

Special Needs Trust Serving DC, MD, & VA

Special Needs Trusts and ABLE Now

March 16, 2024 Ana Hughes, Director of Trusts

Special Needs Trust | The Arc of Northern Virginia | March 2024



The Arc's Mission Statement

To promote & protect the human rights of people with intellectual & developmental disabilities (ID/DD) & actively support their full inclusion & participation in the community throughout their lifetimes.

Who we are:

The Arc of Northern Virginia is a local chapter of the largest non-profit organization supporting thousands of people with ID/DD & their families.

How we're funded:

We receive some funding for the direct services we provide, but we are largely supported by membership dues and donations.



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What We'll Cover Today

1. Benefits To Protect

2. Overview Special Needs Trusts (SNTs)

- First-Party/Self-Funded Trusts
- Third-Party/Family-Funded Trusts
- The Arc of NOVA's Role

3. ABLE Accounts

Naming A Few Means-Tested Benefits

- 1. Medicaid
- 2. Supplemental Security Income
- 3. Housing Choice Voucher
- 4. State Rental Assistance Program
- 5. Virginia Supplemental Nutrition Assistance Program (SNAP)



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Defining Special Needs Trusts (SNT)

A legal vehicle that <u>provides benefit to</u>, and <u>protects the assets</u> of a person with disabilities, and <u>still allows</u> that person to qualify for and receive government benefits



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Who Qualifies For A SNT?

Anyone who has a:

- 1. Physical,
- 2. Mental, and/or
- 3. Developmental Disability

*as defined by the Social Security Act



Why Establish a SNT?

- 1. Protect government benefits (SSI, Medicaid, Housing Vouchers, SRAP, etc.)
- 2. Supporting individuals with money management and long-term financial planning
- **3**. Promoting the dignity, comfort, and happiness of the person with disabilities



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Defining Roles Within SNTs

| Trustee (KeyBank) | (Co-) Trustee(-s) |
|---|-------------------|
| | |
| Trust Manager (The Arc of NOVA) | |
| Grantor (Person/Persons Establishing Trust) | Grantor |
| Beneficiary (Person Benefiting From Trust) | Beneficiary |
| Primary Representative (Supports For Using Trust) | (Trust Advocate) |
| Remaindermen (Receives Remainder) | Remaindermen |



Two Types of SNT Trusts

Third-Party/Family-Funded Trusts

- Established by someone other than the beneficiary
- Funds seeding the account do not belong to the beneficiary
- Upon beneficiary's passing, remainder can be directed to persons without requiring a Medicaid payback (if applicable)

First-Party/Self-Funded Trusts

- Established by the beneficiary or someone with legal authority acting on behalf of the beneficiary
- Funds seeding the account MUST belong to the beneficiary (SSA backpay, unexpected inheritance, etc.)
- Upon beneficiary's passing, remainder is subject to Medicaid payback before directing to other persons, OR, can be left as a contribution as a Personal Support Trust Self-Funded Trust to help support the ongoing services and supports to others with disabilities

Third-Party/Family-Funded Special Needs Trusts

Established by: Parents, Relatives, Friends

<u>Why/When</u>: Second to passing; may fund the trust prior to death with seed money (minimum of \$500)

<u>How to Fund</u>: Inheritance, life insurance policy, transfer from another trust, contributions, real property, etc.

<u>What Happens After Passing</u>: The grantor (who establishes the trust) decides who will inherit the remaining funds

*<u>cannot</u> be the beneficiary's money



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First-Party/Self-Funded Special Needs Trusts

Established by: Individual w/ disabilities, parent, grandparent, Guardian, courtordered, or agent under Power of Attorney

<u>Why/When</u>: **ONLY WHEN NECESSARY:** when person with disabilities needs to apply for or protect benefits &/or cannot manage money

<u>How to Fund</u>: Unexpected inheritance, lump-sum pay back from SSA, jurydecision, settlement, income, adult child support, military survivor benefit (SBP) program, alimony, lottery

<u>What Happens After Passing</u>: Medicaid payback then heirs at law, OR, contribution to The Foundation of The Arc of Northern Virginia

*<u>must be</u> the beneficiary's money



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Items to Consider When Requesting Funds from a Trust



