

The Essentials of Special Needs Planning

Lesley M. Mehalick, J.D., LL.M. and Alissa B. Gorman, J.D., LL.M.
McAndrews Law Office, P.C.
Berwyn, PA

I. Introduction

- a. What is Special Needs Planning?
 - i. Estate planning for families that have a loved one with special needs
 - ii. Focus on providing financial resources to the individual with special needs while retaining crucial public benefits through the use of a special needs trust
 - iii. Provides a global plan of who will care for the family member with special needs when the main caregiver (typically parents) passes away
 - 1. Who will provide care for individual (family member, agency, or institution?)
 - 2. Where will the care be provided (private home, group home, or in a facility?)
 - 3. How will it be funded (Private pay or waiver)
- b. Which clients require Special Needs Planning?
 - i. Currently receiving, or will receive in the future, resource-based public benefits
 - ii. May include planning for family members with drug problems or mental health disorders
 - iii. Largest focus is typically residential care
 - iv. Private health insurance does not cover nursing home care or pay for a person with special needs to live in a group home or institutional setting
 - 1. Cost of residential care for individual with Intellectual Disability can easily exceed \$100,000 per year
- c. Federal/state law
 - i. Social Security: Federal law
 - 1. Disability: 42 U.S.C. §1382c(a)(3)
 - 2. Special Needs Trusts: 42 U.S.C. §1396p(d)(4)
 - ii. Medicaid: Federal and state law, but administered by the state
 - 1. Pennsylvania: Department of Human Services (DHS) administers Medical Assistance program
 - 2. Special Needs Trusts: 62 P.S. §1414

II. Overview of Public Benefits

a. Definition of disabled - 42 U.S.C. §1382c(a)(3)

- i. Over 18: Unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment 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
- ii. Under 18: Medically determinable physical or mental impairment that results in marked and severe functional limitations

b. Definition of Income and Resources:

- i. Income: Any item an individual receives in cash or in-kind, on a monthly basis, that can be used to meet his or her need for food or shelter
- ii. Resources: Resources are cash and any other personal property, as well as any real property, that an individual (or spouse, if any):
 - 1. owns;
 - 2. has the right, authority, or power to convert to cash (if not already cash); and
 - 3. is not legally restricted from using for his/her support and maintenance.
- iii. Excludable resources: Primary residence, one vehicle, term life insurance, irrevocable burial reserve, tangible personal property, properly drafted Special Needs Trust

c. Resource/Income Based Benefits:

- i. Supplemental Security Income (SSI)
 - 1. Monthly cash payment for individuals that cannot work due to a disability
 - 2. Medical disability according to SSA standards
 - 3. Resources less than \$2,000 (house and one car excluded)
 - 4. Monthly income less than approximately \$900.00
 - 5. Maximum monthly payment of \$755.00; benefit can be reduced based on receipt of income from other sources
 - 6. Parents' resources and income are considered in determining whether a child qualifies for SSI
- ii. Medical Assistance (MA)

1. Provides health insurance for individuals if they meet certain medical and financial requirements
2. If individual qualifies for SSI, automatically qualifies for MA
3. Many categories with varying income and resource limits
4. For individuals with disabilities, the standards are generally the same as the SSI rules
5. All children with disabilities qualify for MA until age 21
 - a. Serves as secondary insurance if child has primary insurance
 - b. Only child's income counts in eligibility determination

iii. Medicaid Waiver Programs

1. MA program that provides in-home services for individuals who medically and financially qualify
2. Financial assistance for in-home services are referred to as "waivers"
3. Not an entitlement program
4. To qualify for a waiver, must meet the medical and financial requirements of each specific waiver program
5. Income: \$2,205.00 per month; Resources: \$8,000.00
6. Common waiver programs:
 - a. Person/Family Driven Waiver: Allows individual with intellectual disability (ID) to use funds for in-home care or a day program
 - b. Consolidated Waiver: Provides unlimited funding for individual with ID; typically used for community living arrangement such as a group home
 - c. Commcare Waiver: Provides services for individuals with traumatic brain injuries
 - d. Independence Waiver: Provides services for individuals with physical disabilities

iv. Medicare Savings Program

1. Provides enhanced coverage for low-income Medicare recipients
2. Four programs based on recipient's income
3. Will pay for premiums, copayments, and deductibles on varying levels

d. Non-Income/Resource Based Benefits

- i. Social Security Disability Insurance (SSDI)
 1. Disabled under SSA standards
 2. Payment based on own work history or parent's work history if disabled before age 22

