

ESTATE PLANNING FOR PARENTS OF SPECIAL NEEDS CHILDREN

Bradley R. Coppedge

Hatcher-Stubbs

I. Estate Planning for a parent of a disabled or special needs child.

A. In General. Special care must be given to planning for a special needs child. “Special Needs”, for our purposes, means a child (whether a minor child or grandchild) who at birth or subsequently thereafter is mentally, physically, emotionally or developmentally impaired or disabled to such degree as would enable the child to be eligible, or potentially eligible, for means-tested public or governmental benefits.

A parent who has a special needs or disabled child has basically four (4) planning options:

(1) Effectively disinherit the child, and allow the child to rely solely on public benefits. This is not as harsh as it may sound in that if the parent’s wealth is modest, the child’s needs great, and there are other children to provide for, this may be a reasonable approach. The danger here is that there is no “safety net” for the future.

(2) Make an outright gift/bequest to child. This may be sufficient if the disability is minor, the need for public benefits is small, the parent has a small estate, and there are no other Heirs (spouse or children) to provide for. The downside of course is that any such gift or inheritance could negatively impact any public benefits the child is currently receiving, or potentially make the child ineligible for some period of time for the same if such public benefits were needed in the future.

(3) Distribute assets to a sibling for the benefit of the child. The risk here is the child to whom the money is given could spend it, misappropriate it, poorly invest it, or lose it to his or her own creditors.

(4) Special Needs Trust (SNT). A SNT is most often the best option. The primary purpose of a SNT is to qualify the child for public assistance, means-tested programs, and provide discretionary and supplemental benefits to enhance the child’s

lifestyle. SNTs may be created in life or at death by a third party for the disabled individual, or may be “self settled” trusts if created with the funds of the disabled person.

B. Basic Documents. Parents of a disabled or special needs child should generally have the following estate planning documents in place for each parent:

1. Last Will and Testament
2. Power of Attorney
3. Advance Directive for Health Care
4. Guardianship/Conservatorship for child if child is of legal age
5. SNT (stand alone or through Last Will and Testament).

In addition, once the child is of legal age (18), the child, if competent, should have a Will, Power of Attorney and Advance Directive documents. Bear in mind that even if a child has a disability, the threshold or test for “competency” to execute these documents is lower than in determining capacity to contract. If the child is not competent, a guardianship and conservatorship should be in place.

II. Types of Special Needs Trusts (“SNTs”).

There are two broad categories of SNTs: Self-settled trusts, which are created by (or on behalf of) and with the assets of the special needs individual, and 3rd party trusts which are created and funded with the assets of someone other than the special needs individual.

A. Self-Settled Special Needs Trusts.

Federal law provides special authority for self-settled SNTs, set forth at 42 U.S.C. §1396p(d)(4)(A) [“payback trusts”] and (d)(4)(c) [“pooled trusts”], and at 42 U.S.C. §1382b(e)(5). Most self-settled trusts are referred to as (d)(4)(A) trusts.

A self-settled trust is established with the assets of a person with a disability. It is generally established by the parent or guardian, the disabled person, or under the direction and authority of a court.

The trust must only benefit the disabled or special needs beneficiary, must be irrevocable, must be for a person under 65, and upon their death, the assets remaining in the trust must first be used to repay any state Medicaid agency which provided benefits to the disabled person, with any remaining balance disposed of in to remainder beneficiaries in accordance with the terms of the trust. In addition, upon the creation of such a trust, any existing Medicaid liens must be dealt with.

Once these issues have been addressed, the beneficiary will qualify for means tested public support, and the trust may be used for additional and discretionary support.

These types of trusts are more frequently used when a person who has sustained traumatic injuries receives money as the result of a lawsuit. As such, this outline will not go into further detail on these trusts.

B. Third Party SNTs.

Third party trusts require no enabling federal legislation, as they are trusts created for a disabled or special needs beneficiary with the funds of another party by way of a gratuitous transfer made in life or at the death of the donor.

Third party SNTs may be created, or added to, by anyone (other perhaps than by the beneficiary). It is generally created by a parent, with the goal being to utilize the parent's assets to enrich the life of a child with a disability or special needs, while still preserving the availability of important public benefits.

Unlike a self settled trust, there is no concern with existing Medicaid claims, there are no age limits and no pay-back provisions to state agencies. Such a trust will not count against the beneficiary who will then be available to receive means tested public support, with the trust funds utilized for educational and discretionary support and lifestyle improvement. However, like a self settled trust, income should not be paid directly to the

beneficiary as doing so may reduce or eliminate the public benefits the beneficiary could otherwise be eligible to receive.

* It is imperative that a third party SNT be properly drafted to be purely discretionary, supplemental and NOT provide for Medicaid pay-back provisions!

* It is equally important that upon the death of the beneficiary, the assets are distributed to persons determined by the donor of the trust. At most, the beneficiary may have a limited power of appointment to appoint the residue at his or her death under his or her Will to others, but not to his or her estate or creditors; otherwise, Medicaid could make recovery against it, defeating the purpose of having established the third party trust.

