



SPECIAL NEEDS TRUSTS: A GUIDE FOR FAMILIES

I. Purpose

Special Needs Trusts are designed to permit financial resources to remain available to assist a disabled individual who receives, or may receive in the future, Medicaid (Medical Assistance) and/or SSI and/or Mental Health/Intellectual Disabilities benefits. These Trusts also protect resources from immediate invasion by the state Medicaid agency (in Pennsylvania, the Department of Public Welfare and in Maryland, the Department of Health and Mental Hygiene) to reimburse the public treasury for the provision of MA, SSI or other public benefits.

II. Three Types of Special Needs Trusts – An Overview

- A. Common Law - Third Party Funded - Lang and its progeny
 - Generally created via Wills or inter vivos trusts of family members
 - No payback involved to Department of Public Welfare

- B. Self-Funded Special Needs Trusts (a.k.a. "Payback Trusts") - OBRA-93 -- 42 U.S.C. § 1396p(d)(4)(A)
 - Disabled beneficiary (only one)
 - Must be created by parent, grandparent, guardian or the court
 - Payback to state for Medical Assistance in a beneficiary's lifetime
 - Total discretion of Trustee
 - Irrevocable

***Unless otherwise noted, the discussion set forth in this outline is based upon Pennsylvania law. Please consult your legal professional in your own state for controlling doctrines in that jurisdiction.**

C. Pooled Trust - - 42 U.S.C. § 1396p(d)(4)(C)

- Non-profit Fiduciary must be the Trustee
- Joinder Agreement to be signed to participate in the Pooled Trust.
- Residue typically remains in Trust for other disabled persons upon death of beneficiary
- Pennsylvania's requirement that up to 50% of residue be available for Medical Assistance payback has been overturned. Lewis v. Alexander, 685 F.3d 325 (3d Cir. 2012); 62 P.S. § 1414(b)(3)(iii)

III. Types of Special Needs Trusts - In Depth Analysis

A. "Common Law Special Needs Trust" or a "Third Party Funded Special Needs Trust" - involves a Trust funded by someone other than the disabled person. The controlling cases in Pennsylvania regarding Common Law/Third Party Funded Special Needs Trusts using the resources of third parties are Lang v. Commonwealth, Department of Public Welfare, 515 Pa. 428, 528 A.2d 1335 (1987) (discretionary trust held not invadable to pay DPW for intellectual disability benefits); Commonwealth Bank and Trust v. Commonwealth, Department of Public Welfare, 528 Pa. 482, 598 A.2d 1279 (1991) (trust disqualified beneficiary for MA due to testator's legal duty to care for beneficiary, failure of trust to refer to public benefits as an available resource, and fact that principal could be spent without concern for remaindermen); Snyder v. Commonwealth, Department of Public Welfare, 528 Pa. 491, 598 A.2d 1283 (1991) (trust not an "available resource" for purposes of determining son's eligibility for medical assistance benefits); Estate of Rosenberg v. Department of Public Welfare, 545 Pa. 27, 679 A.2d 767 (1996); (trust disqualified beneficiary for MA where intent of settlor was not clear regarding desire to ensure future eligibility for public benefits); Shaak v. Department of Public Welfare, 747 A.2d 883 (Pa. 2000); (inter vivos trust found to be an "available resource", because the Settlor/Beneficiary "clearly intended that the Trust be used for her benefit during her lifetime" and principal could be used for "maintenance and welfare" of the Beneficiary); Estate of Taylor, 825 A.2d 763 (Pa. Cmwlth. 2003).

In Maryland, see First Nat'l Bank v. Dep't of Health, 284 Md. 720, 399 A.2d 891 (1979) (a properly drafted third-party funded special needs trust is not liable for medical assistance provided to the disabled beneficiary and distribution cannot be compelled from pure discretionary trust unless shown trustee acted in bad faith or beyond bounds of reasonable judgement).

1. Factors To Consider In Establishing A Common Law/Third Party Funded Special Needs Trust

- a. It must be clearly stated that (1) it is the intent of the settlor to supplement and not supplant public benefits; (2) that such benefits be considered prior to distribution of any trust income or principal, and (3) the trustee has total, absolute and unfettered discretion to

pay, or refuse to pay, income or principal from the trust to the disabled beneficiary. Never instruct the trustee to make periodic (e.g. monthly) payments, as all payments should be discretionary and generally cannot be made for food or shelter under MA or SSI rules.

