



ACHIEVA
Family Trust



Protecting Futures.
Enhancing Lives.

***“Future Planning for Individuals
with Disabilities and Their Families”***

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Estate Planning Council of Pittsburgh

HISTORY OF ACHIEVA FAMILY TRUST



- **ACHIEVA - Formerly ARC Allegheny**

 - Grassroots organization started by parents in 1950s out of concern for their children with disabilities*

- **In 1993, the Social Security Administration enacted legislation that allowed for the creation of Pooled Trusts**

 - In 1998, fundraising efforts allowed for the establishment of AFT, making ACHIEVA the first organization in the state with a Pooled Trust*

- **ACHIEVA Family Trust (AFT)**

 - Currently more than 2,300 accounts and more than \$125M assets under management*

 - Services are provided for persons with all disabilities, across Pennsylvania and 12 other states*

SERVICES PROVIDED BY AFT



- **Corporate Trustee for Special Needs Trusts for individuals with disabilities**
- **Trusts can be established for a \$500 minimum deposit, with reasonable fees for administration**
- **Knowledgeable Trust Administrators have extensive experience with social services and government benefits to help preserve eligibility for essential government services, at no additional cost**
- **Manages and distributes funds to improve the quality of life for individuals with disabilities, recognizing their individual preferences and capabilities**
- **Provides Future Planning resources for individuals with disabilities and their families, including referrals, planning tools, supports that augment government funded services and trust management**

SERVICES PROVIDED TO THE LEGAL COMMUNITY



- **No cost Case Consultations and assistance with government benefit questions to determine if a Special Needs Trust is necessary**
- **No cost advice on drafting the trust documents, including providing sample language for a Third Party Special Needs Trust**
- **Continuing Legal Education (CLE) on topics related to Elder Law and Special Needs Trusts**
- **Monthly E-Newsletter**

DISABILITY IN THE U.S. AND PENNSYLVANIA



- **26% of adults in the United States have some type of disability.**
- **Approximately 21.1% percent of Pennsylvania's 12+ million residents have a disability.**
- **Pennsylvania spends \$20.5 Billion per Year on Disability Costs.**

U.S. CDC National Center on Birth Defects and Developmental Disabilities

HOW DOES THE GOVERNMENT DEFINE DISABILITY?



Minor

“An individual under the age of 18 shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental *impairment*, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”

42 U.S.C.S § 1382c

Adult (18+)

“Physical or mental *impairment* or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.”

WHAT IS AN IMPAIRMENT?



“A physical or mental impairment is an impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques.”

42 U.C.S.C. § 1382d

CHOICES IN PAYING FOR MEDICAL CARE FOR AN INDIVIDUAL WITH A DISABILITY



Privately pay or use private insurance for long-term services. This is rarely an option for an individual with a lifelong disability.

OR

Utilize government programs that provide lifelong supports. This is the most realistic route for an individual with a long-term disability.

In-home care / assisted living: \$65,000 - \$120,000 / year

<https://www.care.com/c/stories/10266/special-needs-care-for-adult-children-cost-of-care/>

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**

SUPPLEMENTAL SECURITY INCOME (SSI)



- **These means-tested benefits have strict asset and income guidelines.**
- **Assets are limited to \$2,000 per individual.**
- **The maximum benefit is \$771 for an individual
The maximum benefit is \$1,157 for a couple.**
- **In-kind Support and Maintenance (ISM): Food or shelter that somebody else provides.**
- **If someone is providing ISM to SSI recipient, SSI benefit will be reduced by one-third.**

MEDICAL ASSISTANCE (MA)



- **Medical Assistance (MA) is a means-tested benefit that many individuals with disabilities use. An individual cannot have more than \$2,000 in assets or he may lose his MA.**
- **In PA, individuals who receive SSI (even \$1) are automatically eligible for MA.**
- **Services provided include: Medical and Prescriptions, Long Term Care Services (Nursing Home Care and Home and Community Waiver Services), Medical Assistance for Workers with Disabilities (MAWD)**
- **As of June 2017, almost 3 million Pennsylvanians were on Medicaid.**

OTHER OPTIONS



- **Loophole for children in PA: parental income does not count for children with significant disabilities, but child's income does**
- **Waiver services: funding to provide supports/services for individual in the community rather than institution**
- **Medical Assistance for Workers with Disabilities (MAWD):**
 - **Permits Pennsylvanians with disabilities to obtain employment without losing medical coverage or eligibility for home and community-based services**
 - **2019 Monthly Income Limit to retain MAWD is \$2,530**
 - **2019 Resource Limit to retain MAWD is \$10,000**

SOCIAL SECURITY DISABILITY (SSD)



➤ *An individual qualifies for SSD if:*

- 1. He or she has worked and has paid into SSD.**
- 2. He or she is an adult child diagnosed with a disability before age 22 and a parent who has paid into Social Security is either disabled, retired or deceased.**
- 3. He or she is a spouse/former spouse of someone who has paid into Social Security and has a disability, is retired or deceased.**

MEDICARE



- 1. Social Security recipients who are over 65 or have a permanent disability are entitled.**
- 2. An individual who has railroad retirement benefits or end-stage renal disease is also eligible.**
- 3. An individual with a disability who is receiving SSD will receive Medicare after a 24-month waiting period.**

** Note: An individual with a disability may be dual eligible for Medicare and Medical Assistance*

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 Accounts

THE SPECIAL NEEDS TRUST



- *A SNT is a trust designed for beneficiaries who have a mental or physical disability.*
 - **Used for supplemental and extra care over and above what the government provides**
 - **For the sole benefit of the beneficiary**
 - **The ultimate goal is to allow the beneficiary to keep his or her government benefits.**

SUPPLEMENT VERSUS SUPPLANT



- **SUPPLEMENT:** Can be used for supplemental items such as clothing, vacation, medical needs, transportation, recreation, entertainment.

