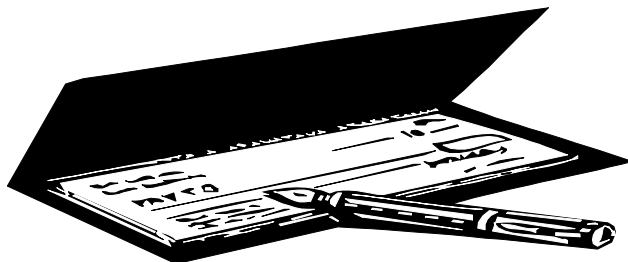


Estate Planning for Families of Persons with Disabilities



Disability Rights Network of Pennsylvania

www.drnpa.org

The Philadelphia Building
1315 Walnut Street, Suite 400
Philadelphia, PA 19107-4798
215-238-8070 (Voice)
215-789-2498 (TDD)
215-772-3126 (Fax)
drnpa-phila@drnpa.org (Email)

1901 Law & Finance Building
429 Fourth Avenue
Pittsburgh, PA 15219-1505
412-391-5225 (Voice)
412-467-8940 (TDD)
412-391-4496 (Fax)
drnpa-pgh@drnpa.org (Email)

1414 N. Cameron Street, Suite C
Harrisburg, PA 17103
800-692-7443 (Voice)
877-375-7139 (TTY)
717-236-0192 (Fax)
drnpa-hbg@drnpa.org (Email)

ESTATE PLANNING FOR FAMILIES OF PERSONS WITH DISABILITIES

I. INTRODUCTION

Estate planning is the process of deciding how you want your property to be distributed during your life and after your death and developing the documents to make sure that your decisions are carried out. While estate planning is important for everyone, it is crucial for families that have members with disabilities. (To avoid confusion, we will refer to these family members with disabilities simply as "relatives.")

If you do not set up an appropriate estate plan, your relative may lose vital government benefits, have to pay more for habilitative services, or receive money or property that he or she is incapable of managing and be declared legally incapacitated. Also, you may be passing up your best opportunity to ensure substitute assistance and guidance for your relative when you are no longer alive to provide it.

Simply because a relative has a disability, however, does **not** automatically mean that you need to be concerned with the special estate planning considerations raised in this booklet. Specialized estate planning is necessary only if your relative is unable to handle finances (either totally or partially) and/or he or she is at risk of losing existing or potential government benefits. This booklet is designed to inform families of persons with disabilities about various kinds of estate plans, to suggest the advantages and disadvantages of each, and to assist you in identifying the kind of information to gather and share with your lawyer. It focuses on the unique problems of estate planning for families with members who have disabilities and is not intended to cover all aspects of estate planning. This booklet, for example, does not discuss the potential tax consequences of the various mechanisms you may employ and choices you may make in planning your estate. **Therefore, it is very important that you speak to an attorney or other qualified professional about the tax consequences of actions you may be considering.**

Support for the publication and distribution of this booklet has been generously provided, in part, by the Edith L. Trees Charitable Trust.

You should also know that an estate plan can be changed at any time (other than irrevocable trusts). It is usually a good idea to review your estate plan every year or two to make sure it will still achieve those goals that you have set. You may also want to contact your lawyer and ask him or her if any recent changes in the law have occurred that affect your estate plan. In addition, you should review your estate plan if a major change has occurred to you or your family, such as divorce, re-marriage, or death of any immediate family member, especially if the person who dies is your relative with a disability. If you have any questions or wish to make any changes, you should contact your lawyer.

Regardless of whether you choose to create an estate plan for your relative at this time, you might want to consider writing a **Letter of Intent**. This is a non-legal document that reflects your relative's current services, needs, likes and dislikes, trusted people, future plans, and other information. The Letter of Intent is designed to communicate the things that you know about your relative that others might not and that are important to assure that the choices made for your relative reflect his needs and wishes. You can contact various community service organizations for more information about Letters of Intent. One model used is available at www.communitytrustpa.org.

