

**COME ON IN, THE WATER'S FINE:  
OPENING UP THE SPECIAL NEEDS POOLED  
TRUST TO THE ELIGIBLE ELDERLY  
POPULATION**

*Jacqueline d. Farinella*

*As the elderly population continues to grow exponentially, the need for satisfactory investment and saving options to offset seniors' long-term health care costs will grow along with it. Congress has foreclosed many options for seniors to transfer into trusts money that could potentially supplement Medicaid benefits. However, the (d)(4)(C) special needs pooled trust, historically used by groups focused on caring for the disabled, is one trust option that Congress has not specifically foreclosed to the elderly population. This note examines the history, statutory language, and potential benefits of 42 U.S.C.A. § 1396p(d)(4)(C). The note then examines the current trends and problems with the operation of special needs pooled trusts and proposes amendments to the Act's statutory language in order to make the trust more visible, viable and appropriate for use by the disabled elderly.*

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Jacqueline d. Farinella is a Member 2004–2006, *The Elder Law Journal*; J.D. 2006, University of Illinois, Urbana-Champaign; B.A. 2001, Miami University, Oxford, Ohio.

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## I. Introduction

In 1997, about seven million people over the age of sixty-five required long-term health care because of mental or physical disabilities that accompany old age, and that number is expected to rise to almost 10.8 million by the year 2030.<sup>1</sup> This information reveals more than just the exceptional needs of the elderly population; it reveals the outstanding growth of those needs in the future as the costs of long-term health care and the numbers in need of long-term health care grow exponentially.<sup>2</sup> For many, chronic illness, disability, and thus increased medical expenses will accompany a longer life—a prospect that could foreclose any opportunity to pass on an inheritance and, more importantly, to enjoy life savings in older age.<sup>3</sup> Although Congress, in an effort to stop a perceived abuse of government benefits programs, closed many options for wealth transfers into trusts that could supplement Medicaid benefits,<sup>4</sup> a few limited and underused trust options remain for estate planning.<sup>5</sup> This note examines one option, the (d)(4)(C) special needs pooled trust.<sup>6</sup>

In 1993, the Omnibus Budget Reconciliation Act (OBRA '93) offered exceptional amendments to Medicaid eligibility by essentially foreclosing the opportunity for individuals to shield their assets in trusts in order to be eligible for Medicaid benefits.<sup>7</sup> Section 1396p(d)(4) of the Act, however, permitted exceptions for three unique trusts: a special needs trust available to disabled people under

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1. NATALIE GRAVES TUCKER ET AL., AARP LONG TERM CARE: FACT SHEET 1 (2000), [http://research.aarp.org/health/fs27r\\_care.html](http://research.aarp.org/health/fs27r_care.html) (last visited Jan. 30, 2006).

2. See *id.* at 2 (Figure 2 reveals that total expenditures in 1998 for nursing home and home health services topped \$117.1 billion, and sixty-eight percent of that was covered either by Medicaid or out of the patient's pocket.).

3. See Clifton B. Kruse, Jr., *Self-Settled Trusts Following OBRA 1993*, 23 COLO. LAW. 1297, 1297 (1994) (“One dominant goal, prevalent as people age, is the desire to pass on an inheritance, the residue of their wealth, to their children.”).

4. See 42 U.S.C.A. § 1396p(c) (West 2003) (applying strict penalties to asset transfers into trusts, with the unattractive effect of disqualifying the individual from Medicaid benefits); Ira Stewart Wiesner, *OBRA '93 and Medicaid: Asset Transfers, Trust Availability, and Estate Recovery Statutory Analysis in Context*, 19 NOVA L. REV. 679, 681 (1995) (“The new Medicaid rules are designed to restrict individuals from arranging their financial affairs in order to retain the economic benefit of their wealth, but nevertheless securing government paid long-term care services.”).

5. 42 U.S.C.A. § 1396p(d)(4)(A)–(C) (outlining three trusts that are exempt from the strict treatment of trusts under Medicaid eligibility rules).

6. *Id.* § 1396p(d)(4)(C).

7. See *id.* § 1396p(c).

sixty-five years old; an income trust that permits preservation of most government benefits, except funds for nursing home facilities; and the (d)(4)(C) trust, a special needs pooled trust available to disabled people that must be run by a nonprofit organization.<sup>8</sup>

The (d)(4)(C) trusts are modeled after special needs trusts, which were historically run by organizations dedicated to the advocacy of disabled people.<sup>9</sup> Because many disabled people are unable to care for themselves and are unlikely to ever earn an adequate income, they depend upon both Medicaid benefits and their special needs trust accounts to maintain a high quality of life and health care.<sup>10</sup> The language of the federal statute indicates that (d)(4)(C) was meant to merely exclude special needs trusts from the restrictive provisions of the rest of the title, but careless drafting has led to a number of other difficult and even dangerous outcomes, including disparate treatment under state law and disparate structures by the managing nonprofit organizations.<sup>11</sup>

As written into OBRA '93, the (d)(4)(C) trusts are often plagued by a number of hardships that keep seniors from utilizing this option, including high start-up and maintenance costs, lack of funds for broader marketing, and conflicts of interest between the management of the trust principal and the sensitive disbursements of the funds to the disabled beneficiary.<sup>12</sup> On the other hand, these exempt trusts can also offer extraordinary benefits, not only to eligible beneficiaries, but also to nonprofit organizations with sufficient capital to establish a trust and to the state Medicaid administering agencies that can benefit from built-in estate recovery provisions.<sup>13</sup> By healing some of the inadequacies of the statutory language and offering a model trust to states in the State Medicaid Manual, Congress could open this estate-planning option to the growing elderly population and offer a solution to the financial problems associated with old age.

This note will begin to examine the (d)(4)(C) trusts in Part II by tracing the history of Medicaid's origins and historical purposes, including the existence of special needs and pooled trusts before federal

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8. *Id.* § 1396p(d)(4)(A)–(C).

9. See Elizabeth L. Luckenbach, *Pooled Accounts Trusts—What Courts Want to Know*, NAELA NEWS, Aug. 2003, at 7.

10. See CLIFTON B. KRUSE, JR., *THIRD-PARTY AND SELF-CREATED TRUSTS—PLANNING FOR THE ELDERLY AND DISABLED CLIENT* 11 (ABA 3d ed. 2002).

11. See discussion *infra* Parts III.B.3, III.C.

12. See discussion *infra* Part III.B.

13. See discussion *infra* Part III.A.

recognition in OBRA '93 and the codification of these trusts in the U.S. Code. Next, the note will outline the functions of the trust by examining the vague statutory language of (d)(4)(C). Part III will look at the potential benefits of (d)(4)(C) trusts, problems plaguing the trusts' function, and current trends in running these trusts. Finally, Part IV will present a resolution to the issues that keep the (d)(4)(C) trusts underutilized by offering amendments to the statutory language in the U.S. Code and offering guidelines for drafting a model (d)(4)(C) trust.

