Pooled Disability Trusts

A History and Survey of Their Use in the United States

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A. History of Pooled Trusts

Pooled trusts, as distinguished from pooled income trusts, are commonly referred to as d(4)(C) trusts; a robotic sounding tag because such trusts were created by virtue of Title 42 U.S.C. § 1396p, which in turn was created by the Omnibus Reconciliation Act of 1993 (OBRA 93). The latter was the most recent of the major attempts to reform Medicaid by curtailing Medicaid planning. In addition to other strictures on the practice of Medicaid planning, OBRA 93 effectively eviscerated the use of trusts as a means of qualifying for Medicaid by barring the use of what had been known as Medicaid qualifying trusts, i.e. placing assets in a trust subject to the restriction that, if Medicaid were to be available to the grantor or the grantor's spouse, trust assets could not be used for services that would be paid for by Medicaid. Instead, OBRA 93 permitted Medicaid eligibility only if assets were placed in a "pooled trust."[1]

Pooled trusts had been in existence long before OBRA 93. The ARC of the United States (Association for Retarded Citizens) and its offshoot state branches had for many years operated pooled disability trusts. The intent then was much as it is now: to pool funds of disabled persons for management purposes and to operate the trust in a manner that maintained the eligibility of the beneficiary for public benefits. Prior to OBRA 93, transfers of the beneficiary's assets into a trust did not incur Medicaid eligibility transfer penalties. Likewise, there were no state estate recovery or payback concerns upon the death of a beneficiary of a pooled trust.

Because there were no payback requirements, a pooled trust beneficiary could specify remainder beneficiaries other than the charity that operated the trust. As a result, most of the pre-OBRA 93 pooled disability trusts were structured such that only a certain percentage of the trust assets of a deceased beneficiary would remain in the trust with the remainder being paid to beneficiaries named by the trust beneficiary. Pre-OBRA 93 pooled trusts typically retained half of the trust funds after the death of the disabled beneficiary.

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As originally drafted, OBRA 93 threatened the continued use of pooled trusts. The preliminary drafts of OBRA 93 required that the initial transfer of assets to any trust, including a pooled trust, created a penalty period for purposes of Medicaid eligibility. The complete exclusion of the use of pooled trusts for disabled persons appeared intentional if short-sighted.

Eleventh hour efforts by lobbyists working for the ARC of the United States saved pooled trusts by creating three trust exceptions to OBRA 93: 1396p(d)(4)(A) for self-settled trusts, 1396p(d)(4)(B) for Miller-type income trusts, and 1396p(d)(4)(C) for pooled trusts. What these three trust exception provisions all have in common is that funds transferred to these trusts by an individual are not subject to the Medicaid transfer penalty provisions, *as long as the trust meets the statutory requirements*. What sets them apart, and has become the source of ongoing debate, is the payback requirement in the first two, but which is lacking in the pooled trust provision.

The three sections, as they appear in § 1396p(d), read as follows:

(4) This subsection shall not apply to any of the following trusts:

(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 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.

(B) A trust established in a State for the benefit of an individual if—

(i) the trust is composed only of pension, Social Security, and other income to the individual (and accumulated income in the trust),

(ii) 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; and

(iii) the State makes medical assistance available to individuals described in section 1396a (a)(10)(A)(ii)(V) of this title, but does not make such assistance available to individuals for nursing facility services under section 1396a (a)(10)(C) of this title.

(C) A trust containing the assets of an individual who is disabled (as defined in section 1382c (a)(3) of this title) that meets the following conditions:

(i) The trust is established and managed by a non-profit association.

(ii) A separate account is maintained for each beneficiary of the trust, but, for purposes of investment and management of funds, the trust pools these accounts.

(iii) Accounts in the trust are established solely for the benefit of individuals who are disabled (as defined in section 1382c(a)(3) of this title) by the parent, grandparent, or legal guardian of such individuals, by such individuals, or by a court.

(continued on page 21)

Pooled Disability Trusts

(continued from page 20)

(iv) 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 under the State plan under this subchapter.

With passage in 1999, of HR 3343, which added Section 1613 to the Social Security Act, another layer of complication arose. This section not only imposed new transfer penalties on the SSI program similar to those under the Medicaid program, it also incorporated the trust exemptions under 42 U.S.C. § 1396p(d)(4)(C), which meant that transfers to pooled trusts were now not only subject to the scrutiny and approval of the state Medicaid agency, but also of the Social Security Administration.