PLEASE NOTE: The information contained in this booklet is intended to be general in nature and should not be construed as legal advice applicable to any specific situation. WE STRONGLY URGE YOU TO CONSULT WITH AN ATTORNEY IF YOU HAVE QUESTIONS ABOUT OR WANT TO PLAN YOUR ESTATE. Also, note that this booklet discusses estate planning under Pennsylvania law as of February 2006. Your attorney should check to see whether the law has been changed since that date, and, if you move to another state, we recommend that you review your estate plan with an attorney in that state to ascertain whether any changes in your estate plan are necessary.

II. SPECIAL CONSIDERATIONS IN PLANNING YOUR ESTATE

In planning your estate, you must carefully consider:

- * the abilities and needs of your relative;

- * the government benefits and services that your relative is receiving or is likely to receive in the future;
- * the eligibility standards for those benefits and services and the effect of the various forms of inheritance on that eligibility; and
- * the kind of guidance and assistance (if any) that your relative will require after your death.

The information contained in the rest of this booklet will help you evaluate these areas and arrive at an estate plan that will meet your needs and those of your family.

III. YOUR RELATIVE'S ABILITIES AND NEEDS

When you meet with your lawyer, you should be prepared to share and discuss information not only about your finances and assets, but also about the needs of your family members, and especially the needs of your relative. Specifically, with regard to your relative, the planner will need to know:

- * the nature of the disability;
- * specific abilities and inabilities (for example: driving, balancing a checkbook, making purchases at a store, reading, feeding, and self-care);
- * educational history and achievement level;
- * work and salary history;
- * the financial picture (assets and income), including both present and likely future entitlements;
- * the individual's legal status (adjudicated incapacitated? court-appointed guardian? representative payee?);
- * the current and projected future life style, including living and work situations; and
- * the kind of assistance, if any, likely to be needed in managing financial and personal affairs.

If at all possible, you should discuss these matters with your relative before providing the information. This discussion will help you to develop a realistic and mutually agreeable life plan to be supported by your estate arrangements and will help to avoid many problems later.

IV. THE RELATIONSHIP BETWEEN ESTATE PLANNING AND GOVERNMENT BENEFITS

Many individuals with disabilities receive government benefits of one kind or another, and it is unlikely, unless you have very considerable wealth, that you will want to substitute your own estate assets for public funding. Rather, you will probably want your estate plan to maximize available government funding and services while using estate funds to supplement them. It is important to consider both the government benefits for which your relative is currently eligible as well as the benefits that will become available at a later date (e.g., upon your retirement or death).

It is essential for you to understand the eligibility requirements for the major governmental sources of assistance to persons with disabilities and the effect of various forms of inheritance on those sources. There are three general categories of government benefits:

- * those available regardless of assets or unearned incomes (e.g., Social Security Disability, Railroad Retirement, and Medicare);
- * 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 Temporary Assistance to Needy Families (the last two types of benefits often are referred to as "welfare")); and
- * those available to otherwise eligible persons regardless of their assets or income, but which may carry a cost based on assessed ability to pay (e.g., Mental Health and Mental Retardation services, Children and Youth services, Vocational Rehabilitation services).

Overall, **it is important to plan your estate so as not to unintentionally disqualify your relative for government benefits or increase liability for services** as well as to assure, if your relative requires assistance, that a mechanism is in place for financial management. The impact of each of the three categories of government benefits on estate plans is discussed below.

A. Category One: Social Security and Medicare

Estate dispositions will have no effect on benefits, such as Social Security Disability and Medicare, that are available regardless of assets and unearned income.

Social Security is a federal insurance program that provides monthly cash benefits to insured workers or their dependents when the worker retires, becomes disabled, or dies. If you are employed and covered by Social Security and retire, become disabled, or die, your children will receive monthly payments based on your earnings record until they are 18 (or 22 if they attend school full-time). If you have an unmarried child with a disability that began prior to age 22, he or she will be eligible to receive payments as long as that disability lasts, regardless of his or her age at the time of your retirement, disability or death. If your relative was employed and covered by Social Security, he or she may qualify for benefits based on his or her own earnings record or that of his or her spouse.

