

*Educational Webinar Series for Adults with
Spina Bifida*

Planning for Life - Your Financial Future



December 2021

Meet the Panelists

- **Timothy Brei, MD: Medical Director, SBA Neurodevelopmental Pediatrics, Seattle Children's, WA**
- **Julie Yindra, M.Ed: Director, Student Access Services and Adjunct Instructor of Specialized Programs in Education, Hofstra University, NY**
- **Libby Powers, MS: Research Assistant, Human Engineering Research Laboratories, PA**
- **Maria Smith: Director of Education & Outreach, Achieva Family Trust, PA**

Send us your questions!

- **Click on the chat box**
- **Type and send your question**

Let's talk about living with Spina Bifida and our financial future ...

- Timothy Brei, MD
- Julie Yindra, M.Ed.
- Libby Powers, MS

FUTURE PLANNING FOR INDIVIDUALS WITH SPECIAL NEEDS



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Family Trust

Protecting Futures. Enhancing Lives.

***PROVIDING PEACE OF MIND TO INDIVIDUALS
WITH DISABILITIES AND THEIR FAMILIES SINCE 1998***

AchievaFamilyTrust.org

HISTORY OF ACHIEVA FAMILY TRUST



- ✓ **Achieva - Formerly ARC Allegheny**
- ✓ **Grassroots organization started by parents in 1950s out of concern for their children with disabilities.**
- ✓ **One of the largest providers of services to individuals with disabilities, in Southwestern Pennsylvania.**
- ✓ **Services are provided through the lifespan of the individual:
Early Intervention, Residential Services, Employment Services,
Protective Services for Older Adults, Advocacy and Government Affairs, and
Special Needs Trust Administration.**

AchievaFamilyTrust.org

HISTORY OF ACHIEVA FAMILY TRUST



- ✓ **Achieva Family Trust (AFT) was established in 1998, in response to Social Security Administration legislation in 1993, that allowed for the creation of Pooled Trusts.**
- ✓ **AFT is a corporate trustee for the three types of Special Needs Trusts, designed to provide access to a wide range of individuals with disabilities and their families.**
- ✓ **AFT also provides no cost consultations and resources for individuals and families to assist with future planning.**
- ✓ **AFT currently has over 2,500 beneficiaries, in Pennsylvania and 12 other states, with over \$175M in assets.**

FUTURE PLANNING PROJECT

✓ *United Way of Southwestern PA*

- Results of a survey conducted with caregivers showed that fewer than half of respondents reported having wills and /or plans for their dependent's care when they can no longer provide that care.

✓ *Future Planning Project - 2014 to Present*

- Education & Outreach for Individuals/Caregivers and Professionals
- Education of and collaboration with Legal Professionals
- Free Future Planning Guide
- Referrals for Future Planning Services

SO MANY QUESTIONS...

Caregivers ask:

- ✓ What would happen if I suddenly became unable to provide or care for my family member?
- ✓ Where will my family member live?
- ✓ Who will look after my family member's finance?

Individuals ask:

- ✓ How do I plan for and protect my financial future?
- ✓ *When should I start Future Planning?*

THINGS TO CONSIDER...

✓ *Government Benefits - SSI, SSDI, Medicaid, Medicare*

✓ *Legal Options*

- Last Will & Testament
- Special Needs Trusts
- Guardianship vs. Powers of Attorney

✓ *Future Planning Tools*

- Special Needs Personal Planning Guide
- ABLE Accounts

GOVERNMENT BENEFITS

✓ *Needs-Based Benefits*

- Supplemental Security Income (SSI)
- Medicaid (Medical Assistance)
- Medicaid Waiver Services - Long Term Care

✓ *Entitlements*

- Social Security Disability Income (SSDI)
- Social Security Survivor's Benefits
- Medicare

FUTURE PLANNING

Leaving assets directly to a disabled individual could disqualify them from receiving their government benefits.

Options To Avoid:

✓ *Disinheritance*

- Puts the assets at risk.
- A non-disabled sibling holding assets for the benefit of a disabled sibling could be subject to liabilities such as judgments from automobile accidents, bankruptcy, or divorce.

FUTURE PLANNING

Options To Avoid:

✓ *Asset Transfers*

- Subject to a 36-to-60 month “look back” period, which means that the disabled beneficiary might not be eligible to receive benefits for up to five years after the date of transfer.

Transfers to certain Supplemental Needs Trusts may be exempt from this “look back” and may not cause a period of ineligibility.

FUTURE PLANNING

✓ *Losing Government Benefits*

- If a person with a disability is on SSI or Medical Assistance or Waiver, there are certain income/resource and asset limits that apply.

✓ *There are options to protect those benefits:*

- Third Party Trust, Pooled Trust or Payback Trust
- ABLE Account - Must apply online at the website:

PAABLE.gov

LAST WILL & TESTAMENT

- ✓ A will specifies what will be done with your assets after your death.
- ✓ A will should not be a do-it-yourself endeavor.
 - Hire a lawyer who is knowledgeable in special needs planning and is aware of your state's disability laws. Once the documents are drafted, have your lawyer keep one and then give copies to any executors or guardians named in the will.
- ✓ If you die without making a will (intestate), your assets will be distributed to your heirs in accordance with the applicable interstate law, which could make your family member ineligible for government benefits.