- **SUPPLANT:** Cannot be used for housing, grocery food, utilities, cash access.
 - **Lang v. Commonwealth of PA, Dept. Of Public Welfare, 515 Pa 428, 528 A.2d 1335 (1987), 528 A.2d 1335 (1987)**

 - * *Note: Home purchases and accessibility renovations may be considered and paid for from a Special Needs Trust, as long as it is the beneficiary's primary residence.*

THREE TYPES OF SPECIAL NEEDS TRUSTS



1. Third Party / Common Law / Supplemental Needs Trust:

Lang v. DPW; et al

***2. Pooled Trust:* 42 U.S.C. §1396p(d)(4)(C)**

***3. Payback Trust:* 42 U.S.C. §1396p(d)(4)(A)**

THIRD PARTY TRUSTS



- **PA Case Law:**
Lang v. Commonwealth of PA, Dept of Public Welfare, 515 PA 428, 528 A.2d. 1335 (1987); et al.
- **Established by friends or family; someone other than the individual with a disability.**
- **Individual and/or Corporate Trustee**
- **Funded with assets belonging to third party (anyone other than the beneficiary)**

THIRD PARTY TRUSTS (*CONTINUED*)



- **Inter vivos or testamentary or both**
- **Must be drafted by an attorney**
- **Magic words: supplement, not supplant**
- **Remaining funds can be left to family / friends / charity**
- **No age limit**

POOLED TRUSTS



- **42 USC §1396p(d)(4)(C)**
- **Trust is established and maintained by a non-profit association.**
- **Beneficiary must be disabled as defined in:
42 U.S.C. §1382c (a)(3)**
- **May be established by the individual with a disability, their parent, grandparent, legal guardian, or Court.**
- **Generally funded with assets belonging to the individual with a disability.**

POOLED TRUSTS (*CONTINUED*)



- **Standard documents allow for accounts to be created quickly and cost effectively.**
- **Distributions must be for the sole benefit of the beneficiary.**
- **Funds are pooled for investment purposes but accounted for separately.**
- **Beneficiary should be under 65.**
- **At beneficiary's death, remaining funds stay with the trust.**
ACHIEVA Family Trust Charitable Residual Program

PAYBACK TRUSTS



- **42 USC §1396p(d)(4)(A)**
- **Individual and/or Corporate Trustee**
- **Beneficiary must be disabled as defined in:
42 U.S.C. §1382c (a)(3)**
- **May be established by an individual with a disability,
their parent, grandparent, guardian or Court.**
- **Generally funded with assets belonging to the individual
with a disability.**
- **Must be drafted by an attorney and approved by DHS.**

PAYBACK TRUSTS (*CONTINUED*)



- **Distributions must be for the sole benefit of the beneficiary.**
- **Court approval required for minors, incapacitated.**
- **Beneficiary must be under age of 65.**
- **Remaining funds at death of beneficiary must first be used to pay back state(s) for all Medicaid (MA) benefits.**
*Any amount remaining after state payback can be left to:
Family / friends / charity*

THE ABLE ACT



- The Achieving a Better Life Experience or ABLE Act was signed into law by President Obama on December 19, 2014
- Created a new provision under §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 was launched in 2017 and is administered by the PA Treasury Department:

PAABLE.gov OR 855-529-2253

THE ABLE ACT



- **Beneficiary is the account owner, but authorized signers can be added to the account.**
- **Beneficiary must be disabled and onset of that disability must have been before the beneficiary turned 26.**
- **Contributions are limited to \$15,000 a year from all sources.**
- **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.**

DECISION MAKING



- Parents are natural guardians of their children until age 18
- Once child is over 18, parents may need to consider options in order to be able to discuss child with hospitals, doctors, service providers, financial institutions, etc.
 - ★ Powers of Attorney
 - ★ Guardianship
- *An attorney should be consulted in order to determine what is appropriate based on the individual's capacity or incapacity.*

CHARITABLE RESIDUAL PROGRAM



- **Since its inception we have distributed more than \$4.5 million.**
- **Funds have been distributed for camp / recreation, home and vehicle modifications, iPads, medical needs or supplies.**
- **Applicants may reside anywhere in Pennsylvania.**
- **Online applications are available at:**

ACHIEVAFamilyTrust.org

FUTURE PLANNING



- **Grant (July 1, 2014 - present) from United Way of Southwestern PA, to provide Education & Outreach for Caregivers and Service Providers on Future Planning for individuals with disabilities and their families.**

- **Activities of Future Planning Project**
 - ***Monthly Newsletter***
 - ***Presentations***
 - ***Vendor Fairs***
 - ***Speaker Series***
 - ***Online Future Planning Guide:***
- ❖ **Can be downloaded at achieva.info/future-planning-project**

*****New Service: Employment Benefits Counseling Program for individuals who want to work, but are concerned about losing their benefits.**

FUTURE PLANNING



- **The Future Planning Project also involves facilitating additional access for families to competent legal services.**

Activities include:

- Free Continuing Legal Education (CLE) for Attorneys**
- Monthly Lunch & Learn Presentations for local law firms**
- Free Legal Clinics for Families**



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