Your relative will be considered to have a disability for the purpose of Social Security eligibility if he or she has a physical or mental impairment that prevents him or her from doing substantial gainful work, and the impairment has lasted or is expected to last at least 12 months. Many sheltered workshop employees are eligible for Social Security disability payments because they do not earn enough money to be considered as doing substantial gainful work. Also, disability payments may continue for a trial period after a new job or training program has begun.

Social Security disability benefits are not based on financial need and are not affected by unearned income (for example, gifts, inheritances, or interest) or by the assets of the person with a disability. You can, therefore, plan your estate without having to worry about disqualifying your relative from eligibility for Social Security benefits.

Anyone who has received Social Security benefits for at least two years, regardless of his or her age, is also eligible for Medicare. Medicare can help pay the cost of hospital care, certain follow-up services, and physician's services, but it does not cover all hospital and physicians' costs and is subject to an annual deductible, which must be paid before benefits begin. You may want to purchase supplemental private medical insurance (sometimes called Medigap or 65-Special insurance) for your relative to cover the additional charges. Before you do, be sure to determine whether your relative is also eligible for Medical

Assistance (Medicaid), discussed in the next section. Additional information on Social Security and Medicare is available from your local Social Security office or at the Social Security web site, www.ssa.gov.

B. Category Two: Supplemental Security Income (SSI) And Medical Assistance (Medicaid)

The second category of government benefits -- those available to otherwise eligible persons only if their income and assets remain below a certain limit -- can be lost entirely if a person with a disability has too many assets or too much income (either earned or unearned). Of the government benefits in this category, Supplemental Security Income (SSI) and Medical Assistance (Medicaid) are the most common and the most important.

SSI is a federal program that provides monthly cash payments to individuals with disabilities who have little income and few assets. SSI is important both for the financial support it provides and because eligibility for SSI is used as a touchstone for eligibility for other services. For example, eligibility for even the minimum monthly SSI payment renders a person eligible for full Medical Assistance benefits and various rehabilitative programs and social services.

The maximum SSI monthly payment amount changes from time to time and is determined by the federal and state governments. SSI is designed to supplement whatever income is available from other sources and to bring it up to that maximum amount. Therefore, it is possible for a person to be eligible both for Social Security disability payments and for SSI payments. SSI is administered by the Social Security Administration, but it is not the same as the Social Security disability program. While the criteria for determining whether a person has a disability are the same in both programs, a person must have no more than a very limited amount of assets and a limited income to be eligible for SSI. Because an individual's unearned income and assets are considered in determining eligibility for SSI, gifts, inheritances and trust assets/income may disqualify a person from receiving SSI. Therefore, your relative's continued eligibility for SSI may be an important consideration in planning your estate.

Medical Assistance (Medicaid) benefits are even more important to people with disabilities than SSI payments. Medicaid is a program of medical insurance administered by the state and jointly funded by the state and federal governments. Medicaid provides beneficiaries with basic medical care (such as doctors' visits, dental services, drugs, therapies, home health services). Medicaid can also fund an array of services and benefits that enable people with disabilities to remain in their own homes and communities (including residential services, case management, habilitation, and vocational services). If a person with a disability is eligible for both Medicare and Medicaid, Medicaid will pay the Medicare deductible. This extremely valuable medical benefit, like SSI, can be lost if a person has too many assets or too much earned and unearned income, and therefore careful estate planning is critical to preserve Medicaid eligibility.

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

The third category of benefits are those provided on an ability-to-pay basis. They are available to otherwise eligible people regardless of their assets or income, but people without assets or income get them for free, and people with assets and income are charged according to their ability to pay. The amount that a person is expected to pay for these services is called **liability**. The most common example of this kind of benefit is MH/MR services. In Pennsylvania, parents have no liability for MH/MR services provided to their children over age 18, but those individuals have a liability based on their own assets and income. The amount of the liability is determined by the regulations of the Department of Public Welfare. In planning your estate, you should carefully consider whether an inheritance will increase your child's liability for MH/MR services.