- b. The courts also appear to consider other factors, perhaps as indicia of the settlor's intent;
 - i. The existence of other beneficiaries;
 - ii. The existence of remaindermen with a statement of intent that the settlor wishes the trustee to attempt to preserve at least some assets for the remaindermen;
 - iii. The trustee is instructed to consider the interests of all other beneficiaries, including contingent beneficiaries, before making distributions;
 - iv. The lack of a duty of the settlor to support the disabled beneficiary.

B. Self-Funded or "Payback" Special Needs Trusts -- 42 U.S.C. Section 1396
p(d)(4)(A)

1. Amendments to the Medical Assistance rules under OBRA-93 require that where the beneficiary's own monies are used:
 - a. The Trust must be created irrevocably for the benefit of a disabled individual under age 65. Pennsylvania and other states interpret this provision to require that the Trust be used for the sole benefit of the disabled beneficiary.
 - b. the trust must be created by the beneficiary with a disability (if a competent adult), the beneficiary's parent, grandparent, legal guardian or a court;
 - Pennsylvania requires that "before the funding of a Special Needs Trust, all liens and claims in favor of the Department for repayment of cash and Medical Assistance shall first be satisfied." 62 P.S. Section 1414(d). No provision in the Social Security Act requires that all such liens be satisfied prior to the creation of a Special Needs Trust, although where the Special Needs Trust is funded through the proceeds of a personal injury action, Pennsylvania and federal law have long required that Medical Assistance paid on account of the accident be

repaid before any recovery is paid to the plaintiff or a Trust for the plaintiff. Query: Does this mean that all prior Medical Assistance expenditures must be repaid before funding the Trust, including Medical Assistance payments which were unrelated to an accident which gave rise to the recovery which will fund the Trust? It would appear that DPW has no formal "lien" to recover for Medical Assistance payments except 1) from a litigation fund to repay Medical Assistance for benefits provided as a result of the accident, 62 P.S. §1409(b)(1), and 2) for Medical Assistance provided after the age of 55. 62 P.S. §1412. With respect to DPW's claims concerning cash assistance, see 62 P.S. §1974.

- In Lewis v. Alexander, 685 F.3d 325 (3d Cir. 2012), the Court held that various sections of 62 P.S. Section 1414 (Special Needs Trusts) were impermissibly more restrictive than the federal law with respect to Pooled Special Needs Trusts under 42 U.S.C. 1396p(d)(4)(C). While the Court upheld Section 1414(c) which allows DPW to petition the Court to terminate an SNT that violates 1414(b)'s provisions to protect the beneficiary, the Court held that the following sections are preempted by federal law; while the court only held these sections to be preempted and thus void as to Pooled SNTs, the rationale of the court generally appears applicable to all Self-Funded Special Needs Trusts.

- Section 1414(b)(2) - the beneficiary must have "special needs that will not be met without the trust"
- Section 1414(b)(1) - a person over age 65 cannot participate in a pooled trust (but the Court noted that elsewhere in the Medicaid Act such transfers result in a period of ineligibility)
- Section 1414(b)(3)(ii) - any expenditure must have a "reasonable relationship" to the needs of the beneficiary
- Section 1414(b)(3)(iii)- after the death of a beneficiary the state may recover up to 50% of the remaining corpus to repay the state for Medical Assistance provided to the beneficiary, and the pooled trust can retain only the remaining 50%.

The Court was not asked to review the lower court's approval of Section 1414(b)(3)(i), which requires that all distributions from the trust must be for the sole benefit of the beneficiary.