B. Discrepancies in Interpretation of Payback Requirement and Legal Analysis

The OBRA 93 provisions had the intended effect of allowing the pre-existing pooled disability trusts to continue to function seamlessly. The statute also created new planning opportunities for disabled persons wishing to establish self-settled trusts without running afoul of the new transfer penalty rules. However, it remains unsettled as to how much of the trust assets must be paid to the state Medicaid agency upon the death of the disabled beneficiary.

When the three trust exceptions are examined together, it is immediately evident that the rules governing the income trust and the individual, self-settled trust require that both pay over to the state Medicaid agency all amounts remaining in the trust upon the death of the trust beneficiary up to an amount equal to the total medical assistance paid on behalf of the individual under the Medicaid program. In contrast, the pooled trust exception sets out 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 under the State plan under this subchapter (emphasis added).

A plain reading of this provision suggests that it is within the province of the charity and the language of its pooled trust instrument that determines how much the charity retains, because payback to the state is only required in the event that the pooled trust does not retain all of the assets of deceased beneficiaries. Most state Medicaid agencies that have visited the issue of pooled trusts have reached the conclusion that the charity operating the trust is free to dictate what portion of the funds in a deceased beneficiary's sub-account will stay in the trust, and only that portion that is not retained by the trust is subject to payback to the state. (See addendum, Chart of States with or without Pooled trusts and Payback Requirements, at **http://www.naela.com/Applications/News-app/Files/addendum.pdf**) Nonetheless, several state Medicaid agencies do not agree, and some states have legislated or enacted rules mandating that specific percentages of a pooled trust beneficiary's sub-account that must be paid to the state as reimbursement for the state Medicaid expenditures on behalf of the deceased disabled beneficiary.

For example, Kansas requires that 100 percent of what remains in a deceased beneficiary's sub-account be available to reimburse the state. Nevada also requires that all of the remainder of a sub-account be available to reimburse the state up to the amount of medical benefits paid on behalf the deceased beneficiary. Vermont lumps together supplemental needs, special needs and pooled trusts, providing that all of these trusts must contain a provision that the department will first be paid back all of the Medicaid payments it made on behalf of the deceased beneficiary.

Other states have arbitrarily picked a percentage that the charity is allowed to retain, regardless of the amount of Medicaid benefits paid. Alabama allows the charity to retain 10 percent, reduced from the 25 percent that was initially allowed. Oklahoma requires that the state must be paid back to the extent of medical assistance paid to the beneficiary and that the charity may retain "a maximum of 30% of the amount remaining." Maine's Medicaid manual essentially tracks the 1396p(d)(4) language; when negotiations were underway with the state to initiate the first pooled trust in Maine, the Department initially insisted that 100 percent of the funds be subject to payback, but eventually agreed to lowering this to 50 percent. Massachusetts regulations state that the trust may retain reasonable and appropriate amounts as determined by the Division; thus leaving it to the discretion of their state agency to determine on a case by case basis. The Berkshire County ARC's pooled trust, for example, is allowed to keep 25 percent of the assets of a deceased beneficiary.

Finally, there are those states whose regulations require 100 percent payback, but which have not enforced this rule. South Carolina's Medicaid Manual pooled trust provision mandates that "the state will receive all amounts remaining in the individual's account up to the amount expended by Medicaid on the individual's behalf. However, the Babock Foundation Pooled Trust of South Carolina provides that the trust may retain 20 percent of the funds. To date, this has not been challenged by the state. Similarly, New Mexico's Medicaid rules provide that "amounts remaining in the applicant/recipient's account upon his/her death will first be used to pay the State an amount equal to the total amount of Medicaid benefits paid on behalf of the applicant/recipient. Yet several pooled trusts operate in New Mexico and all have taken the position that the charity may retain the funds left in the sub-account of a deceased beneficiary.

Aside from the plain meaning of 1396p(d)(3)(C), there are several other reasons why states are wrong to demand that trusts turn over assets to them. To mandate payback raises the question, "what is the purpose of having a pooled trust exception?" What would anyone gain from putting assets in a pooled trust that could not be attained with a self-settled trust under 1396p(d)(4)(A)? In other words, only two trust exceptions would have been needed; one for self-settled trusts and one for income trusts. The pooled trust exception is rendered

(continued on page 22)

Pooled Disability Trusts

(continued from page 21)

superfluous if payback is required. Indeed, this plain reading of the statute interpretation is supported by the drafters of the statute. Furthermore, no payback is consistent with the historical use of pooled trusts, because the purpose of 1396p(d)(4)(c) was to allow pooled trusts to continue to operate as they had pre-OBRA 93.

A case decided by the Supreme Court of the State of New York that involved the UJA Federation pooled trust is of particular note. In that case, the Court made it very clear that the payback provision does not apply to pooled trusts. It noted that if Congress had intended that the state be allowed to mandate what the charity retains, it would have included such provision in the statute, as it had in the other two trust exceptions. The Court criticized the state Medicaid agency for attempting to usurp federal law by maintaining that it was empowered to determine how much the charity could retain.

