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PLANNING FOR A LOVED ONE WITH SPECIAL NEEDS

1. What Does Planning Involve?
 - a. Preserving your child's financial security and quality of life
 - b. Addressing key issues
 - i. Understanding the role of public benefits
 - ii. Using estate planning/trusts to protect assets
2. Understanding Public Benefits
 - a. Public Benefits at a Glance
 - i. Financial Benefits
 - (1) Supplemental Security Income (SSI) - Needs based benefit
 - (a) Means tested: Limited income and assets
 - (2) Social Security Disability Insurance (SSDI) - Entitlement benefit
 - (a) Not means tested but subject to work credits or parents' eligibility
 - ii. Medical Benefits
 - (1) Medicaid - needs based benefit
 - (a) Automatic with SSI
 - (b) Must apply for SS/SSDI
 - (2) Medicare - Entitlement benefit
 - (a) Automatic after two years of SSDI

- b. Supplemental Security Income (SSI)
 - i. Must meet the Social Security Administration's definition of "disabled" and have limited assets and income
 - (1) Disability for a minor is defined as a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months
 - (2) Disability for an adult is defined as the inability to engage in any "substantial gainful activity" (SGA) due to any medically determinable physical or mental impairment, or combination of impairments, that has lasted or can be expected to last for a continuous period of at least 12 months, or result in death
 - ii. SSI provides monthly income for food and shelter
 - iii. Gateway to Medicaid which covers in-home support services
 - iv. SSI can be impacted as follows: (use \$585 example)
 - (1) It is reduced, dollar for dollar, if the individual has more than \$20 in unearned monthly income, such as gifts, interest or rent
 - (a) \$585 of unearned income causes \$565 loss of SSI ($\$585 - \$20 = \565)
 - (2) It is reduced by one dollar for every two dollars earned if the individual has earned income (wages) above \$85 a month
 - (a) \$585 of earned income causes \$250 loss of SSI ($\$585 -$

$$\$85 = \$500/2 = \$250)$$

- (3) In Kind Support and Maintenance
 - (a) If SSI recipient lives in another's house throughout a month and receives *both* food and shelter from a person inside the house and does not meet his or her pro rata share of the cost of food and shelter
 - (i) Loses \$224.67 of SSI
 - (b) If SSI recipient is living alone but having rent paid by a third party
 - (i) Loses \$244.67 of SSI
- (4) For eligible individuals, SSI pays up to \$674 a month for food and shelter

v. A person must have countable resources of \$2000 or less to qualify.

Resources that do not count include:

- (1) Home
- (2) Household goods
- (3) Life insurance-up to \$1,500 face value
- (4) Burial plot
- (5) Burial fund
- (6) Car

vi. Deeming - is the process used by the SSA when determining SSI eligibility of considering income and resources of one person's to be "available" to another person living in the same household

(1) Parent to Child Deeming

(a) Requirements

- (i) unmarried child
- (ii) under age 18 (or under age 21 if student)
- (iii) living with one or both parents
- (iv) child otherwise eligible for SSI (eligible before deeming rules taken into account)
- (v) at least one parent ineligible for SSI

(b) Effect: income and resources of parent will be “deemed” to be available to child, whether actually available or not. In most cases, child not eligible for SSI

(c) Ends:

- (i) beginning the month following the month the child attains age 18 (or age 21 if student); or
- (ii) child leaves home without an intent to return; or
- (iii) child marries (then spouse-to-spouse deeming rules apply)

(2) Spouse-to-Spouse Deeming

(a) rules similar to parent-to-child deeming

(b) When an otherwise eligible individual is living with his or her ineligible spouse, the income and resources of the spouse will be “deemed” to be available to the individual

(c) Deeming ends when couple separates - divorce not required

- c. Social Security (SS)/Social Security Disability Insurance (SSDI)
 - i. Childhood Disability Beneficiary Program for individuals
 - (1) Disabled before age 22 and
 - (2) With parents eligible based on their work records who are retired, disabled or deceased
 - ii. Social Security for individuals with work record
 - iii. A growing number of parents over age 65 are caring for adult children with special needs. As parents retire, become disabled or die, their children become eligible to receive their Social Security benefits as follows:
 - (1) If a parent who is eligible for Social Security is retired or disabled, the child receives an amount equal to $\frac{1}{2}$ of the parent's benefit
 - (2) If a parent who was eligible for Social Security dies, the child receives an amount equal to $\frac{3}{4}$ of what the parent was receiving or would have received at retirement
 - (3) If a child is receiving SSI, it can be reduced, dollar for dollar by Social Security. A large Social Security benefit can even disqualify the child for SSI, triggering the loss of Medicaid. The child then must reapply for Medicaid separately
 - (a) SS will not eliminate SSI if the child is receiving more than \$245 in benefits
- d. Medical Assistance and Support
 - i. Medicaid