## II. Background

### A. Medicaid Overview

Medicaid was established in 1965 in Title XIX of the Social Security Act<sup>14</sup> with a relatively modest goal of providing health care to the poor, and it has grown to become the nation's largest single purchaser of nursing home services, providing for the health care needs of almost forty-four million Americans.<sup>15</sup> Among the multitude of federal government benefit programs, Medicaid is one of the few means-based programs that require prospective participants to meet a minimum asset level in order to be eligible. The program was originally intended to work as a welfare program for Americans who were truly unable to pay for the costs of health care.<sup>16</sup> While the program is overseen at the federal level by the Department of Health and Human Services,<sup>17</sup> it is primarily run at the state level by a state designated agency. State participation is voluntary, but all fifty states and the District of Columbia currently participate in the program.<sup>18</sup>

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14. Title XIX of the Social Security Act, 79 Stat. 343 (1965) (codified as amended at 42 U.S.C. § 1396 (1990)).

15. CTR. FOR MEDICARE & MEDICAID SERVS., MEDICAID FRAUD & ABUSE-GENERAL INFORMATION, <http://www.cms.hhs.gov/MCAIDFraudAbuseGenInfo> (last visited Jan. 30, 2006).

16. Kenneth Hubbard, *The Medicaid Cost Crisis: Are There Solutions to the Financial Problems Facing Middle-Class Americans Who Require Long-Term Health Care?*, 43 CLEV. ST. L. REV. 627, 635 (1995).

17. 42 U.S.C.A. § 1396a(a)(4) (West 2003) (providing guidelines for state plans for medical assistance and providing that states' determinations of availability must follow standards prescribed by the Department of Health and Human Services). See The Centers for Medicaid and Medicare Services, at <http://www.cms.hhs.gov> (federally run website providing information on the government programs and links to state-related agencies).

18. Incentives for participation include providing federal funds to assist in running the program and permitting flexible methods to determine eligibility at

The fundamental administrative power of this notoriously complicated program is derived from the Social Security Act,<sup>19</sup> but states are given wide discretion in a number of areas, most notably in determining program eligibility.<sup>20</sup> All participating states are required to provide assistance to people defined as “categorically needy,” and some states may elect to expand eligibility and provide assistance to those defined as “medically needy.”<sup>21</sup> General categories of those eligible for Medicaid include: (1) pregnant women; (2) children and teenagers; (3) elderly persons who are sixty-five and older; (4) the blind or disabled; and (5) others deemed eligible due to exceptionally high medical expenses, exceptionally low income, or other circumstances found sufficient for eligibility by the state administering agency.<sup>22</sup> However, once a potential participant meets these preliminary qualifications, eligibility is still restricted to those who meet an income level as dictated by individual state law.<sup>23</sup>

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the state level. See Omar N. Ahmad, *Medicaid Eligibility Rules for the Elderly Long-Term Care Applicant*, 20 J. LEGAL MED. 251, 252–53 (1999).

19. Title XIX of the Social Security Act, 79 Stat. 343 (1965) (codified as amended at 42 U.S.C. § 1396 (1990)).

20. Hubbard, *supra* note 16, at 636–38 (describing the history, development, and general structure of Medicaid); see also The Ctrs. for Medicare & Medicaid Servs., *Medicaid Eligibility Groups and Less Restrictive Methods of Determining Countable Income and Resources—Questions and Answers*, at A1, <http://www.cms.hhs.gov/MedicaidEligibility/downloads/DefinitionElig1902r2.pdf> (describing regulations enacted in 2001 that permit states to use more flexible methods to determine eligibility for Medicaid benefits) (last visited Mar. 27, 2006).

21. Hubbard, *supra* note 16, at 636–37. The article explains that the original eligibility requirements defined “categorically needy” as those who fit into one of the four other programs in existence at that time: Old Age Assistance, Aid to Families with Dependent Children, Aid to the Blind, and Aid to the Permanently and Totally Disabled. Three of these programs, excluding Aid to Families with Dependent Children, were repealed when their provisions were merged into the Supplemental and Security Income for the Aged, Blind, and Disabled, commonly known as SSI. The “medically needy” are defined as “persons lacking the ability to pay for medical expenses, but with incomes too large to qualify for categorical assistance.” *Id.* at 637 (citing *Schweiker v. Gray Panthers*, 453 U.S. 34, 37 (1981)).

22. See Dep’t of Health & Human Servs., Ctrs. for Medicaid & Medicare Servs., *Medicaid Eligibility Overview?*, <http://www.cms.hhs.gov/MedicaidEligibility> (federally run website defining general categories of eligibility).

23. In Illinois, for example, the rules governing eligibility for medical assistance programs are governed by ILL. ADMIN. CODE tit. 89, § 120, which states, “Eligibility for medical assistance exists when a client meets the nonfinancial requirements of the program and the client’s countable nonexempt income (sections 120.330 and 120.360) is equal to or less than the applicable Medical Assistance-No Grant (MANG) standard and for AABD MANG, countable nonexempt assets are not in excess of the applicable asset disregards.” ILL. ADMIN. CODE tit. 89, § 120.10(a) (2005).

The requirements for meeting financial eligibility vary by state, but they are generally derived by determining the fair market value of all resources available to the potential participant.<sup>24</sup> After disqualifying certain exempt assets, including the homestead, one automobile deemed necessary, burial funds, and certain insurance policies, remaining income and resources must be sufficiently low to qualify under state financial criteria.<sup>25</sup> At a minimum, the remaining assets must be low enough to qualify for Supplemental and Security Income for the Aged, Blind, and Disabled (SSI), another means-based government benefit program.<sup>26</sup> Further, some states allow eligibility for Medicaid to be met through a “spending down” method, which permits eligibility if leftover income after paying for medical expenses is below the state-set minimum limit.<sup>27</sup> Spend down requirements are mandatory for states that deem only the categorically needy eligible, but are optional for states that open up assistance to both categorically needy and medically needy residents.<sup>28</sup>

In 1988, Congress expanded eligibility to protect the growing elderly population in the Medicare Catastrophic Coverage Act of 1988 (MCCA).<sup>29</sup> The Act was intended to prevent assets held by a spouse still living in the community from disqualifying an institutionalized elder from Medicaid eligibility, protecting both the “community” spouse’s assets and the institutionalized spouse’s benefits eligibility.<sup>30</sup> The spirit behind this Act reveals a shift of congressional emphasis from providing services to the disabled, or to those who, for other reasons, have exceptionally high medical expenses, to providing simply for the *financially* needy.<sup>31</sup> This expansion of eligibility quickly drew

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24. Jon M. Zieger, *The State Giveth and the State Taketh Away: In Pursuit of a Practical Approach to Medicaid Estate Recovery*, 5 *ELDER L.J.* 359, 362–63 (1997); see also LAWRENCE A. FROLIK & RICHARD L. KAPLAN, *ELDER LAW IN A NUTSHELL* § 12.1 (3d ed. 2003).