V. COMMON ESTATE PLANNING MECHANISMS

The property a person owns at the time of death is called his or her **estate**. You have the right to decide who will become the owner of your estate after your death. Usually, an estate consists of real estate (called **realty**) and cash, bank accounts, stocks, bonds, and personal property, such as jewelry and automobiles (called **personalty**). The term "estate

planning," though, can also include decisions to distribute your assets prior to death. Effective estate planning ensures that your estate will be distributed in accordance with your wishes after your death and can be a valuable tool in providing for and helping your relative.

The estate planner has available an entire arsenal of different options that can be used to accomplish your purposes. In the following sections, we will review some of these options and point out some of the advantages and disadvantages of each, so that you, working with your attorney, can choose the ones that best meet your needs.

A. Property Passing Outside the Will

Not all property is distributed according to the provisions of a will. In fact, it is quite common for a large percentage of a person's property to be transferred without regard to a will.

For example, any property that you **jointly own** with another person (bank accounts, real estate, etc.) is subject to the "right of survivorship." This means that the property will automatically belong to the other person upon your death, regardless of any provisions in your will. Similarly, any bank account or other property you hold "**in trust for**" another person will automatically belong to that person on your death. **If you have concluded that it would be undesirable to leave substantial cash outright to your relative because of the potential loss of benefits described above, you should avoid establishing joint accounts with your relative or "in trust for" accounts with your relative as a beneficiary.**

Life insurance benefits also do not usually pass under your will, but instead are distributed in accordance with the terms of the life insurance policy to the named beneficiary. Therefore, **naming your relative with a disability as a beneficiary of your life insurance has the same effect as making a direct gift to him or her and may need to be avoided in order to preserve eligibility for government benefits.** As alternatives, you can name beneficiaries with instructions that they use the insurance for your relative with a disability (see the section on Morally Obligated Gifts, below), or you can create a trust for

the benefit your relative that will include the insurance proceeds (see the section on Trusts, below).

B. Property Passing By A Will

A will is a written legal document signed by an individual that determines who will get his or her property after his or her death. 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**.

Each state has its own intestacy law. In Pennsylvania, if you die 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. Again, this can leave a substantial sum of money directly to your relative and jeopardize his or her eligibility for benefits. **Because of the problems that can be caused by intestacy, it is important for you to make a will.**

For a will to be valid, it must be **executed** -- signed and usually witnessed according to formal procedures required by law. You should therefore consult a lawyer when you plan to draw up a will.

You can change your will at any time prior to your death, following the strict procedures required by law. To make certain that the procedures are being followed correctly, you should not change your will without the aid of a lawyer. You should review your will every time there is a marriage, death, birth, adoption, or divorce in your family to see if it still meets your needs.

Your will should name an **executor** of your estate. (A female executor is sometimes called an **executrix**). The executor is responsible for collecting and maintaining the property, paying the debts of the estate out of that property, and, under the supervision of the court, distributing the property in accordance with the will. The court will appoint as

executor whomever you name in your will. You can appoint one or more individuals or corporate entities, such as banks, to be your executor(s). Once the estate is distributed, the executor's job is over. There are several ways you can treat a relative with a disability in your will.

1. Outright Gift

An outright gift or "bequest" to your relative will count as available resources to him and can result in his loss of eligibility for government benefits or increased financial liability for those benefits. You must decide whether the assistance potentially available to your relative through your estate is sufficient to make government benefits unnecessary to meet his or her lifetime needs. To do this wisely, you must review the value of your estate, the needs of your relative, the degree and type of care he or she will require, his or her other sources of income, and the needs of your spouse and other children.

In addition to the undesirability of losing valuable benefits, it is equally undesirable in most cases to leave valuable assets to an individual unable to handle them. In such a case, a court is likely to appoint a guardian for that individual's estate, person, or both. The drawbacks of guardianship are discussed below.

