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The Special Needs Trust Fairness Act of 2016

The Special Needs Trust Fairness Act allows individuals with a disability, and under the age of 65, to establish their own “payback” special needs trust. Prior to the enactment of this law, only a parent, grandparent, guardian or court could establish this type of “Medicaid exception” trust, which is authorized by 42 U.S.C §1396p(d)(4)(A). This change reflects

more than 20 years of advocacy on the part of the National Academy of Elder Law Attorneys and other advocates for persons with a disability.

This type of special needs trust allows a person to retain her Medicaid benefits while using the funds in the special needs trust for goods and services that are not covered by Medicaid. Those types of services may include dental care, eyeglasses, hearing aids, caregivers and more. The trade-off is that when the individual dies, funds remaining in the trust are used to reimburse the Medicaid program, up to the amount Medicaid paid for the individual’s care. This type of trust is often used for a windfall from a personal injury claim or perhaps an inheritance when the decedent failed to incorporate a third-party special needs trust in his estate plan.

The change is included in the “21st Century Cures Act” (P.L. 114-255). Section 5007 includes “Fairness in Medicaid Supplemental Needs Trusts,” which adds two words (“the individual”) to the law governing the payback trust for people under the age of 65. With those two important words inserted, the law now reads as follows:

(A) A trust containing the assets of an individual under age 65 who is disabled (as defined in section 1382c(a)(3) of this title) and which is established for the benefit of such individual by **[the individual]**, 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 under a State plan under this subchapter.

— 42 U.S.C §1396p(d)(4)(A).

Self-settled special needs trusts are an important planning tool for many individuals with disabilities who receive certain government benefits, such as Medicaid and Supplemental Security Income (SSI), and who receive funds from other sources, such as an inheritance or personal injury lawsuit. Without such a trust, these individuals would lose government benefits that are essential for basic living and medical expenses. Prior to enactment of this new law, individuals with disabilities who did not have a living parent or grandparent could not create their own self-settled special needs trust without going to court. This new law moves us forward in addressing the needs of many people with disabilities who can and should be able to handle their financial affairs without the need for court intervention or other obstacles that stand in the way.¹

Beware: Malpractice Landmine!

If the special needs trust described above were included in a third party’s estate plan, it would be considered malpractice. A “third party” is someone who decides to create a special needs

trust in his estate plan for another individual with a disability. For example, these third parties may be the individual's parents, siblings, grandparents, spouse, friends — anyone but the individual. When drafting a third party special needs trust, **do not include a payback provision.**

When a third party establishes a special needs trust for an individual with a disability, the third party is funding that trust with his assets and not those of the individual with the disability. In contrast, when an individual with a disability receives a windfall, that money belongs to the individual. Unless the windfall is set aside in a special needs trust authorized by 42 U.S.C. 1396p(d)(4)(A) or (C), then the individual will lose her Medicaid benefit and Supplemental Security Income (SSI).

A key process in correctly drafting a special needs trust is to determine and name the correct beneficiary upon the death of the individual with the disability. For trusts funded by the individual with the disability, the State² Medicaid program (up to the amount paid for the individual's care) must be named as the beneficiary upon the death of the individual with a disability. However, for trusts established as a part of a third party's estate plan, THEN, upon the death of the individual with a disability, the beneficiary should NOT be the State. Instead, the person who establishes the trust in his estate plan names the beneficiaries of his choice, such as his children or grandchildren.

For example, "Wilma and Fred Flintstone" requested a review of their estate planning documents by an elder law attorney. About a year before the meeting, they had met with their attorney, "Perry Masonry," and explained that Fred's father left \$400,000 to Fred so that Fred would use the funds for his disabled sister, "Roxy." Fred was

concerned about protecting these funds for Roxy's benefit in the event he were to die before Roxy. Fred explained that Roxy suffers from Alzheimer's disease and receives care at home through CHOICES (TennCare/Medicaid).


Perry, who has a fine reputation in estate planning, drafted a Will for Fred, which included a trust for Roxy. The Trust was titled as a "special or supplemental needs" trust. It provided that the funds in the trust are to be used for Roxy's sole benefit to provide for her needs above and beyond any means-tested government benefits to which she may be entitled. This language is fine and should be included in any special needs trust. Fred stated that Perry did not inform him that he was not required to name the State as the beneficiary but instead could name his family as the trust beneficiaries.

Unfortunately, the scrivener wrote that upon Roxy's death, if any funds remained in the trust, those funds were to be distributed to the State's Medicaid program. Yikes! Bear in mind that the funds belonged to Fred. Fred was not required to establish a special needs trust for Roxy in his estate plan. He chose to establish the special needs trust, but he preferred that his children receive any funds remaining at Roxy's death and not the State Medicaid program.

What could have happened if this mistake had not been remedied? Assume that Fred died first, and the personal representative of his estate distributed \$400,000 to the Trustee of Roxy's special needs trust. The Trustee used \$20,000 for Roxy's needs, and then she died.

The Trustee would have been required to contact the Bureau of TennCare to determine the amount of Medicaid dollars spent on Roxy's care. The Trustee would have been required to reimburse TennCare for that amount before making any distributions to the

residuary beneficiaries. If the State were owed \$380,000, then the residuary beneficiaries would not have received one penny of those funds. This is where a malpractice lawsuit would come into play. In this hypothetical, the attorney breached the standard of care causing damages in the amount of \$380,000. Obviously, this is an outcome we all want to avoid.

The Special Needs Trust Fairness Act provides an encouraging example of the growing recognition that "one size does not fit all" when considering the person with a disability's ability to take part in planning for future needs. The insertion of those two important words, "the individual," empowers persons with a disability with greater control over their destiny without incurring the additional expense and time once required to seek a court's approval for the establishment and funding of a "(d)(4)(A)" special needs trust. This change in the law is an opportunity to review the crucial issue of when a payback provision in a special needs trust is necessary, and when it is unnecessary, as we guide our clients through the public benefits maze. 

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Notes

1. Ford, Marty, "Two Small Words Bring Meaningful Change for Special Needs Trusts," Posted on Dec. 21, 2016 by *The Arc*, <https://blog.thearc.org/2016/12/21/two-small-words-bring-meaningful-change-special-needs-trusts/>

2. The Social Security Administration does not require reimbursement for SSI benefits.