

Estate Planning for Families of Persons with Disabilities

Lawyer's Edition



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 (TTY)
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 (TTY)
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
LAWYER'S EDITION

I. INTRODUCTION

The estate planning client who has a relative with a disability typically wants to use the estate plan to achieve several goals.¹ First, like all estate planning clients, he wants to distribute assets. Additionally, though, he wants to provide continuing support and personal guidance for his relative as well as to assure that his relative's eligibility for government benefits are not jeopardized and that his relative's financial liability for government services is not increased. This booklet reviews the various types of financial and estate planning devices that can be used to accomplish these goals. Because it is important to understand how properly drafted trusts can be used to protect the eligibility of a person with disabilities for means-tested benefits (such as Supplemental Security Income and Medical Assistance), this booklet focuses in particular on federal and Pennsylvania law that impacts trusts for people with disabilities.

PLEASE NOTE: THE INFORMATION CONTAINED IN THIS BOOKLET IS INTENDED TO BE GENERAL IN NATURE AND IS NOT INTENDED TO CONSTITUTE LEGAL ADVICE APPLICABLE TO SPECIFIC FACTUAL SITUATIONS.

II. GATHERING INFORMATION ABOUT THE PERSON WITH DISABILITIES

Every good estate planner begins by gathering information about the client's finances, assets, and family. If that family includes a relative who has a disability, the planner will need to have detailed information about that individual as well. This is necessary both to insure that the plan developed will be tailored to accomplish the testator's wishes and to

¹ The term "client" is used to identify the person whose property is to be distributed by the estate plan and the term "relative" is used to identify the client's family member who has a disability.

avoid doing unnecessary and unintentional harm to the relative by reducing or eliminating his eligibility for governmental benefits or increasing his financial liability for government benefits. Specifically, the planner will need to know:

- * the nature and effects of the relative's disability;
- * the relative's specific abilities and inabilities (*e.g.*, driving, balancing a checkbook, making purchases at a store, reading, feeding and dressing self);
- * the relative's work and salary history;
- * the financial picture of the relative (assets and income), including both present and likely future entitlements;
- * the relative's legal status (Has he been adjudicated incapacitated and a guardian appointed for him? Does he have a representative payee for Social Security or Supplemental Security Income benefits?);
- * the relative's current and projected future lifestyle, including living and work situations; and
- * the kind of assistance, if any, the relative is currently receiving and is likely to need in managing financial and personal affairs.

The planner should encourage the client to discuss these matters with the relative, if feasible, before developing an estate plan. This discussion will help the client to formulate a realistic life plan to be supported by the estate arrangements and, because the plan is one that is agreeable to the relative, the pre-planning discussion should help to avoid many problems later. The planner may also wish to meet with the relative directly, if the client agrees.

III. GOVERNMENT BENEFITS

Many individuals with disabilities receive government benefits of one kind or

another, and it is rarely the intention of the client to substitute private assets for public funding. Rather, it is the usual function of the estate plan to retain and maximize the available government funding and services while using the client's property to supplement those benefits to the extent necessary. It is, therefore, essential to understand the eligibility requirements for the major sources of governmental assistance to persons with disabilities.

The first category of benefits consists of those that are available without charge to persons with disabilities regardless of assets or unearned incomes. The most common types of these benefits include Social Security (including Social Security Disability), Railroad Retirement, veteran's benefits, and Medicare. Since these benefits are not dependent on the recipient's financial status and the recipient is not charged for the services, estate dispositions will have no impact on the availability of these benefits to the relative.

A second category of benefits consists of those available to otherwise eligible persons only if their income and assets remain below a certain level, i.e., benefits which are "means-tested." The primary types of these benefits include Supplemental Security Income (SSI), Medical Assistance (Medicaid), Food Stamps, General Assistance, and Temporary Assistance to Needy Families. SSI and Medicaid are the most frequently encountered means-tested benefits for people with disabilities. SSI provides monthly cash payments to persons who have disabilities and low incomes. To be eligible for SSI benefits, a person must meet disability standards prescribed in federal regulations and have income/resources that fall below federally-prescribed limits.

Medicaid can be even more important than SSI for people with disabilities. Medicaid provides beneficiaries with health insurance that includes not only basic medical care (such as doctors' visits, dental care, drugs, therapies, and home health services), but also can

provide an array of services and benefits that enable people with disabilities to remain in their own homes and communities (such as case management, habilitation, residential services, and vocational training). Individuals can become eligible for Medicaid in a variety of ways. By far the most common way for people with disabilities to secure Medicaid benefits is through eligibility for SSI benefits. Regardless of the way in which a person becomes eligible for Medicaid, he may lose his benefits if his income or resources exceed federal limits.² Thus, careful estate planning is critical to maintain SSI benefits, Medicaid benefits, and other means-tested benefits.