An outright gift by will to your relative is desirable only when he or she is able to manage his or her fiscal affairs and when government benefits will not be jeopardized by, or are far outweighed by, the bequest. Direct gifts do not allow much room to maneuver to avoid an undesirable outcome.

2. Disinheritance

If the lifetime needs of your relative are too great to be provided for by your estate, government benefits will be required. One way to insure that such benefits will not be jeopardized is by disinheritance, *i.e.*, not providing your relative with any of your property either by outright gift or by a trust. The law allows a parent to disinherit a child. Disinheritance may be a good option if the estate is small, and it is not feasible to establish a trust. However, disinheritance is too often the only option considered.

Even if you choose not to leave anything of significant monetary value to your relative, you may wish to leave a gift of some sentimental or personal significance. In addition, if you choose disinheritance, your lawyer should consider adding explicit language to make it plain that: (1) your choice was deliberate (and not unintentional or an oversight); (2) that your choice was not the result of malice but, to the contrary, was the result of a careful assessment of your relative's best interests and, specifically, the impact of a direct bequest on your relative's government benefits; and (3) if applicable, that you have made alternative arrangements for your relative.

3. Morally Obligated Gift to Another

Another simple, inexpensive, and frequently used method is to leave property to a person other than the relative with instructions that he or she should use it to benefit that relative. This is called a **morally obligated gift**, and the instructions are called **precatory language**.

This estate planning method, however, has several significant drawbacks. This method creates no legally enforceable right in the relative to the property and no enforceable duty on the other person to use it in accordance with your wishes. The other person must pay any taxes on income arising from the property and may feel obligated to use his or her own assets to care for the relative if the inheritance is insufficient. The inheritance legally belongs to the other person, may be able to be reached by that person's creditors to satisfy debts or by a spouse in a divorce proceeding, and, when that person dies, is a part of his or her estate. Moreover, if that person dies or becomes disabled during the relative's lifetime, your relative will have no guarantee of continuity of care.

On the positive side, a morally obligated gift is uncomplicated, poses little risk to your relative's government benefits, and entails no ongoing fees. If you are confident of the person you choose to carry out your wishes, this option may be viable.

C. Trusts

A trust is a legal document that allows property to be held and managed by one person (the trustee) for the benefit of another (the beneficiary). A properly drafted trust can both protect your relative's eligibility for benefits as well as provide for fiscal management without the need for guardianship.

Unlike the person holding a morally obligated gift, a trustee cannot use the trust for his or her own benefit, but only for the benefit of the beneficiary. When the trust ends (usually upon the death of the beneficiary), any assets remaining in the trust are distributed as provided in the trust.

A trust is a very flexible arrangement, and the terms of the trust are defined almost exclusively by the person setting it up. A trust can be created during your lifetime (an “**inter vivos trust**”) or can be created at your death by your will (a “**testamentary trust**”). Also, a trust can be created during your lifetime but not be funded until your death with, for example, the proceeds from your life insurance policy. Trusts may have more than one beneficiary and/or more than one trustee.

A trust can be either **revocable** or **irrevocable** -- terms that indicate whether the trust can be terminated. The trust instrument may identify certain circumstances under which the trust will terminate or identify certain persons with authority to decide to terminate the trust. Such a trust is termed revocable. An irrevocable trust is one that cannot be terminated other than by the distribution of all assets according to the terms of the trust instrument.

A trust also can be **mandatory** or **discretionary**. A **mandatory trust** requires the trustee to make disbursements to the beneficiary, usually in prescribed installments or amounts. While this kind of trust assures that your relative will receive specific benefit from the trust, mandatory trusts generally count as a resource in determining eligibility for SSI and MA.

A **discretionary trust**, on the other hand, allows the trustee to determine what amount of the trust principal and/or income will be distributed to the beneficiary, when it will be distributed, and to whom it will be distributed (if the trust names more than one beneficiary).

