



ESTATE PLANNING FOR FAMILIES OF PERSONS WITH DISABILITIES

by
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I. INTRODUCTION

1. Why plan your Estate? No one likes to think about the prospect of death. However, if you postpone planning for your demise until it is too late, you run the risk that your intended beneficiaries – that is, those you love the most – may not receive what you would want them to receive.
2. Definition of Estate Planning: is the process of deciding during your life how you want your property to be distributed after your death and developing the documents to make sure that your decisions are carried out.
3. Why do Estate Planning?: Relative may:
 - (1) Lose vital government benefits;
 - (2) Have to pay more for habilitative services; or
 - (3) Receive money or property that he/she is incapable of managing and be declared legally incapacitated.
2. Who needs specialized estate planning? Only if:
 - (1) Relative is unable to handle finances (totally or partially); and/or
 - (2) Relative is at risk of losing existing or potential government benefits.
3. When should you review your estate plan?
 - (1) Changes in Family Relations:
 - Dissolution of a marriage (divorce/separation)
 - Death of a spouse
 - Marriage of a single person
 - Changes regarding child, grandchild or other beneficiary
 - Birth of a child
 - Death of a child

- Marriage of a child
- Marriage dissolution of a child
- Adoption of a child
- Illness of a child
- Economic changes (good fortune or bad fortune)
- Attitude change towards spouse
- Financial irresponsibility
- Asset values (increase or decrease)
- Changes in insurability (life insurance)
- Changes in employment
- Changes in business interests
- Property acquired in a different state
- Changes in health of a spouse
- Retirement from business or profession

(2) External Changes:

- Changes in laws
- Changes of residence to different state
- Death of executor, trustee, or guardian

II. SPECIAL CONSIDERATIONS IN PLANNING YOUR ESTATE

1. Abilities and needs of relative;
2. **Government benefits** and services that relative is receiving or is likely to receive;
3. **Eligibility standards** for those benefits and services, and effect of various forms of inheritance on those benefits;
4. **Kind of guidance and assistance** your relative will require after your death.

III. RELATIVE'S ABILITIES AND NEEDS

1. Letter of Intent (See: Form in handout).
2. Discuss with your lawyer not only your finances and assets, but also about the needs of your family members, and especially your relative. (See: Estate Questionnaire in handout).

IV. RELATIONSHIP BETWEEN ESTATE PLANNING AND GOVERNMENT BENEFITS

1. **Category One: Social Security and Medicare**

Those available regardless of assets or unearned¹ incomes (e.g., *Social Security Disability; Railroad Retirement, and Medicare*).

2. **Category Two: Supplemental Security Income (SSI) and Medical Assistance (Medicaid)²**

Those available to otherwise eligible persons only if their income and assets remain below a certain level (e.g., *Supplemental Security Income (SSI), Medical Assistance (Medicaid), Food Stamps, General Assistance, and Aid to Families with Dependent Children (“welfare”)*); and

3. **Category Three: Mental Health/Mental Retardation (MH/MR) Benefits**

Those available to otherwise eligible persons regardless of their assets or income, but which may carry a cost based on assessed ability to pay (“liability”)(e.g., *Mental Health and Mental Retardation services, Children and Youth services, Vocational Rehabilitation services*).

V. COMMON ESTATE PLANNING MECHANISM

1. Definitions (in handout folder)

A. How Does Property Pass Upon Death?

(a) *By operation of law:*³

1. Property titled as “Joint Tenants with Right of Survivorship”;
2. “Paid On Death” (POD) accounts;
3. “In Trust For” accounts (ITF)

¹ Gifts, inheritances or interest.

² Medicaid covers doctor’s bills, hospital care, home health care, and medication.

³ Retitle assets to prevent them from vesting directly on disabled relative. A Designation of Beneficiary (DOB) form would have to be completed.

- (b) *By Contract:*⁴
 - 1. IRA designation of beneficiary;
 - 2. Pension Plan beneficiary;
 - 3. Life Insurance beneficiary
- (c) *By Last Will and Testament*

B. Property Passing by a Will

- (a) If you do not make a will, state law will determine who gets your property. A person who dies without a will is said to have died *intestate*, and the property passes by intestacy.
- (b) In PA, if you die intestate and before your spouse and children, your spouse will get a share of your estate (specified by statute), and the remainder will be split equally among your children, regardless of whether they have disabilities or are minors. If you die after your spouse but before your children, your property will be split among your children in equal shares. This can leave a substantial sum of money directly to your relative and jeopardize his/her eligibility for benefits. ***Because of the problems that can be caused by intestacy, it is important for you to make a will.***
- (c) Elements of a valid will:
 - (1) Signed and dated by testator;
 - (2) Witnessed by 2 adults who do not stand to inherit anything under the Will;
 - (3) Notarized;
 - (4) The document must expressly state that it's your Will
- (d) Executor: Collects, maintains, pays debts; and distributes property of the estate.