- Requested funds from a Trust are referred to as "disbursements"
- Processes below are followed to ensure benefits are protected when using your Special Needs Trust
 - To process a disbursement, The Arc of NOVA requests a completed disbursement form and clear supporting documentation to demonstrate the need for an item and how it benefits the person
 - Cash cannot be disbursed from a Special Needs Trust with The Arc of Northern Virginia
 - The Arc of Northern Virginia has sole discretion on approval of disbursements
 - We encourage requesting pre-approval for any non-medical expense over \$300
- A Special Needs Trust does not operate like a typical bank account; reviews of requests are required to ensure proper management of assets
- Processing of requests requires ten business days upon submitting a request
 - Five business days for The Arc of NOVA to review documentation
 - Five business days for KeyBank to process the payment to the identified payee

Some Examples of Allowable Disbursement Requests



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- Monthly bills (cell phone, utilities*, insurance premiums, co-pays, etc.)
- Living expenses* (food, clothing, shelter)
- Personal needs
- Recreational activities
- Vacations
- Vehicles*
- Taxes
- Pre-paid burial plans*
- Environmental Modifications*
- Assistive Technology*

*Evaluated on a case by case basis based on the benefits received by the beneficiary



The Arc of Northern Virginia SNT Fees

The Arc's one-time enrollment fee: \$1050.00

• 2nd trust for same individual or their sibling: \$775.00

Annual fee of each after trust establishment:

Unfunded account: \$65.00

OR

- Funded account:
 - Seed money minimum: \$500.00
 - Annual Management and Trustee fee: 1.44% (0.12% monthly)
 - Tax preparation fee for active accounts: \$40.00 (if applicable)

Termination fee: \$250.00

*Fees are subject to change



How To Establish a SNT with The Arc

- 1. Learn about SNTs and determine if one is right for you/your loved one (our website has lots of free information)
- 2. Schedule a consultation, if more information is needed, or you want to discuss your case
- 3. Schedule an establishment appointment (online, or with our Administrative Coordinator)
- 4. Collect documentation needed for trust establishment (we will provide information on what is required prior to the establishment appointment)
- 5. Pay enrollment fee and attend your establishment appointment
- 6. After the appointment, we require a notarized copy of the signature page to officially process the trust
- 7. Upon receipt of necessary documents, your trust is sent to KeyBank and will be established

Who To Contact To Establish a Trust with The Arc of Northern Virginia

- The Arc of Northern Virginia offers a complimentary consultation (50 minutes) to discuss your family's needs before moving forward with an establishment appointment
- Options to schedule a consultation and/or establishment appointment can be done via our website OR emailing our Administrative Coordinator (Grace Rhodes):
 - Visit our website at <u>https://thearcofnova.org/program/trust/</u> to schedule a time that works for you
 - Email Grace Rhodes (grace.rhodes@thearcofnova.org) to request an appointment





What Is The ABLE Act?

Stands for: Achieving a Better Life Experience (ABLE) • Signed by President Barack Obama on December 19, 2014

Purpose: Authorizes states to create a new category of savings programs for people with disabilities who qualify

 Like a Special Needs Trust, it allows assets to be held in accounts without affecting eligibility for Medicaid and Supplemental Security Income (SSI)

Intention: To be used for "qualified disability-related purposes"

*<u>https://secure.ssa.gov/poms.nsf/lnx/0501130740</u>



Facts about ABLE

| Onset of Disability: | Qualifying disability exists prior to the age of 26 |
|--------------------------|---|
| Who establishes: | Beneficiary, parent, guardian, authorized representative |
| Number of Accounts: | ONE |
| Fees: | Financial institution fees |
| Contribution Limits: | \$18,000/year (for 2024); SSI suspended when account is over \$100K |
| Investment Options: | Investment strategies may be changed twice per year |
| Allowable Distributions: | Items defined as a "qualified disability expenses" |
| Taxes: | Earned income is tax-free |
| Medicaid Payback: | Yes, for Federally funded Medicaid; No, for State funded VA-Medicaid. |



Defining "Qualified Disability Expenses"

Must be:

- Related to blindness or disability of designated beneficiary
- For the benefit of the designated beneficiary

Some examples include:

- Education
- Housing
- Transportation
- Employment training/support
- Assistive Technology and related services
- Health

- Prevention and wellness
- Financial management and administrative services
- Legal fees
- Funeral and burial
- Expenses for ABLE account oversight and monitoring
- Basic living expenses



How To Establish an ABLE Account

- 1. Navigate to website (<u>https://www.ablenow.com/</u>) and select "Open an ABLE Account"
- 2. Be prepared to provide:
 - Name
 - Address
 - Date of Birth
 - Social Security Number
 - Bank Account Information (optional)
- 3. Select "Complete Application" and fill out information
- 4. You'll then receive a welcome email on how to use your ABLE Now
- 5. ABLE Now card will be mailed and will arrive within 7-10 business days



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Questions?

Please feel free to contact me should you have any additional questions:

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