

I. Introduction: Beginning at the End

When discussing special needs trusts with a client, one normally begins with distinguishing a third-party special needs trust from a first party special needs trust. Assuming the focus of the discussion is on first party special needs trusts, the foregoing would follow with the requirements to establish a first party special needs trust, one of which is to provide for reimbursement to Medicaid on termination of the trust. Although Medicaid's right to reimbursement from a first party special needs trust would no doubt be discussed with a client, it may not be given the attention it is due. This discussion is going to instead begin with and primarily focus on all things termination as it relates to a first party special needs trust. Hopefully, at the conclusion of the discussion, one will have a greater appreciation for the importance of beginning at the end, that is, ensuring that those contemplating a first party special needs trust arrangement enter into it knowingly when it comes to what happens at the time the trust terminates.

II. In the Beginning, . . .

How can it be that first party special needs trusts were codified more than thirty years ago?! It bears reviewing the originating legislation and developments in the law that have since followed with an eye towards the language surrounding termination of these trusts and Medicaid's right to reimbursement.

A. Omnibus Budget Reconciliation Act of 1993 (OBRA '93)

OBRA '93 carved out three critical exceptions to the newly penalized transfers into irrevocable trusts and the countability of the income and assets of such trusts pursuant to 42 U.S.C. § 1396p(d)(4), all of which require reimbursement to Medicaid on their termination as follows:

1. Under subsection (A), a "disabled under age 65" must provide that **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. A “disabled under age 65” trust arguably contends with reimbursement to Medicaid upon the death of the beneficiary more frequently than the other exempt trusts.

2. Under subsection (B), an “income-only or Miller” trust must provide that **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.** An “income-only or Miller” trust as this trust is commonly known or referred to is the least likely of the three exempt trusts to have anything remaining in the trust upon its termination.

3. Under subsection (C), a “pooled” trust must provide that, **to the extent that amounts remaining in the beneficiary’s account upon the death of the beneficiary are not retained by the trust, the trust pays to the State from such remaining amounts in the account an amount equal to the total amount of medical assistance paid on behalf of the beneficiary.** A majority of “pooled” trusts retain some portion or all amounts remaining upon the death of the beneficiary and, as such, reimbursement to Medicaid may not be at issue or, if so, limitedly so.

B. HCFA Transmittal 64¹

This famous transmittal of the Health Care Financing Administration (“HCFA”) now Center for Medicare and Medicaid Services (“CMS”) was published as guidance for State Medicaid Manual Chapter 3 Eligibility Sections 3257 to 3259.8, which sections addressed the transfer of assets and treatment of trusts post-OBRA ’93. With regards to Medicaid’s right to

¹ [The State Medicaid Manual | CMS](#). As recently as 2024, this manual was also available on the Department of Health and Human Services website but no longer is.

reimbursement from one of the exempt trusts established pursuant to 42 U.S.C. § 1396p(d)(4), the guidance of the transmittal essentially parrots the statute.

C. Foster Care Independence Act of 1999

OBRA '93 only affected eligibility for long-term care Medicaid. For the decade that followed, it was unclear whether the Supplemental Security Income (“SSI”) program recognized special needs trusts. The Foster Care Independence Act of 1999 caught up with Medicaid by not only providing for penalties for uncompensated transfers by SSI recipients,² but also adopting and mirroring the Medicaid special needs trust exceptions.³

D. SSA’s Programs Operations Manual System (POMS)

The SI POMS has gone through many iterations when it comes to special needs trusts and termination or Medicaid payback language, with the most substantial overhaul being in 2009. As it stands, the POMS is protective of Medicaid’s interests and requires a first party special needs trust to provide for repayment to the State Medicaid program all amounts remaining (but in the case of a pooled trust, only to the extent not retained by the trust) at the time of termination up to an amount equal to the total amount of medical assistance paid on behalf of the individual.⁴ The POMS broadly contemplates termination of a first party special needs trust and reimbursement to Medicaid and does not limit it to time of death but at any time during the lifetime of the beneficiary.

III. First Party/Self-Settled SNT Termination Provisions

A. Early Termination Provisions

Federal Medicaid law and regulations expressly provide for reimbursement to Medicaid from a special needs trust at time of death only⁵ while the SSA, as just noted, requires such a trust

² 42 U.S.C. § 1382b(c)(1)(A)(iv).