25. *Id.* at 363–64.

26. *Id.* (citing 20 C.F.R. § 416.1100, which describes how income is determined for SSI eligibility).

27. Hubbard, *supra* note 16, at 638 (providing the example, “if a state has decided that a Medicaid applicant will only be accepted if his or her income is below \$600 per month, then the applicant with a monthly income of \$700 must spend one hundred dollars on medical care each month before Medicaid will cover the remaining medical bills. If the applicant incurred medical expenses totaling \$1,000 that month, Medicaid would then pay \$900.”).

28. *Id.* at 637 (citing *Roloff v. Sullivan*, 975 F.2d 333, 336–38 (7th Cir. 1992)).

29. See Pub. L. No. 100-360, 102 Stat. 683 (1988); Wiesner, *supra* note 4, at 681.

30. Ahmad, *supra* note 18, at 254–55.

31. See generally *id.*

fire from long-term health care insurance providers, who feared wider eligibility for Medicaid would reduce need for their services. The Act was later substantially limited by OBRA '93.<sup>32</sup>

### B. Special Needs Trusts and Pooled Trusts Prior to OBRA '93

Long before the federal government recognized pooled trusts and supplemental needs trusts in 1993, both were commonly established by parents of disabled children. The trusts were intended to provide for disabled children after their parents' death and to shield that income in order to prevent the disqualification of the child from federal medical assistance.<sup>33</sup> Supplemental needs trusts are designed to accomplish just that goal. The supplemental needs trust drew some of its qualities from other typical third-party trusts, where the trust is set up by a third party for a beneficiary and administered by a trustee.<sup>34</sup> The third party has been defined as someone not legally obligated to provide for the beneficiary, and is commonly a family member who wants to assist a loved one with burdensome medical expenses due to disability.<sup>35</sup> The amount of discretion granted to a beneficiary on the disbursements of the trust's funds distinguishes various third-party trusts.<sup>36</sup>

The supplemental needs trust has been considered a "hybrid" of three common third-party trusts—the spendthrift trust, the support trust, and the discretionary trust.<sup>37</sup> The spendthrift trust has a long history in the United States and is commonly used to provide for an irresponsible family member.<sup>38</sup> Historically, these trusts were set up to ensure that minors and female family members would be financially secure after the death of the caregiver or guardian,<sup>39</sup> but are now

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32. See Wiesner, *supra* note 4, at 681; see also discussion *infra* Part II.C.

33. See Luckenbach, *supra* note 9, at 7 ("For decades, parents of children with disabilities and nonprofit organizations had been using 'pooled' or 'umbrella' trusts to hold assets for the benefit of their disabled children."). See generally Joseph A. Rosenberg, *Supplemental Needs Trusts for People with Disabilities: The Development of a Private Trust in the Public Interest*, 10 B.U. PUB. INT. L.J. 91, 99–127 (2000) (discussing the development of third-party trusts from feudal England through U.S. case law and state law treatment of trusts for the purposes of government benefit eligibility).

34. See Rosenberg, *supra* note 33, at 106–09.

35. See KRUSE, *supra* note 10, at 51.

36. Rosenberg, *supra* note 33, at 108–09.

37. *Id.* at 108.

38. *Id.* at 109.

39. *Id.* at 107.

more commonly thought to benefit the lazy, wealthy heir who is not trusted to manage the family inheritance.<sup>40</sup> The trust shields its funds from abuse by the beneficiary and from access by the beneficiary's creditors by prohibiting the beneficiary from assigning any portion of the trust's principal.<sup>41</sup>

The support trust operates in a similar manner, but its purpose is to provide for certain, occasionally enumerated basic needs of the beneficiary, such as education or essential living expenses, and the trustee is under a duty to maintain and disburse the funds for this purpose.<sup>42</sup> Even this limited discretion and control over the trust's principal by the beneficiary, however, has resulted in treatment of these funds as available to the beneficiary by some courts, and, therefore could disqualify him or her from means-based government benefit programs.<sup>43</sup>

The third common type of third-party trust is the discretionary trust, which places complete control over the trust's funds in the hands of the trustee.<sup>44</sup> Thus, the principal of discretionary trusts is considered "unavailable" and will not disqualify the trustee from means-based government benefit programs.<sup>45</sup>

A typical supplemental needs trust incorporates qualities of each of these third-party trusts. Like a spendthrift trust, the beneficiary of a supplemental needs trust cannot assign the funds, and the beneficiary's creditors cannot reach the trust's principal.<sup>46</sup> Further, supplemental needs trusts provide for the special needs of the beneficiary, much like a common support trust, and, typically due to the beneficiary's disability, the trustee exercises substantial control over the trust disbursements.<sup>47</sup>

Pooled trusts, considered a type of supplemental needs trust, also have a history of use before federal recognition in OBRA '93 and are generally created with similar intentions. Pooled trusts essentially operate by consolidating the assets of each beneficiary under an "umbrella" trust for management and investment purposes, with interest

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40. *Id.* at 109.

41. *Id.* at 106-07.

42. *Id.* at 108.

43. *Id.*

44. *Id.*

45. *Id.*

46. *Id.* at 108-09.

47. *Id.*



credited to each beneficiary's subaccount.<sup>48</sup> Historically, parents of disabled children created pooled trusts to provide for their children after their own death.<sup>49</sup> In the 1950s, parents of disabled children and advocates of disabled citizens' rights helped found the National Association of Retarded Citizens, now known as The Arc of the United States. The group's purpose has grown to also provide for aging people with disabilities who, for a number of reasons, are no longer supported by family members.<sup>50</sup> State-based affiliates of The Arc pooled the assets of the parents of disabled people into one trust with individual subaccounts. Pooling the assets in this way both minimizes administration costs and maximizes profitability of investment of the trust.<sup>51</sup> Many of these pooled trusts remained in existence after OBRA '93 created extensive penalties for asset transfers. These trusts served as a model for the (d)(4)(C) trusts as one of three methods of providing for disabled people without disqualifying them from means-based government benefits.<sup>52</sup>

Individual states' treatment of trusts differ, and the differences can materially affect the eligibility determination of these trusts for means-based government benefit programs, such as Medicaid. In Illinois, for example, if the trustee is given any power over disbursements of the trust's principal, funds in a discretionary trust are considered "unavailable" to the beneficiary for purposes of Medicaid eligibility.<sup>53</sup> In Texas, however, the corpus of a supplemental needs trust held for a mentally ill beneficiary cannot exceed \$50,000 if the

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48. See A. Frank Johns, *Legal Ethics Applied to Initial Client-Lawyer Engagements in Which Lawyers Develop Special Needs Pooled Trusts*, 29 WM. MITCHELL L. REV. 47, 63-64 (2002).