State law may not usurp federal law as illustrated by the New York case of *Matter of Moretti*. The case involved a supplemental needs trust and the State of New York's interpretation that self-settled trusts did not comply with 1396p(d)(4)(A). The court pointed out that "to the extent that these provisions or any other State statutes or regulations may be construed as being inconsistent with, more restrictive, than or in contravention of the spirit of OBRA '93, they are not binding . . . since any such inconsistency would be violative of the supremacy clause of the United States Constitution."

There are many pooled trusts that do not provide for any payback, yet they have never been challenged by their respective states. Any state's insistence on payback priority over the charity's right to retain the remainder has either been laid to rest through successful negotiations or abandoned prior to being appealed in a court of law. There are a multitude of agency letters and opinions that document several states' and Social Security Administration offices' positions. These include: a Social Security Administration letter from Florida overturning a denial stemming from a transfer to the Florida Institute for Health Care Advocacy Trust; a letter from the Director of Medical Services Administration in Michigan (8/17/99) relative to a pooled trust established there which allows the charity to retain 100 percent; a memorandum from the Area III Social Security Administration office indicating that the Pooled Accounts Trust of Springfield qualifies as an OBRA 93 exempt trust; a letter from the Pennsylvania Department of Public Welfare (8/10/00) approving the ARC of the United States trust, also with 100 percent retention by the charity and an email from the Social Security Administration, Philadelphia region (1/20/00) regarding the same trust; a strong opinion letter from the Attorney General of the State of Delaware (8/28/01) indicating that the State may not determine what the charity may retain in pooled trusts; a letter from chief counsel of the Arkansas Department of Human Services (2/17/99) indicating that a trust allowing for 100 percent of the remainder funds to be retained by the charity as long as the trust also provided that if the entire trust should terminate, all remaining proceeds would be subject to reimbursement to the state for benefits paid to the trust beneficiaries; and a letter from the Wisconsin Secretary of State's Department of Health and Family Services dated March 5, 2005 approving a proposed trust in which the charity retains all of the funds upon the death of a beneficiary.

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C. Philosophical Divides Over Pooled Trusts

Some charities believe that the state is entitled to at least a portion of the remainder of a deceased beneficiary's sub-account. The ARC of the United States speaks to this in its Pooled Trust Policy, adopted by the Board of Directors on 11/10/02, which recognizes that pre-OBRA 93 pooled trusts typically allowed the charity to retain only a percentage, usually 50 percent. In its policy recommendations, this paper states, "the spirit and letter of the federal law (OBRA '93 and the 1999 changes to SSI law) must be observed, with no attempts to circumvent the required pay-back to state Medicaid" and percentages of funds remaining with the pooled trust after the beneficiary's death should be negotiated on a state-by-state basis taking into consideration the original intention of the provision regarding pay-back to Medicaid." The policy paper further states:

The purpose of and marketing of pooled trusts should be for the provision of services to the beneficiary, not for fund-raising for the chapter. Percentages remaining with the pooled trust after the death of the beneficiary should not go to the general operating funds of any chapter of The ARC. Such amounts should only be available to the pooled trusts for paying for services for beneficiaries or others with disabilities or for operating expenses of the pooled trust.

One of the fears of many of the people who have been deeply involved in the administration of pooled trusts over the years is that, if too many new charities take overreaching stances with regard to circumventing payback to the state, a backlash may result in the way of restrictive amendments or even the repeal of 1396p(d)(4)(C). This fear has created a divide in philosophy among charities currently sponsoring pooled trusts. Some favoring a partial payback, while others view the remainder in sub-accounts as a way to create an endowment to be used for the good of disabled individuals.

There is also a divide as to how to interpret the requirement that the beneficiaries of a pooled trust must be disabled and the lack of any age requirement in 1396p(d)(4)(C). The Addendum at **http://www.naela.com/Applications/News-app/Files/addendum.pdf** lists many, though not all of the states that prohibit pooled trust beneficiaries over the age of 65. Here,

(continued on page 23)

Pooled Disability Trusts

(continued from page 22)

again, the ARC of the United States takes a conservative stance on this issue. Its policy paper specifies that ARC's pooled trusts are intended for people with a disability under the age of 65. This is one other area where practice and interpretation deviate from the plain reading of 1396p(d)(4)(C). The fact that the self-settled trust exception of 1396p(d)(4)(A) specifically limits the use of such trust to disabled persons under the age of 65 and the fact that neither the 1396p(d)(4)(B) or 1396p(d)(4)(C) trust exceptions make reference to age should, on its face, lead to the interpretation that no age limit was intended for pooled trusts. But the question remains as to how "disabled," as used in d)(4)(C), is to be interpreted? The state's and the pooled trust's interpretation will dictate what class of individuals will be allowed to utilize a pooled trust. Indeed, some pooled trusts are established for a narrowly defined group of disabled individuals, such as developmentally disabled, while others accept a much broader spectrum of disabled individuals, including those over 65 years old who have never had a disability determination.

