

# Financial Planning Considerations for Families with Special Needs


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# Introduction



In the United States today, millions of families grapple with the challenges and triumphs of raising a child with special needs.

According to recent statistics from the U.S. Census Bureau and the Centers for Disease Control and Prevention (CDC), approximately 1 in 36\* children are diagnosed with autism spectrum disorder, while about 1 in 6 children are estimated to have some form of developmental disability. Beyond these figures, countless families encounter varying needs related to physical disabilities, learning disabilities, and mental health conditions. Each family's journey is unique, but common financial considerations tie them together, requiring thoughtful and deliberate planning.

Families raising a child with special needs often find themselves overwhelmed by the uncertainties and complexities involved in providing adequate care. Key financial concerns typically include navigating government benefits, optimizing income tax planning, managing medical expenses, and ensuring long-term estate planning and guardianship.

This eBook aims to demystify the complexities of financial planning for families with special needs children and help arm these families with potential and recommended tools and resources to overcome these complexities. We will explore practical strategies to alleviate the financial strain, from optimizing government benefits to estate planning. Together, we will uncover paths toward greater financial security, allowing you to focus more fully on providing the best possible care for your loved one.

*\*Source: CDC - Data and Statistics on Autism Spectrum Disorder*

# Special Education

One of the critical components of financial planning for families with special needs children is understanding the framework of special education laws, particularly the landmark Individuals with Disabilities Education Act (IDEA), passed in 1990. This crucial legislation ensures that children with disabilities are provided with Free Appropriate Public Education (FAPE) that is tailored to their individual needs. At its core, FAPE aims to provide children with access to public education that meets the standards of the state educational agency. Under IDEA, children with disabilities are entitled to an education that is designed to their specific needs, at no cost to the parents, including special education and related services.

IDEA also emphasizes the importance of preparing children for further education, employment, and independent living. To achieve this, it mandates an Individualized Education Program (IEP) for each child, which is developed in a team setting and outlines tailored educational goals, including the services and support the child will receive. Parents play a significant role in this process, advocating for their child's needs and ensuring the educational program is properly aligned with their developmental goals.



## FAPE

All children have a right to a Free and Appropriate Public Education (*age cutoff varies by state*)

Connecticut: **22**

New York: **22**

New Jersey: **21**

## KEY HIGHLIGHTS OF IDEA

- An appropriate evaluation is necessary to determine the needs of your child
- Children with disabilities are assigned an Individualized Education Plan (IEP) and a team to implement it
- The goal is to provide the Least Restrictive Environment, integrating with non-disabled students to extent appropriate
- Parents or legal guardians (and if appropriate, child) have rights to participate in determinations, reviews
- Procedural Safeguards include right to due process hearing and civil litigation
- Transition Planning, i.e., from school to first job; from high school to post school; from living at home to living outside the home
- To qualify, the child must start at age 16 or earlier
- For more information on IDEA, click on this link [here](#)



## Post-Secondary Education

Transitioning to post-secondary education may represent a significant shift for students with disabilities. Unlike secondary education, where laws such as IDEA provide a structured framework, post-secondary institutions are governed by the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. These laws ensure that students with disabilities have equal access to education and related services but do not guarantee the type of individualized instruction provided under IDEA.

Parents and guardians should be aware that while colleges and universities are required to offer appropriate academic adjustments and support services, the responsibility shifts more to the student to seek out these resources and advocate for their needs. This means that students, their families, or legal guardians should be well-prepared to articulate their needs and understand the accommodations available to them.

In this transition, it is crucial for families to research institutions thoroughly to understand the support services available, such as adaptive technology, tutoring programs, and accessibility services. Early planning and open communication with potential post-secondary institutions can significantly smooth this transition, ensuring that students with disabilities can continue to thrive academically and personally beyond high school.

### KEY HIGHLIGHTS FOR POST-SECONDARY EDUCATION

- IDEA rights expire on graduation from high school
- Americans with Disabilities Act continues to protect children in post-secondary schools (e.g., 504 accommodations, accessibility)
- School policies are often more protective than the ADA, and may bring over concepts from the IEP even though not legally required (e.g., extended time on exams)
- Tuition insurance is another way to protect parents

# Government Benefits and Assistance

Medical costs can be especially daunting. Many children require specialized therapies, assistive technologies, or modifications to the home. In some cases, ongoing care may be needed throughout adulthood. Families must assess their insurance policies and identify additional funding sources to cover these recurring expenses.