49. *Id.* at 51.

50. See Introduction to The Arc: Mission Statement, at <http://www.thearc.org/about.htm> (website for The Arc of the United States, stating a part of its purpose as, "The Arc works to ensure that the estimated 7.2 million Americans with mental retardation and related developmental disabilities have the services and supports they need to grow, develop and live in communities across the nation. These services include early intervention, health care, a free appropriate public education and support for their families.").

51. THE ARC, POOLED TRUST PROGRAMS FOR PEOPLE WITH DISABILITIES: A GUIDE FOR FAMILIES 7 (2002), [http://www.uic.edu/orgs/rtrcamr/300005\\_PooledtrustPrograms.pdf](http://www.uic.edu/orgs/rtrcamr/300005_PooledtrustPrograms.pdf).

52. See Johns, *supra* note 48, at 51; Renee Lovelace, *The Dark Side of Pooled Trusts*, NAELA Q., Summer 2001, at 6, 6; Luckenbach, *supra* note 9, at 7.

53. 760 ILL. COMP. STAT. § 5/15.1 (2000) ("Property, goods and services purchased or owned by a trust for and used or consumed by a disabled beneficiary shall not be considered trust property distributed to or under the control of the beneficiary."); see Rosenberg, *supra* note 33, at 126.

beneficiary resides in a state hospital or \$250,000 for a beneficiary in a care facility.<sup>54</sup> Amounts that exceed this ceiling will be considered available to the individual<sup>55</sup> and could cause disqualification for essential government benefits. Generally, in determining eligibility for means-based government benefits, a trust will either be subject to court interpretation, state laws governing treatment of trusts, or the sweeping restrictions OBRA '93 created.<sup>56</sup>

### C. OBRA '93—Federal Recognition of the Pooled Trust

In 1993, President Clinton's proposal for the 1994 federal budget included a reduction in spending on long-term health care of \$7.8 billion.<sup>57</sup> In an effort to reduce a growing Medicaid budget, and also in response to growing concern over perceived abuse of the program, Congress tightened the eligibility rules under the Medicaid program.<sup>58</sup> This agenda was put into effect through the Omnibus Budget Reconciliation Act of 1993 (OBRA '93),<sup>59</sup> which effectively extinguished the possibility of qualifying for Medicaid benefits by shielding assets in the most commonly used types of trusts.<sup>60</sup>

Although a need to tighten the federal budget is largely considered the impetus of this legislation, politics played a significant role in shaping the restrictions of OBRA '93.<sup>61</sup> After the Medicaid Catastrophic Coverage Act of 1988 (MCCA)<sup>62</sup> expanded eligibility for the program's benefits, many otherwise "wealthy" people began to use these benefits, contrary to the program's intended purpose of providing health care to those of limited means.<sup>63</sup> A practice commonly referred to as "Medicaid planning" became prevalent for middle-class elders who faced certain impoverishment either from the costs of health care or the costs of health care insurance.<sup>64</sup> With the help of lawyers or other planning advisors, many elders began to shield their estates in

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54. Rosenberg, *supra* note 33, at 126.

55. *Id.*

56. *See id.* at 109–10.

57. KRUSE, *supra* note 10, at 5.

58. *See* Wiesner, *supra* note 4, at 694.

59. Omnibus Budget Reconciliation Act of 1993, H.R. 2264, 103d Cong. §§ 13611, 13612 (1993) (amending 42 U.S.C.A. § 1396p (West 1985)).

60. 42 U.S.C.A. § 1396p (West 2003).

61. Wiesner, *supra* note 4, at 682–87.

62. Pub. L. No. 100-360, 102 Stat. 683 (1988).

63. Wiesner, *supra* note 4, at 682–87.

64. Peter M. Macy, *Medicaid Planning After OBRA-93: Placing the Home in a Revocable Trust*, 79 MASS. L. REV. 2, 3 (1994).

trusts or through asset transfers to family members in order to qualify for Medicaid benefits.<sup>65</sup> Most cognizant of this perceived abuse was the long-term insurance industry, probably because of the effect the Act had on enrollment numbers.<sup>66</sup> Focusing on a prevalent use of asset transfers by Medicaid recipients, long-term health care insurance industry advocates and state Medicaid agencies sought restructuring of the Social Security Act to curb this practice and limit eligibility, thus decreasing the growing federal health care budget.<sup>67</sup> Their efforts focused on prohibiting the use of trusts to meet eligibility.<sup>68</sup>

Against the force of the long-term health care insurance industry's and state Medicaid agencies' cries to tighten Medicaid eligibility, advocates for the rights of disabled citizens lobbied for their interests in the Act as well.<sup>69</sup> These groups worked to secure exemption for the several trusts historically set up by families of disabled adults to provide for their well-being after primary caregivers passed away. The groups' efforts focused on a number of trusts in jeopardy of becoming obsolete through the proposed restrictions, including supplemental needs trusts established by a parent of a disabled child that had historically been considered "unavailable" for Medicaid eligibility purposes, trusts funded by medical malpractice settlements or inheritances received by similarly treated disabled persons, and existing pooled trusts, such as those in operation under The Arc.<sup>70</sup>

The result of these opposing forces was OBRA '93, incorporating both great restrictions and narrow exceptions to the Social Security Act's Medicaid eligibility rules. The Act essentially closed the loophole for permitting asset transfers to trusts to qualify a person for Medicaid benefits.<sup>71</sup> OBRA '93 effectively treated the body of all revocable trusts and portions of irrevocable trusts from which payments to the beneficiary could be made as resources available to the beneficiary.<sup>72</sup> Most uncompensated asset transfers by the Medicaid applicant became subject to a thirty-six-month look-back period, recently ex-

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65. *Id.*

66. Wiesner, *supra* note 4, at 688–94.

67. *Id.*

68. *See, e.g.*, Wiesner, *supra* note 4, at 703 (“Congress identified ‘trusts’ as the single most offensive Medicaid estate planning vehicle and tried, in almost every manner short of criminalization, to inhibit their use.”).

69. Johns, *supra* note 48, at 51–52.

70. Rosenberg, *supra* note 33, at 128.

71. *See* 42 U.S.C.A. § 1396p (West 2003).