D. Pooled Trust Innovations

In speaking to many people who have played roles in formulating and implementing pooled trusts across the country, it has become apparent that a lot of creativity and innovations have been worked into the use of pooled trusts. One practitioner, in a state in which pooled trusts existed prior to OBRA 93, commented that one such trust, although not amended to meet the requirements of OBRA 93, continued to take pooled trust beneficiaries under the auspices of the old trust merely by drafting an addendum to the joinder agreement to satisfy 1396p(d)(4)(C) requirements for new pooled trust members.

The recently approved, but not yet implemented, Wisconsin Initiatives of Sustainable Housing Trust (WISH Trust) has taken a unique approach with regard to housing for disabled persons. This trust has a mechanism that allows a trust beneficiary to transfer a house to the trust, which the trust will continue to hold and manage the house as the beneficiary's residence. What makes this trust unique is that, after the death of the beneficiary, the trust will, to the extent practicable, retain the house for the use of other disabled trust beneficiaries. Consistent with its emphasis on providing housing for disabled citizens, the WISH Trust group is actively pursuing property tax exemptions on the real estate transferred to the trust as a means of ensuring viability of the program.

The State of Washington has created an endowment that will match funds contributed to a pooled trust for developmentally disabled persons in a percentage formula up to the first $35,000 contributed. The endowment was established to provide an incentive for families of developmentally disabled children to put money aside for their future needs. This is one example of how a state has taken the long view as to the financial benefit pooled trusts can yield as an alternate source of funds other than public funding of support for disabled individuals.

In those instances in which there is enough remaining in the sub-account to fully reimburse the state for Medicaid expenditures on behalf on the disabled beneficiary, several pooled trusts permit payout upon the beneficiary's death to a remainder beneficiary specified by the disabled beneficiary. Although such provision in these trusts creates a risk that the charity will get nothing at the death of a beneficiary, the charities permit the use of the provision because it is as a way of attracting trust beneficiaries who would like to leave part of the trust assets to selected remainder beneficiaries.

E. Summary

Much time and many resources have been expended in pursuit of implementing pooled trusts, both to gain the states' acknowledgment of their use as a federally mandated vehicle into which disabled beneficiaries may place their assets without having transfer penalties imposed, and as vehicles that may retain the funds of deceased beneficiaries to benefit other disabled beneficiaries. The arduous task has been successful for most, but unfortunately, not for all pooled trusts. Some recalcitrant agencies have simply refused to pass judgment on proposed trusts, leaving proponents to find willing trust participants to "test" the trust by funding it, only to receive eligibility denial letters once they had dutifully notified their state agencies of participating in the trust. The good news is that almost every state has finally come around, and at a minimum, accepted that pooled trusts are mandated under federal law, and that disabled persons may not be penalized for placing assets in them. Furthermore, most states that have analyzed the issue have accepted that the OBRA 93 language leaves to the discretion of the trust whether or not some or all of the funds will be retained by the trust upon the death of a beneficiary. For the elder law or disability benefits attorney facing a state challenge and willing to litigate to prove the point, precedent now exists in the form of the New York case, and letters from state Medicaid agencies and regional Social Security offices supporting the right of pooled trusts to retain the disabled beneficiary assets to assist other disabled individuals.

Although there is ample legal basis to challenge a state agency that insists on some percentage of remainder assets being subject to payback or claims that transfers to a pooled trust are not exempt or that they are only exempt for those under the age of 65, the question is whether it is worth taking on the proverbial 800 pound gorilla. Indeed, many proponents of pooled trusts have decided the answer is no. Rather than fight a protracted, costly battle, many have chosen to reach a swift resolution by compromising with their state agency. There is also the question of the greater good. Even if the legal battle is won, will there be a breaking point at which policy makers react and write the pooled trust exemption out of existence? Hopefully, the answer will be no when states recognize that pooled trusts, by supporting the disabled, ultimately benefit the state and its disabled citizens.

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Footnotes

1 In addition to the pooled trust exemption, Title 42 U.S.C.§ 1396p d(4) created two other trust exemptions, which are set out below. The most common of these is the d(4)(A) trust, or self-settled trust.