- (1) SSI recipients receive automatically
- (2) Covers:
 - (a) Medically necessary services
 - (i) doctor visits
 - (ii) diagnostic testing
 - (iii) surgery
 - (iv) hospitalization
 - (v) prescription drugs
 - (vi) dental services
 - (vii) optometry services
 - (viii) occupational and physical therapy
 - (ix) outpatient drug abuse services
 - (x) nursing facility stays
 - (xi) intermediate care facilities for developmentally disabled individuals
 - (xii) adult day health care
 - (b) Medical equipment and supplies
 - (c) In home services:
 - (i) personal care
 - (ii) housekeeping
 - (iii) cooking
 - (iv) transportation to doctors

- ii. Medicare
 - (1) Medical coverage including:
 - (a) Doctors
 - (b) Hospital
 - (c) Skilled care
- iii. How Benefits Work Together
 - (1) SSI eligible for Medicaid
 - (2) SSDI eligible for Medicare

3. Making Decisions About the Future

a. Case Study: Nathan

- i. 18-year-old with autism
- ii. Lives with mom
- iii. Income from work programs, SSI, Social Security (for dad who is deceased)
- iv. Limited personal assets (clothing, TV)
- v. Qualifies for Medicaid
- vi. While Nathan's mom is alive and able-bodied
 - (1) Nathan will continue to live at home
 - (2) Mom will make his medical and financial decisions
 - (3) Nathan's mom is not currently eligible for Social Security

b. Future Situation

- i. Who will make health care decisions?
- ii. Who will make financial decisions?

- iii. Where will he live?
 - iv. How will his medical expenses be paid?
 - v. After Nathan's mom dies, his SSI will increase but his resources will not be sufficient to preserve his quality of live
- c. What Plans Could Nathan's Mom Make?
- i. No plans-Nathan inherits assets under mom's will
 - (1) He will be disqualified from SSI
 - (2) Forced to live on the inheritance and income from Social Security and work programs
 - (3) When inheritance is gone, Nathan will qualify for SSI again
 - (a) Will have no supplemental income to preserve quality of life
 - ii. Disinherit-leaving all assets to Nathan's sister with understanding that she will care for Nathan
 - (1) He will remain eligible for SSI
 - (2) Could become destitute if sister cannot or will not comply with the mom's request
 - (3) Non-SNT Trust
 - (a) Income and principal will be counted as assets and he will lose SSI
 - (4) Third-Party SNT
 - (a) Nathan will keep SSI
 - (b) Benefit from supplemental funds, which trustee will

distribute

- (c) Trust can be structured to help ensure involvement of people important to Nathan
- (d) At Nathan's death, there will be no "payback" to Medicaid
- (5) First-Party SNT-If Nathan has his own assets
 - (a) Works same way as third-party SNT
 - (i) Except at Nathan's death, any funds remaining in trust are subject to Medicaid payback

4. Creating an Effective Plan for Your Child

a. Step 1: Envision Your Child's Future

i. Planning ahead makes a difference

- (1) Where and with whom will your child live?
- (2) What type/level of care will be required?
- (3) Will a guardian be necessary?
- (4) Who else will be involved?
- (5) What kind of lifestyle is desired?
- (6) What unforeseen challenges could arise?

b. Step 2: Create a Memorandum of Intent

i. Should include ample information to help anyone involved in your child's future care understand the child's