Understanding government benefits such as Supplemental Security Income (SSI), Medicaid and Social Security Disability Insurance (SSDI) is essential, yet this landscape is often filled with convoluted rules that can be difficult to interpret. Parents must stay well-informed to maximize the support available while avoiding unintentional pitfalls, such as exceeding the income or asset limits that could jeopardize these benefits.

## Supplemental Security Income

- Payments to people with disabilities who have minimal or no income or assets

## Social Security Disability Insurance

- Provides payments to the insured or members of the insured's family
- To qualify, the insured must have worked long enough and recently enough to earn the work credits needed

## Medicare

- Medical insurance for people with disabilities under age 65, generally if the individual has received SSDI benefits for 24 months

## Medicaid

- State administered federal program that covers medical costs, including nursing home and personal care
- Must have minimal or no income or assets, with limits varying state to state

## Supplemental Security Income

**Supplemental Security Income provides** payments to people with disabilities

**Benefits (2024):** Up to \$11k/year federally (states may provide additional monthly payments which vary state to state)

- Reduced by earned income (and deemed income, such as rent-free accommodations)

**Eligibility:** (parents' income and resources may count if child is under 18 years of age)

- **Income Limit (2024):** < \$1,971/month
- **Asset Limit (2024):** < \$2,000 countable assets
- **Disability:**
  - **Between 18-65 years of age:** medical impairment that results in ability to do substantial gainful activity (i.e. work activity that earns income) and has lasted or is expected to last at least 12 months or result in death
  - **Under 18 years of age:** medical impairment that results in severe functional limitations and has lasted or is expected to last at least 12 months or result in death

**Qualification for SSI** generally means automatic qualification for Medicaid

**For more information** on SSI, click on this link [here](#)



# Special Needs Planning

Special needs planning focuses on setting up a plan that enables you to give assets to your disabled family members for their lifetime use without jeopardizing their financial eligibility for needs-based government benefits like Medicaid and Supplemental Security Income (SSI). This is generally accomplished with special needs trusts (also referred to as supplemental needs trusts) and ABLÉ accounts.

Disabled individuals are often eligible for needs-based government benefits such as SSI, Medicaid, and food and housing assistance. However, these needs-based benefits require the disabled individual to meet an income/resource limit in order to qualify. Disabled individuals who exceed this income/resource limit (which varies depending on the benefit and the state) are generally not eligible to receive these needs-based benefits. Disabled individuals who are under this income/resource limit must remain so in order to continue receiving these benefits.

Both Special Needs Trusts and ABLÉ accounts allow the disabled beneficiary to keep some private funds without jeopardizing their eligibility for these needs-based government benefits. Special Needs Trusts and ABLÉ accounts for a disabled individual's benefit are ignored when determining whether the disabled individual is financially eligible for needs-based government benefits. Special Needs Trusts and ABLÉ accounts give the disabled individual access to private funds needed to pay for disability-related expenses that supplement, but do not replace, needs-based government benefits, including services that are not otherwise covered by needs-based benefits. For example, funds can be used to pay for the beneficiary's housing, utilities, furniture and appliances, household items, education, entertainment, clothing, vehicle or transportation, job training and support, assistive technology, personal support services, financial management, and other expenses that improve the beneficiary's health, independence, or quality of life. However, funds should not be used for expenses that are otherwise paid for or covered by needs-based government benefits such as Medicaid and SSI.