The third category of benefits consists of those available to otherwise eligible persons regardless of their assets or income, but which may carry a cost (usually called "liability") based on ability to pay. This category of benefits includes mental health/mental retardation (MH/MR) services, children and youth services, and vocational rehabilitation services. Of these services, MH/MR services often are the most important.

As noted above, many MH/MR services are funded by Medicaid. If a person is eligible for Medicaid, he will not be assessed separate liability for those services. Liability for MH/MR services that are not funded by Medicaid varies depending on the type of service.³ Liability for community-based MH/MR services provided by the counties (*e.g.*, community residential programs, vocational programs, supported work programs) is based only on an assessment of income. *See* 55 Pa. Code § 4305.31-4305.44. In contrast, liability

² For example, a person with a disability who receives Social Security Disability (SSD) benefits may still be eligible for Medicaid. Such an individual would lose his Medicaid benefits, but not his SSD (which is not means-tested) if his income or resources exceed the federal Medicaid limits.

³ Liability for MH/MR services can be assessed against the individual with disabilities, his or her spouse, and, if the person is under 18, his or her parents. 50 Pa. Cons. Stat. Ann. §§ 4501-4502.

for services in state MH/MR facilities is based on an assessment of both income and assets, *see* 55 Pa. Code §§ 4310.7-4310.13, though neither assets in irrevocable and court-ordered burial accounts that can be released only upon the individual's death nor assets in trusts that are "legally restricted from invasion of the principal amount for care and maintenance" will count as assets for purposes of assessing liability for such services (though income distributed from a trust could be assessed in determining liability). 55 Pa. Code § 4310.12(1)-(2).⁴

IV. SOME COMMON ESTATE PLANNING MECHANISMS

The estate planner has available an entire arsenal of estate devices and forms that can be used to effectuate the client's purpose. The choice of which of these to use will depend not only on the needs of the relative with disabilities but also on the needs of other persons that the client wants to benefit and on any other intended functions of the estate plan. Leaving aside for the moment these other considerations and concentrating only on the needs of the relative with disabilities, the following are some guidelines for choosing among the available options.

A. Property Passing Outside the Will

Sometimes, the client (even before developing an estate plan) may establish joint accounts with the relative or "in trust for" accounts that name the relative as the beneficiary. Since that property will automatically pass to the relative upon the client's death regardless

⁴The Pennsylvania Supreme Court questioned the continued vitality of 55 Pa. Code § 4310.12(2), which permits the Commonwealth to exclude only those trusts that are "legally restricted from invasion of the principal amount for care and maintenance." *Lang v. Commonwealth, Dep't of Public Welfare*, 515 Pa. 428, 528 A.2d 1335, 1338-39 n.2 (1987). As discussed below, the Court in *Lang* held that a discretionary support trust (one that permits a trustee to provide for the support of a beneficiary) is not always countable as an asset in assessing liability for MH/MR services, depending on the intent of the settlor.

of any provisions in the client's will, such accounts should be discouraged (and terminated) if it would be undesirable to leave property directly to the relative either because it could adversely affect his eligibility or liability for government benefits or because he would be unable to handle such sums independently. For the same reasons, you should ascertain whether the client has named the relative as a beneficiary in any life insurance policy and whether it would be preferable to create a pour-over trust for the relative that uses the proceeds of the life insurance policy.

B. Property Passing By Will

1. Disinheritance

Too often disinheritance is the only option considered, usually because the client is concerned that his relative may be unable to manage financial matters or because the client is unaware of the mechanisms available to assist his relative in doing so, such as the use of representative payees for government benefits or trustees. Sometimes disinheritance may be warranted, as in cases where the estate is small, and setting up a trust is simply not feasible. Even if nothing of significant monetary value is being left to the relative, the client may wish to leave a gift of some sentimental or personal significance. In addition, the will should include explicit language to make plain that: (1) the client's choice was deliberate (and not unintentional or an oversight); (2) the client's decision not to leave his relative a significant gift was not the result of malice but, rather, was the result of a careful assessment of the relative's best interests and, specifically, the impact of a direct bequest on the relative's government benefits; and (3) if applicable, that the client has made alternative arrangements for the relative.

2. Direct Bequest

A direct bequest to the relative with disabilities is desirable when the relative is able to manage his fiscal affairs and when government benefits will not be jeopardized or far outweighed by the bequest. Direct bequests, however, do not allow much room to maneuver to avoid an undesirable outcome.