3. No resource limit
 4. Cannot earn more than \$1,090.00/month of income
 5. Monthly payment varies based on years worked and wages
- ii. Medicare
 1. Provides health insurance for individuals over age 65 and individuals who receive SSDI for more than two years
 2. No income or resource limit
- e. Dual Eligibles
- i. Individuals who receive a combination of resource/non-resource based benefits
 - ii. Some clients receive SSI, SSDI, MA, and MC
 - iii. Common to have SSDI and MC recipient who relies on MA waiver program to remain in his/her home

III. Special Needs Trusts

- a. Purpose: Permit financial resources to remain available to assist a person with disabilities who receives, or may receive in the future, Medicaid, SSI, or both
- b. Self-Funded Special Needs Trusts
 - i. Required when beneficiary owns or receives monies over the resource limit
 - ii. Created under 42 U.S.C. §1396p(d)(4)(A)
 1. Settlor
 - a. Parent, Grandparent, Guardian, Competent Beneficiary, Court
 - b. Irrevocable
 2. Trustee
 - a. Individual
 - b. Corporate
 - i. Nonprofit
 - ii. Financial Institution
 3. Beneficiary
 - a. Minor, Incapacitated Person (IP), Competent Adult
 - b. Disabled under the standards of 42 U.S.C. § 1382c(a)(3)
 - c. Under age 65 at time of funding
 - d. Upon death of beneficiary or other termination of trust, payback to the state for Medical Assistance provided during lifetime of beneficiary
 - iii. Trust Provisions
 1. Trustee removal/appointment
 - a. Beneficiary cannot serve as Trustee
 2. Limited power of appointment
 3. Remainder beneficiaries

- a. Payback to state
 - b. Minor/IP: intestate heirs
 - c. CA: anyone
 - 4. Termination
 - a. During life of beneficiary
 - i. Payback to state
 - ii. Remainder to beneficiary
 - b. At death of beneficiary
 - i. Payback to state
 - ii. Remainder to beneficiaries designated in trust
 - 5. Accounting if ordered by the court
 - a. No affirmative accounting requirements to state
 - iv. Public Agency Notification
 - 1. Department of Human Services 62 P.S. §1414
 - a. DHS must approve trust
 - 2. Social Security
 - a. Must receive copy of trust (does not approve, but will deny benefits if trust is not compliant)
 - v. Taxes
 - 1. Income taxes: Grantor trust as to beneficiary
 - 2. Death taxes: Included in beneficiary's estate
 - 3. Deduction for MA repayment to state
- c. Third-Party Funded Special Needs Trusts
 - i. Required if someone other than the beneficiary is transferring money to the trust
 - ii. Created under common law
 - 1. Settlor:
 - a. Anyone other than beneficiary
 - b. Need not be irrevocable
 - 2. Trustee:
 - a. Individual
 - b. Corporate
 - c. Trust Advisory Committee/Trust Protector
 - 3. Beneficiary
 - a. Minor, IP, CA, and other individuals
 - b. Disabled under SSA standards
 - c. No age limit on funding
 - iii. Trust Provisions
 - 1. Trustee removal/appointment
 - a. Beneficiary cannot serve as Trustee
 - 2. Limited power of appointment
 - 3. Remainder beneficiaries
 - a. NO payback to state
 - b. Any remainder beneficiary
 - 4. Termination

- a. During life of beneficiary
 - i. By trustee is trust no longer meets the needs of the beneficiary
 - ii. If trust corpus is too small to justify maintaining the trust
 - b. At death of beneficiary
 - i. Remainder to beneficiaries designated in trust
 - 5. Accounting
 - a. No accounting requirements to state or court unless DHS alleges misuse
 - iv. Public Agency Notification
 - 1. DHS need not approve TPF-SNT, but must be disclosed on application for Social Security and Medical Assistance and a copy must be provided to agencies
 - v. Taxes
 - 1. Can be drafted as grantor trust
 - 2. Death taxes: Not included in beneficiary's estate
 - 3. No payback to state upon death of the beneficiary
- d. Pooled Trusts
 - i. 42 U.S.C. §1396p(d)(4)(C)
 - ii. Administered by non-profit trustee
 - iii. Parent, grandparent, guardian, court, or beneficiary can sign joinder to master trust agreement
 - iv. Separate accounts, invested together
 - v. Upon beneficiary's death, remaining funds retained by pooled trust and distributed among living beneficiaries
 - vi. No payback to state