III. Discussion Issues.

A. Means Tested Public Benefits.

In both types of SNTs, the trust assets are used to supplement the beneficiary's lifestyle rather than to replace public benefits.

Bear in mind the particular special needs or the degree of disability when considering either type of trust, however. If the utilization of means tested public support programs are not anticipated to be needed during the beneficiary's lifetime, there is no need to create a SNT (as compared to a "regular" trust). But if there is any reasonable basis for believing such public benefits will be needed, a SNT should be utilized.

"Means Tested" public benefits include the following:

- SSI (supplemental security income) – provides monthly income to eligible individuals
- Medicaid – medical payment program for disabled individuals and ancillary services which may include housing, personal care, etc.

- Section 8 Housing
- Food Stamps
- Group Homes (generally Medicaid funded)
- Misc. other programs

The following are not means tested:

- SSDI
- Medicare
- Special Education

B. SNTs compared to other trusts.

The key behind a SNT is that the assets are not “available” to the disabled or special needs beneficiary, thus qualifying the person for public benefit programs. This is why the drafting of a SNT must be handled carefully, to avoid the trust being able to make significant distributions directly to the beneficiary, or otherwise having the trust treated as a general support trust. For example, a trust that provides the funds can be used for the health, maintenance, support and education of a beneficiary is generally a support trust if not otherwise limited. This standard is an “ascertainable” (or determinable) standard, on which distributions may be compelled to meet the standard. As such, the assets are “available” to the beneficiary and will jeopardize public benefits if not limited and carefully drafted.

Even a “purely discretionary” trust, in which the trustee has sole and absolute discretion regarding payments to or for the disabled or special needs beneficiary, or even a “discretionary support trust”, can cause problems, as some state courts have held that the exercise of such discretion is rarely absolute and must be exercised in a reasonable manner, otherwise the purposes of the trust may be thwarted.

Due to this, it is essential, if it is your intent to create a third party SNT, that you have the trust document or your Will professionally drafted by a competent estate planning attorney familiar with the issues.

What if the proposed beneficiary is not currently receiving means-tested benefits such as SSI or Medicaid? A SNT may still be the best choice, especially if these benefits are contemplated as being needed later in life. In addition, a third party SNT will serve to protect the disabled or special needs child from his or her inabilities, disabilities, creditors and predators.

C. Distributions.

1) In general.

A SNT must be not only properly drafted, but distributions must be handled properly to not jeopardize public support. In general, this will mean disbursements should be made directly to third parties engaged, hired, or provided under the trustee's direction, and not at the direction of the beneficiary.

Any significant assets purchased by the trust for the beneficiary (house, car, etc.) should be titled in the name of the trust, and not in the name of the beneficiary.

2) Examples of Discretionary Distributions.

By having either type of SNT in place (self settled or third party) the lifestyle of the beneficiary can be greatly enhanced, while preserving eligibility for valuable and important public benefits. Some of the discretionary/supplemental expenditures that can be made with a SNT without jeopardizing or losing the public benefits include the following:

- i) medical services or equipment not covered by governmental program
- ii) domestic and personal care services (housekeeper, meal prep, companions/sitters)
- iii) computer and internet

- iv) T.V. and other electronic equipment
- v) clothing
- vi) a vehicle used for transport
- vii) membership in recreation clubs
- viii) academic or recreational courses or classes
- ix) home décor, furniture, etc.
- x) home expense
- xi) stationary
- xii) phone and phone services
- xiii) therapies not covered by benefits programs
- xiv) tickets to cultural or sporting events
- xv) vacations

D. Trustee.

Neither the beneficiary of a SNT, nor his or her spouse, should serve as Trustee, due to certain SSI and Medicaid rules.

E. Use of Life Insurance to fund a SNT.

An estate tax planning method in common use is what is known as an Irrevocable Life Insurance Trust. From an estate tax planning perspective, the benefit these trust offer is the ability to keep life insurance proceeds from being included in the estate of the owner, such that they incur no estate tax.

Apart from estate tax planning, life insurance is an excellent funding mechanism for SNTs. First, it frees up other assets to be used to benefit the surviving spouse or other children. Second, it can help insure there are adequate funds available to meet the needs of a special needs beneficiary upon the death of a parent.

Life insurance could be purchased on the lives of one or both parents as a 10, 20 or 30 year term policy, or as a second to die policy.

F. Custodial Accounts - Use of UTMA accounts. Placing funds in a UTMA account for a minor beneficiary who has a disability or special needs is not an effective planning method if means-tested public support is or will be needed. Generally, the funds will not be treated as “available” prior to age 21, such that there is no immediate disqualification from public benefits. However, upon attaining age 21, the child is legally entitled to the funds. As such, they are “available” by age 21, and will jeopardize means-tested public benefits.

This outline is intended to serve only as an overview of the topics contained herein and was provided as a courtesy to our friends and clients, not as legal advice or a legal opinion. You should consult with your attorney for specific legal advice.