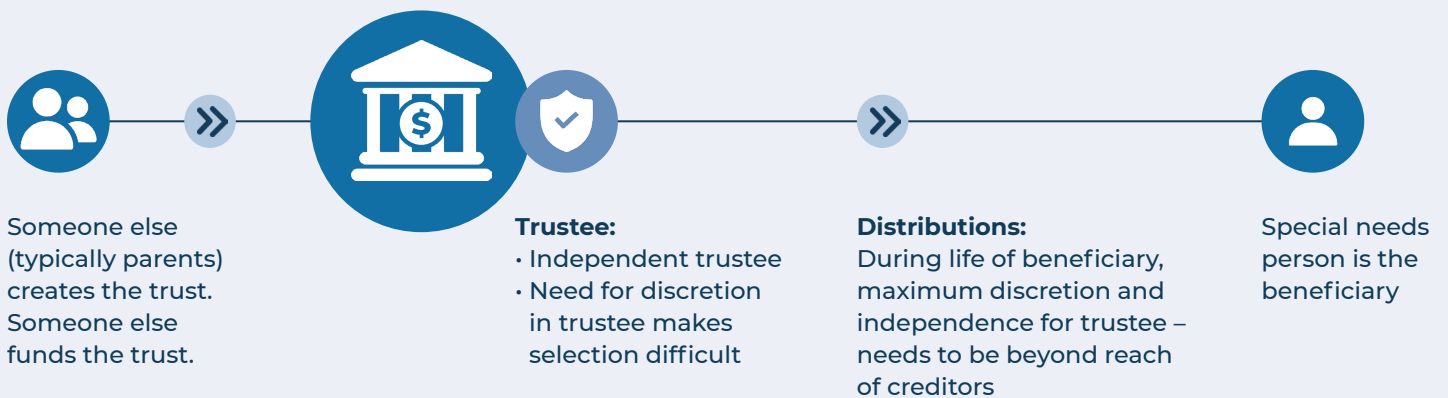
## Special Needs Trusts

A [Special Needs Trust \(SNT\)](#) is a trust that may be set up and funded for the lifetime benefit of a disabled beneficiary. SNTs should be drafted by a qualified attorney, as there are specific trust provisions that must be included in the trust document in order to qualify the trust as an SNT under both federal and state law. For example, the trust should include specific SNT language that generally prohibits distribution of funds directly to the disabled beneficiary but allows funds to be used to pay for goods or services for the beneficiary that supplement but do not replace goods or services provided by needs-based government benefits.

SNTs may be funded with the disabled beneficiary's assets ("first-party SNT") or by another person's assets ("third-party SNT").

- A first-party SNT may only be set up by a disabled beneficiary under 65 years old. The trust must be irrevocable for the disabled beneficiary's sole benefit and upon the disabled beneficiary's death, the remaining trust assets must be used to reimburse Medicaid first. First-party SNTs are typically funded to preserve a disabled beneficiary's inheritance or personal injury proceeds.
- A third-party SNT may be set up for the sole benefit of a disabled beneficiary, fully funded by others. For example, parents may set up a third-party SNT for their disabled child, funded either during the parent's lifetime or at the parent's death. Unlike first-party SNTs, third-party SNTs may be set up for the disabled beneficiary at any age and the trust assets remaining upon the disabled beneficiary's death do not have to be reimbursed to Medicaid. Instead, trust assets remaining at the disabled beneficiary's passing may be distributed to other family members such as the disabled beneficiary's children or siblings.

## SPECIAL NEEDS TRUST STRUCTURE



### Termination:

Flexible in distribution to other family members, charities, etc.



### Estate Plan:

Special Needs Trust must be woven into the estate plan



### Funding:

- Expense modeling is biggest challenge
- Ensure adequate funding through some combination of: Financial plan and liquid assets and insurance

## TAX CONSIDERATIONS FOR SNTS

First-party SNTs are treated as grantor trusts, which means that the income earned by a first-party SNT is reported on the disabled beneficiary's personal income tax return. If the first-party SNT has its own Taxpayer Identification Number (separate from the disabled beneficiary's Social Security Number), the trustee of the first-party SNT will need to file a pro forma informational

tax return. However, the income on the information tax return will still need to be reported on the disabled beneficiary's personal income tax return and the disabled beneficiary will be responsible for paying the taxes. Distributions from the first-party SNT may be made to the beneficiary to cover these taxes.

Third-party SNTs may be set up as either grantor trusts or non-grantor trusts.

If set up as a grantor trust, the income earned by the third-party SNT is reported on the grantor's personal income tax return and the grantor is responsible for paying the taxes. If the third-party SNT has its own Taxpayer Identification Number (separate from the grantor's Social Security Number), the trustee of the third-party SNT will also need to file a pro forma informational tax return.

If set up as a non-grantor trust, the trustee of the third-party SNT will need to file a tax return for the trust, and the SNT will be responsible for paying the taxes.

## ABLE Account Benefits

ABLE accounts are tax-advantaged savings accounts for disabled individuals. The disabled beneficiary is the account owner. Contributions to an ABLE account may come from any source, including the disabled beneficiary's earnings, family members, friends, or even SNTs. Like contributions to 529 plans, contributions to ABLE accounts are not tax deductible for federal income tax purposes, but the state where the ABLE account is established may allow deductions. ABLE accounts are offered at the state level and opening an ABLE account can usually be done via the state's ABLE program website. Upon the disabled beneficiary's passing, Medicaid may make claims to recover the funds disbursed for medical care during the disabled beneficiary's lifetime.



### ASSET PROTECTION

Funds held in ABLE accounts are not counted as a resource when determining eligibility for federal means-tested benefits. This allows individuals with disabilities to save money for qualified disability-related expenses without risking the loss of crucial benefits.



### TAX ADVANTAGES

Contributions to ABLE accounts are made on an after-tax basis, but earnings and withdrawals for qualified disability expenses are tax-free. This offers a valuable tax advantage that can help savings grow over time.



