

Types of Special Needs Trusts and Public Policy Considerations

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1. The Special Needs Trust Approach.

The special needs trust is often a good approach when a person has a disability. However, it is not appropriate in all circumstances. If a person with disabilities does not have a guardian and is able to manage his or her own finances, keeping the money and property in his or her own name is certainly the most straightforward approach. This approach also gives the person with disabilities the most independence and control over his or her own finances. This would not be a good approach, however, if a person has difficulty handling money. Also, whether or not a person has difficulty with money, having property in one's own name can cause disqualification from vital public benefits including Social Security Supplemental Security Income (SSI) and Medicaid. Even if a person does not receive Medicaid at the present time, it may be vital later as a safety net. Whether the money or property pertaining to the person with disabilities is an inheritance, a personal injuries settlement, a social security lump sum payment or funds raised in a community for a person with disabilities, disqualification can occur when funds are held in the name of the person with disabilities receiving needs-based public benefits.

A special need trust is not an ideal solution in all circumstances, and it must be structured to follow complex rules, but for many people it is the best alternative. Other options to consider include NH MEAD accounts and ABLE Act accounts. These types of accounts can be used in addition to special needs trusts. The first step with special needs trusts is to determine the type of special needs trust to use.

2. Types of Special Needs Trusts.

There are several different types of special needs trusts to choose from, and there are various names such as “supplemental needs trust,” “discretionary trust” and “spendthrift trust” which are sometimes used in addition to the name “special needs trust”. Regardless of the label, look at how the trust is designed to function.

All trusts are “management trusts” in the sense that someone is managing the trust. Special needs trusts are also typically “discretionary trusts” to give the trustee discretion to decide about investments and distributions, allow use assets (such as real estate, motor vehicles and furniture), have an anti-alienation (“spendthrift”) clause to protect the trust from claims, and state that the trustee may not duplicate public benefits (“supplemental needs trust”). Also, special needs trusts often provide examples of what the trust could purchase for the person with disabilities. Most trusts for people with disabilities have these features in common. The fundamental differences among the different types of trusts for people with disabilities arise from (1) the question of where the assets come from, (2) the question of whether the trust is created under state law or under federal statute and (3) the question of who the trustee is. These distinctions are very important in terms of whether the trust is a “third-party” trust or a “self-settled” trust, in terms of whether the trust (if it is a federal statutory trust) is a “subsection (A) trust” or a “subsection (C) trust” under 42 USC 1396(d)(4), and also in terms of whether the State may make a claim when the person with disabilities dies to be reimbursed for Medicaid benefits provided to the person with disabilities prior to death.

a. Trusts Established with Assets of Parents or Other Party (called Third Party Trusts).

If the assets in the trust came as a gift or inheritance from parents or someone else and are not considered to have been owned by the person with disabilities before going into the trust, then the trust may be considered to be a “third party trust.” These third party trusts are established under state law principles and constitutional concepts of the right to pass on property as a decedent determines. This is the traditional law school scenario where P, a trustor parent, leaves a specified limited interest in property in trust with T, the trustee, for the benefit of child A for life, with the remainder going to child B upon child A's death. P the parent has not given a fee simple absolute to child A, but merely a specified limited interest which child A has no right to apply to child A's debts or child A's estate. At child A's death, child A has no rights left in the property. The trustor's intent is paramount. See Heckler v. Turner 470 U.S. 184, 200, 105 S. Ct. 1138, 84 L.Ed. 2d 138 (1985), which prohibited “imputing financial support from persons who have no obligation to furnish it or by overvaluing assets in a manner that attributes nonexistent resources to recipients.”