Unlike a mandatory trust, which can be counted as a resource and therefore disqualify your relative from MA and SSI, a properly drafted discretionary trust can enable you to provide for the supplemental needs of your relative without jeopardizing his or her right to government benefits or increasing his or her liability for MH/MR services.¹ Such trusts often are called "supplemental needs trusts." **It is imperative, however, that the trust be carefully drafted to assure that the trust does not jeopardize your relative's right to SSI or MA or to increase his or her liability for MH/MR services.**

A discretionary trust can be written to accomplish practically any legal purpose. Because the trustee in a discretionary trust often has a lot of decisions to make about the personal needs of your relative, great care should be taken in choosing the person who will serve as trustee. Money management ability alone may not be enough, so you may wish to appoint a person with some fiscal skills as well as a good understanding of your relative and his or her disability. In addition, there are non-profit organizations available that can act as the trustee and will manage, invest, and disburse trust funds according to your wishes.

A trust can be used not only as a means to provide your assets to your relative without jeopardizing government benefits, but also as a means to protect your relative against loss of government benefits if he has his **own** assets. If your relative acquires sudden wealth as a result of a lawsuit settlement, legal judgment, or inheritance, or if he has income from earnings or investments, federal and Pennsylvania law may exempt such sums from counting as resources and income for purposes of determining Medicaid eligibility if those sums are placed in one of the following types of trusts:

Pay-back Trust (also known as a "special needs trust")

- * Your relative must be under age 65.

¹ The one exception to this is trusts created by a person with his assets for the benefit of his spouse. Federal Medicaid rules basically treat such a trust as a resource available to the spouse for whose benefit the trust was created.

- * The trust must be created by a parent, grandparent, legal guardian, or the court.²
- * The distributions from the trust must be solely for the benefit of your relative and any expenditure from the trust must have a reasonable relationship to the needs of your relative.
- * The trust must provide that any assets remaining in the trust upon your relative's death or the termination of the trust will be paid to Pennsylvania, up to the amount paid by Medicaid on behalf of your relative.

Pooled Trust

- * A pooled trust is one established and managed by a non-profit association that maintains separate accounts for each beneficiary but that pools all of the accounts for purposes of management and investment.
- * The trust must provide that any amounts remaining after the death of your relative will remain in the pooled trust (for the benefit of other persons with disabilities) or be paid to Pennsylvania, up to the amount paid by Medicaid on behalf of your relative. No more than 50 percent of the amount remaining in your relative's pooled trust account, however, may be retained by the trust without an obligation to reimburse Pennsylvania for Medicaid spending.

The rules governing these types of trusts can be complex, and your attorney should review them carefully before drafting such a trust.

Various local disability organizations provide services to families to educate them about estate planning options, provide services to administer special needs trusts, and operate pooled trusts. These organizations include:

- * ARC Community Trust of Pennsylvania, 610-265-4700, www.arccommunitytrustpa.org.
- * The Family Trust, 412-995-5000, www.achieva.info/thefamilytrust
- * Berks County Community Trust, 610-603-0227, www.berksiu.org/arc/trust/htm

VI. OTHER PEOPLE'S ESTATES

Often, friends and relations of your relative may wish to help by leaving him or her something in a will or by giving gifts. These bequests and gifts, while well-intentioned, can

² This type of trust cannot be created by your relative (who owns the assets) and, therefore, unless your relative is a minor some type of limited financial guardianship may be necessary to create this trust.

affect eligibility for benefits in the same way that they would if they came from you. Be especially careful about joint accounts and "in trust for" accounts or savings bonds in a relative's name.

Once you have decided the best way to provide for your relative, it is very important that you make that decision known to others so that such persons do not take action that is inconsistent with your estate plan. For example, if you have structured your estate in order to avoid having your relative exceed the eligibility limits for SSI and Medicaid, you do not want your former spouse, sibling, parent, or a close friend to leave your relative money or other assets that will jeopardize that eligibility.

VII. GUARDIANSHIP

A parent may designate a guardian for a minor in his or her will, and a court will appoint that designee absent unusual circumstances. In contrast, guardians are not assumed to be necessary for a person over age 18, regardless of whether that person has a disability. When an individual reaches the age of 18, regardless of any functional limitations or abilities, she or he is presumed to have the legal right to make decisions on her or his own behalf. In Pennsylvania, guardianship of an adult can be obtained only if a court, following a hearing, determines that the individual is **incapacitated**.

