SPECIAL NEEDS TRUSTS: FINANCIAL SUPPORT FOR TRANSITION THROUGH DIFFERENT LIFE STAGES
Protect Benefit Eligibility with a Special Needs Trust (SNT)

Presented By: NYSARC Trust Services
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What is a Special Needs Trust (SNT)?

When planning for the future of a loved one, a special needs trust can play a critical role in your child’s financial future while helping to provide the best quality of life possible.

A special needs trust, also referred to as a supplemental needs trust, is an irrevocable trust that holds assets for the benefit of a person with a disability while preserving that person’s eligibility for means-tested government benefits and protecting financial assets for future use.

A SNT is primarily used to protect a person’s eligibility for Medicaid and/or Supplemental Security Income (SSI) benefits.
Purpose of a SNT

• Qualify and maintain eligibility for means-tested government benefits
• Secure a better financial future for your loved without jeopardizing benefits or financial assets he or she is entitled to
• Protect funds for supplemental needs that enhance quality of life
• Avoid having to spend-down funds quickly in order to avoid reducing benefits or jeopardizing benefit eligibility
Using a SNT for Excess Resources (Assets)

For a person with a disability to be eligible for SSI or Medicaid, he or she must meet certain financial requirements. For someone on Supplemental Security Income (SSI) benefits, receiving any more than $2,000 could jeopardize that person’s eligibility for benefits.

- 2019 NY SSI Resource Limits:
  - Individual - $2,000/month
  - Couple - $3,000/month

- 2019 NY Medicaid Resource Limits:
  - Individual - $15,450
  - Couple - $22,800

Examples of Countable Assets:
- cash or money in the bank
- cash value of life insurance policy
- stocks and bonds
- Motor vehicle (except for one)
- Real estate (primary residence is not counted)
Using a SNT for Excess Income

Income received by an individual and placed into a SNT in the same month will be disregarded for Medicaid eligibility purposes.

2019 NY Community Medicaid Income Limits:
- Individual - $859/month (+$20)
- Couple - $1,267/month (+$20)

2019 NY Medicaid Buy-in Program Income Limit:
- 250% of the Federal Poverty line

2019 NY Medicaid Buy-In Resource Limits:
- Individual - $20,000
- Couple - $30,000

Examples of Monthly Income:
- Social Security
- Pension
- IRA Distributions
- Wages (when participating in Medicaid Buy in Program)
What can a SNT pay for?

Funds in a SNT can be used to enrich the quality of life of a person with a disability by paying for goods and services that a person’s benefits do not provide, such as uncovered medical expenses and life-enhancing purchases.

Funds in a SNT are intended to supplement not replace the services otherwise available to the beneficiary through government benefit programs.

For example, if the trust beneficiary receives SSI, distributions from the trust to pay for food and shelter expenses can reduce a person’s benefits.
Parties of a Special Needs Trust (SNT)

There are three parties needed to create a trust:

1. Donor/Grantor – person who funds the trust
2. Beneficiary – person who ‘benefits’ from the trust
3. Trustee – person or entity who manages the trust administration
Types of Special Needs Trusts

• **1	extsuperscript{st} Party Special Needs Trust (SNT)** – funded with money that belongs to the person with a disability

• **3	extsuperscript{rd} Party SNT** – funded by someone other than the person with a disability

• **Individual SNT** – can be 1	extsuperscript{st} or 3	extsuperscript{rd} party funded, requires an attorney to draft the trust and a trustee to manage the funds, typically more costly for individual and more work for the family if serving as trustee

• **Pooled SNT** – typically 1	extsuperscript{st} party funded, low cost and easy to set up, a not-for-profit organization serves as trustee to manage the funds
When to set up a trust?

3rd Party SNT - Set up a 3rd party SNT if you want to gift money or real property to your loved one with a disability without jeopardizing his or her eligibility for means-tested government benefits. This can be done during your lifetime or as part of your estate plan.

