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Long Term Planning for Your Family Member

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As self-advocates, parents, and family members, we have learned the power of sharing experiences and knowledge, of advocacy, and of looking toward a future of high expectations.

We must continue to work toward fulfilling the promise of independence and self-determination for all people.
Knowledge is power.

The Importance of Planning for the Future

- What we'll learn today
  - Bit about Medicare and Medicaid
  - Bit about Social Security Income
  - Bit about Social Security Disability Income
  - The different types of trusts

What is a Special Needs Trust?

- Trust for someone with a long-term disability which is designed to meet the specific needs of that individual
- Important tool which can help ensure an individual has financial resources to meet his/her special needs
- A way to arrange resources in order to protect an individual's access to his/her needed government benefits.
Who is eligible for Special Needs Trust in PA?

- Individual with a disability
- Some issues if individual is age 65 or older and trust is self-funded

Definition of Disability

- Social Security Act 1614
- Unable to maintain Substantial Gainful Activity ($1000/mo disabled non-blind; $1640 blind—2010 Figures)
- Because of medically determinable physical or mental impairment which is expected to
  - Result in death or
  - Last for a continuous period of at least 12 months

Let’s Look at the Money

- The following slides will talk about the different financial programs that support people
Typical Supports and Services for an Individual with High Support Needs

- Nursing Home Care .......... $6000/month
- Attendant Care ............. $14/hour
- Residential .................. $35,000/year
- Day Program ............... $35,000/year
- OT/PT/Speech ............ $30/hour
- Medical .................. ??????????????

Major Government Programs for People with Disabilities

- Medicare
- Medicaid
- Supplemental Security Income (SSI)
- Social Security Disability (SSDI)

Eligibility and Coverage: Medicare

- Eligibility
  -- entitlement
  -- disability
  -- work history (self, spouse, parent—if disability happened before age 22)
- Extent of coverage
  -- limited medical
  -- limited prescription
Eligibility and Coverage: Medicaid

- **Eligibility**
  - needs based (disability and poverty)
  - asset limit – as low as $2000 savings
  - income limit – as low as $923/month

- **Extent of coverage**
  - medical and prescriptions
  - "waiver services" – residential, attendant care, respite, day program, therapies

Eligibility and Coverage: SSI

- **Eligibility**
  - needs based (disability and poverty)
  - asset limit and income limits

- **Extent of coverage**
  - cap of $674/month
  - reduced if person receives in-kind services, cash or cash equivalents
  - linked to Medicaid

Eligibility and Coverage: SSDi

- **Eligibility**
  - entitlement
  - disability
  - income limits (SGA)

- **Extent of coverage**
  - based on wage earner’s contributions and number of dependents
  - linked to Medicare
Home and Community-Based Waiver Services

- Medicaid waiver programs are available to provide services and supports, for people who qualify, to help them remain in their homes and communities rather than being placed in an institution.
- Pennsylvania has 10 waivers currently.

Home and Community-Based Waivers

- Financial limits to continue qualifying for Medicaid and waiver services $2022/mo (January 2010)
- If you receive Home and Community-Based waiver services in Pennsylvania you can continue to be eligible for Medical Assistance and waiver services with income up to 300% of SSI

Types of Special Needs Trusts

- Common Law Trusts
- Payback Trusts
- Pooled Trusts
Exemption

- Means that the resources are not considered available and counted against eligibility standards
- Have above $2000 limit as regulated for waiver and SSI

Common Law Trust

- Also referred to as a discretionary, non-support, supplemental, third party funded or special needs trust
- Recognized by case law not statute

Third Party Trust/Common Law Trust

- Trust can hold assets that will not count against assets limit of individual. The trust can be set up by a family member with specific restrictions on distributions for comfort and special needs
- At the death of person, assets are directed to the individuals specified by the person who established the trust
Common Law Trust

1. Trustee has full control of money and how it is used
2. Cannot permit distributions for support (basic food, housing or medications)
3. Cannot contain the assets of the beneficiary
4. Cannot be legally enforceable by the beneficiary

Common Law Trust

1. Can be established by Will or inter vivos
2. Person creating trust can direct residual to other people at beneficiary's death

Common Law Trust

• Each trust is established independently
• Each trust is reviewed separately
• Beneficiaries cannot establish for themselves
• Each trust bears its own start-up and operating costs
• Trust will need a trustee (whether individual or corporate) and possible successor
Common Law Trust

- If funds are “legally available” to the beneficiary, the trust assets are subject to spend-down
- Funds to establish the trust must be from a third party, not the individual
- Trust relies on the discretion of the trustee—whether the funds will be spent and in what amounts
- Beneficiary cannot force payment from the trustee

Supplement, Don’t Supplant

- Award or settlement paid to the victim can disqualify the victim from receiving SSI and/or Medicaid
- Part of structure should include payments into a Pooled or Payback Trust to preserve government benefits

Payback Trust

- Referred to as a “Special Needs Trust” by Medicaid
- Social Security Act : 42 U.S.C. 1396p (d)(4)(A)
- 55 PA Code 178.7(f)(1)
Payback Trust

1. For an individual under 65 years of age
2. Beneficiary must be disabled as defined in 42 U.S.C. 1382c (a)(3)
3. Must be established by a parent, grandparent, legal guardian or court
4. Residual funds at beneficiary’s death must payback state for all MA benefits

Payback Trust

• Can be funded with assets available to the beneficiary and protects assets from spend-down
• Possibility that any amounts remaining after the State is paid back can be directed to others.

Payback Trust

• Beneficiaries cannot establish for themselves
• Trust must be established independently
• Trust bears its own start-up and operating costs
• Trust will need a trustee (whether individual or corporate) and possible successor
Pooled Trust
- Also referred to as an “OBRA Trust” or “C Trust”
- Social Security Act: 42 U.S.C. 1396p (d)(4)(C)
- 55 PA Code 178.7(f)(2)

Pooled Trust
- For the benefit of an individual who has a disability as defined in 55 PA Code 178.7(f)(2)
- Trust is established and maintained by a non-profit association
- Funds are pooled for investment but accounted for separately

Pooled Trust
- Must be established by a parent, grandparent, legal guardian, court or individual with a disability
- At beneficiary’s death, remaining funds stay with the trust to benefit others with disabilities or pay back the state
**Pooled Trust**
- Can be funded with assets available to the individual with a disability
- Protects assets from spend-down
- Can be established by the individual with a disability
- Funds are pooled for investment
- Shared costs for trust

**Pooled Trust**
- Non-profit association acts as trustee
- No need for successor trustees
- Limited or no start-up costs due to use of standard documents
- Individual accounts can be established quickly

**Knowledge is power… USE IT!**
Thank you!

Institute on Disabilities

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