Clifton B. Kruse, Jr. in Third-Party and Self-Created Trusts, American Bar Association. (3rd Ed. 2002) at p. 82, summarized third party trusts as follows, after surveying third party trust cases across the country:

Discretionary supplemental care trusts providing for the needs of beneficiaries not supplied by way & of public benefit programs, created by non-beneficiary settlors, appear to be legal, appropriate, and encouraged by both state common law and statutes. These trusts are sensitive responses by caring family members or others to make available to the chronically ill and disabled community the extra needs, beyond basic support, that such beneficiaries reasonably require or from which greater comfort can be achieved. A number of cases have been construed where the discretionary-extras trust has been clear as to the settlor's intent. Where supplemental trusts have been considered by courts and no support duty to the beneficiaries is owed by the settlors, and where the funds used are in fact not the funds of the beneficiary, there is no suggestion that such trusts violate public policy. Conversely, such trusts appear to be encouraged. To hold otherwise would eliminate a necessary source for the satisfaction of the uncompensated realistic and reasonable needs of the chronically ill and otherwise institutionalized disabled.

b. Trusts Established with Disabled Individual's Assets, Including Personal Injury Awards (called Self-Settled Trusts).

Self-settled trusts are established with assets already owned by the person with disabilities. One example would be a personal injuries settlement. Another example would be a lump sum social security check paid to correct for prior lack of periodic payments to a person with disabilities who should have received them. This often occurs when a person is first found qualified to receive social security monthly checks and the finding relates back to an earlier onset of the disability. A self-settled trust could also be the appropriate type of trust if a person with disabilities has already received a gift or inheritance outright and then establishes a special needs trust.

Also, at times, what would otherwise be a state law third-party trust is converted or instead established as a self-settled trust in order to come under the “safe harbor” of 42 USC 1396p(d)(4) and 42 USC 1382b(e)(5). Sometimes people prefer the safe harbor protection of the federal statute compared to state law. So a federal statutory trust might be chosen by parents for an inheritance even though they could instead have chosen a common law third-party trust.

Self-settled trusts are typically established under the federal statutes 42 USC 1396p(d)(4) and 42 USC 1382b(e)(5). In 1993 Congress enacted 42 USC 1396p(d)(4) providing a uniform protection for special needs trusts in the context of Medicaid. In 1999, Congress enacted 42 USC 1382b(e)(5) to apply the same uniform protection in the context of Supplemental Security Income (SSI).

The language used in both statutes calls for three separate types of statutory special needs trusts all of which are not counted against Medicaid or SSI eligibility: (A) the federal pay-back special needs trust established under 42 USC 1396p(d)(4)(A); (B) the Miller income-only special needs trust (not applicable in most instances); and (C) the not-for-profit pooled special needs trust established under 42 USC 1396p(d)(4)(C).

The federal pay-back special needs trust established under 42 USC 1396p(d)(4)(A) must be established as follows: A trust containing the assets of an individual under age 65 who is disabled (as defined in 42 USC Section 1382c(a)(3)(A)) and which is established for the benefit of such individual by a person with disabilities or a parent, grandparent, legal guardian of the individual, or a Court, if the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance; paid on behalf of the individual, subject to hardship considerations under 42 USC 1396p(d)(5), and then the balance may be inherited by persons selected by the trustor or as determined by the laws of intestacy.

The not-for-profit pooled trust established under 42 USC 1396(d)(4)(C) authorizes and requires a not-for-profit organization to be trust manager. The not-for-profit pooled trust may be established and funded for an individual with disabilities at any age (unlike the 42 USC 1396(d)(4)(A) federal pay-back trust which requires both establishment and funding prior to age 65.) Also (like the 42 USC 1396(d)(4)(A) federal pay-back trust), the not-for-profit pooled trust may be established by an individual with disabilities or by a parent, grandparent, legal guardian or Court.

In addition, with the not-for-profit pooled trust, the funds are pooled for investment purposes with other accounts, but separate accounts are maintained for each beneficiary and each beneficiary's funds are allocated to that beneficiary alone while living. Then, at death, remaining funds may be retained by the nonprofit organization for the benefit of other people with disabilities as a priority over other claims including the State's claim for Medicaid reimbursement. The ability of the not-for-profit pooled trust to retain funds, which would otherwise have gone to the State, differs from the federal statutory pay-back trust which contains no such “retaining language.”