1st Party Special Needs Trust (SNT) – Set up a 1st party SNT if your loved one receives or is entitled to receive money that will put them over the financial limits for Medicaid and/or SSI

1st Party Pooled SNT – Pooled trusts offer an affordable alternative to an individual trust that can be established quickly if your loved one has money to protect for benefit eligibility purposes. A pooled trust is the only option for a person over the age of 65.
3rd Party Special Needs Trust

3rd Party SNT - funded by someone other than the trust beneficiary

- Most often set up in a Will as part of your estate plan where the Donor/Grantor names the trust as beneficiary of an inheritance, life insurance policy, other asset/s, or monetary gift
- Can also be established during the Donor’s lifetime if you have funds or assets available now that you wish to gift to your loved one with a disability
- Early planning is critical because you never know when something could happen to you and even a small inheritance could reduce your loved one’s benefits
- Upon the death of the trust beneficiary, any funds remaining in a third party SNT will be distributed to remainder beneficiaries as outlined in the trust document
Example: 3rd Party SNT

• Joe is disabled and receives Medicaid and SSI benefits for his daily living needs

• Joe’s grandmother would like to leave him $20,000 without putting his benefits at risk

• Joe’s grandmother can direct her Will to fund a 3rd party SNT with his inheritance so that he can maintain eligibility for his benefits and services without having to spend all of the money in the same month he receives it
1st Party Individual SNT

1st Party SNT - funded with money that belongs to the disabled beneficiary

- Person with a disability is the Donor/Grantor and the trust beneficiary
- Attorney must draft the trust and submit the trust to the Social Security Administration for approval
- Need to select an appropriate individual or entity to serve as trustee
- Typically funded with a direct inheritance, settlement proceeds, retroactive Social Security Award, or other monetary gifts
- Can be used to shelter excess resources accrued from Disabled Adult Child (DAC) benefits or earned income
- Can be used to shelter excess income that would cause Medicaid ineligibility
- If the disabled beneficiary does not have the capacity to create the trust themselves, a parent, legal guardian, or agent under power of attorney can set up the trust on his or her behalf
- Upon the death of the beneficiary, any funds remaining are subject to Medicaid payback to the State(s) that provided services before funds can go to remainder beneficiaries.
Responsibilities of a Trustee

The trustee has a fiduciary responsibility to ensure that the money in a trust is used appropriately and efficiently to enhance the trust beneficiary’s quality of life.

A trustee is responsible for:

- Regular communication with the trust beneficiary/ies
- Making appropriate distributions that do not impact benefit eligibility now or in the future
- Collecting proper documentation of distributions from the trust for reporting purposes
- Prudent investment management of trust assets
- Annual tax reporting for the trust
- Providing statements and accountings to appropriate agencies as needed
Best Practices When Choosing a Trustee

When selecting a trustee, be sure that the person or entity is committed to understanding and complying with the regulations set by the Social Security Administration for making disbursements and keeping track of paperwork to show proof of how the money is used.

Be sure to ask:

- Do you understand the differences between government benefits programs like SSI, SSDI, Medicare and Medicaid?
- What is your level of knowledge with the current laws governing special needs trusts and the means-tested government benefit programs?
- Do you understand the difference between a first and third party SNT and how the type of trust may affect what my trust can pay for?
- Are you going to be able to take the time to get to know my loves one and help them make the most of their use of this money?

A good trustee is knowledgeable, trustworthy, and exercises due diligence.
1st Party Pooled SNT

1st Party Pooled SNT - funded with money that belongs to the disabled beneficiary

- Trustee is a not-for-profit organization and a financial institution serves as co-Trustee
- Funds are pooled for investment and management purposes
- Trust activity is tracked separately for each trust beneficiary, similar to a bank account
- Affordable alternative to an individual trust – you are not required to hire an attorney
- Professional administration eases the burden for family and ensures a responsible use of funds, you do not need to find your own trustee
- Trust account closes upon the death of trust beneficiary
- Non-profit typically retains remainder funds, or a portion of funds, at death to support people with disabilities
- Any funds not retained by the trust are subject to Medicaid payback to the State(s) that provided services
When to Choose a Pooled Trust

Individual SNTs can be costly to set up and maintain. A pooled trust is an affordable alternative that offers greater investment power and lower initial and monthly fees because the funds are pooled into one account.