3. Morally Obligated Gift To Another

Another frequently used method is for the client to leave property to a third person with a precatory instruction that it is to be used to benefit the client's relative with disabilities. This method, of course, creates no enforceable right in the person with disabilities to the property and no enforceable duty on the third party. Thus, the person chosen as the beneficiary should be one who the client trusts implicitly to do the right thing. Still, a morally obligated gift has the advantage of being simple and may be appealing to a client, even after the potential hazards and alternatives are fully explained.

C. Trusts

1. Trusts Generally

A trust is probably the most effective means to create an estate plan that fulfills the client's desire to provide for his relative's future without jeopardizing the relative's eligibility or liability for government benefits. Careful drafting is critical, however, to assure that these dual purposes both are accomplished.⁵

⁵ Creation of a trust to benefit a relative with a disability may also protect the client-settlor's potential eligibility for Medicaid benefits (such as care in a nursing facility). Under federal law, transfers of assets for less than fair market value generally will render an individual ineligible for Medicaid benefits for a certain time period. 42 U.S.C. § 1396p(c)(1). Certain transfers, however, are exempt from the general rule of disqualification. 42 U.S.C. § 1396p(c)(2). Any transfer of a house to the transferor's child (either directly or to a trust established solely for the child's benefit) will not render the transferor ineligible for Medicaid benefits. 42 U.S.C. § 1396p(c)(2)(B)(iii). So too, assets transferred to a trust established solely for the benefit of an individual under 65 who has a disability (whether or not he is the transferor's child) will not render the transferor ineligible for

Generally, a mandatory trust cannot provide the flexibility that allows the trustee to meet the changing needs of the beneficiary with disabilities and the ever-changing standards for benefit eligibility and liability. Depending on the required disbursements, a mandatory trust may render a beneficiary ineligible for governmental benefits and may therefore succeed only in substituting private for public resources. Even where this is not a problem (*e.g.*, in a trust requiring monthly disbursements of one dollar less than the SSI income limit), the mandatory trust does not permit the trustee to respond to changing conditions (*e.g.*, if the SSI monthly benefit proves inadequate to support the individual).

In contrast, a discretionary trust -- one that allows the trustee to determine what shall be distributed, when it shall be distributed, and, in some cases, to whom it shall be distributed -- is the most flexible estate planning mechanism and can be used to accomplish the client's purposes of providing for his relative while protecting the relative's government benefits. Because the trustee in a discretionary trust often has many decisions to make about the personal needs of the beneficiary, the client should choose the trustee with care. Money management ability alone may not be enough, so the client may wish to appoint a person with some fiscal skills as well as a good understanding of his or her relative and the relative's disability. Alternatively, there are non-profit organizations available which can act as the trustee and will manage, invest, and disburse trust funds according to the settlor's wishes and may provide other services to the client's relative as well.⁶

Medicaid benefits. 42 U.S.C. § 1396p(c)(2)(B)(iv).

⁶ These non-profit organizations offer “pooled trusts,” which are discussed below, and may also offer educational materials and services relating to non-pooled trusts for people with disabilities. These organizations include: (1) ARC Community Trust of Pennsylvania, 610-265-4700, www.arccommunitytrustpa.org; (2) The Family Trust, 412-995-5000, www.achieva.info/thefamilytrust; and (3) Berks County Community Trust, 610-603-0227,

More and more, families of persons with disabilities have looked to trusts to assure both that their relatives' access to government benefits is not impaired and that all of their needs are met. *See generally* Kemp C. Scales and Linda M. Anderson, *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, Pa. Bar Ass'n Q. 169 (Oct. 2003); 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); Randall D. Van Dolson, *Medicaid Eligibility Rules and Trusts for Disabled Children*, 133 Trusts and Estates 51 (Apr. 1994); Michael Gilfix, *Special Trusts for Asset Preservation Planning*, 132 Trusts and Estates 62 (Feb. 1993).

2. Federal and State Guidelines for Trusts

The mere fact that a trust is "discretionary" does not, by itself, insulate the trust assets from counting for purposes of determining the beneficiary's eligibility and liability for government benefits. Rather, one must look to federal and state statutes, federal regulatory materials, and state common law to assess whether a discretionary trust will adversely impact your client's relative's government benefits. The law differentiates between third-party trusts (*i.e.*, trusts created solely with the assets of a person other than beneficiary/relative with a disability) and self-settled trusts (*i.e.*, trusts created solely with the assets of the beneficiary/ relative with a disability).

