

**ESTATE PLANNING FOR A SPECIAL NEEDS CHILD:**

**A PARENT’S GUIDE**

If you are the parent of a child who will need lifelong financial support, there is a good chance that some part of that support will eventually come from state or federal benefits. Many such benefits are *means-tested*; in other words, they are payable only if the recipient has less than $2,000 in countable assets. How do you provide for a loved one whose ability to own assets outright is so severely restricted? The obvious solution is to use a special needs trust to hold funds that would otherwise be counted against the child. This material is designed to help you determine whether your estate plan should include a special needs trust, and to acquaint you with the basic characteristics of the two most commonly used types of special needs trusts.

**IS A SPECIAL NEEDS TRUST APPROPRIATE?**

Special needs planning is so important for the people who need it, and it is so complicated to do it properly, there is a tendency to focus on getting it done right without stopping to consider whether it needs to be done at all. In many cases, a special needs trust IS appropriate for your child with disabilities. But before you jump to that conclusion, you should ask the following questions:

**Is the child disabled for public benefits purposes?**

* A child under age 18 is considered disabled if he has a medically determinable physical or mental impairment that results in “marked and severe functional limitations.” 42 U.S.C. § 1382c(a)(3)(C).
* An adult is “disabled” for the purpose of determining whether that person qualifies to receive benefits if that person “is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months. The impairment must be so severe that the claimant is unable to do his or her previous work or any other ‘substantial gainful activity’ [i.e., paid work] which exists in the national economy.” 42 U.S.C. §§ 1382c(a)(3)(A), (B), 416(i)(1).

**Does the child presently receive any state or federal benefits?**

* If the child is under age 18 and receives Medicaid, it is likely to be because he qualifies for the Katie Beckett Deeming Waiver, which allows the child’s family assets to be disregarded for Medicaid purposes. However, it is possible that a young child may not receive benefits of any kind, even if he has a disability that will eventually allow him to qualify for benefits. This does not necessarily mean that a special needs trust is not appropriate for that child.

**If the child does receive benefits, are any of those benefits *means-tested*?**

* *Means-tested* benefits are benefits that are paid after the agency considers what assets are either owned by or available to the recipient of the benefits. If the recipient of means-tested benefits owns or has access to assets in excess of $2,000, the benefits will be lost. The two most common types of means-tested benefits are Social Security Insurance (SSI) and Medicaid.
* SSI is a federal welfare program, established under 42 U.S.C. § 1381 *et seq*. It pays a monthly benefit (up to $841 per month for calendar year 2022) for food and shelter. SSI payments can be reduced, or eliminated altogether, if a recipient has countable income or support from some other source. When a developmentally disabled child reaches age 18, he becomes a “household of one” and can get SSI based on his own resources (or lack of resources), even if he lives with a parent. Depending on circumstances, the child may or may not be eligible for SSDI as well.
* Medicaid is a federal program, administered by the states, that provides basic medical and hospital care, access to prescription drugs, and long-term care. It is established under 42 U.S.C. § 1396 *et seq*. Although in many cases a family’s assets are “deemed” available to a child who seeks benefits, there is a program in Georgia (and many other states) called the Katie Beckett program (created under 42 U.S.C. § 1396a(e)(3)) that allows a severely disabled child to qualify for Medicaid without regard to the parents’ assets. Medicaid benefits are subject to a payback requirement. This means that when a Medicaid recipient dies, the agency can seek payback from the recipient’s estate for every cent spent on that recipient during his lifetime. Medicaid often begins this tally of expenditures at age 55, but it has the right to seek reimbursement for benefits paid earlier in the recipient’s life. It is often critically important for a payee not to lose SSI, even if the dollar amount is small, because SSI in Georgia is linked to Medicaid. If a recipient’s SSI benefit is reduced to zero, that recipient will also lose Medicaid coverage until SSI is restored.

* Even if the child is not receiving benefits, or is receiving non-means-tested benefits like SSDI, it is good planning to establish special needs trusts for the child now if there is any chance that the child will get means-tested benefits in the future. There is no way to predict what benefits the child will receive later, and settling assets on the child now, or failing to plan for the child’s needs in a manner that protects his future assets from payback claims, could be disastrous. It is relatively easy to reform a special needs trust if the child turns out to be a fully functional adult. It is impossible to rescue assets that are owned directly by the child from Medicaid payback requirements.