You may consider choosing a pooled trust when:

• You want to maximize the value of the funds with lower fees and greater investment power
• You have a modest amount of money to protect that does not warrant an individual trust
• There is not an appropriate person to serve as trustee of an individual SNT
• Your loved one has complex medical needs and could benefit from a professional trustee who understands government benefits and the needs of people with disabilities
• The trust beneficiary is over the age of 65, therefore they can no longer use an individual SNT
Establishing a Pooled Trust

• A pooled trust is quick and inexpensive to set up because approved trust documents are already in place

• We encourage you to consult with a legal professional, however, you do not need an attorney because the not-for-profit organization that administers the program has already created the trust document and submitted it to the Social Security Administration for approval

• Set up fees will vary by trust and typically amount to a few hundred dollars compared to the thousands you might pay to hire an attorney to set up an individual trust

• You can typically establish a pooled trust within a week

• A pooled trust also has lower monthly administrative fees because the money is pooled and everyone shares the costs of administration
Example: 1st Party SNT

• Mary was disabled at birth and is entitled to receive a large settlement from a medical malpractice lawsuit when she turns 18

• She is about to finish high school and her parents intend to apply for benefits to provide her with the necessary supports and services she needs to live independently in the community through SSI and Medicaid

• Mary can deposit the proceeds from her settlement into a 1st party SNT to protect the funds for her use while being able to qualify for the services through public benefits
Example: 1\textsuperscript{st} Party SNT

• Martin has cerebral palsy and receives SSI and Medicaid benefits
• His father is retired and just found out that Martin is eligible for Disabled Adult Child (DAC) benefits to collect Social Security payments based on his father’s work record
• Additionally, he will receive a retroactive payment from Social Security for the money he is entitled to that he has not collected
• Martin can put the lump sum from the retroactive Social Security Award into a 1\textsuperscript{st} Party SNT to protect his benefit eligibility now and make monthly deposits to spend-down any excess funds that accrue in his bank account from his DAC benefits in the future
Apply for a NYSARC Pooled Trust

Follow the steps below to enroll in a pooled trust with NYSARC Trust Services:

1. Complete the Joinder Agreement (trust application) and have it notarized

2. Attach a copy of the trust beneficiary’s Social Security card, benefits award letter, and a check for the initial funds to open the trust (minimum initial deposit = $300)

3. Joinder Agreement creates sub-trust account for the beneficiary and may be completed and signed by: the trust beneficiary, an agent under Power of Attorney, Parent/Grandparent, or other legal Guardian
   a) Copy of POA or Guardianship required if JA is signed by agent or guardian
   b) Court Order can direct the execution of the Joinder Agreement and funding of the Trust on behalf of a disabled individual
   c) If account is established by Court Order, a copy of the Court Order is required to set up the trust
About NYSARC Trust Services

• The Arc New York is a family-based non-profit serving people with I/DD since 1949

• The Arc New York established NYSARC Trust Services in 1972, to administer SNTs for people with disabilities

• Trust has since helped thousands of people across New York State protect benefits and improve quality of life

• Extensive knowledge of disability benefits and eligibility protection

• Leader in developing and administering pooled SNTs

• NY’s original provider of Medicaid income spend-down trusts
NYSARC Special Needs Trust Programs

• **Unrestricted Fund** – SNT funded by a third party to benefit people with I/DD

• **Community Trust I** – pooled SNT funded by a person with a disability with a direct inheritance, Social Security Award, structured settlement, lump sum, or other excess resources (assets)

• **Community Trust II** – pooled SNT funded by individual with excess monthly income (i.e. Medicaid income spend-down or Net Available Monthly Income (NAMI))

• **Community Trust III** – pooled SNT funded by individual with larger assets ($250K+)

For more information, visit [www.nysarctrustservices.org](http://www.nysarctrustservices.org)
Questions?
We’d love to hear from you!

If you have additional questions, please contact us at:

(518) 439-8323

www.nysarctrustservices.org
Establishing a Special Needs Trust – Tips to Prepare for Your First Meeting

Early planning is critical when setting up a special needs trust (SNT) to protect and preserve your loved one's eligibility for means-tested government benefits. Here are some things you should prepare to bring with you and questions to ask when meeting with your attorney or a trust company about establishing an SNT for your loved one.

Things to Consider and Information to Bring...

✓ How will the trust be funded? Be sure to have information about your finances, household income and other assets, and any money your child currently has in their name or is entitled to receive.

✓ Bring a copy of your Will if you have one already and any other legal documents that pertain to your loved one such as Guardianship, Power of Attorney, health care proxy, etc.