- c. The Trustee must have total discretion to pay, or refuse to pay, resources of the Trust to the beneficiary;
 - COMAR 10.09.24.08-2(a)(b) (Maryland) mandates that expenditures from the trust shall be used for the sole benefit of the beneficiary and shall be directly related to the beneficiary's health care, education, comfort, or support.
- d. The trust must state that monies in the trust at the beneficiary's death be made available to repay the state for Medical Assistance payments made on behalf of the beneficiary during his/her lifetime. Upon the death of beneficiary, the Trustee in Pennsylvania must contact:

Department of Public Welfare
Third Party Liability Casualty Unit
Special Needs Trust Depository
P.O. Box 8486
Harrisburg, PA 17105
(717) 772-6257

- e. Pennsylvania Act 42 of 2005 requires DHS to determine whether the Trust conforms with "any regulations or statements of policy adopted by the Department to implement this section." 62 P.S. Section 1414(b)(4). Query: Does this mean that even informal policy statements of the Department become binding law in determining the legality of Special Needs Trusts? This circumstance presents real concerns, especially given the current policy of the Department in stretching federal law beyond the express mandate of the Social Security Act through the provisions of Act 42.
- f. Pennsylvania Act 42 of 2005 provides that "if at any time it appears that any of the requirements of [Act 42] are not satisfied or the Trustee refuses without good cause to make payments from the Trust for the special needs of the beneficiary...the Department or other public agency may petition the court for an Order terminating the Trust." 62 P.S. Section 1414(c). This provision apparently gives broad authority to not only the Department, but any "other public agency" to petition the Court to terminate the Trust if it believes that, for example, the beneficiary's special needs can be met without the Trust or that expenditures from the Trust have not had a "reasonable relationship to the needs of the beneficiary". Therefore, it is possible that agencies such as County Mental Health/Intellectual Disability Administration or other social service agencies might petition the court to terminate the Trust in order to

avoid providing public entitlements. See, Lewis v. Alexander, discussed above, which upheld this provision.

- g. Pennsylvania Act 42 of 2005 requires that “at the death of the beneficiary or upon earlier termination of the Trust, the Trustee shall notify and request a Statement of Claim from the Department, addressed to the Secretary.” 62 P.S. Section 1414(e). This provision refers to “earlier termination of the Trust” in a manner which does not fully mirror federal law, which speaks only to termination on the death of the beneficiary.
- h. Some additional Maryland requirements include:
 - The trust beneficiary may not serve as trustee, co-trustee, trust protector, trust advisor, or in any other capacity that would allow the beneficiary to influence or exercise authority or control over distributions from the trust;
 - Any leases or mortgages that the trust may hold must contain a provision that they either terminate or become due and payable upon the death of the beneficiary or termination of the trust;
 - If the trust owns titled property that is valued at more than \$500, the property must be titled in the name of the trust, except for securities, which may be held in the name of a nominee;
 - Trust assets may not be used to compensate family members of the beneficiary for serving the beneficiary in any way, including caring for the beneficiary, accompanying the beneficiary on travel, providing companionship to the beneficiary, or serving as trustees or members of a trust advisory committee;
 - Trust assets may not be used to purchase gifts;
 - The only real property in which the trust may invest is in a single home property, which is used as the residence of the beneficiary and is titled in the name of the trust;
 - The trust may not disburse more than \$100,000 for the purchase of property without the approval of the State circuit court in the jurisdiction in which the beneficiary resides;

- An annual accounting of the trust, including a listing of the current assets, income, and itemized distributions during the previous year, must be sent to the Maryland Medical Assistance Program, Division of Recoveries and Financial Services
 - i. Other state limitations on the uses and applications of self-funded special needs trusts include differences in what types of distributions are proper, to whom certain distributions are proper, what is defined as income, and what are exempt resources.
 - In New Jersey, if a person other than the disabled beneficiary is to receive a benefit from the trust, that individual must contribute back to the trust something of equivalent value.
 - Arizona, Maryland and Mississippi both bar payment to family members for personal care services
 - Arizona does not allow for travel expenses for a person accompanying the disabled beneficiary.
 - New Mexico prohibits disbursements to persons other than the beneficiary, as well as to disbursements to the beneficiary that benefit another.
 - Distributions for food and shelter are treated as income in New Jersey and Colorado; New Mexico will not approve a trust that allows for distributions for food, shelter or cash.
- 2. The Pennsylvania Rules of Civil Procedure explicitly permit the use of self-funded special needs trusts in resolving civil litigation. See Rules 2039 (minors), 2264 (incompetents), and 2206 (settlements in death cases where a minor or incompetent has an interest). See also, Local Rule 41.2 of the Rules of Civil Procedure for the Eastern District of Pennsylvania.
- 3. Where SSI eligibility is also an issue, and the beneficiary's own monies are used to fund the trust, the SSI Guidelines may consider the trust to be revocable (and thus an available asset) unless a contingent beneficiary is named.