a. Third-Party Trusts

(1) Federal SSI Guidelines for Third-Party Trusts

The Social Security Administration (SSA) has established general, internal guidelines concerning when a third-party trust will be counted as a resource and/or income for purposes

of determining SSI eligibility. SSA will count the trust principal as an available resource if the claimant/beneficiary: (1) has legal authority to revoke the trust (and then can use the trust to meet his food, clothing, or shelter needs), or (2) can direct the use of the trust principal for his support and maintenance under the terms of the trust. Program Operations Manual System (POMS) § SI 01120.200(D).⁷ If trust principal is not considered an available resource, cash disbursements from the trust to the claimant/beneficiary will count as unearned income, and disbursements by the trustee to a third-party for food, clothing, or shelter for the claimant/beneficiary will be considered income in the form of in-kind support and maintenance (though disbursements to a third party that results in the claimant/beneficiary's receiving items other than food, clothing, or shelter are not considered income). POMS § SI 01120.200(E)(1).⁸

**(2) State Guidelines for Third-Party Trusts'
Impact on Medicaid Eligibility**

While the SSA has standards that govern when a third-party trust will affect a beneficiary's SSI, there are no federal standards or state statutory standards that determine when a third-party trust will affect a beneficiary's Medicaid benefits. The Pennsylvania judiciary, however, has issued a series of decisions that discuss the impact of a trust on a beneficiary's Medicaid benefits. While the Pennsylvania Supreme Court has indicated that "supplemental needs trusts" can be an effective means to provide for the needs of a person with a disability without jeopardizing his government benefits, it has not held that such

⁷ The POMS are available on SSA's website, www.ssa.gov.

⁸ If the trust principal is considered a resource to the individual, disbursements from the trust principal received by the claimant/beneficiary are not considered income but, rather, a conversion of resources. Trust earnings (*e.g.*, interest) on a trust that is considered a resource will be considered as income to the claimant/beneficiary. POMS SI § 1120.200(E)(2).

trusts are automatically immune from counting as available resources for purposes of determining benefit eligibility and liability. The key factor (though not the only factor) is the intent of the settlor. Since the trust language and structure reflects the settlor's intent, the utmost care must be used in drafting a supplemental needs trust.

In *Lang v. Commonwealth, Dep't of Public Welfare*, 528 A.2d 1335 (Pa. 1987), the court held that the income and assets of a discretionary testamentary trust created for the benefit of all of the settlor's children was not an available resource to one of the children, who had a disability, for purposes of determining Medicaid eligibility and liability for mental retardation services. In determining whether a trust is a resource that should be counted, the court indicated that the critical inquiry "is whether [the] testator created a duty in [the] trustee ... to provide for [the claimant/beneficiary's] basic support" because, if the trustee had such a duty, the claimant/beneficiary could compel distributions from the trust for his basic support so that the trust assets "would be considered available for his use." *Id.* at 1339. In examining the language of the trust, the *Lang* Court stressed that the "testator intended to give [the] trustee the power, as opposed to a duty, to provide support for [the claimant/beneficiary], to the exclusion of the other beneficiaries, should that be necessary." *Id.* at 1341. Given this discretion, the claimant/ beneficiary would not have the power to compel distributions from the trust unless other adequate funds, including public funds, were not available. *Id.*

In addition to examining the discretion given the trustee, the *Lang* Court also stressed that it was important to determine "whether the testator intended [the] trustee to consider other sources of support available to [the claimant/beneficiary]." *Id.* at 1343. Although the trust did not address the issue explicitly, the court identified several factors revealing the

testator's intent to require the trustee to consider other resources before determining whether to distribute trust income or principal for the claimant/beneficiary's support:

- * that the testator established a discretionary support trust rather than a mandatory trust or "pure" support trust;
- * that the testator established one trust to benefit all of his children -- not just a trust to benefit his child with a disability; and
- * that during the testator's lifetime, he accepted Commonwealth support to partially subsidize the care of his child with a disability, showing that he intended the trust to supplement other resources available to his child and only to provide support if such resources prove inadequate or are discontinued.

Id. at 1343-44.

Although *Lang* seemed to resolve the question favorably, two decisions issued by the Supreme Court concurrently in 1991 emphasized the fact-based nature of *Lang* and the importance of the careful drafting of the trust instrument.

In *Commonwealth Bank and Trust Co., N.A. v. Commonwealth, Dep't of Public Welfare*, 598 A.2d 1283 (Pa. 1991), the court held that the principal of a testamentary trust was an available resource for purposes of determining the beneficiary's eligibility for Medicaid.

The trust provided, *inter alia*:

I hereby authorize my Trustees, in their uncontrolled discretion, but having in mind the income or principal that may be available to or for her from other sources, to pay over to my Mother so much of the principal of this trust as my Trustees shall deem needful or desirable for her support and maintenance, including medical, surgical, hospital, or other institutional care.