✓ Does your child already receive benefits? If so, bring a copy of their Social Security benefits award letter and any other information about the benefits and services they are currently receiving.

✓ If your child is receiving a settlement, bring any court documents or other information.

If your child is not receiving benefits currently, what benefits or services might they need in the future?

____________________________________________________________________________________

____________________________________________________________________________________

Be prepared to discuss your loved one's cognitive abilities and limitations as well as their interests and life goals. Based on your loved one's current and future needs, start to think about what you might want the money in a trust to pay for.

____________________________________________________________________________________

____________________________________________________________________________________

____________________________________________________________________________________

What is your child's current living situation? Also, consider where they intend to live in the future. Do they live with you? What about when you are no longer able to be their primary caregiver? Will they be able to live independently in the community or need the support of a residential facility?

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<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>What is the process to establish the trust and about how long will it take?</td>
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<td>What are the costs to establish the trust and ongoing management of the account?</td>
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<tr>
<td>How can the money be used to support my child’s needs now and in the future? What happens to any money that may be left in the account upon the death of the trust beneficiary?</td>
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<td>Are there any tax implications of establishing the trust for my loved one or myself?</td>
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<tr>
<td>If you are considering the attorney or trust company to serve as trustee, ask about their experience with SNTs and the rules that govern the benefits your loved one receives.</td>
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<tr>
<td>If you plan to have a family member serve as co-trustee, ask about how that relationship will work. What level of involvement will your family have in determining the use of trust funds?</td>
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<tr>
<td>What advance directives should I have in place for my loved one? Make the most of your meeting by getting as much information about other legal documents you may need to plan for making decisions related to your child’s financial and health care needs in the future.</td>
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Special Needs Trusts and ABLE Accounts:
Planning for the Future of a Loved One with a Disability

For people with disabilities who receive Supplemental Security Income (SSI) and/or Medicaid benefits, saving money can be a challenge because of the resource limits for those programs. Special needs trusts (SNT) have traditionally been the most common way to secure the financial future of a loved one with a disability without putting their benefits at risk. ABLE Accounts are a new tool that could also help your loved one save while protecting benefits.

What is the difference between ABLE accounts and SNTs?
An ABLE account is a tax-advantaged savings account that allows people with a disability prior to age 26 to set aside money for qualified disability expenses. The individual can deposit their own funds into the ABLE account or a third party can also put money into the ABLE account to benefit the disabled individual.

A SNT is a special type of trust that allows people with disabilities that began at any age to protect excess funds without jeopardizing their eligibility for Medicaid and/or SSI benefits. A trustee manages the funds for the benefit of the person with a disability, called the trust beneficiary. SNTs can be used to protect the individual’s own money or created by third parties to set aside money for a loved one with a disability.

Who can set up these accounts?
An ABLE Account can be established by the individual with a disability or by a parent, legal guardian, or agent under power of attorney. An SNT can be established by the individual with a disability, or by a parent, grandparent, legal guardian, agent under power of attorney, or court order.

What can an ABLE account pay for?
The funds in an ABLE account can pay for qualified disability expenses (QDEs) related to a person’s blindness or disability. Some examples of qualified expenses include housing, transportation, education, health and wellness expenses, employment training and support, financial management, legal fees, assistive technology, personal support services, funeral and burial expenses. Distributions from an ABLE account for non-qualified expenses may be taxable and could affect someone’s eligibility for benefits.

What can an SNT pay for?
The money in a SNT can be used for the same things that an ABLE account can be used for—and much more—as long as the funds are used for the sole benefit of the trust beneficiary and for items that a person’s benefits do not provide. For example, if the trust beneficiary receives SSI, distributions from the trust to pay for food and shelter expenses can reduce a person’s benefits. However, the funds in a SNT are intended to supplement government benefits and can be used for life enhancing purchases that are not disability related that an ABLE account cannot pay for.

Which option is best?
There is much to consider when choosing the best financial vehicle to protect your loved one and help them secure a better financial future. To help you determine the best option for your loved one, we have put together a comparison chart on the next page outlining some advantages and disadvantages of each program. When possible, SNTs and ABLE accounts can be used in conjunction to maximize the benefit to your loved one.