⁴ Retitle assets to prevent them from vesting directly on disabled relative. A Designation of Beneficiary (DOB) form would have to be completed.

4. Ways to Treat Relative:

(1) Outright Gift:

- a. Is lifetime needs are greater than estate?
- b. Can relative handle finances? If not, Court will appoint a guardian.

(2) Disinheritance:

- a. Good if small estate and not feasible to establish a Trust.

(3) Morally Obligated Gift to Another:

- a. Precatory language (not enforceable right in the relative to property and no duty on the other person to use it in accord with your wishes).
- b. *Positives:* Uncomplicated; little risk to government benefits; no ongoing fees.

C. Trusts

(1) *Inter vivos trust v. testamentary trust*

(2) *Revocable v. Irrevocable:* Terms that indicate whether the Trust can be terminated or revoked.

(3) *Mandatory v. Discretionary:* Describe the manner and frequency of distributions to the beneficiary.

i. **Mandatory:** Prescribed installments or amounts.
Downside: Counts as a resource in determining eligibility for SSI and MA.

ii. **Discretionary:**

1. Called “SNT” or “Supplemental Needs Trusts”

2. A properly drafted discretionary Trust can enable you to provide for the supplemental needs of your relative

without jeopardizing his/her right to Gov. benefits or increase the liability for MH/MR services.

3. *Trust Administration* (Trustee): Should be someone with some fiscal skills and a good understanding of your relative's disability. May be appropriately delegated to a caring sibling or friend who is familiar with the nature of your relative's disability.

- a. Professional Trust Administrators: What if there is no sibling or caring individual to serve as Trustee or parents feel uncomfortable trusting that responsibility upon another child or friend? → Professional Trust Administrators may be designated within the Trust to serve as Trustees. Banks or trust companies routinely charge a nominal fee for their services. Unfortunately, most Trust Administrators are not familiar with the nature and needs of persons with disabilities. These Trust Administrators make excellent investment advisors, but know little about care management issues. As a rule, it is wise that when utilizing a Corporate Trustee, parents also designate a sibling, friend, or agency familiar with the nature and special needs of the relative to serve as Co-Trustee and to provide guidance in regards to the care management of the relative.

- b. *What if the Disabled Relative has no living relatives?* ARC Community Trust of PA: is a 501(c)(3) organization created to service and administer Special Needs Trusts. The Arc Community Trust serves as Trustee for other Special Needs Trusts, including payback, education and common law trusts. The program also provides consultation to attorneys, and information and referrals to clients, families and caregivers. The Arc is a collaboration of The Arcs of Chester, Delaware and Montgomery Counties and works with Arcs all over Pennsylvania. (See: Arc brochure in handout).

4. *Funding SNT*: SNTs may be funded in a number of different ways:

- (1) Share of Estate: Parents may designate a share of their estate to be directed into the SNT for the benefit of the disabled relative;
- (2) Annuities: Parents may purchase annuities which would have designated maturity dates to fund Trusts during their lifetimes for such extraordinary expenses as the costs of participation in a new, private group home.
- (3) Insurance: Parents may purchase life insurance to fund SNTs. The purchase of life insurance is a sure way to guarantee that there will be funds available for the disabled individual notwithstanding any financial crisis which might occur due to illness or other reasons during the lifetime of the parents.
- (4) Pay-back Trust (or self-settled trusts):
 1. Used to protect relative's own assets if relative acquires sudden wealth, e.g., lawsuit or inheritance.
 2. Create a lien against the Trust estate for the reimbursement of Medicaid for relative. Must provide that any assets remaining in the Trust upon relative's death will be paid to DPW, up to the amount paid by Medicaid on behalf of your relative.
 3. Relative must be under 65;
 4. Must be created by either:
 - Parent;
 - Grandparent;
 - Legal guardian; or
 - Court
- (5) Pooled Trust:
 1. Established and managed by a non-profit organization;
 2. Maintained in separate accounts for each beneficiary, but pools all of the accounts for purposes of management and investment.