72. Wiesner, *supra* note 4, at 703–05.

tended to a sixty-month period,<sup>73</sup> during which the applicant is not eligible for certain Medicaid benefits, including nursing facility services, home or community-based services, and other long-term care services.<sup>74</sup> Beyond these broad restrictions, OBRA '93 also required all states participating in Medicaid to implement estate recovery programs in order to receive federal support.<sup>75</sup> The intricacies of these programs vary from state to state and essentially reimburse the state for amounts paid under Medicaid by placing a lien on the individual's property and a claim to the individual's estate, typically defined broadly.<sup>76</sup>

Within these sweeping restrictions, OBRA '93 carved out three exceptions to the treatment of trusts for Medicaid eligibility—(d)(4)(A), (d)(4)(B), and (d)(4)(C).<sup>77</sup> Two of the three exempt trusts, the (d)(4)(A) and the (d)(4)(C), are available only to disabled beneficiaries, as defined by the Social Security Act.<sup>78</sup> The (d)(4)(A) trust is a third-party trust, similar to a traditional support or discretionary trust, and must be established for the benefit of a disabled person under the age of sixty-five by a parent, grandparent, legal guardian, or a court.<sup>79</sup> Upon the death of the beneficiary, the state may recover all amounts remaining in the trust up to the total amount of assistance paid through Medicaid or other state benefit plan.<sup>80</sup> The most significant restriction of the exempt trust is its imposition of an age limit, making this option unavailable to those over sixty-five years old, which includes many potential Medicaid recipients.<sup>81</sup> The (d)(4)(B) trusts are income trusts exempt from OBRA '93 trust treatment if composed of only pension or Social Security income.<sup>82</sup> These trusts are also subject

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73. See Deficit Reduction Omnibus Reconciliation Act of 2005, S1932, 109th Cong. (2006) (enacted) (to be codified as amended at 42 U.S.C.A. § 1396).

74. 42 U.S.C.A. §§ 1396p(c)(1)(A), (c)(1)(B), (c)(1)(C)(i)–(ii); see also Wiesner, *supra* note 4, at 695–96.

75. 42 U.S.C.A. § 1396p(b)(1); see also Zieger, *supra* note 24, at 368–70; Wiesner, *supra* note 4, at 716–19.

76. Zieger, *supra* note 24, at 369–70.

77. 42 U.S.C.A. § 1396p(d)(4)(A)–(C).

78. *Id.* § 1382(c)(a)(3)(A) (defining “disability” as the inability “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 (or, in the case of a child under the age of eighteen, if he suffers from any medically determinable physical or mental impairment of comparable severity).”).

79. *Id.* § 1396p(d)(4)(A).

80. *Id.*

81. *Id.*

82. *Id.* § 1396p(d)(4)(B).

to recovery by the state and will not permit eligibility for Medicaid benefits covering the costs of nursing home facilities.<sup>83</sup> The third exempt trust, the (d)(4)(C) pooled trust, does not expressly impose an age restriction, but it includes other limiting conditions that make this exempt trust mostly unavailable to the largest group of individuals in need of Medicaid assistance, the disabled elderly.<sup>84</sup>

On February 8, 2006, President George W. Bush signed the Deficit Reduction Act,<sup>85</sup> aimed at reducing Medicaid spending through a number of new revisions, including increased penalties for asset transfers by people over sixty-five and an extended look-back period during which these penalties may be incurred.<sup>86</sup> Although these changes may encourage state Medicaid agencies to enact stricter regulation on the use of trusts,<sup>87</sup> the language in Medicaid creating the (d)(4)(C) exempt pooled trust is left untouched. Thus, these trusts remain an exception to the restrictions on asset transfers.

#### D. (d)(4)(C) Pooled Trusts—Exempt Trust Available to Elderly

State application of OBRA '93 provisions has created varying interpretations,<sup>88</sup> and some questions about application of the exempt trusts remain.<sup>89</sup> Confusion and lingering questions about the

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83. *Id.*

84. *Id.* § 1396p(d)(4)(C).

85. Deficit Reduction Omnibus Reconciliation Act of 2005, S1932, 109th Cong. (2006) (enacted) (to be codified as amended at 42 U.S.C.A. § 1396).

86. *Id.* at tit. VI (A), ch. 2 (A), § 6001–6016 (2006).

87. Upon signing the Act, President Bush stated, “The bill tightens the loopholes that allowed people to game the system by transferring assets to their children so they can qualify for Medicaid benefits.” President George W. Bush, Remarks at the Signing of S.1932, Deficit Reduction Act of 2005 (Feb. 8, 2006) (transcript available at <http://www.whitehouse.gov/news/releases/2006/02/20060208-8.html>) [hereinafter Remarks].

88. Some of the state legislation has restricted the federal provisions so much that some states have drawn sharp criticism and challenges in court. See Clifton B. Kruse, Jr., *OBRA '93 Disability Trusts—A Status Report*, PROB. & PROP., May/June 1996, at 17, 15–18 (describing state provisions, which limit the source of the funds transferred into exempt trusts “to the balance of personal injury settlements after Medicaid advances are repaid,” and discussing subsequent challenges that argue this limited definition of “assets,” in light of the broad, unlimited federal definition, “ignore[s] federal priority and is a violation of the Supremacy Clause of the Constitution.”). Although these issues, and individual state treatment of (d)(4)(c) trusts, are important to those planning to use this option, this note will refer only to operation of these trusts under the federal government’s broader definition.

89. See Wiesner, *supra* note 4, at 712 (“A number of issues affect [the (d)(4)(A)] trust and its required components: 1) What is the status of the fund when the individual attains age sixty-five? Is it then ‘available’ for Medicaid purposes? Will credit be given for the amount repayable to the state? Must payments out to or for

(d)(4)(C)'s application and specific trust pool restrictions may be the result of the provision's last minute inclusion in the Act.<sup>90</sup> Nonetheless, the statutory language has been described as "eloquently simple."<sup>91</sup> It plainly, and arguably inadequately, lays out the conditions for the (d)(4)(C) exempt trust.<sup>92</sup> The (d)(4)(C) trust is the only exempt trust that was not written with an express age limit.<sup>93</sup> No formal explanation exists as to why Congress restricted use of the (d)(4)(A) exempt trust to disabled persons under sixty-five years old, or why this restriction was absent in the conditions of the (d)(4)(C) trust.<sup>94</sup>

While the changes recently enacted through the Deficit Reduction Act will affect many current estate-planning methods in use for people over sixty-five,<sup>95</sup> the language creating an exemption for special needs pooled trusts remains unchanged and remains without a defined age restriction. Thus, in order for the assets transferred into a pooled trust to be considered "unavailable" and therefore shielded from Medicaid eligibility conditions, a number of conditions must be met.<sup>96</sup>

First, the trust must contain the assets of a disabled individual.<sup>97</sup> Under the current version of the Social Security Act, a person is considered disabled

if he is unable to engage in any substantial gainful activity by rea-

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the beneficiary first be paid to the state? 2) What is the status of the trust if the beneficiary ceases to be disabled?").

90. See Wiesner, *supra* note 4, at 683-84 n.15.

91. Kruse, *supra* note 88, at 18.

92. 42 U.S.C.A. § 1396p(d)(4)(C) (West 2003).