To the extent that funds which belonged to the beneficiary before going into the trust are not retained by the nonprofit trustee to benefit other people with disabilities, then the State has the

opportunity to make a claim for reimbursement for Medicaid funds provided, subject to hardship considerations under 42 USC 1396p(d)(5), and then the balance may be inherited by persons selected by the grantor or as determined by the laws of intestacy.

There are a number of non-profit organizations established around the country to provide special needs trust management including New Hampshire's Enhanced Life Options Group whose website is www.elonh.org.

Families across the country have selected not-for-profit organizations as special needs trust managers basically because: (1) a trust manager with knowledge of disabilities issues can add value beyond financial arrangements; (2) a non-profit trust manager can handle the trust in collaboration with or under the supervision of a family member, professional advisor or bank trustee; (3) a non-profit trust management organization is established to continue indefinitely whereas relatives and individual advisors are mortal; (4) a not-for-profit pooled trust can accept funds after the beneficiary is 65 years of age; and (5) not-for-profit organizations are specifically referenced in the federal law governing Medicaid and social security as permitted special needs trust managers.

Since the beneficiary of a special needs trust may not serve as trustee, one or more family members may come to mind to serve as trustee. Often, however, no family member comes to mind who is available, or the family member being considered is a generation or two older than the beneficiary, and may not be living when the beneficiary may most need the trust. Sometimes a family member wants to be involved but does not have the time to actually manage the trust.

The directors of these not-for-profit special needs trust organizations include people who have a person with disabilities in their family and people who are active in the disabilities community.

They are typically 501(c)(3) public charities, and are bonded, audited, charge non-profit fees and receive grants and gifts. No minimum or maximum asset balance is typically required to be eligible for services, and services are available regardless of the specific type of disability. These non-profit groups have their own websites, such as, for example, New Hampshire's Enhanced Life Options Group's website at www.elonh.org.

3. Legal References Concerning Special Needs Trusts.

There are a number of statutes, regulations and other reference materials relevant to special needs trusts to consider in addition to your own State's statutes. Currently relevant federal statutes are found on the US Government Printing Office at <http://www.gpoaccess.gov/>.

The **federal Medicaid statutes** to start with are 42 USC 1396 et seq including 1396a(10)(C)(i)(III). The **federal SSI statute** to start with is 42 USC 1382b(e)(5).

The **federal Medicaid regulations** at 42 CFR 435 are available at <http://www.gpo.gov/fdsys> and **federal SSI regulations** at 20 CFR 416 are now available at <http://www.gpo.gov/fdsys>.

Start with 20 CFR 416.1102, CFR 416.1121(h) and 20 CFR 416.1103. To access these

regulations go to <http://www.gpo.gov/fdsys> homepage, then go to Search Government Publications, and then type in the regulation in the search box.

The **federal SSI regulations** pertaining to SSI are also currently found at http://www.ssa.gov/OP_Home (then go to Code of Federal Regulations (CFR), then to number 416).

In the context of Medicaid, extensive interpretive guidance is also provided by the US Centers for Medicare and Medicaid Services in the **US CMS State Medical Manual** (also referred to as Section 3259 of Transmittal No. 64, November 1994). Section 3259 may be found at Appendix C of Clifton B. Kruse, Jr. *Third-Party and Self Created Trusts* American Bar Association (3rd Ed. 2002).

The Social Security Administration's **Program Operations Manual System (POMS)** is currently available online at http://www.ssa.gov/OP_Home (then go to The Program Operations Manual System (POMS), then go to the Table of Contents, then go to SI-Supplemental Security Income, then go to SI 008 and SI 011). The POMS have extensive interpretive guidance on special needs trusts.

Also, the Social Security Administration **SSI information release** entitled “Spotlight on Trusts” is currently available at www.socialsecurity.gov/ssi/spotlights/spot-trusts.htm. This “Spotlight on Trusts” specifically states: “Money paid directly to someone to provide you with items other than food and shelter does not reduce your SSI benefits. (Items that are not “food or shelter” include medical care, telephone bills, education, entertainment, etc.)”