C. Pooled Trusts - Authorized by 42 U.S.C. Section 1396p (d)(4)(C) and 62 P.S. Section 1965.1 et. seq.

1. Must use non-profit agency as Trustee.

2. Under the federal statute no payback is required, but resources remain in the pooled trust after the death of the beneficiary for the benefit of persons with disabilities. See discussion regarding payback from pooled trusts in the preceding section.

3. Examples of pooled trusts:

The Ardent Community Trust of Pennsylvania (ACT) (610) 265-4788

(King of Prussia)

The Family Trust, Achieva (412) 995-5000 (Pittsburgh)

III. Thorny Issues in the Creation and Maintenance of Special Needs Trusts

A. Creation of Special Needs Trusts - Preliminary Issues

1. Must state agency approval for the Trust be obtained?

- a. Is the money arising from litigation involving a minor or incapacitated person? In what county?
- b. What will the state agency require?
 - (i) notice of expenditure of principal
 - (ii) some limits on types of expenditures

2. Should you create a SNT if

- the beneficiary is marginally disabled?
- the beneficiary does not currently receive SSI or Medical Assistance, but may in the future?
- the trust corpus is relatively small -- can you spend down without losing eligibility (even if only for one month)? See, Mulherin v. Department of Public Welfare, 395 A.2d 40 (Pa.Cmwlth. 2007) (attorneys fees necessary to obtain medical assistance are proper debts to be excluded from calculations of resources in determining eligibility); Brobst v. Department of Public Welfare, 915 A.2d 160 (Pa. Cmwlth 2006)(discussing spenddown on medical expenses).
- the trust corpus is so large that SSI and MA could be irrelevant (and can the SNT be drafted in such a way as to pay out monies for food, shelter, clothing and cash payments until the beneficiary goes on to MA/SSI)
- Other health benefits are available (e.g. Medicare, tobacco settlement programs)
- Did the Affordable Care Act's provisions regarding elimination of restricted access based on pre-existing conditions reduce the need for Special Needs Trusts?

3. Whose money is it, anyway? OBRA-93 Trust vs. Common Law Special Needs Trust -- The Payback Issue
 - a. inheritance not yet paid out
 - b. injury settlement
 - c. past Social Security award
 - d. compensatory education fund
 - e. reversionary interest in property
 - f. can you combine - and is it ever wise to combine -- assets of the person with disabilities and assets of others?
 - g. life insurance companies are now marketing to families with persons with disabilities
4. What must the Trustee know about administering the Trust?
5. Must the Settlor have the legal authority to manage the assets of the disabled beneficiary? What are the differing demands of the state agency, SSA, local agencies?
6. What Social Security number do you use?
7. Who should be the contingent beneficiaries?
8. How do you obtain court approval for the court to act as settlor for the trust when no parent, grandparent or guardian is available?
9. Beneficiary issues
 - a. Should the trustee accede to requests which will quickly deplete the corpus?
 - b. Can principal be invaded? Will the state agency object?
 - c. How should the corpus be invested?
10. Can you keep a trustee happy if the beneficiary or his/her family is demanding? Issues can involve payment of fees to trustee, investment counseling, and supportive/intervention/casework services. Avoid reimbursement to families for purchases – pay vendors directly and/or provide a credit card to families.

B. Larger Trusts

1. Should you use a corporate or non-corporate trustee? If a private trustee is used, will an expensive bond be required? State agencies may require a bond of an individual (rather than a corporate) Trustee, especially for Self-Funded Special Needs Trusts.

2. Which corporate trustee is best? Issues to consider are fees, customer service history, knowledge of SNTs and disability issues, and investment strategies.
3. Financial demands upon the trustee by the beneficiary and the family can be vexatious, and can include salaries for family members to care for the disabled beneficiary, housing for entire family, family vacations, vehicles not specially designed for the disabled beneficiary, food, clothing, rent/mortgage, or cash for disabled beneficiary, furniture, electronic equipment, professional services.

C. Smaller Trusts

1. Trustee
 - a. Can you find a capable corporate trustee?
 - b. Will the Court appoint a non-corporate trustee in matters involving a minor or incapacitated person?