An adult will be determined to be incapacitated if his ability to receive and evaluate information effectively and to communicate decisions in any way is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical safety. To determine whether the person meets this standard, a court must examine: the nature and extent of the person's disabilities, the person's adaptive behavior and social skills, the services utilized to meet the person's physical and financial needs, the types of assistance the person needs, and whether less restrictive alternatives would be appropriate.

If the court determines that the person is incapacitated and needs guardianship services, it must determine the scope of the guardian's duties (i.e., whether the guardianship

should be limited or plenary) and the duration of the guardianship. The court will prefer to appoint a limited guardian if the person is partially incapacitated.

While guardianship is one means of providing assistance to an individual with disabilities, it has numerous disadvantages, and your relative may find genuine security without the need for a guardian through appropriate education, vocational training, community services, financial benefits, advocacy organizations that secure and monitor the services to which he or she is entitled, and the use of trustees and representative payees.³ Additionally, you often can avoid the need for a fiscal guardian through proper estate planning.

If you want additional information about guardianship, you can request a copy of a booklet titled "Guardianship in Pennsylvania" from the Disability Rights Network of Pennsylvania at the addresses and phone numbers listed at the end of this booklet.

VIII. LEGAL ASSISTANCE AND ADVICE IN ESTATE PLANNING

If you do not have an attorney, ask other parents or your local advocacy group to refer you to one experienced in preparing estate plans for persons who have relatives with disabilities, or join with other parents to locate an attorney in your community who is willing to become familiar with your unique estate planning needs. You can also contact the Pennsylvania Bar Association (800-692-7375 or 717-238-6715) for a list of lawyers who have received training in this area of the law.

When you discuss estate planning with your lawyer, you should bring this booklet with you for your lawyer's information and use. Your lawyer may also obtain a copy of

³ A representative payee is a friend or relative appointed, when necessary, to manage SSI and Social Security disability payments. Unlike a guardian, a representative payee can be appointed without having to go to court. You can apply to become your relative's representative payee or to have someone else appointed by simply providing the Social Security Administration with evidence that your relative is not capable of managing his or her income without help. The representative payee must spend the checks for the benefit of the recipient and must account to the Social Security Administration for how the funds are spent. By using a representative payee, you can insure that the benefits are safely managed without having to secure a legal guardian. Note, however, that a representative payee is empowered to deal only with SSI or Social Security Disability funds and not with any other assets.

"Estate Planning for Families of Persons with Disabilities (Lawyers' Edition)" (discussing the legal aspects and ramifications of estate planning in this area and the relevant case law) by contacting the Disability Rights Network of Pennsylvania at the addresses and numbers listed at the end of this booklet.

In addition, you should try to bring the following materials and information to your attorney's office on the first visit:

- * A list of all assets;
- * The identities of the persons holding title to the assets;
- * The present value of the assets;
- * Any indebtedness or encumbrances upon those assets;
- * Information on all insurance policies, including (a) who owns each policy; (b) whose life is insured by each policy; (c) the face value of each policy; (d) the cash surrender value of each policy; and (e) the beneficiaries of each policy.
- * The designated beneficiaries on any assets, including contingent beneficiaries; and
- * Copies of all financial documents, passbooks, savings accounts, IRA's, C.D.'s, etc., if possible.

Listed at the end of this booklet are some relevant legal citations of which your lawyer should be aware.

IX. CONCLUSION

As a parent, you have acted as your relative's protector, teacher, and advocate. Your relative may very well have needs in these areas that will continue throughout his or her adult life. In the normal course of events, you will not always be there to fill those needs. By carefully assessing what those needs are, maximizing your relative's competence and independence while you are still here to do it, increasing your relative's interaction with the family and community, and developing a solid estate plan with your attorney, you will be giving your relative the best chance for a successful and happy life.