SPECIAL NEEDS TRUSTS

SPECIAL NEEDS TRUSTS ARE DESIGNED FOR PEOPLE WHO ARE DISABLED, EITHER PHYSICALLY OR MENTALLY



- ✓ Used for “supplemental and extra care over and above what the government provides.”
- ✓ For the sole benefit of the beneficiary.
- ✓ **SUPPLEMENT:** Can be used for supplemental items such as clothing, vacation, medical needs, transportation, recreation, entertainment.
- ✓ **SUPPLANT:** Cannot be used for **housing, food, utilities, cash access.**
 - Home purchases and accessibility renovations may be considered and paid for from a Special Needs Trust.

SPECIAL NEEDS TRUSTS

✓ *Types of Special Needs Trusts*

- Third Party (also known as Common Law) / Payback / Pooled

✓ *Trustee*

- All Special Needs Trusts need a Trustee, either corporate or an individual.
- Can have more than one Trustee (except for Pooled Trust)

✓ *Exemption*

- Resources in trust are not considered available, and therefore, do not count against eligibility standards
- Allows individual to have above the \$2000 SSI limit or the \$8000 Waiver limit

SPECIAL NEEDS TRUSTS

✓ *Third Party*

- Family and friends of an individual with a disability can create to benefit the individual with a disability while still preserving eligibility for supports and services such as Medical Assistance, Waiver Services and Supplemental Security Income
- Family and friends can fund the Third Party Trust during their lifetimes and/or through their estate plans
- Can be very flexible and remaining funds can be left to other family members/friends/charity
- No payback to state Medical Assistance agency
- No age limit

SPECIAL NEEDS TRUSTS

✓ *Payback*

- May be established by the individual with a disability, their parent, grandparent, legal guardian, or Court
- Beneficiary must be disabled as defined in §42 USC §1396(d)(4)(a)
- For an individual under age of 65
- Individual and/or Corporate Trustee
- Must be drafted by an attorney and approved by DHS
- Remaining funds at beneficiary's death must "pay back" state(s) for all Medicaid (M.A.) benefits
- Any amounts remaining after State payback can be directed to family/friends/charity

SPECIAL NEEDS TRUSTS

✓ *Pooled*

- May be established by the individual with a disability, their parent, grandparent, legal guardian, or Court
- Beneficiary must be disabled as defined in §42 USC §1396(d)(4)(c)
- Individual should be under age of 65
- Trust is established and maintained by a non-profit association
- Standard form Joinder Agreement used in place of drafted document.
- Funds are pooled for investment but accounted for separately
- At beneficiary's death, remaining funds stay with the trust
- Achieva Family Trust Charitable Residual Grant Program

SPECIAL NEEDS TRUSTS

✓ MYTH

- I have to be rich to establish a Special Needs Trust...FALSE!
 - Some corporate trustees, such as banks, require a minimum of \$500,000 to serve as Trustee
 - \$500 minimum to start a trust with AFT

✓ FACT

- Implementation of a proper estate plan that includes a family member with a disability should involve an attorney who is knowledgeable about drafting Special Needs Trusts and government benefits

THE ABLE ACT

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- ✓ The ABLE Act was signed into law by President Obama on December 19, 2014.
- ✓ Created a new provision under Section 529 of the IRS Code establishing ABLE accounts, which allow individuals with a disability to save for qualified disability related expenses, much like a traditional 529 plan allows for saving for education-related expenses.
- ✓ The Pennsylvania ABLE Savings Program is administered by the PA Treasury Department:

PAABLE.gov or 855-529-2253

THE ABLE ACT

ACHIEVING A BBETTER LLIFE EEXPERIENCE



- ✓ Beneficiary is the account owner, but authorized signers can be added to the account.
- ✓ Beneficiary must be disabled and the onset of that disability must have been before age 26.
- ✓ Contributions are limited to \$15,000 per year from all sources. Individuals who are working can add \$12,490 above the \$15,000 each year.
- ✓ SSI recipients can save up to \$100,000 without SSI being affected.
- ✓ Remainder funds can be transferred to a disabled sibling or beneficiary's estate.

FUTURE PLANNING RESOURCES

- ✓ *AFT Monthly Newsletter*
- ✓ *AFT Speaker Series*
- ✓ *ABLE National Resource Center -
ablenrc.org/select-a-state-program*
- ✓ *SSA.gov/work/wipa.html*
- ✓ *nationaldisabilityinstitute.org*

QUESTIONS?



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THANK YOU FOR YOUR TIME!

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Thank you!

- **View a recording of this presentation on SBA's YouTube channel.**
- **Visit the SB-YOU playlist on SBA's YouTube channel for many more presentations for, about, and by adults with Spina Bifida Association on YouTube, or click on the YouTube icon on spinabifidaassociation.org**
- **Questions? Reach out to SBA's National Resource Center**
 - **Juanita Panlener, jpanlener@sbaa.org**