³ 42 U.S.C. § 1382b(c)(1)(C)(ii)(IV).

⁴ POMS SI 01120.203.B.8 and C.1.

⁵ See 42 U.S.C. § 1396p(d)(4)(A)-(C) and HCFA Transmittal 64 at *supra* note 1.

to also provide for reimbursement to Medicaid in the event the trust is terminated during the lifetime of the beneficiary.⁶ In so doing, the SSA speaks to why a special needs trust may provide for early termination, implying that these are the only permissible reasons for early termination: The beneficiary is no longer disabled or otherwise becomes ineligible for SSI and Medicaid, or the trust no longer contains enough assets to justify its continued administration.⁷ As such, specifically referencing the foregoing in an early termination provision may be advisable. One must also be mindful of and include in an early termination provision of a special needs trust the limitations imposed by the POMS on the payment of administrative expenses (i.e., state and federal taxes due, reasonable fees and administration expenses associated with the termination of the trust).⁸ What happens next if, after reimbursing Medicaid and paying administrative expenses as permitted, trust assets remain? They must be paid to the trust beneficiary!⁹

Despite federal Medicaid law and regulations limiting Medicaid's right to reimbursement from a special needs trust to time of death, some state Medicaid programs, Arizona's for one, have gone astray in also requiring reimbursement in the event the trust is terminated during lifetime¹⁰ and placing limitations on the payment of administrative expenses.¹¹ In this author's experience, which is limited to Arizona, its Medicaid program does not seek to be reimbursed from a special needs trust in the event the trust is terminated during lifetime if the beneficiary is solely

⁶ See POMS SI 01120.200.H.1.b. stating that "Medicaid trusts generally have a payback stating that upon termination of the trust, or the death of the beneficiary, the State Medicaid agency will be reimbursed . . ." and POMS SI 01120.199.E.1 that requires an early termination provision to provide for reimbursement to Medicaid.

⁷ POMS SI 01120.199.

⁸ See *id.*

⁹ See *id.*

¹⁰ See A.R.S. § 36-2934.01.A.1 which requires the trust to contain "specific language that protects the state's beneficiary interest in the trust and that names the administration or the state medicaid agency as the primary beneficiary of the trust **if the trust is terminated before or on the death of the member.**"

¹¹ See A.R.S. § 36-2934.01.B.1 that limits disbursements from a special needs trust to reasonable legal and professional expenses related to the trust not just at time of termination but throughout the entirety of the administration of the trust.

eligible for Medicaid by virtue of being eligible for SSI, i.e., is categorically eligible for Medicaid, but only if the beneficiary is eligible for long-term care Medicaid. The foregoing is ironic, to say the least, given the POMS's requirement to provide for reimbursement to Medicaid on early termination.

B. Termination at Death Provisions

When it comes to termination of a special needs trust upon the death of the beneficiary, no one questions Medicaid's right to reimbursement. Again, though, limitations on payment of administrative expenses prior to such reimbursement exist¹² and, payment of expenses of last illness, funeral and burial may not be made until after Medicaid has been reimbursed.¹³ In Arizona, if funeral and burial arrangements have not been made prior to the beneficiary's death, the trustee will be permitted to disburse up to but no more than \$1,500 for such expenses with the prior approval of Medicaid (through its recovery agent).

If trust assets then remain, who may be the residual beneficiary? That is a loaded question. From a purely estate planning perspective, whether or not the beneficiary is or may one day be mentally capable of doing their own estate planning, preserving their ability to do so with a limited power of appointment is an option.¹⁴ If this power is not exercised, then, presumably, the laws of intestacy will apply. If SSI eligibility is at issue for the beneficiary, a special needs trust may be presumptively revocable under state law if no residual beneficiary is named, thereby rendering the trust assets countable.¹⁵ So, it may behoove the drafting attorney to name a residual beneficiary of a nominal interest before providing for distribution by intestacy.

¹² See POMS SI 01120.203.E,

¹³ See *id.*

¹⁴ A general power of appointment is inadvisable as it may subject it to the claims of creditors of the beneficiary's estate.

¹⁵ See POMSSI 01120.200.D.3.