### FLEXIBILITY

ABLE account funds can be used for a wide range of disability-related expenses, including education, housing, transportation, assistive technology, healthcare, and more. This flexibility allows families to address the unique needs of their special needs child effectively.



### CONTROL AND INDEPENDENCE

Unlike certain other types of savings vehicles, ABLE accounts allow the account owner, typically the individual with the disability, to retain control over the funds. This empowers individuals with disabilities to make decisions about their financial future and maintain a sense of independence.



## Using ABLE Accounts Effectively



### ELIGIBILITY

The ABLE Act limits eligibility to disabled individuals of any age whose disability began prior to their 26th birthday. The disabled individual must be unable to perform work for or intended for pay or profit because of a physical or mental impairment that is either expected to result in death or has lasted or is expected to last at least 12 consecutive months, as certified by a licensed physician.



### CONTRIBUTION LIMITS

Annual contributions from all sources to ABLE accounts are limited to the federal gift tax annual exclusion amount. Contributions can come from the account beneficiary, family members, friends, or third parties. Each state has its own cap for how large an ABLE account can be. However, once the ABLE account exceeds \$100,000, the beneficiary's SSI benefits may be suspended until the ABLE account balance drops back down below \$100,000.



### QUALIFIED EXPENSES

Funds withdrawn from an ABLE account must be used for qualified disability expenses to maintain their tax-advantaged status. It's essential to keep detailed records and receipts to ensure compliance with IRS guidelines.



### COORDINATION WITH OTHER BENEFITS

Families should consider how ABLE accounts fit into the broader financial plan, including coordination with government benefits and special needs trusts. Seeking guidance from financial advisors and disability planning professionals can help optimize the use of ABLE accounts.

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## Estate Planning and Guardianship

Estate planning is crucial to safeguarding the future. Guardianship and establishing special needs trusts are vital steps to ensure the child receives appropriate care and financial security after the parents are gone. Without careful planning, inheritances or gifts could interfere with eligibility for crucial benefits.

### Estate Planning for Parents

- **SNT provisions** need to be contained within Wills or trusts, or Wills or trusts need to direct distributions to a separate SNT so that the individual with disabilities does not receive assets outright which jeopardize eligibility for needs based benefits.

- **Particularly with multiple children**, financial planning is essential when determining division of assets
- **Trustee succession** raises the question of “who will take care of them when I’m gone?”
- **Estate Planning for Special Needs Person:**
  - If the special needs person has capacity, all estate planning documents should be signed when an adult is present
  - Power of Attorney and Health care proxy are extremely important
  - Please note that biological parents of the disabled individual will lose authority to act on behalf of the special needs person upon turning 18 years old.
- **Guardianship** (required if no Power of Attorney and Health Care Proxy for special needs person):
  - Significant court involvement/interference
  - Significant initial and ongoing expense
  - Last resort but necessary sometimes (i.e. if special needs person lacks capacity)
- **Involuntary commitment:**
  - Highly state specific
  - Some states will have temporary holds (e.g., 72 hours under Florida’s Baker Act)
  - Some special rules around substance abuse, like Florida’s Marchman Act

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## Income Tax Planning

Income tax planning introduces another layer of complexity. Special deductions, exemptions, and credits may be available, yet many families are unaware of the financial relief they could receive or how to effectively structure their tax planning strategies.

### Medical Expenses

- Deductible subject to floor (7.5% of AGI for 2024)
- Many of the expenses resulting from treating a disability will come under medical expense definition (e.g., IEE)



## Conclusion

Navigating the financial planning landscape for families with special needs considerations can be daunting, but it’s a journey that no one needs to experience alone. Our advisors at Wealthspire Advisors have deep expertise and personal experience working with families and can provide guidance to create a stable framework for the future so that they can focus on what matters most – providing the best life for their family.

# About the Authors



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Mike is a Managing Director and financial advisor at Wealthspire Advisors. Mike uses his extensive prior experience as an attorney to help his clients solve complex financial, tax, investment, and other problems. Given this background, much of his work is for other attorneys, as well as clients with family businesses, special education/special needs issues, and complex estate planning structures. Michael is a frequent author and speaker on his topics of expertise. He has been featured in numerous national media publications and has appeared as a guest on nationally syndicated radio shows. He has authored or edited treatises such as Settlement of Estates in Connecticut and Illinois Estate Planning, and articles such as “HEET Wave,” “Design GRATs to Reap Court-Approved Extra Tax Savings,” “Pecuniary Dynastic Offshore Trusts,” and “Financial Reporting for the Family Office.”



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