93. *Id.*

94. The federal administering agency, the Health Care and Financing Administration (HCFA) has confirmed the (d)(4)(A) age restriction. KRUSE, *supra* note 10, at 13-14 (reproducing a portion of a letter written by the Health Care and Financing Administration in response to an inquiry by author Clifton Kruse, Jr. of the age restrictions imposed on the exempt trusts: "With regard to your question about why certain trusts for the disabled are subject to an age limit, the conference report accompanying the enabling legislation (OBRA '93) provided very little insight into why Congress elected to write the legislation (including those portions that apply an age limit to the trusts in question) as it did . . . . As a technical point, however, we would note that while an age limit does apply to two of the trusts [cited], the statute does not impose an age limit on the trust cited at 42 U.S.C.A. § 1396p(d)(4)(C).").

95. Before the Act was signed by President Bush, the Congressional Budget Office drafted a report summarizing the relevant provisions and defining the new estate-planning restrictions, stating that the new Act includes "revisions to the rules relating to individuals' asset transfers prior to gaining eligibility for long-term care services under Medicaid." Remarks, *supra* note 87.

96. 42 U.S.C.A. § 1396p(d)(4)(C).

97. *Id.*

son 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.<sup>98</sup>

Second, the trust must be established and managed by a nonprofit organization.<sup>99</sup> While there are no limits on what types of nonprofit organizations are contemplated by this condition, the organization must be incorporated with tax-exempt status under the Internal Revenue Code and comply with similar state regulations on nonprofit organizations.<sup>100</sup> The majority of nonprofit organizations currently running pooled trusts within the guidelines of OBRA '93 are national organizations dedicated to serving and representing individuals with disabilities.<sup>101</sup> A third condition requires a separate account for each beneficiary of the trust, and these accounts must be pooled for investment purposes, meaning the trust must operate as a typical pooled trust.<sup>102</sup>

The fourth condition necessary to establish a (d)(4)(C) trust is that the trust must be established for the disabled person by a parent, grandparent, legal guardian, the court, or *the beneficiary*.<sup>103</sup> This condition creates an important distinction between (d)(4)(C) trusts and traditional supplemental needs trusts in that it can be a self-settled trust, created by the beneficiary with his own assets. This is an important factor for the availability of the (d)(4)(C) trust to the elderly, in contrast to traditional disabled beneficiaries of these trusts, whose trusts are set up by family members.<sup>104</sup>

A final condition for creating an exempt (d)(4)(C) trust concerns the fate of the trust's principal upon the death of the beneficiary. The statute permits the trust to retain an amount of the principal left in the beneficiary's account upon termination of the trust, and any remain-

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98. *Id.* § 1382(c)(a)(3)(A).

99. *Id.* § 1396p(d)(4)(C)(i).

100. See Johns, *supra* note 48, at 59 ("There are no extraordinary elements necessary to create and operate the [nonprofit organization] that qualifies to manage [(d)(4)(C) special needs pooled trusts]. There must be compliance with the charitable corporations or non-profit associations statutes in the state where the [nonprofit organization] is a resident . . . . At times, the lawyer serves in all positions just to create sufficient inertia to bring those operating and supporting the [nonprofit organization] into a forum that will serve the lawyer's clients and others as well.").

101. See *id.* at 59–60 (providing an example of a national nonprofit organization running pooled trusts within the guidelines of OBRA '93 dedicated to serving and representing people with disabilities).

102. 42 U.S.C.A. § 1396p(d)(4)(C)(ii).

103. *Id.* § 1396p(d)(4)(C)(iii).

104. See Luckenbach, *supra* note 9, at 7.

ing amounts are to be paid to the state up to an amount equal to the amount of medical assistance provided to the beneficiary under the state's assistance plan.<sup>105</sup> This condition, which reflects obvious congressional intent throughout the statute to reimburse the states' Medicaid programs, is commonly cited as the least attractive provision of the exempt trusts of OBRA '93.<sup>106</sup> To ease the effect, Congress included a hardship clause that permits states to establish reasonable procedures to waive this provision by establishing that undue hardship would result from its application.<sup>107</sup>

Inclusion of the (d)(4)(C) trusts in OBRA '93 is likely the result of lobbying by organizations currently running similar trusts and of fear that restrictions on the treatment of trust assets would invalidate current trusts by defining these assets as available to the beneficiary, thus disqualifying the beneficiaries' Medicaid eligibility.<sup>108</sup> Inclusion of these three exempt trusts has been credited to Congressman Henry Waxman.<sup>109</sup>

### III. Analysis

#### A. Benefits of the (d)(4)(C) Pooled Trust

The (d)(4)(C) trust option stands to benefit eligible participants, nonprofit organizations, and state Medicaid programs. The great benefits of this health care planning option can be realized if it is more widely visible to eligible participants and more viable for the establishing and managing nonprofit organizations.

##### 1. PARTICIPANT

While some characteristics of the (d)(4)(C) pooled trust do not represent the most desirable choice for the elderly, particularly trustees' discretion on disbursements and pay back/pay over provisions, most eligible people will find that use of (d)(4)(C) trusts represent the best option available. Most people considering using a (d)(4)(C)

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105. 42 U.S.C.A. § 1396p(d)(4)(C)(iv).

106. See Lovelace, *supra* note 52, at 6.

107. 42 U.S.C.A. § 1396p(d)(4)(C)(iv)(5).

108. See Luckenbach, *supra* note 9, at 7 ("The inclusion of the pooled accounts trust into the OBRA '93 legislation in fact was an explicit endorsement and statement of public policy as to the continued use of such trusts.")

109. See Wiesner, *supra* note 4, at 712 ("The excepted trusts initially found their way into the law as a result of the Waxman Amendment, principally to ameliorate the harshness of the Administration proposal.")



pooled trust are likely facing significant medical expenses due to their disability, and therefore, have essentially two options. The first option is to simply pay for long-term health care. Considering the increasing costs of health care, this option will likely result in the depletion of an estate, foreclosing the opportunity to leave an inheritance to family members. The second option is to invest in an exempt trust and retain Medicaid eligibility. This option allows use of the trust to supplement living expenses, maximize quality of life, and, although the chance to leave an inheritance to family members is rare, the estate will ultimately benefit a nonprofit organization and its charitable purpose.<sup>110</sup>

A brochure distributed by a nonprofit association running a (d)(4)(C) qualifying pooled trust compares the operation of a private “pay back” trust still available, but significantly restricted by OBRA ’93, with the operation of a (d)(4)(C) pooled trust.<sup>111</sup> Under OBRA ’93, a private pay back trust may still be used by a qualified Medicaid participant as long as the funds in the trust are not the beneficiary’s own funds and come from either an inheritance, personal injury settlement, or Social Security back payments.<sup>112</sup> These trusts are subject to a number of restrictions intended to make their use an unattractive option for “wealthy” individuals, thus preventing the abuse OBRA ’93 sought to eliminate.<sup>113</sup> A comparison between private pay back trusts and (d)(4)(C) pooled trusts reveals that the benefits of investing in a (d)(4)(C) pooled trust outweigh those of a private trust with the same operation. Both trusts are typically established to maintain eligibility while supplementing a beneficiary’s financial needs with trust disbursements. However, the (d)(4)(C) pooled trust tends to be the best

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110. “Pooled trusts hold the promise of serving as an amazing technique to promote respectful quality of care and independent living options for persons with disabilities of all ages.” Lovelace, *supra* note 52, at 6.