Id. at 1280. Despite the discretion vested in the trustees to disburse the principal and the

requirement that the trustees consider other income or principal available in exercising that discretion, the court held that the trust principal was a resource available to the beneficiary/Medicaid claimant. *Id.* at 1282. The court cited several factors to support its conclusion:

- * at the time the testator executed his will, he had a duty to care for the beneficiary (his mother);
- * there was only one life beneficiary;
- * the trust directed the trustee only to consider "income or principal that may be available" in deciding whether to distribute the trust principal to the beneficiary -- it did not refer to any other type of resources -- and "public benefits, while they are a resource, are neither income nor principal"; and
- * the trust to benefit his mother did not contain the bulk of the testator's resources, which went to other legatees.

Id.

In *Snyder v. Commonwealth, Dep't of Public Welfare*, 598 A.2d 1283 (Pa. 1991), the court concluded that the trust in question could not be counted as an available resource to a trust beneficiary for purposes of determining his Medicaid eligibility. Reviewing *Lang*, the court discussed the nature of the inquiry:

The critical issue to be resolved in *Lang* was '[w]hether [the] testator created a duty in [the] trustee, independent of any statutory duty, to provide for [the child's] basic support.' ... In resolving that issue, the Court focused on one primary factor, that being the intention of the settlor who created the trust; and in the view of the Court in *Lang*: 'If [the] testator gave trustee discretion to consider funding otherwise available from the Commonwealth in determining whether to distribute trust income and principal (or either) for [the child's] support, the trust (or its income or principal) would not be available for [the child's] use and could not be considered his asset or resource.'

Id. at 1286 (citations omitted). In holding that the trust principal could not be counted as an available resource, the court examined the trust language and highlighted the following factors:

- * the trust names two life beneficiaries, neither of whom's needs were to be considered dominant by the trustee so that the trustee would be required to review how his actions toward one beneficiary would affect the other and so that he could not act to benefit one beneficiary if it would result in irreparable damage to the other; and
- * at the time of the settlor's death, her child with a disability (one of the two life beneficiaries) had been receiving public benefits so that the settlor was aware of the availability of such benefits and it was unlikely that the settlor intended to deprive that child of the benefits to which he had become entitled (and, by so doing, deprive her other child and beneficiary of the benefit of the trust).

Id. at 1287. The court distinguished its decision in *Commonwealth Bank*, writing that "there are distinguishing characteristics in that case which are not present here, the most notable of which is that the trust there had but one life beneficiary whose ability to compel the trustee to act was superior to all of the contingent remaindermen there affected, and for whose benefit the entire amount was specifically bequeathed." *Id.* at 1287 n.8.

Subsequently, the Pennsylvania Supreme Court again addressed the issue in *Estate of Rosenberg v. Dep't of Pub. Welfare*, 679 A.2d 767 (Pa. 1996). In that case, the court concluded that the principal of a testamentary trust should be counted as an available resource to a Medicaid claimant who was the trust beneficiary. The Court reasoned:

In comparing the salient factors of *Lang*, *Snyder*, and *Commonwealth Bank* with this case, we observe the following: There is only one life beneficiary, the settlor's widow. During the settlor's lifetime, she received no public assistance. Thus, the considerations of *Lang* and *Snyder* do not apply; rather this

is a case virtually indistinguishable from *Commonwealth Bank*.

Id. at 770. While the court agreed "that the fundamental question is the ascertainment of the settlor's intent" and that the factors in *Lang*, *Snyder*, and *Commonwealth Bank* "were not meant to exhaust the possible indications of a settlor's intent," it stressed that such factors "remain persuasive and prominent indicators [of intent]." *Id.* at 771. Additionally, the court rejected a "presumption that every testator intends his survivors to utilize public assistance if possible" *Id.* at 772. The court wrote: "Although *Lang* condemned the notion that receiving public assistance is shameful, we do not subscribe to the opposite notion, that receiving public assistance is the presumed goal of estate planning." *Id.*; see also *Shaak v. Pennsylvania Dep't of Public Welfare*, 747 A.2d 883 (Pa. 2000) (describing the trust as nearly identical to those involved in *Rosenberg* and *Commonwealth Bank*, the court held DPW properly counted the trust as a resource).