IV. Integrating Special Needs Trusts with Estate Planning Documents

- a. Any share of estate passing to individual with special needs shall be distributed directly to trustee of third-party special needs trust
- b. Testamentary vs. inter vivos Special Needs Trust
 - i. Gifting
 - ii. Inheritance from other family members
 - iii. Fundraising
 - iv. Beneficiary can get comfortable with trustee and trust distributions
- c. Gifting
 - i. Crummey powers can be included in TPF-SNT for lifetime gifting
 - ii. The beneficiary with special needs MUST be specifically excluded as demand beneficiary
- d. Income Taxes
 - i. TPF-SNT can be drafted as grantor trust
 - ii. Can be drafted as qualified disability trust
 - 1. Trust can use personal exemption amount

V. Non-Probate Assets and Special Needs Trusts

- a. All assets passing to individual with special needs, whether probate or non-probate, must flow into Third Party SNT
- b. Beneficiary designations for life insurance, pensions (if permitted), and retirement assets must identify TPF-SNT
- c. Tax-deferred Assets (IRA/401(k))
 - i. Stretch for RMDs
 - 1. See through trust (5 Rules)
 - a. Valid under state law
 - b. Trust is irrevocable or will, by its terms, be irrevocable upon the death of the participant
 - c. Identifiable beneficiaries
 - i. Must be able to identify the oldest beneficiary
 - d. Trust provided to plan administrator
 - e. All trust beneficiaries are individuals
 - i. No charities, estates, or power of appointment
 - 2. Accumulation Trust
 - a. TPF-SNT cannot be a conduit trust since RMD distributions would disqualify the beneficiary from public benefits
 - b. Get income out of trust by purchasing items for the beneficiary
- d. Consider asset allocation
 - i. Direct tax-deferred retirement assets to children without special needs and provide funding from additional estate assets
 - ii. Life insurance is a preferred way to fund TPF-SNTs

VI. Administration of Special Needs Trusts

- a. Distributions
 - i. Items, goods, and services for the (sole) benefit of the beneficiary with special needs
 - ii. Discretionary income and principal
 - 1. SF-SNT: Principal restrictions for minor and IPs based on county
 - iii. For the special needs of the beneficiary
 - iv. Supplemental but not supplant public benefits
 - v. Consider all public benefits available to beneficiary
 - vi. Restrictions:
 - 1. No gifting
 - 2. Trustee cannot provide cash to beneficiary and must pay vendors directly
 - 3. If beneficiary is receiving SSI, should not use for food and shelter as it will reduce SSI check
 - vii. Examples:

1. Clothing
 2. Transportation
 3. Computer/electronics
 4. Vacation
 5. Entertainment
 6. Unreimbursed medical expenses
 7. Respite care
 8. Irrevocable burial reserve
- viii. If trust is for sole benefit of beneficiary, there are exceptions for distributions that are not purely for the sole benefit of the beneficiary:
1. Payments to a third party that result in the receipt of goods or services by the trust beneficiary
 2. Payment of third party travel expenses which are necessary in order for the trust beneficiary to obtain medical treatment
 3. Payment of third party travel expenses to visit beneficiary who resides in nursing home, group home, or other long-term care facility in which a non-family member or entity is providing residential services to the beneficiary. Travel must be for purpose of ensuring safety/medical well-being of beneficiary
 4. Reasonable trustee fee and costs associated with investment, legal, or other professional services
- ix. Special purchases:
1. House
 - a. Trust can own a home which serves as a primary residence for beneficiary
 - b. Trust cannot pay for rent, mortgage, essential utilities, or property taxes without reducing SSI check
 - c. Titled in the name of the trust
 - d. If SF-SNT, house is subject to payback
 - i. Better to own home in beneficiary's own name?
 - e. If SF-SNT, family members living in home must contribute rent or pay carrying costs of home
 - f. Trust can be a co-owner of home with family member
 2. Vehicle
 - a. Trust can own one vehicle that serves as primary transportation for beneficiary
 - b. Beneficiary need not be able to drive vehicle or have driver's license
 - c. Title placed in name of driver and trust takes a lien
 - d. Trust can pay insurance, gas, maintenance
- b. Trustee
- i. Individual
 1. Typically for TPF-SNT
 2. Modest SF-SNT
 3. If SF-SNT, must obtain bond for amount over \$100,000

4. Can hire investment advisor
- ii. Corporate
 1. Large trusts
 2. Non-profits for modest amounts or if no family member available
- iii. Responsibilities
 1. Open trust account
 2. Invest funds
 3. Maintain complete and accurate records
 4. Distribute funds for benefit of beneficiary
- iv. Documentation
 1. Must keep all receipts for purchases
 2. Must keep record of all distributions
 3. Can reimburse family members for purchases
 4. Accounting to DHS or SSA on annual basis not required, but must comply with agency request for information