The question of a residual beneficiary for SSI purposes is a non-issue if Medicaid is considered the residual or contingent beneficiary. The POMS assert that, according to the law in most states, the State is not considered a residual or contingent beneficiary but, rather, a creditor and reimbursement to Medicaid is considered the payment of the debt unless the trust reflects a clear intent that the State is a beneficiary rather than a creditor.¹⁶ Who in their right mind would name Medicaid as a beneficiary?! Probably no one except when required to do so by Medicaid, which happens to be the case in Arizona.¹⁷

C. When All Else Fails. . .the Power to Amend

Even the most artfully crafted termination provision is bound to fail with the SSA or Medicaid eventually given changes in the law, regulation, policy, and the winds. With that in mind, a provision that provides for the power to amend a special needs trust is recommended. To ensure that a special needs trust is not rendered countable for SSI purposes, the power to amend should belong to someone other than the beneficiary and should be limited such that the trust assets are not considered available to the beneficiary for their maintenance and support.¹⁸ The power to amend should not be general or broad in nature, but limited, so as not to jeopardize its status as irrevocable in the eyes of the pertinent governmental assistance programs.¹⁹ For example, a limited power to amend could provide for amendments that ensure that the special needs trust continues to comply with the provisions of 42 U.S.C. § 1396p(d)(4), the POMS, and/or pertinent state Medicaid laws and regulations with the objective of ensuring the beneficiary remains financially eligible for public benefits or governmental assistance programs

¹⁶ POMS SI 01120.200.H.1.b.

¹⁷ See A.R.S. § 36-2934.01.A.1.

¹⁸ See POMS SI 01120.D.1.a.

¹⁹ Stating a special needs trust is “irrevocable” is not sufficient in and of itself for SSI eligibility purposes. See POMS SI 01120.D.e.

that are needs-based.

D. Third Party Special Needs Trusts

Keeping this short n' sweet--unless charitably inclined, do NOT provide for reimbursement to Medicaid as it is NOT required!

IV. The Nuances of Paying the Piper

No ifs, ands or buts, the time has come to pay the piper, so to speak--to at long last pay to “the State all amounts remaining in the trust up to an amount equal to the total medical assistance paid on behalf of the [beneficiary]” of the special needs trust²⁰ (other than from those amounts retained by a pooled trust). If the beneficiary leaves survivors who were the beneficiary’s caregivers and who may not have been compensated or compensated adequately for the care they rendered their loved one, the prospect of inheriting very little or nothing, is a harsh reality. Does no basis exist to deny Medicaid’s claim for reimbursement in whole or in part?

A. Medicaid Estate Recovery

Just as OBRA '93 created exceptions for special needs trusts from the transfer penalty rules and their countability for eligibility purposes, this very law also mandated the states to institute an estate recovery program to seek to recover from the estate²¹ of a Medicaid enrollee who was 55 years of age or older, at a minimum, payment for nursing facility services, home and community-based services, and related hospital and prescription drug services.²² States may not recover from the estate of a deceased Medicaid enrollee who is survived by a spouse, child under age 21, or blind or disabled child of any age. States are also required to establish procedures for waiving estate recovery when recovery would cause an undue hardship.²³

²⁰ See 42 U.S.C. § 1396p(d)(4)(A)-(C).

²¹ See 42 U.S.C. § 1396p(b)(1)(A).

²² See 42 U.S.C. § 1396p(b)(1)(B)(i).

²³ See 42 U.S.C. § 1396p(b)(2)(A) and (3).

The obvious question is whether the limitations on estate recovery also apply to Medicaid's right to reimbursement from a special needs trust. Unfortunately, case law has arrived at the consensus that the age limitation, survivor exemptions, and undue hardship waiver that apply to estate recovery do not to apply to a special needs trust.²⁴ The statutory schemes and requirements are distinct primarily in that the special needs trust exceptions allow for individuals to financially qualify for Medicaid who otherwise would not. As such, those who choose to avail themselves of a special needs trust exception are opting for that reimbursement arrangement rather than that of estate recovery.²⁵

B. Pre- and Post-Establishment of Special Needs Trust

Logic would have it that the requirement to reimburse Medicaid from a special needs trust would be limited to medical assistance paid from the time the trust was established. But who says logic is at play here? To the contrary, Medicaid's right to reimbursement from a special needs trust is not limited in duration and dates back to when the beneficiary was first eligible for and receiving such medical assistance. Take the POMS, for instance, which leaves no ambiguity on this point: "Medicaid payback . . . cannot be limited to any particular period of time; for example, payback cannot be limited to the period after establishment of the trust."²⁶ Case law follows suit finding that 42 U.S.C. § 1396p(d)(4) does not limit the payback to a particular period of time²⁷ and that the State can recover an amount equal to the total medical assistance paid.²⁸

²⁴ See Herting v. California Dept. of Health Care Services, 235 Cal.App.4th 607 (Cal. App. 2015); see also Gonzalez v. City National Bank, 36 Cal App.5th 734 (Cal. App. 2019).

