaptive technology
- Care management and advocacy services
- Educational programs and vocational training
- Recreational activities, travel, and social engagement
- Other goods, services, and activities that enhance quality of life

All distributions are made at the sole discretion of the trustee, and payments are typically made directly to providers of goods and services. Any money paid directly to the beneficiary will be counted for purposes of eligibility for SSI and Medicaid.

## **Choosing the Right Trustee**

The trustee role requires both technical competence and personal commitment. This person (or institution) will manage investments, coordinate with service providers, understand complex benefit rules, and make discretionary decisions about your loved one's care. Many families choose a corporate trustee or co-trustees to balance professional expertise with personal knowledge of the beneficiary.

## **Preserving Benefit Eligibility**

A properly drafted SNT preserves eligibility because:

- The trust is not counted as the beneficiary's resource
- Distributions are made at the trustee's sole discretion
- Payments go directly to providers, not to the beneficiary
- The beneficiary has no legal right to demand distributions

**IMPORTANT:** Certain types of assistance may still affect SSI benefits, even if Medicaid eligibility is preserved. For example, in-kind donations of shelter when someone gives the beneficiary a place to live for free or at a reduced rate will generally reduce SSI payments by up to one-third, but in New York are not counted as income or a resource for Medicaid purposes.

Effective September 30, 2024, the Social Security Administration eliminated the reduction of SSI benefits based on receipt of food assistance. However, assistance with shelter expenses may still affect SSI eligibility and benefit amounts. Because rules evolve, ongoing review and guidance are essential.

## VI. Choosing the Right Type of Special Needs Trust

There are three types of SNTs. The right choice depends on whose assets will fund the trust and your family's specific circumstances.



### Third-Party SNT

- Who Creates It: Parent, relative, or friend
- Funded With: Creator's assets (not beneficiary's)
- Medicaid Payback Required? No
- Best For: Estate planning; leaving inheritance to loved one with disability

### First-Party SNT

- Who Creates It: Beneficiary, parent, grandparent, guardian, or court
- Funded With: Beneficiary's own assets
- Medicaid Payback Required? Yes
- Best For: Personal injury settlements; unexpected inheritances received by beneficiary

### Pooled Trust

- Who Creates It: Nonprofit organization
- Funded With: Either third-party or first-party assets
- Medicaid Payback Required? Depends on trust terms
- Best For: Smaller amounts; when no suitable individual trustee available

## A. Third-Party Trusts

These trusts are called "third-party trusts" because they are created by someone other than the beneficiary - typically by a parent or other relative.

Historically, parents would establish an SNT in their Wills, which takes effect upon the death of the surviving parent and is funded by estate assets, life insurance, or other 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 estate planning as it avoids probate, eliminates ongoing court supervision of the trust, and allows immediate asset access for the beneficiary. The SNT is established within the revocable living trust and becomes funded upon the parents' death. For a comprehensive discussion of revocable living trust benefits, see our [2026 Estate Planning Guide](#).

Caring relatives or friends may also want to set up a trust to ensure their money is used to improve the beneficiary's quality of life. In such cases, we may recommend a "free-standing" third-party SNT so that multiple benefactors can "pour over" funds into a common trust for management and investment efficiency.



### **Key Advantages:**

- No Medicaid payback requirement
- Remaining assets pass to other family members after beneficiary's death
- Can be created during parent's lifetime or at death
- Complete control over remainder beneficiaries

Parents of a child with a disability must be careful that the child is not named as direct beneficiary of any life insurance policy, retirement plan, or joint account. These assets would vest in the child when the parent dies, potentially disqualifying them from benefits. Instead, these assets should flow through your estate plan or directly into an SNT.

## **B. First-Party Trusts**

A first-party SNT is funded with assets that belong to the beneficiary. It can be established by the beneficiary themselves (if they have capacity), a parent, grandparent, legal guardian, or court.