C. What can the Trustee of a SNT safely pay for?

Unfortunately, the rules in this area are not very clear. As such, the Trustee must proceed with care, since the interpretation by the local public benefits authorities may vary. It is generally agreed, however, that the following distributions for the disabled relative are not counted as income:

1. Uninsured medical expenses. This is true even if the distribution is made directly to your relative, instead of a third party, such as the medical provider.
2. Occasional distributions for items such as a vacation.
3. Purchase of an automobile would probably not be considered income.
4. Occasional miscellaneous purchases such as a health club membership or holiday gifts.
5. An emergency expenditure, such as payment for a large overdue electric bill or oil bill, would probably not cause a problem.

D. What recreational expenses may the Trustee pay for?

1. Paid companions;
2. Gifts
3. Club memberships
4. Movie and Concert Tickets
5. Restaurant meals
6. Vacations and Travel

E. What should the Trustee of the SNT not pay for?

1. *Food, clothing or shelter items (or equivalent):* These items are called “in-kind” income.
2. *Regular Distributions:* The Trustee should avoid making regular distributions from the trust directly to the

disabled relative. For example, the Trustee should not give the relative a monthly cash distribution, as this would probably be considered income for program purposes.

3. *Regular Payments:* Also, the Trustee should avoid making regular payments from the trust for the tenant/relative's benefit. For example, if the Trustee pays the relative's monthly rent or utility charges, then this would probably be considered income.

VI. OTHER PEOPLE'S ESTATE

1. Discuss your Estate Planning with relatives, ex-spouses, siblings, parents, so as not to affect eligibility for government benefits.
2. Educate family about the risks associated with the loss of government benefits if your relative receives an inheritance.

VII. GUARDIANSHIP

1. Minority Guardian: Guardian in Will. Only for minor, not for children over 18 years of age.
2. Court-Appointed Guardian: Guardianship of adult only obtained by the Court, following a hearing, determines that the individual is incapacitated. (See: Guardianship in Pennsylvania handout).
3. Incapacitated Adult Child: Although parents can name someone to act for them if they become incapacitated, they cannot name someone to act on behalf of an incapacitated adult child without court involvement.
4. What is the Definition of an Incapacitated Person? An incapacitated person is an adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that he or she is partially or totally unable to manage his or her financial resources or to meet essential requirements for his or her physical health and safety.
5. Types of Guardianship:
 - a. Guardian of the PERSON

- b. Guardian of the ESTATE
- c. Plenary vs. Limited Guardianships

6. Who May be Appointed a Guardian? A person who does not have interests that conflict with those of the incapacitated person, and

- a. Any qualified individual,
- b. corporate fiduciary,
- c. non-profit corporation, or
- d. county agency may serve as guardian.
- e. a guardianship support agency may be appointed by the Court.

7. Burden of Proof. The petitioner must establish by **clear and convincing** evidence that the disabled relative is incapacitated.

8. What are the Duties of a Guardian of the Person?

- (1) assertion of the rights and interests of the incapacitated person;
- (2) respect for the wishes and preferences of the incapacitated person to the greatest extent possible;
- (3) participation, where appropriate, in the development of a plan of supportive services to meet the person's needs; and
- (4) encouragement of the incapacitated person to participate to the maximum extent of his or her abilities in all decisions that affect him or her, to act on his or her behalf when he or she is able to do so, and to develop or retain his or her capacity to manage his or her personal affairs to the maximum extent possible.

9. Exceptions to the Above-Listed Duties: Unless expressly included in the Court Order, a guardian may NOT have the power to:

- (1) consent on behalf of the incapacitated person to an abortion, sterilization, electroconvulsive therapy, or removal of a healthy body organ;
- (2) prohibit the marriage or consent to the divorce of the incapacitated person;
- (3) consent on behalf of the incapacitated person to the performance of any experimental biomedical or behavioral medical procedure

or to the participation in any biomedical or behavioral medical experiment.

- (4) admit the incapacitated person to an inpatient psychiatric facility or state center for persons with mental retardation; or
 - (5) consent to the termination of the incapacitated person's parental rights.
10. In a situation where an adult disabled individual has not been adjudicated incapacitated by a Court and where that individual is not competent to make financial or health care decisions and he/she has no substantial assets, Mother or Father, cannot make decisions for the Relative, but has a right to ***participate*** in the care and maintenance of the Relative on the basis of being next of kin. The only time it would be an issue is when another relative is challenging the decisions made by the parents; or a Doctor does not agree with the course of treatment being sought by the parents and believes such course to be against the best interest of the Relative.

VIII. OTHER ESTATE DOCUMENTS

1. Durable Power of Attorney for health care and financial affairs: Names an agent(s) to handle financial and personal business matters if you cannot.
2. Living Will (Health Care Directive / Health Care Proxy): Names person(s) to make medical decisions for you if you cannot.

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