The Pennsylvania Supreme Court's decisions in *Lang*, *Snyder*, *Commonwealth Bank*, and *Estate of Rosenberg* reveal its willingness to respect the settlor's intent as to the use of public benefits and underscore the necessity of making that intent plain within the trust document itself. It remains to be seen, however, whether a clear expression of the settlor's intent (*e.g.*, a statement in the trust that it is intended to supplement, not supplant, government benefits)⁹ will render irrelevant the other elements identified by the courts (*i.e.*,

⁹ One author has suggested the following "Trust Purpose" paragraph for use in drafting supplemental needs trusts:

The purpose of this trust is to supplement, but not to supplant, whatever benefits and services [the beneficiary] ... may from time to time be eligible to receive by reason of age, disability, or other factors, from federal, state, and local governmental and charitable sources It is, therefore, my intent and direction that the trustee use the principal of the trust to provide the primary beneficiary with those

multiple life beneficiaries; the percentage of the settlor's estate with which the trust is funded; a duty on the settlor to support the beneficiary during settlor's lifetime; and receipt of government benefits by the beneficiary during the settlor's lifetime).¹⁰ In any event, a close reading of these cases and cautious drafting is required to ensure that a discretionary trust does not endanger eligibility for present or future benefits.

(b) Self-Settled Trusts

Although this booklet focuses on financial planning by family members for the benefit of a relative with a disability, there are times when an individual with a disability receives assets in his own right (*e.g.*, through inheritance or as a result of a legal judgment or settlement) which may jeopardize his continued eligibility for SSI or Medicaid. Congress,

benefits and services, and only those benefits and services, that, in the trustee's judgment, are not otherwise available.

Harry S. Margolis, *Elder Law Forms Manual Essential Documents for Representing the Older Client* § 13.1 (1992), *quoted in* 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, 568 n.74 (1994); *see also* Kemp C. Scales and Linda M. Anderson, *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, 74 *Pa. Bar Ass'n Q.* 169, 174-75 (Oct. 2003) (discussing various trust language distribution standards).

¹⁰ Commentators have advanced other suggestions for trust provisions to prevent placing the beneficiary's government benefits in jeopardy, including: (1) identifying the types of expenditures the trustee can make (*e.g.*, payments for personal items not provided by other sources, seasonal gifts, travel, advocacy services); (2) limiting the trustee's discretion so that he cannot make distributions that will be counted as resources or income to the beneficiary for purposes of SSI and/or Medicaid; (3) a "forfeiture clause" that states that the interest in the trust of the beneficiary with a disability will terminate if the trustee determines that the trust will affect his eligibility for government benefits; and (4) a "spendthrift clause" protecting against consideration of the trust as an available resource. *See* 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, 568 (1994); Randall D. Van Dolson, *Medicaid Eligibility Rules and Trusts for Disabled Children*, 133 *Trusts and Estates* 51, 52 (Apr. 1994); Robert Weinberg, 2 *Pennsylvania Estate Planning and Drafting*, Ch. 22 § 22.8.3 (Supp. 1998); Kemp C. Scales and Linda M. Anderson, *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, 74 *Pa. Bar Ass'n Q.* 169 (Oct. 2003).

though, has enacted stringent guidelines that must be followed to assure that trusts created with the assets of an individual or his spouse (self-settled trusts) do not jeopardize the individual's eligibility for SSI or Medicaid. Following Congress's lead, Pennsylvania has also enacted statutes that standards as to when self-settled trusts will impact the relative's Medicaid benefits.

In an effort to limit the use of self-settled trusts by individuals to transfer their assets or their spouse's assets so as to become eligible for Medicaid, Congress amended the Medicaid statute (Title XIX of the Social Security Act) in 1993. 42 U.S.C. § 1396d. In 1999, Congress amended the SSI Statute (Title XVI of the Social Security Act) to impose similar restrictions on the use of self-settled trusts to secure SSI eligibility. 42 U.S.C. § 1382b(e).

The general rule established by these statutes is that self-settled trusts established for the benefit of a Medicaid claimant and comprised of his assets or his spouse's assets generally will count in determining the claimant's Medicaid eligibility. 42 U.S.C. §§ 1382b(e)(1)-(3), 1382b(e)(6), 1396p(d)(1)-(3), 1396p(e)(1). If such a self-settled trust is revocable, the corpus is considered an available resource. 42 U.S.C. §§ 1382b(e)(3)(A), 1396p(d)(3)(A)(I). If the self-settled trust is irrevocable, any portion of the corpus (and income on the corpus) from which payment to benefit the individual could be used is considered a resource. 42 U.S.C. §§ 1382b(e)(3)(B), 1396p(d)(3)(B)(I).¹¹ Payments from a self-settled trust (revocable or irrevocable) that benefit the claimant are considered income.

¹¹ Any portion of an irrevocable trust from which no payments benefitting the individual can be made will be considered a transferred asset and may subject the individual to disqualification for SSI or Medicaid as an improper transfer of resources. 42 U.S.C. §§ 1382b(c)(1)(B)(ii)(II), 1396p(d)(3)(B)(ii).

