

Special Needs Trust Serving DC, MD, & VA

# Special Needs Trusts and ABLE Now

March 16, 2024 Ana Hughes, Director of Trusts

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## 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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