PA R.C.P., Rules 2039 and 2064 technically requires use of a corporate trustee, but counsel should also examine any available non-corporate trustee. Will the Court approve a family member, friend, financial planner, or attorney? Are conflicts of interest involved?

D. Payback Issues

1. Planning for payback during trust administration.
2. Dealing with the state agency at the termination of the Trust.

E. Fees in Personal Injury Cases Where Court Approval is Necessary

1. The payment to the attorney who drafts the trust should be charged as a cost of litigation and paid via the personal injury attorney.

F. IRAs

1. IRS Rulings
 - PLR 20060025 indicated that where a child with disabilities is named outright as the beneficiary of an IRA, the inherited IRA can be transferred to a separate IRA for that disabled beneficiary. The distributions from the new IRA would flow as income to the child's Self-Funded Special Needs Trust, thus allowing the child to avoid negative income tax consequences, and the child's life

expectancy can be used to calculate the required annual distributions from the IRA.

- However, PLR 201117042 indicated that a Special Needs Trust cannot itself own or maintain an IRA. Therefore, it remains questionable as to whether a mechanism exists to allow a person with disabilities to exclude the IRA itself from counting as a resource toward Medical Assistance and SSI benefits.

2. The Social Security Administration, the Department of Public Welfare and IRAs

- Both the SSA and DPW consider IRAs to be a "resource" which can disqualify an individual for Supplemental Security Income and Medical Assistance so long as it can be converted into cash, even if penalties or taxes are imposed upon such a conversion. But see, POMS of SSA at SI 01120.210(B) and (E)(1); SI 00510.001(B)(3), (D)(1) and (D)(4), all of which indicate that if a retirement program is subject to periodic payments, it may not be a resource. In any case, an IRA can generally be converted to cash, any taxes paid, and the remainder placed into a Self-Funded Special Needs Trust to allow for continued/future eligibility for benefits.

G. Structured Settlements - They may properly fund a Special Needs Trust, but care and planning is needed.

1. When deciding how to fund a Special Needs Trust with a Structured Settlement, it is important to initially fund the trust with sufficient "seed money" to address the following issues:
 - a) The Settlor should have a broad choice of corporate Trustees, but a minimal initial corpus will deter most such Trustees;
 - b) Sufficient resources must be immediately available to address unforeseen early needs of the beneficiary; and
 - c) The Trustee must have enough available resources upon the death of beneficiary to pay death taxes and the payback to the Department of Public Welfare.
2. Arrange for a commutation clause to be effective upon the death of beneficiary.
 - a) Otherwise, the Trust could remain open for years, and the estate may be unable to pay death taxes.
 - b) Carefully consider the residual beneficiary of a Structured Settlement, which funds the Special Needs Trust--The Department of Public Welfare now insists that the residual beneficiary be the Special Needs Trust, not a third party who could take the cash and evade DPW's payback.

- c) Structured Settlement Protection Act - 40 Pa. C.S.A. 4003, et seq., requires court approval of the sale or transfer of structured settlements.

H. Deficit Reduction Act of 2005 (enacted February 2006) Created Major Changes to the Social Security Act Regarding Elder Law Planning for Medical Assistance - No apparent effect on Special Needs Trusts

I. Medicare Part D Drug Plan For “Dual Eligibles” Who Also Receive Medical Assistance

- 1. There is less need to create a Special Needs Trust for some persons dually eligible for Medicare and Medicaid where larger settlements are involved, because Medicare recipients can 1) purchase Part B (doctor visits) at modest cost, and 2) privately pay for Part D's exclusions together with any Medicare deductibles and co-pays.

J. Fixing “Broken” Trusts

- 1. The Department of Public Welfare and the Social Security Administration are reasonable in reforming broken trusts so long as a new payback trust is created, which gives Department of Human Services prior notice regarding principal expenditures--even where the Trust is purportedly irrevocable.
- 2. A beneficiary or representative could also petition the court to reform the defective trust.
- 3. The Structured Settlement Protection Act can be used to transfer payments to a payback trust where the periodic payments disqualify a disabled beneficiary from public benefits.
- 4. Notice must be given to all beneficiaries and their approval obtained, and ideally such notice and consent should extend to residual beneficiaries

K. Effect of Special Needs Trust On:

- 1. Section 8 Housing (generally no disqualification, as the regulations focus mostly on income, not assets, and the law is murky) - See, 24 C.F.R. § 5.603(b)(2) - (value of irrevocable trust funds will not be considered an asset so long as the fund continues to be held in trust, and no members of the family or household have control of the trust. However, any income distributed from the trust is counted when determining annual income under 24 C.F.R. § 5.609); See, also 24 C.F.R. § 5.603(b)(3) - (value of any business or family assets disposed of by an applicant or tenant for less than fair market value, including a disposition in trust, during the two

years preceding the date of application for the program or reexamination is considered part of net family assets).