42 U.S.C. § 1396p(d)(3)(A)(ii), 42 U.S.C. § 1396p(d)(3)(B)(i)(I); *see also* POMS § SI 01120.201(I) (regarding treatment of disbursements as income for SSI eligibility).¹²

While these general rules require SSA to count self-settled trust assets as resources, Congress directed that those rules would "not apply" (for purposes of Medicaid eligibility) to certain types of trusts created after August 10, 1993 (and, in the case of SSI eligibility, for trusts created after January 1, 2000). The two types of self-settled trusts that would be used by people with disabilities to maintain their SSI and Medicaid eligibility are: (1) "special needs trusts" (also known as "payback trusts"), and (2) "pooled trusts." 42 U.S.C. §§ 1382b(e)(5), 1396p(d)(4).¹³ The general guidelines for each of these trusts are discussed below.¹⁴

(1) "Special Needs" or "Payback" Trusts

¹² Payments from a trust that do not benefit the individual are considered asset transfers that may subject the individual to disqualification for SSI or Medicaid as an improper transfer of resources. 42 U.S.C. §§ 1382b(c)(1)(B)(ii)(I), 1396p(d)(3)(A)(iii), 42 U.S.C. § 1396p(d)(3)(B)(i).

¹³ Congress simply stated that the general trust rules did not apply; it did not state specifically how pay-back trusts and pooled trusts should be treated. *See* Patricia Nemore, *et al.*, *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, 12034 (Feb. 1994). "A reasonable assumption seems to be that they would be treated under ordinary Medicaid eligibility principles of availability, in which the income and the resource aspects of the trust are treated separately." *Id.*; *see also* Randall D. Van Dolson, *Medicaid Eligibility Rules and Trusts for Disabled Children*, 133 *Trusts and Estates* 51, 55 (Apr. 1994); Sanford J. Schlesinger and Barbara J. Scheiner, *OBRA '93 Makes Sweeping Changes in Medicaid Rules*, 21 *Estate Planning* 74, 78-80 (Apr. 1994); Patricia Tobin, *Medicaid Basics and A Review of Amendments to Medicaid Law Under OBRA '93*, in *Estate Planning and Administration* (PLI Tax Law and Estate Planning Course Handbook Series, (1994)). SSA treats these types of trusts as exceptions to the general rules of counting trusts as income and resources. POMS § SI 01120.203(B).

¹⁴ You should note, however, these types of trusts are subject to Medicaid liens outstanding when the trusts were created. 62 Pa. Cons. Stat. Ann. § 1414(d); *Sullivan v. County of Suffolk*, 174 F.3d 282, 285-86 (2d Cir.), *cert. denied*, 528 U.S. 950 (1999); *Norwest Bank of North Dakota, N.A. v. Doth*, 159 F.3d 328, 333 (8th Cir. 1999).

Under federal law, to qualify as a special needs trust (also known as a payback trust) that will not be counted as income and/or resources for purposes of establishing SSI or Medicaid eligibility, a trust must: (1) contain the assets of a person with a disability under age 65 (or his spouse's assets); (2) be established for the individual's benefit by a parent, grandparent, or legal guardian; and (3) specifically provide in the trust document that when the individual dies, the state will receive any amount remaining in the trust up to the Medicaid payments made by the state for the individual. 42 U.S.C. § 1396p(d)(4)(A); accord POMS SI § 01120.203(B)(1). You should note that an individual cannot establish his own special needs trust, and so a competent adult who has a disability may need to accept a limited financial guardianship to establish a pay-back trust. *See Patricia Nemore, et al., 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, 1204 (Feb. 1994).

In July 2005, Pennsylvania enacted a statute that also establishes the requirements for “special needs” trusts. 62 Pa. Cons. Stat. Ann. § 1414. The statute defines special needs trusts as self-settled trusts established for the purpose or with the effect of establishing or maintaining the beneficiary’s resource eligibility for Medicaid. *Id.* § 1414(f). The statute provides that a special needs trust must comply with the following requirements: (1) the beneficiary must be under age 65 and have a SSI-level disability; (2) the beneficiary must have “special needs” that will not be met without the trust;¹⁵ (3) the trust must provide (a)

¹⁵ The statute defines “special needs” quite narrowly. Only items, products, or services (1) that are not covered by Medicaid or other insurance, (2) that can increase the beneficiary’s quality of life, and (3) assist in and are related to the treatment of the beneficiary’s disability. 62 Pa. Cons. Stat. Ann. § 1414(f). This would seem to exclude many non-medical, non-treatment items that often are funded by a special needs trust. However, the statute only uses the term “special needs” to require

that all distributions are for the sole benefit of the beneficiary, (b) that any expenditure from the trust must have a reasonable relationship to the needs of the beneficiary, and (c) that, upon the death of the beneficiary or the termination of the trust, the state will be reimbursed from the funds remaining in the trust up to an amount equal to the total Medicaid paid on behalf of the beneficiary before any other claimant is paid. *Id.* § 1414(b). The statute also requires special needs trusts to be approved by a court, “if required by rules of court.” *Id.* § 1414(a).