- (1) Unique personality
- (2) Strengths
- (3) Challenges

- (4) Needs
- ii. Should provide details about all aspects of the child's lifestyle, including:
 - (1) Medical and rehabilitation needs
 - (2) Recreational activities
 - (3) Educational expectations
 - (4) Work goals
- iii. Example-Residential Directions
 - (1) State that child will one day own a home or
 - (2) Live in caregiver will be given rent-free accommodations in the home
- iv. Memorandum of Intent is not legally binding document
 - (1) Because it can contain information not appropriate for SNT documentation
 - (2) Can enhance trustee's understanding of child's situation and needs
- c. Step 3: Estimate Income and Expenses
 - i. When estimating your child's income consider:
 - (1) Whether you will be receiving Social Security benefits
 - (2) Whether your child will qualify for SSI
 - (a) Have earned income from employment
 - (b) Have unearned income, such as from investment returns
 - ii. When considering monthly expenses, list costs for items under such categories as:
 - (1) Housing

- (2) Care assistance
- (3) Personal Needs
- (4) Education
- (5) Transportation
- (6) Medical/dental
- (7) Food
- (8) Social/recreational

iii. If child's expenses exceed income, this shortfall represents the minimum amount that should be set aside in an SNT

d. Step 4: Utilize a Third-Party SNT

i. May be established by parents:

- (1) Through will
- (2) Through living trust
 - (a) "Living" SNT lets others contribute

ii. SNT offers good way to preserve public benefits while providing the supplemental funds needed for a higher quality of life

- (1) Assets in the SNT do not disqualify the beneficiary from public benefits because they are owned by the trust
- (2) Trustee distributes assets for the benefit of the beneficiary according to strict guidelines

iii. Nathan's parents might have funded the SNT with life insurance and left assets accumulated over their lifetime to their daughter

- (1) Have allowed them to preserve Nathan's quality of life by

maximizing public and private resources

(2) Still meeting other important estate planning goals

(3) Preserving harmony between brother and sister

iv. SNT also can be tailored to meet individual situations, such as the need for an:

(1) Advocate

(2) Care manager

(3) Guardian

v. Carefully consider role of Trustee

(1) Responsibilities are complex and errors can result in child losing public benefits

(2) Responsibilities include:

(a) Investing/Managing assets

(b) Distributing funds

(c) Keeping books

(d) Filing tax returns

(e) Hiring advocates and care managers as needed

(3) It is important to name a successor trustee

(4) Some families also set up a Trust Advisory Panel

(a) Allows members (parents, siblings, advocates) to weigh in on important decisions regarding the trust

vi. Who should be Trustee

(1) Parent *with* professional Trustee

- (2) Professional or corporate Trustee
 - (3) Name successor Trustee
- vii. Other important considerations regarding SNTs
 - (1) Once SNT is in place anyone wishing to bequest assets from a retirement plan, insurance policy and/or will should be told to name the SNT rather than the child as the beneficiary
 - (2) Parents with more than one child who wish to pass assets equitably can provide for the child with special needs by funding the SNT with life insurance
 - (3) Funding an irrevocable SNT removes the transferred assets from the parent's taxable estate
- viii. What Parents Should Do
 - (1) Create Memorandum of Intent
 - (2) Calculate future financial need
 - (3) Establish SNT through will or living trust
 - (4) Fund SNT with life insurance
 - (5) Name SNT as beneficiary of accounts, plans, etc.
 - (6) Reduce taxable estate
- ix. What Your Child Should Do
 - (1) If individual with special needs is competent, at legal age, he or she should put in place critical estate-planning documents
 - (a) Will
 - (b) Medical Power of Attorney

- (c) Financial Power of Attorney
- (2) If individual is not competent, parent or other individual can be named as guardian of both individual and estate
 - (a) Parents must be named as guardians to continue making legal decisions for a child who has attained legal age
 - (b) Role of guardian can be challenging when an individual is developmentally disabled and/or mentally ill
- x. What if Your Child Has Assets?
 - (1) Establish First-Party SNT
 - (a) Provides funds for living expenses not covered by other income sources
 - (b) Maintains eligibility for public benefits
 - (c) Must be established by parent, grandparent, legal guardian or the court
 - (d) State must be reimbursed from the trust for all Medicaid expenses
- xi. Pooled Trusts
 - (1) Established by disability organizations
 - (2) Provides an alternative for families with limited assets
 - (3) Can be established by adult with own assets (who by law cannot establish First-Party SNT)
 - (4) In Pennsylvania one half of the remainder goes to the Commonwealth and one half goes back to the pool

5. Get Started Today

- a. Understand your child's eligibility for public benefits
- b. Make plans for the future to maximize public and private resources for your child's benefit
- c. Make the SNT a key part of your estate plan
- d. Contact a special needs attorney for the assistance you need