If you have questions, contact NYSARC Trust Services at 518-439-8323 or visit www.nysarctrustservices.org.
<table>
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<tr>
<th>Special Needs Trust (SNT)</th>
<th>ABLE Accounts</th>
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<tbody>
<tr>
<td>Available to people whose onset of disability began at any age and there is no limit on how many SNTs a person can have</td>
<td>A person is eligible if the onset of disability was prior to age 26 and a person can only have one ABLE account</td>
</tr>
<tr>
<td>No limit on how much or how often you can put money into a SNT</td>
<td>Annual contributions capped at $15,000 from any source</td>
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<tr>
<td>Funds in a SNT are exempt when determining a person's eligibility for SSI benefits as long as there are no distributions for food or housing expenses</td>
<td>Any amount of funds in an ABLE account that exceeds $100,000 is counted as a resource for SSI eligibility</td>
</tr>
<tr>
<td>More expensive to create and administer an individual SNT. Pooled SNTs are inexpensive to set up and maintain.</td>
<td>Inexpensive to set up and maintain</td>
</tr>
<tr>
<td>No Medicaid payback on third party funded trusts, remainder funds are distributed as directed in the trust document. Individual first party trusts require Medicaid payback and distribute any remaining funds as directed in the trust document. Pooled trusts, run by non-profit organizations, typically retain funds or a portion of funds at death to support other people with disabilities.</td>
<td>Any funds that remain in an ABLE account upon the death of the beneficiary are subject to Medicaid payback, even funds deposited by third parties</td>
</tr>
<tr>
<td>Trustee is responsible for maintaining records including substantiating documentation of trust activity and handles trust tax reporting. The trustee you choose may be a family member or professional organization who is responsible for administering the trust and following the regulations set by the Social Security Administration. Professional Trustee has a legal obligation to safeguard the funds. Different professional trustees provide different services beyond those listed above.</td>
<td>Promotes independence with greater access to funds, however, responsibility is on the individual to track and substantiate account activity. Best for a capable individual who can manage their own finances independently or with the assistance of a trusted individual. With beneficiary in control, there is risk of mismanagement of funds and the individual may be susceptible to exploitation.</td>
</tr>
<tr>
<td>You will have greater control and flexibility with investment options because the trustee manages investments and can make changes any time</td>
<td>Investment options are provided by the State's program and typically limit investment changes to twice a year</td>
</tr>
<tr>
<td>Earnings on a SNT may be taxable. Tax implications vary based on the type of trust and source of funding.</td>
<td>Earned interest and qualified distributions are tax-free if used for qualified disability expenses</td>
</tr>
</tbody>
</table>

References:
2. IRS, ABLE Accounts - [Tax Benefit for People with Disabilities](https://www.irs.gov/retirement-planning/abi-accounts)
3. NY ABLE website, [About NY ABLE, Eligibility, Qualified Expenses](https://www.nysable.com)
Join us for monthly series of live streamed, interactive online workshops on a wide variety of disability topics.

Below is an archive of all of our past episodes with resources you can use to follow along.

You can also register for an upcoming episode here.

- Bodies, Curiosity, and Touching For Parents of Young Children
  - Video | Resources
- Charter Schools and Students with Disabilities
  - Video | Resources
- Specialized Programs for Students with Disabilities
  - Video
- Inclusion Programs for District 75 Students
  - Video | Resources
- Turning 18 and Supplemental Security Income (SSI)
  - Video | Resources
- Puberty, Sexuality, and Behavior: How to Guide Young People with Disabilities
  - Video | Resources
- Disability vs. Language Barrier for English Language Learners
  - Video | Resources
- Positive Supports for Young Children with Challenging Behaviors
  - Video | Resources
- Applied Behavior Analysis (ABA) for Infants and Toddlers with Autism
  - Video | Resources
- How to Talk to Your Child About Bullying
  - Video | Resources
- From School to Work
  - Video | Resources
Supported Decision Making - Alternative to Guardianship for People with Disabilities
Video | Resources

How to Get Assistive Technology on Your Child’s IEP
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Moving from Early Intervention to Preschool Services
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Student-led Individualized Education Program (IEP) Process
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Get the special education Services you want through mediation
Video | Resources

Discover how accessible reading materials work for students with disabilities
Video | Resources

Ask an Expert: Special Education
Video

Independence & Travel Training
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Is your child **struggling** in school? Does your child have **special needs** or an **IEP**? Do you have questions about your young person with a **disability**?

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