(2) “Pooled” Trusts

Under federal law, qualify as a "pooled trust" that will not be counted as income and/or resources for purposes of establishing SSI or Medicaid eligibility, the following criteria must be satisfied: (1) a non-profit corporation establishes and manages the trust; (2) each beneficiary's assets are retained in a separate account but are pooled for purposes of investment and management; (3) the accounts are established solely for the benefit of individuals with disabilities either by the individuals themselves or by their parents, grandparents, legal guardians, or courts; and (3) specifically provide in the trust document that any amounts remaining after the individual's death will be retained in the pool or be paid to the state up to the amount of Medicaid paid by the state for the individual. 42 U.S.C. § 1396p(d)(4)(C); see also POMS SI 01120.203(B)(2).¹⁶

In 2002, Pennsylvania enacted the Pooled Trust Act, which also establishes standards

that the beneficiary have “special needs” that cannot be met without the trust. *Id.* § 1414(b)(3)(ii). The statute does not limit distributions from the trusts to fund items relating to the beneficiary’s “special needs”; rather, the statute provides that distributions must simply be for the sole benefit of the beneficiary and have a “reasonable relationship to the needs of the beneficiary.” *Id.* § 1414(b)(3)(iii).

¹⁶ Several non-profit entities that administer pooled trusts are listed on page 7 n.6.

for pooled trusts operating in the Commonwealth. 62 Pa. Cons. Stat. Ann. § 1965.1 *et seq.* The Pooled Trust Act explicitly provides that the interest of any beneficiary with a disability in a pooled trust will not be considered as a resource for purposes of determining the beneficiary's eligibility for Medicaid. *Id.* § 1965.6(a).

More importantly, Pennsylvania's enactment of the "special needs" trust statute in 2005, discussed above, also affects pooled trusts. "Special needs trusts" are defined by the statute to include accounts in pooled trusts (as well as other self-settled trusts for beneficiaries with disabilities). 62 Pa. Cons. Stat. Ann. § 1414(f). As such, pooled trusts must meet the standards for other special needs trusts required by that statute outlined above at 17. The only difference in treatment relates to the state's ability to access any remaining funds in the trust following its termination or the beneficiary's death. While federal rules allow all remaining funds in a pooled trust account to be retained by the trust for the benefit of other beneficiaries with disabilities, 42 U.S.C. § 1396p(d)(4)(C)(iv), the Pennsylvania special needs statute requires that a pooled trust instrument must provide that the pooled trust cannot retain more than fifty percent of the remaining account funds and the rest must be made available as reimbursement to the Commonwealth up to an amount equal to the total Medicaid paid on behalf of the beneficiary. 62 Pa. Cons. Stat. Ann. § 1414(b)(3)(iii).

Although pooled trusts (unlike special needs/payback trusts) limit the state's right to receive reimbursement for Medicaid expenditures, one Pennsylvania court has held that the Commonwealth cannot force an individual to choose special needs/payback trusts over pooled trusts. In *Lewis v. Magee Women's Hosp. of UPMC*, 67 Pa. D. & C.4th 362 (C.P. Allegheny County 2004), a person with a disability received a significant settlement in a medical malpractice action and petitioned the court to place the proceeds in a pooled trust

account. The Commonwealth objected, arguing that the proceeds should be placed in a special needs/payback trust so that any remaining funds would be available to the Commonwealth as reimbursement for its Medicaid payments made during the beneficiary's lifetime. The Court of Common Pleas held that the interests of Pennsylvania taxpayers had no bearing on the choice of trust instrument, but, rather, the only issue is whether the choice is consistent with the individual's best interests. *Id.* at 368-69.

V. CONCLUSION

Estate planning to meet the needs of people with disabilities and their families is a challenging field. Familiarity with the needs of people with disabilities and the public resources available is necessary to help the client get the most out of his estate assets. The estate planner should also advise the client to encourage the person with disabilities, where possible, to become involved in community life and to get training in skills of independent living. Connection, competency, and careful estate planning are all necessary to accomplish the client's ultimate goal -- to help the relative with disabilities live a full and happy life.

February 2007

NOTE: THIS PUBLICATION MAY NOT BE REPRINTED WITHOUT THE EXPRESS WRITTEN PERMISSION OF THE DISABILITY RIGHTS NETWORK OF PENNSYLVANIA. COPYRIGHT 2007. ALL RIGHTS RESERVED.