VII. Alternatives to Special Needs Trusts

- a. Spenddown
 - i. Competent adult can spend monies on items for him/herself
 - ii. Requirements
 1. Must be fully spent down within calendar month of receipt of funds
 2. Must pay full fair market value (FMV) for items
 3. No gifting
 - iii. Recipient must report spenddown to SSA and DHS
 1. Keep record of all purchased items
 2. Keep all receipts/invoices
 3. Bank account must be below \$2,000.00 before first day of month following spenddown
 - iv. Funds still income in month of receipt but if properly spent down, will not be resource in following month
- b. Disinheritance
 - i. Parent may wish to leave inheritance to an adult child without disabilities with the hope that they use the funds for the benefit of the child with special needs
 - ii. While the availability of TPF-SNTs makes disinheritance unnecessary, in certain circumstances it may be appropriate to consider, particularly in smaller estates or where assets are all held in tax-deferred vehicles
 - iii. Client should be cautioned that when assets are left to a child without special needs (to be used for the child with special needs), these assets could be subject to creditors, bankruptcy or divorce of the child without special needs
 1. TPF-SNT will protect monies from the above situations
- c. Achieving a Better Life Experience (ABLE) Act

- i. Federal law that allows states to enact legislation permitting individuals with disabilities to fund an account that grows tax-free and is not considered an available resource for Medicaid and SSI purposes.
- ii. Modeled after IRC §529 educational accounts
- iii. Key points:
 1. Beneficiary must be disabled prior to obtaining age 26
 2. One account per beneficiary
 3. Established by beneficiary, parent, grandparent, guardian
 4. Anyone can contribute money to the account
 - a. Beneficiary can put income into the SNT
 5. Aggregate contribution limit of \$14,000 per year
 6. Competent beneficiary can control distributions from the account
 7. Withdrawals must be used for “qualified disability expenses”
 - a. Education, housing, transportation, wellness, legal fees, administrative fees, financial planning, funeral
 8. If distributions not used for qualified disability expenses, must pay 10% penalty and income tax
 9. If total amount of account exceeds \$100,000, SSI benefits are suspended until account runs below \$100,000
 10. At death, account not subject to PA inheritance tax, but if beneficiary was over age 55, can be subject to the Estate Recovery Act
- iv. Pennsylvania and the payback
 1. Federal legislation states that ABLE accounts may have a payback to state Medicaid Agency
 2. Pennsylvania did not institute immediate payback, but account may be subject to payback if beneficiary over age 55
 3. SF-SNT cannot contribute money to ABLE account since it has potential to avoid payback
 4. TPF-SNT can make contributions to ABLE account but if beneficiary passes away after age 55, it could subject the funds to payback
- v. ABLE accounts beneficial for:
 1. Competent individuals who work
 2. Individuals who would like to use funds to pay shelter expenses
 3. Small personal injury settlement or inheritance
- d. Compare and Contrast SNT v. ABLE Account

	SNTs	ABLE Accounts
Age Limit:	TPF-SNTs: None SF-SNTs: Under age 65	Beneficiary must be determined to be disabled prior to age 26
Funding Limit:	None	-\$14,000.00 per year (2017) -Maximum limit equal to state's

		529 plan limit - Funds over \$100,000.00 count as resource for SSI eligibility
Establishment:	- TPF SNT: Anyone - SF SNT: Competent Beneficiary, parent, grandparent, legal guardian, or court	- Beneficiary, Parent, Agent under POA, Legal Guardian
Management:	Trustee responsible for all management and investment	- State agencies responsible for managing and investing accounts - Beneficiary may have involvement in investments
Distributions:	Trustee has absolute discretion for all distributions	Beneficiary may withdraw funds and use debit card if available
Income Taxes:	SF-SNT: Income taxed to beneficiary TPF-SNT: Income taxed to grantor or to trust	- Income earned is not taxable if used for QDE - Non-QDE distributions are taxable to beneficiary and subject to 10% penalty
Types of Distributions:	- No food/shelter without reduction in SSI - No cash to beneficiary - Sole use (SF SNT)	Qualified Disability Expenses
Housing:	Distributions made for housing will reduce SSI	Distributions for housing QDEs will not reduce SSI
Distributions and SSI Eligibility:	No distributions directly to beneficiary	Distributions held past the month of distribution may be counted as resource depending on intended use and how held
MA Payback:	TPF SNTs: None SF SNTs: Payback for MA received during beneficiary's lifetime	- Federal law: Payback for MA received following establishment of ABLE Account - PA ABLE: DHS will not enforce payback - If over 55 can be included in Beneficiary's estate and subject to Estate Recovery Act