**FUNDING THE SPECIAL NEEDS TRUST:**

**DIRECTING ASSETS TO THE CORRECT TYPE OF TRUST**

There are two main categories of special needs trusts: first-party trusts (also commonly referred to as “(d)(4)(A) trusts” or “self-settled trusts”) and third-party trusts. These two types of trusts have very different jobs, and each type has an important role to play in a comprehensive special needs estate plan. The primary distinguishing characteristic between the two is the source of the trust funds. A first-party trust holds assets that belong to the beneficiary. A third-party trust holds assets that belong to anyone other than the beneficiary. A brief discussion of each type of trust is below.

**First-party Trusts:** Federal statutory authority for a first-party special needs trust is found at 42 U.S.C. § 1396p(d)(4)(A). Because it is a creature of statute, it is subject to a great many restrictions and limitations that do not apply to third-party trusts. It is important to note the following characteristics of these trusts:

* A first-party special needs trust can only be created by a parent, a grandparent, a guardian, the trust beneficiary whose assets will fund the trust (assuming that beneficiary is competent to create a trust), or pursuant to a court order (usually in the context of a lawsuit that has resulted in an award of damages).
* A first-party special needs trust holds funds that belong to the trust beneficiary (“first-party” funds). “First-party” assets include anything that the trust beneficiary owns outright or has a beneficial ownership interest in. An incidental advantage to establishing a first-party trust is that it acts as a safety net to catch assets that would otherwise belong to the child outright and would therefore disqualify the child from receiving benefits. Examples include: assets in a trust that is not a special needs trust; intestate distributions; future tort settlements or surprise income; child support payments; and beneficial interests in life insurance or inherited retirement accounts.
* A first-party special needs trust must name the disabled person as the sole beneficiary during that person’s life, and it must include a provision that any assets remaining in the trust after the beneficiary’s death be used to pay back Social Security and Medicaid for expenditures made on the child’s behalf.
* A first-party special needs trust must be irrevocable.
* A first-party special needs trust cannot be created for a beneficiary who is over age 65, and no additional funds can go into the trust after the beneficiary turns 65.
* A first-party special needs trust must be *inter vivos* (created during the grantor’s life).

**Third-party Special Needs Trusts:**  There is no federal statutory authority for third-party special needs trusts, but they are recognized by Social Security and Medicaid, and they are honored if they are drafted properly. The following characteristics apply to third-party special needs trusts:

* A third-party special needs trust can be established by anyone except the trust beneficiary.
* A third-party special needs trust can be funded with funds that belong to anyone except the beneficiary. This makes it a useful planning tool for a number of reasons: 1) not only can the trust hold assets that belong to you, it can hold gifts from other friends or family members. 2) Once the trust exists, both parents (and other family members) can use it as part of their estate plan. They can have a pour-over provision in their Wills that puts testamentary assets into the trust, rather than giving those assets to the child directly.

* A third-party special needs trust has no payback requirement, so any assets that remain in the trust at the death of the primary beneficiary can go to any successor beneficiary, rather than being used to pay back Medicaid.
* A third-party special needs trust can be revocable during the lifetime of the grantor. Generally if the trust is revocable when it is signed, the trust document includes at least one triggering event that will cause the trust to become irrevocable. The most common triggering event is the death of the grantor, but trusts also often provide that the trust will become irrevocable when it holds assets above a certain dollar amount.
* A third-party special needs trust can be created for a beneficiary of any age.
* A third-party special needs trust can be either *inter vivos* (created during the grantor’s lifetime) or *testamentary* (created by the grantor’s Will). If the special needs trust is testamentary, it is not effective until the grantor’s death. A testamentary special needs trust is not ideal because it can’t be funded until it exists; this means that no one else in the family can leave or gift assets to the trust until after the grantor dies.

Estate planning for a family with a special needs child is more complex than estate planning for a family with typical children; however, if the proper trusts are used and funded, it is possible to care for a child whose support depends on keeping benefits in place.