The Centers for Medicare and Medicaid Services (CMS) also has a **CMS Medicaid reference document** recognizing special needs trusts at https://wayback.archive-it.org/2744/20110818213338/http://www.cms.gov/MedicaidEligibility/11_TreatmentofTrusts.asp

New Hampshire adopted a helpful special need trust law in 2007, **RSA 167:4 V**, which provides as follows:

Distributions of the income or principal, or both, of a special needs trust to or for the benefit of the disabled beneficiary shall be disregarded for income eligibility purposes of all categories of public medical assistance to the same extent that such distributions are disregarded for purposes of Title XVI of the Social Security Act. Funds expended by a trustee of a special needs trust to purchase or maintain assets owned by the trustee in his or her capacity as trustee of the trust shall also be disregarded for such income eligibility purposes. For the purposes of this paragraph ‘special needs trust’ means any trust established by a third party for the sole benefit of an individual who is considered disabled under the provisions of section 1614(a)(3) of the Social Security Act, and any trust funded with the resources of such an individual and complying with the provisions of section 1917(d)(4) of such Act.

This state law confirms that New Hampshire decisionmaking about what individuals and special needs trusts can buy, when people are receiving medical assistance under the Medicaid program,

must be in line with the federal SSI distribution standards and must be no more restrictive than the methodology used in the SSI program in accordance with 42 USC 1396a(a)(10)(C)(i)(III).

4. Special Needs Trust Public Policy Considerations.

People with severe disabilities, such as a developmental disability, physical disability, mental illness or brain injury, often must rely on federal and state benefit programs in order to meet their minimal health care and physical support needs. Annual health care costs for these individuals are substantial. The public benefits serve as an economic safety-net, usually including a combination of cash payments (such as SSI) and certain health related benefits (including Medicaid). Medicaid covers many medically related expenses, such as prescription drugs, and is required in order to assist individuals to access other necessary programs, such as personal care assistance or direct care support in order to live.

Eligibility for these benefits is based on two factors: 1) definition of disability; and 2) financial need. Essentially, individuals must be poor and stay poor in order to be eligible. Gifts and inheritances from a parent or sibling or life insurance benefits from a deceased parent or sibling can terminate these benefits, ultimately resulting in an individual's loss of health care and disability-related support needs. People with disabilities must maintain Medicaid as their economic safety-net, but doing so limits their ability to accumulate resources, leading to life-long impoverishment. Personal and family funds are almost never able to replace public benefits. Public benefits do not claim to provide all that is necessary to provide what a person in ordinary life assumes to be the minimum. People are handicapped by a lack of resources available to them. From a public policy standpoint, there needs to be a way that families can help families and people can help other people in partnership with public programs.

The special needs trust is a mechanism which allows individuals and families to shelter resources for the purpose of enhancing the individual's quality of life and help with gaps in the public benefits system. Trusts established by family members accumulate resources for items and services not funded through state and federal programs for a specific beneficiary. Special needs trusts allow for a partnership between family funds and public funds.

Special needs trusts fulfill a number of specific functions for people with disabilities. Special needs trusts hold assets which are specifically allocated for the beneficiary but managed by an independent trustee. These trusts are in-between (1) the concept of outright ownership of assets, on the one hand, and (2) the concept of eligibility for public benefits on the other hand. As a result, special needs trusts can be used to address public policy goals. Special needs trusts are fundamentally a way to prevent a stark and arbitrary line between eligibility and ineligibility for benefits.

Special needs trusts are established for people with disabilities for a number of reasons: (1) to hold lump sum social security checks (paid where warranted to correct prior lack of delivery of periodic payments to a person with disabilities who should have received them) so that the lump sum can be saved for future use and not required to be spent down quickly to prevent loss of disability benefits based on financial eligibility criteria; (2) to have a permitted place to put funds raised in a community when someone has a tragic, debilitating injury, and neighbors, service

clubs, community leaders, extended family members, and friends want to raise money to make a difference in that person's life; (3) to receive personal injuries settlements so that a person with disabilities can be compensated for a permanent injury caused by another; and (4) to permit an inheritance to continue to do some of what the parents of a disabled child did for the disabled child before the parents died.