111. LIFE’S PLAN INC., TRUST OPTIONS FOR THE DISABLED: OPTIONS TO PROTECT THE ASSETS OF A PERSON WITH A DISABILITY (2004) [hereinafter TRUST OPTIONS] (on file with The Elder Law Journal); *see also* Life’s Plan, Inc., <http://www.lifesplaninc.org> (last visited Mar. 10, 2006).

112. *See* Wiesner, *supra* note 4, at 694–98 (describing restrictions on the use of trusts, including the origin of the funds used to establish the trust, the availability of the funds through limited disbursements, and the limitation on look-back periods when the beneficiary will be disqualified from public benefits). With the recent enactment of the Deficit Reduction Act of 2005, these penalties and restrictions on the use of traditional trusts have increased. Deficit Reduction Omnibus Reconciliation Act of 2005, S1932, 109th Cong. (2006) (enacted) (to be codified as amended at 42 U.S.C.A. § 1396).

113. *See* Wiesner, *supra* note 4.

option for people without a family member available to act as trustee because the nonprofit organization fills this role, as opposed to pay back trusts that require the beneficiary to name a trustee. Ideally, a nonprofit organization running a (d)(4)(C) pooled trust will have both experience in managing trust funds for a disabled beneficiary and an understanding of the regulations governing the trust needed to ensure that the beneficiary does not lose medical assistance. Creating a private pay back trust requires designating a trustee, who could be a family member without the expertise necessary to manage the trust disbursements carefully. Further, assets remaining in both trusts are subject to payback requirements; thus, establishing a private trust will not permit an individual to avoid this unattractive provision of the (d)(4)(C) trust.

In her testimony before the House of Representatives Ways and Means Committee, Elizabeth Boggs, Ph.D., member of The Arc Governmental Affairs Committee, urged Congress to harmonize Social Security Income amendments with OBRA '93 and include exemptions similar to (d)(4)(C) pooled trusts.<sup>114</sup> Boggs indicated the importance of supplemental resources to people with disabilities, noting that Medicaid and SSI benefits typically fall short of meeting their financial needs.<sup>115</sup> Further, these trusts become the only source of supplemental funds after the death of a parent, guardian, or other caregiver.<sup>116</sup> Moreover, because a nonprofit organization may act as trustee, the (d)(4)(C) trust may be the only option for many people who could benefit from supplementing public benefits but do not have the ability to designate their own trustee.<sup>117</sup> Further, the use of a pooled trust permits the creation of trusts by people who may not have sufficient funds to establish a viable trust on their own.<sup>118</sup>

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114. *Testimony Before the Subcomm. on Human Resources of the S. Comm. on Ways & Means Regarding the Supplemental Security Income Program*, 103d Cong. 119, 125–26 (1993) (testimony of Elizabeth M. Boggs, Member Governmental Affairs Committee, The Arc).

115. *Id.*

116. *Id.*

117. *See id.*

118. *See* LIFE'S PLAN INC., SELF FUNDED PAYBACK TRUST (2004) [hereinafter SELF FUNDED] (on file with *The Elder Law Journal*); *see also* Life's Plan Inc., <http://www.lifesplaninc.org> (last visited Mar. 10, 2006).

## 2. NONPROFIT ORGANIZATIONS

Nonprofit organizations able to sustain a (d)(4)(C) pooled trust have a lot to gain, most significantly the income from fees and the pay over of trust principal, as well as exposure for their charitable purpose. Although many difficulties plague (d)(4)(C) trusts, a properly and responsibly managed (d)(4)(C) trust could serve as an alternative fund-raising resource for a nonprofit organization. Organizations established with the purpose of benefiting disabled or elderly people, either by providing support and services or educating the public, will find that running a (d)(4)(C) trust will serve many of their current charitable purposes. Other organizations may find that running a (d)(4)(C) trust will provide a service to its members, such as a nonprofit university's alumni, members of a religious organization's congregation, or a nonprofit hospital's patients. By introducing this planning option to its members, the nonprofit organization will provide for their care through administration of the trust and ensure a lifetime of support for the organization's charitable purpose through the individuals' estates.

## 3. STATE MEDICAID AGENCY

The benefits of a (d)(4)(C) pooled trust also extend to the state's Medicaid agency, which secures an easier estate recovery through the use of these trusts.<sup>119</sup> Estate recovery programs have a history as old as the public aid programs they reimburse, and OBRA '93 mandated that every state enact an estate recovery program by threatening to revoke federal financial support absent such a program.<sup>120</sup> Estate recovery programs are intended to either recoup expenditures or, alternatively, discourage application for Medicaid assistance by individuals with assets capable of funding long-term care insurance.<sup>121</sup> States may recover through liens attached to the Medicaid recipient's property or directly from the estate upon the recipient's death; however, the state will typically have to wait until the death of dependent relatives of the deceased before seeking recovery.<sup>122</sup> Expenses associated

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119. See Zieger, *supra* note 24, at 362–63 (detailing the intricacies of estate recovery programs under Medicaid following OBRA '93).

120. *Id.* at 368.

121. *Id.* at 374.

122. *Id.* at 380 (“Recovery from a recipient's estate while children of the recipient are living is . . . an area over which courts have differed. Some courts have held that if a minor, blind or disabled child of the recipient was not a beneficiary of the

with litigating challenges to estate recovery add further difficulty in estate recovery programs.<sup>123</sup>

Through (d)(4)(C) pooled trusts, however, state Medicaid programs are guaranteed to recover at least a substantial portion of the assistance paid out to the participant.<sup>124</sup> The nonprofit organization running the (d)(4)(C) pooled trust must use funds remaining in the beneficiary's subaccount to reimburse the state program upon the beneficiary's death, eliminating some of the agency's costs of seeking out recovery from the individual's estate.<sup>125</sup> Thus, the state Medicaid agency is reimbursed and any additional costs incurred by growth due to use of the (d)(4)(C) trust may be recouped.