### **Key Features:**

- Must include Medicaid payback provision (state reimbursed for benefits paid during beneficiary's lifetime)
- Can only be established for someone under the age of 65
- Requires notice to local Department of Social Services (Human Resources Administration in New York City)

### **Common Uses:**

- Personal injury settlements or lawsuit awards
- Unexpected inheritance received directly by beneficiary
- Back payment of Social Security disability benefits
- Divorce settlements

- The county Department of Social Services must be notified when the first-party SNT is created or funded, before the trust makes certain transactions, and when the beneficiary dies.

## C. Pooled Trusts

A pooled SNT is established and administered by a nonprofit organization, which pools each beneficiary's separate trust account for investment and management purposes.

Individual trust accounts are established by the beneficiary if they have capacity, or a "sponsor" who signs a sponsor agreement. There are two basic forms: third-party pooled trusts funded with assets from parents, relatives, or friends, and first-party pooled trusts funded with assets of the individual with a disability.

The sponsor can be the individual with a disability, a parent, legal guardian, court, or a duly appointed agent under a power of attorney. Pooled trusts usually require a minimum amount to set up an account.

### Key Features:

- Professional management by nonprofit
- Can be funded with either third-party or first-party assets
- If funded with beneficiary's assets, Medicaid payback applies but remaining funds may stay in pool for other beneficiaries rather than going to state
- Each pooled trust has different policies regarding distributions after beneficiary's death

### Best For:

- Families without suitable individual trustees
- Smaller amounts that don't justify standalone trust administration costs
- Beneficiaries who want professional management

## VII. ABLE Accounts

The Achieve a Better Life Experience (ABLE) Act allows individuals with qualifying disabilities to save funds for future needs into a tax-advantaged account. Permissible uses include higher education, 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 for qualification purposes for benefits like Medicaid and SSI.



## Eligibility and Contribution Rules

ABLE accounts are currently for individuals whose disability arose at or before age 26; however, the SECURE Act 2.0 raises the age to 46 for taxable years beginning on or after January 1, 2026. This change opens the door to a broad range of people diagnosed later in life.

### Key Rules:

- Annual contribution limit: \$19,000 (as of 2025, tied to federal gift tax exclusion)
- Earnings in account are not subject to income tax
- Annual contribution limits apply (currently tied to gift tax exclusion amount)
- The first \$100,000 in the ABLE account is excluded for SSI eligibility purposes
- In some states, the Medicaid resource limit matches the state's 529 Plan amount (\$375,000 in New York)
- Roll-over of 529 Plan assets into ABLE accounts is permitted, subject to annual contribution limits, only from a 529 owned by the beneficiary or a family member
- There is a payback provision for Medicaid recipients

## VIII. Accessing Government Benefits and Services



Navigating the web of federal and state programs can be overwhelming. At Pierro, Connor & Strauss, our team advocates for families to access critical benefits and services, including:

- Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)
- Medicaid and related waiver programs
- Special education services and IDEA protections
- OPWDD Home and Community-Based Services through Care Coordination Organizations (CCOs)
- New York Long Term Health Care Program
- New York Nursing Home Transition and Diversion Waiver
- New York TBI Waiver programs
- Children's HCBS Services Waiver

Early comprehensive evaluation is critical. Proper documentation facilitates timely access to special education, SSI, and a wide spectrum of Medicaid-funded services. At Pierro, Connor & Strauss, our team has extensive experience helping families navigate these systems and advocating when applications are denied.

## Common Special Needs Planning Mistakes to Avoid

In our decades of experience, we've seen families face preventable challenges:

- Naming a loved one as direct beneficiary of life insurance or retirement accounts, causing immediate benefit disqualification
- DIY trust documents from online sources that don't comply with SSI/Medicaid rules
- Failing to update plans after law changes (like SECURE Act 2.0)
- Choosing an unprepared trustee without understanding the role's complexity
- Delaying planning until a crisis occurs, limiting available options
- Not documenting care preferences, leaving future advocates without guidance
- Assuming siblings will "figure it out" without formal legal structure
- Improperly structuring personal injury settlements, jeopardizing benefit eligibility

Proper planning prevents these costly mistakes.