2. Food Stamps - 7 C.F.R. § 273.8(e)(8) - (resources having a cash value which is not accessible to the household, such as irrevocable trust funds, are excluded from the resources of a household).
3. General Assistance (usually received by recipient while awaiting Supplemental Security Income determination)-DPW will disqualify for assets in Trust despite regulations which appear to exclude Special Needs Trusts -- See, 55 Pa. Code § 177.23 (only resources which are legally available to the client are applied to the resource limitation); and 55 Pa. Code § 177.2 (legally available resource is defined as real or personal property or interest property which a person has, or can make available for his use, including partial interest in property which a person has the right, authority and power to liquidate).
4. Support Obligations: Ricco v. Novitski, 874 A.2d 75 (Pa. Super 2005) (The existence of a Special Needs Trust for a child with disabilities is not a factor in determining the support obligations of the parents of the child, and a parent cannot evade support obligations due to the existence of a Special Needs Trust). Mercer v. Rush, 928 A.2d 294 (Pa. Super 2007) (Distributions from discretionary Special Needs Trust to father of minor child may be considered "income" in calculating father's support obligation). Query: How do these cases relate to the broad familial support obligations under Act 43 of 2005, 23 Pa. C.S.A. Section 4601 et seq.?

L. Rapid Spend down

1. Use to maintain SSI and/or Medical Assistance without use of a payback trust.
2. Must purchase assets for fair market value (keep receipts).
3. Spend down in calendar month of receipt.

4. Caution: a Social Security Administration caseworker may disqualify anyway--be proactive with the caseworker if necessary

M. How Does a Court “Create” a Trust Where No Parent, Grandparent, or Guardian is Available?

1. The court acts only as the technical Settlor
2. The court need not sign the Trust but should issue an order approving the Trust
3. Review the Trust to make sure that it is consistent with the court acting as Settlor, e.g. the “\$20 rule” required by Social Security Administration (no judge will pay the \$20!)

N. Social Security Administration Idiosyncracies

1. Trust must be created by a person with right to manage the monies of the beneficiary, (i.e., “The \$20 Rule”)
2. Trust must have a named contingent beneficiary
3. Cannot use Trust for funeral or burial of a deceased beneficiary except via prepaid funeral/burial plans
4. In-Kind-Support-and-Maintenance Rule (IKSM) and Presumed Maximum Value Rule (see below)

O. Payments for In-Kind-Support-and-Maintenance

1. Presumed Maximum Value Rule limits reduction of SSI to about 1/3 of SSI regardless of the amount of IKSM actually paid.
2. The Trust should not put cash in family’s account to pay for shelter; rather the Trust should directly pay vendors;
 - Reimburse the family for receipts of actual payments already made; or
 - Provide to the family a credit card where feasible.

P. Payments to Family as Caregivers - Court approval should generally be obtained.

1. Reasonable rates must be used and should reflect replacement of lost income of the caregiver.
2. Who is the employer for withholding, workers compensation, unemployment, etc?
3. Will a medical license of some type be required?

Q. Purchase of Homes - Obtain approval of Court and Department of Public Welfare

1. The house should be titled in the name of the Trust.

2. The use of the home will likely be considered In-Kind-Support-and-Maintenance subject to the Presumed Maximum Value Rule, as will taxes and essential utilities.
3. Will the Trustee agree to manage property?
4. What if the property declines due to neglect or due to declining property values?
5. Will the court require the beneficiary's family to pay some rent/expenses?

R. Expansion of the Pool of Available, Competent Corporate Trustees since 1993

1. Both commercial and non-profit fiduciaries
2. Caution - Trustees sometimes request provisions in the Trust which limit their liability and allow the Trustee to use Trust resources to pay for extensive outsourcing of typical Trustee services from the Trust, but some courts are unwilling to approve these provisions.