²⁵ See Gonzalez, 36 Cal. App. 5th at 782 (*citing Herting*, 235 Cal.App.4th at 609, 614).

²⁶ POMS SI 01120.203.B.8. It is also in this provision that the POMS make clear that reimbursement cannot be limited to a particular state.

²⁷ See Matter of Abraham XX, 11 N.Y.3d 429 (N.Y. App. 2008); Cockrell v. Comm. of Social Security, Civ. Action 2:18-cv-1124 (S.D. Ohio 2019).

²⁸ See Matter of Abraham XX, 11 N.Y.3d 429 (N.Y. App. 2008).

That being said, in those instances where the special needs trust is funded with a third party recovery, i.e., a personal injury settlement, consider whether a Medicaid lien²⁹ was paid prior to funding the special needs trust. If so, make sure that Medicaid is not double dipping in seeking to be reimbursed from the special needs trust at the time the trust terminates. In other words, the amount of the lien that was asserted by Medicaid against the third-party recovery and paid should be deducted from Medicaid's claim for reimbursement. An argument can be made that, if the lien was compromised, the amount to be deducted is not limited to what was paid but the total amount of the lien that was fully and finally satisfied by payment of the compromised amount.

C. "Medical Assistance"

So, what is included in the medical assistance for which Medicaid seeks to be reimbursed from a special needs trust at the time of its termination? "Medical assistance" is not amorphous or broadly defined but, rather, is defined as "payment of part or all of the cost of the following care and services," followed by 21 enumerated services.³⁰ In those states where Medicaid is a fee-for-service system, make sure the claim for reimbursement presented by Medicaid only includes the services specified under federal law. What is not included in the list are capitated payments or payments paid by Medicaid to a managed care organization if Medicaid opts to deliver services in that manner.³¹

However, in 2001, CMS updated the Medicaid Manual regarding its estate recovery provisions as it relates to managed care. Specifically, Transmittal 75 requires Medicaid to seek to recover premium payments in its claim against an estate when the Medicaid beneficiary was

²⁹ See 42 U.S.C. §§ 1396k(a)(1)(A) and 1396a(a)(25)(H).

³⁰ 42 U.S.C. § 1396d(a).

³¹ See In re Estate of Ecklund, 991 N. W.2d 232 (Minn. Ct. App. 2025); see also Pottsgieser v. Kizer, 906 F.2d 1319 (1990),

enrolled in a managed care organization (“MCO”).³² Transmittal 75 further requires Medicaid to provide a separate notice to the Medicaid beneficiary that explains that the premium payments made to the MCO are included in a claim against the estate.³³ Two takeaways and points of negotiating Medicaid’s claim for reimbursement from a special needs trust for a beneficiary who was enrolled in a MCO are that Transmittal 75 is limited in application to estate recovery and, if separate notice of the intent to seek to recover capitated or premium payments was not given, the claim fails.³⁴

V. Conclusion: Ending Where One Should Begin

Now that you know all things about termination of a first party special needs trust, which is presumably more than you care to know, let us circle back to the beginning. The beginning is when you are sitting with a client who is confronted with the question, to SNT or not to SNT. Discussion about Medicaid’s right to reimbursement from a first party special needs trust is more often than not given de minimus attention. The client does not fully appreciate that termination can occur during lifetime not just at time of death, that a significant claim may already exist at the time the trust is established, what is included in “medical assistance,” nor which expenses are disallowed until after Medicaid is reimbursed. With this discussion, the author hopes that the practitioner will have a greater understanding of Medicaid’s right to reimbursement from a first party special needs trust, and, as such, devote the time and attention necessary to counseling clients about this oft-overlooked requirement.

³² State Medicaid Manual, Part 3 – Eligibility, Health Care Financing Administration Pub. No. 45-3, Transmittal 75, § 3810.A.6 (Jan. 11, 2001).

³³ *See id.*

³⁴ *See Executive Office of Health and Human Services v. Trocki*, 100 Mass. App. Ct. 117 (2021).