## IX. Taking the First Step

Special needs planning is not a one-time event - it's an ongoing process that evolves with your loved one's needs, your family's circumstances, and changing laws. The most important decision is to begin.

Future Care Planning is a unique combination of legal, financial, and personal care planning designed to ensure that your loved one has an appropriate system of financial support, personal care management, and advocacy beyond basic

government entitlements—even after you become unable to provide care and supervision.



Effective Future Care Planning involves consideration of the needs of both the caregiver and the individual with a disability. A properly drafted SNT often serves as the foundation of a comprehensive Future Care Plan. Like any legal document, the SNT should be designed to meet the needs of the

individual with a disability and should be part of comprehensive estate and long-term care plans.

It is common to hear financial professionals talk about the need to periodically "review a plan" to ensure it still meets a family's needs. This advice is equally 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 without the help of their parents or primary caregivers.

Laws governing taxes, property rights, and government benefit programs are changing constantly. The resources, needs, and preferences documented in the Life Care Plan will also change with time. 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 implemented, you could miss the opportunity to answer the question: “Who will take care of my loved one when I am unable to do so?”

A properly structured Special Needs Trust, combined with comprehensive legal and financial planning, ensures your loved one will have:

- Financial security without losing essential benefits
- Professional management and advocacy
- A support system that honors your values and knowledge
- Dignity, independence, and quality of life

At Pierro, Connor & Strauss, we've helped hundreds of families create plans that provide both protection and peace of mind. We work as part of your care team—coordinating with financial advisors, service providers, and care coordinators to develop solutions tailored to your family. We have an established network of government, private, and nonprofit professionals who provide advice and support in developing comprehensive Future Care Plans.

If you're ready to begin planning, or if you have questions about an existing plan, contact us at (866) 951-PLAN or visit [www.pierrolaw.com](http://www.pierrolaw.com).

## Specialized Planning Resources

Pierro, Connor & Strauss offers detailed guides on related planning topics:

- **Estate Planning Guide:** Comprehensive strategies including revocable living trusts
- **Medicaid Planning Guide:** Asset protection and long-term care planning
- **High Net Worth Estate Planning Guide:** Advanced tax and wealth transfer strategies
- **Business Planning Guide:** Framework for transitioning your business

*Request these guides during your consultation or visit [www.pierrolaw.com/resources](http://www.pierrolaw.com/resources)*

# Special Needs Planning Readiness Checklist

Use this checklist to assess whether your current planning adequately protects your loved one:

- Have you created or updated your Will or revocable trust with SNT provisions?
- Have you reviewed beneficiary designations on life insurance and retirement accounts?
- Does your loved one have a health care proxy, and if capable, a power of attorney?
- Have you documented your loved one's care routine, preferences, and medical history?
- Have you identified and discussed the trustee role with potential candidates?
- Have you applied for SSI, SSDI, or Medicaid benefits if your loved one is eligible?
- Do you have a Letter of Intent or Life Care Plan document?
- Have you coordinated special needs planning with your own long-term care planning?
- Have you considered an ABLE account as a supplemental savings tool?
- Have you consulted with a special needs planning attorney?

**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.

## LOCATIONS

### **CAPITAL REGION**

43 British American Boulevard  
Latham, NY 12100  
Phone: (518) 459-2100

### **NEW YORK CITY**

260 Madison Avenue, 16th Floor  
New York, NY 10016  
Phone: (212) 661-2480

### **HUDSON, NY**

### **GARDEN CITY, NY**

**AFFILIATE OFFICE: RONKONKOMA, NY**

**OF COUNSEL OFFICE: UTICA, NY**

**SERVING CLIENTS IN NY, NJ, FL, and CT**

### **CONTACT US**

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