Dated: February 2007

Relevant Cases

Commonwealth Bank and Trust Co., N.A. v. Commonwealth, Dept. of Public Welfare, 528 Pa. 482, 598 A.2d 1279 (1991).

Estate of Rosenberg v. Department of Public Welfare, 545 Pa. 27, 679 A.2d 767 (1996).

In re Estate of Glesenkamp, 378 Pa. 635, 107 A.2d 731 (1954) (capacity of testator with disabilities to make a valid will).

Lang v. Commonwealth, Dept. of Public Welfare, 515 Pa. 428, 528 A.2d 1335 (1987).

Lewis v. Magee Women's Hosp. of UPMC, 67 Pa. D. & C.4th 362 (Ct. Com. Pls. 2004).

Shaak v. Pennsylvania Dep't of Public Welfare, 561 Pa. 12, 747 A.2d 883 (2000).

Snyder v. Commonwealth, Dept. of Public Welfare, 528 Pa. 491, 598 A.2d 1283 (1991).

Stoudt v. Commonwealth, Dept. of Public Welfare, 76 Pa. Commw. 576, 464 A.2d 665 (1983) (validity doubtful after *Lang*).

Vecchione v. Wohlgemuth, 377 F. Supp. 1361 (E.D. Pa. 1977), *aff'd*, 558 F.2d 150 (3d Cir.), *cert. denied*, 434 U.S. 943 (1977).

Relevant Statutes

42 U.S.C. § 1396p(c)-(d) (Medicaid provisions relating to transfers of assets and trusts).

20 Pa. Cons. Stat. Ann. § 5501 *et seq.* (Pennsylvania guardianship law).

62 Pa. Cons. Stat. Ann. § 1414 (special needs trusts).

62 Pa. Cons. Stat. Ann. § 1965.1 *et seq.* (pooled trusts)

Relevant Articles:

Comment, *Supplemental Needs Trusts: A Means to Conserve Family Assets and Provide Increased Quality of Life for the Disabled Family Member*, 32 Duquesne L. Rev. 555 (1994).

Effland, R., and Heckt, M., "Trusts and Estate Planning," *The Mentally Retarded Citizen and the Law*, 116-143 (Kindred, M., Cohen, J., Penrod, D., and Shaffer, T., eds.; Freedom Press, 1976).

Gilfix, M., *Special Trusts for Asset Preservation Planning*, 132 Trusts & Estates 62 (Feb. 1993).

Frolik, L., *Discretionary Trusts for the Disabled Beneficiary: A Solution or Trap for the Unwary*, 46 U. Pitt. L. Rev. 335 (1985).

Frolik, L., *Estate Planning for Parents of Mentally Disabled Children*, 40 U. Pitt. L. Rev. 305 (1979).

Hodgson, R., *Guardianship of Mentally Retarded Persons: Three Approaches to a Long Neglected Problem*, 37 Albany L. Rev. 407 (1973).

Nemore, P., Regan, M. and Perkins, J., *Just When You Thought You Had Learned The Rules, They Went and Changed Them: OBRA-93 Provisions Concerning Medicaid Transfers of Assets, Treatment of Certain Trusts, and Estate Recoveries*, 27 Clearinghouse Review 1199 (Feb. 1994).

Scales, K.C. and Anderson L.M., *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, 74 Pa. Bar Ass'n Q. 169 (2003).

Schlesinger, S.J. and Scheiner, B.J., *OBRA '93 Makes Sweeping Changes in Medicaid Rules*, 21 Estate Planning 74 (1994).

Tobin, P., *Medicaid Basics and a Review of the Amendments to Medicaid Law under OBRA '93*, 231 P.L.I. 203 (1994).

Van Dolson, R.D., *Medicaid Eligibility Rules and Trusts for Disabled Children*, 133 Trusts & Estates 51 (Apr. 1994).

Weinberg, R., *2 Pennsylvania Estate Planning and Drafting*, Ch. 22, § 22.8.3 (Suppl. 1998).