Without special needs trusts, lump sums from social security could not be saved for the future; nor could community fund-raising work effectively to benefit people with disabilities. It is difficult to raise funds if donors feel that their contributions will make no difference other than disqualification from public benefits.

If people with disabilities who are receiving public benefits were not able to derive any effective benefit from recoveries from tortfeasors who have brought about the disabilities by willfully or negligently injuring them, then tortfeasors would be less deterred from causing others harm. People with disabilities in many instances would be cut off from seeking or obtaining redress if they could not actually benefit from the redress. When there is no effective Court access for perceived serious injury caused by another, then "self-help" leads to violence and the rule of law is undermined.

With regard to inheritances, special needs trusts give parents a realistic option other than disinheritance of a child with disabilities. There is no minimum or maximum amount required to establish a special needs trust. A small life insurance policy or savings account diligently built up can do a lot after a parent's death. Most people have a natural human desire to leave an inheritance for their children. In many people this nurturing instinct is demonstrably even stronger when the child has a disability. However, family funds built up over many years prior to the parents' deaths, could not benefit a person with disabilities if disqualification from public benefits would result from the inheritance and the inheritance had to be spent down until exhausted to replace the public benefits. Family money goes elsewhere in the event there cannot be any benefit for the child with disabilities. Money left to siblings in the hope that they will do what the parents have done for a family member with disabilities, can fail to achieve the intended result, due to the sibling's death, disability, divorce, debts or disinterest. For many families who are unaware of special needs trusts, death carries a poignant penalty following a lifetime of family sacrifice. Without the special needs trust, the parents' death causes an economic free-fall for a child with disabilities just at the time when the parents are no longer there to protect their child.

It must be remembered that involved families, whatever their standard of living, do spend considerable family resources to benefit a family member with disabilities. It all adds up over the course of a lifetime until the parents' death. The special needs trust continues this effort after the parents have died in partnership with public benefits. Disability does not have to mean impoverishment. Family money can help. The Medicaid safety net helps too but leaves out a lot. What Medicaid does cover sometimes is not enough to get the job done. For example: a basic Medicaid wheelchair - compared to a specialized one adapted for individual needs; occasional Medicaid funded transportation, when available, to doctors' appointments - compared to van ownership; tooth extraction paid for by Medicaid - compared to more comprehensive dental care.

When special needs trust funds are used to pay for items such as vans and wheelchairs, there is a reduction in public benefit expenditures as a result. Special needs trusts replace public benefits to an important extent (e.g.: a car or van purchase which reduces the need for Medicaid funded transportation; an adapted wheelchair which reduces the number of Medicaid funded wheelchairs). If special needs trusts were not a part of the picture, family money would by and large go elsewhere and public expenditures would increase. Special needs trusts provide a needed service for people with disabilities. Some examples show how.

George was born with cerebral palsy. His parents set up a special needs trust for him. George receives Medicaid. He is completely dependent on his family for many things. His parents are his care givers and do not work the same shift so one of them can stay at home with him. His trust has purchased special equipment to aid his motor skills. The trust has also purchased an adapted van so that his family can take him to activities and visits with friends and their extended family.

Bill, who has paraplegia, is establishing a special needs trust from a personal injury settlement. Bill receives Medicaid to survive but he basically has stayed in his small apartment and has gone nowhere except for the doctor's office. His special needs trust will be able to, purchase for him a used modified van and also pay for van insurance, registration and repairs to keep him on the road, so that he will be able to leave his apartment to see people he has not seen, and do things he has not done, in years. This trust will change his life by going beyond what the public benefits can pay for. He will also be able with his trust to purchase pictures to decorate his apartment.

Susan was born with Down syndrome. She relies on Medicaid. Her mother set up a special needs trust for her daughter's benefit before her mother's death. The trust has recently purchased a reclining chair for Susan's apartment. She has a very active day. When she comes home, she likes to sit in the chair and listen to music. She remembers that her mother did this for her. Her trust has also purchased other items for her which she enjoys very much. Susan's trust has also purchased a burial plot for her. Having a special needs trust has enhanced her life beyond what the public benefits have provided. This is her American Dream.

07/2017