## **B. Current Problems with the (d)(4)(C) Pooled Trust**

### **1. COSTS ARE TOO EXCESSIVE FOR MOST NONPROFIT ORGANIZATIONS**

To establish a (d)(4)(C) pooled trust, either an existing nonprofit organization must direct significant resources to the costs of establishing a trust or a distinct nonprofit organization must be established for the purpose of running a trust.<sup>126</sup> One elder law attorney and noted author on the topic of special needs pooled trusts, Rene Lovelace, MBA, JD, CELA, remarked that estimated costs for a nonprofit organization wishing to start a qualifying pooled trust could reach \$150,000.<sup>127</sup> Establishing a new nonprofit organization to set up a

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recipient's estate, the agency may still seek recovery. Others have held that . . . if any family member mentioned in the statute survives, . . . recovery will not be allowed." (citations omitted).

123. *Id.* at 380–83 (describing a number of challenges to estate recovery actions or constitutional challenges to state estate recovery programs).

124. 42 U.S.C.A. § 1396p(d)(4)(C)(iv) (West 2003).

125. *Id.* § 1396p(d)(4)(C)(iv).

126. Lovelace, *supra* note 52, at 6 (listing the start-up steps of a typical pooled trust). In a March 2005 telephone interview with the author, Mr. Tim Takacs, noted elder law attorney and founder of the Tennessee Special Needs Pooled Trust, indicated that the sources of start up costs for most (d)(4)(C) trusts are in fact limited to existing funds of a nonprofit organization interested in establishing a trust as a service to its members or donors with an interest in setting up the trust. For example, Mr. Takacs, already a successful certified elder law attorney, funded the start-up of the Tennessee Pooled Trust largely with his own money. Telephone Interview with Tim Takacs, Founder of the Tennessee Pooled Trust, Named Partner, Elder Law Practice of Timothy L. Takacs, in Hendersonville, Tenn. (Mar. 31, 2005) [hereinafter Takacs Interview].

127. Telephone Interview with Renée Colwill Lovelace, Named Partner, the Lovelace Law Firm, P.C., in Austin, Tex. (Jan. 6, 2005) [hereinafter Lovelace Interview].

pooled trust requires the organization to apply for federal tax-exempt status and to incorporate in the state as a tax-exempt organization.<sup>128</sup> A relationship with an investing organization, typically a bank, must be secured in order to invest and grow the trust's corpus. Attorneys must be retained to prepare all necessary documents and agreements.<sup>129</sup> Staff must be hired and trained in order to manage both the investment of the trust principal and the sensitive area of disbursements of trust funds,<sup>130</sup> which must be carefully administered to protect the beneficiary from losing benefit eligibility.

If the trust is able to survive this initial start-up and attract a sufficient number of participants to sustain itself, the trust then faces the daunting obligation to keep itself afloat. A direct reading of the statute's language makes the nonprofit organization solely responsible for the management of the trust.<sup>131</sup> Some trusts outsource the legal and financial work required,<sup>132</sup> and a few organizations have been established to provide assistance in the management of these trusts, although as written, this is not expressly codified in the statute's language.<sup>133</sup> Further, it can be fairly difficult to secure substantial legal assistance on a pro bono basis, and legal services will likely require the trust to incur additional expenses. A significant part of the expense of running the trust is due to managing disbursements of the trust's subaccounts and maintaining the investments of the pooled trust.<sup>134</sup> These tasks ordinarily require some financial savvy and understanding of financial benefits eligibility requirements, but they are further complicated by the extraordinary pooled structure of the

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128. See generally Johns, *supra* note 48, at 59–63 (discussing the operation of a (d)(4)(C) trust, in particular the necessity to qualify for tax-exempt status to meet the conditions of OBRA '93).

129. Lovelace, *supra* note 52, at 6.

130. *Id.*; 42 U.S.C.A. § 1396p(d)(4)(C)(i) (mandating that a proper (d)(4)(C) trust is established and managed by a nonprofit organization).

131. *Id.* § 1396p(d)(4)(C)(i).

132. Ms. Patty Dudek, an elder law attorney in Detroit who has been involved in the creation of a number of special needs pooled trusts, typically drafts the legal documents necessary to establish the trust and ultimately retains the books. While the nonprofit organization is the legal Trustee of the (d)(4)(C) trust, Ms. Dudek acts as de facto trustee, handling the distributions and trust management. Takacs Interview, *supra* note 126.

133. 42 U.S.C.A. § 1396p(d)(4)(C)(i) (stating simply, "The trust is established and managed by a nonprofit association," with no mention of the ability of the trust to use other organizations' assistance in this management).

134. See generally *id.* § 1396p(d)(4)(C)(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.").

(d)(4)(C) trust. While the statute requires separate subaccounts to be maintained for each beneficiary, the accounts are pooled to maximize investment potential.<sup>135</sup> As a result of pooling the accounts for investment purposes, the nonprofit must assign interest proportionately to each trust. The nonprofit must also ensure that the disbursement of trust funds are carefully administered, and this requires clear understanding of the complex, state-specific eligibility requirements for Medicaid benefits.

The legal and financial duties expected of a nonprofit organization running a pooled trust are substantial.<sup>136</sup> As Ms. Lovelace has noted, the trust manager is expected to be “Mother Teresa with an M.S.W., M.B.A., and J.D.”<sup>137</sup> Further, undertaking the considerable responsibilities of managing the investments of the trust and administering disbursement of the trust funds creates an inherent conflict of interest.<sup>138</sup> Life’s Plan, an organization currently running a (d)(4)(C) trust, has addressed this sensitive issue within the trust agreement, directing that the “use of the Trust assets is to be determined solely on the basis of the needs of the Participant, without regard to the interests of the remainderman.”<sup>139</sup> Nevertheless, the potential for a conflict of interest further complicates and frustrates the serious burden of both establishing and managing a pooled trust, as the nonprofit organization is the ultimate beneficiary of the trust’s principal.

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135. *Id.*

136. Mr. Takacs stated that the major limitation on the number of these trusts is lack of expertise, not lack of funds. According to Mr. Takacs, “a special needs pooled trust requires people to run these trusts, and that is primarily why they fail. [Nonprofit organizations] hire the wrong people and don’t continue to support the trust. This is the main impediment to keeping (d)(4)(C) trusts in operation.” Takacs Interview, *supra* note 126.

137. Lovelace, *supra* note 52, at 8.

138. *Id.* at 8–9 (“Where the trustee has discretion over distributions and the trust keeps the remainder, a potentially serious conflict of interest exists.”); Mr. Takacs recognized that the conflict exists, but he believed that few trustees think about this when operating the trust. In the Tennessee Special Needs Pooled Trust, the funds that are left to the nonprofit organization are referred to as “retained money.” The retained money is used only for the benefit of other disabled people and is not used for operations or salaries. The trust is able to use this fund of retained money to market itself. For example, if the trust can build a sizeable retention fund, it can approach an organization such as the Alzheimer’s Association and offer money from the fund to help people establish an investment in the trust. By using the money to help others, the trust gives new potential beneficiaries a positive image of the trust. This approach helps both to build and to market the trust. Takacs Interview, *supra* note 126.

139. SELF FUNDED, *supra* note 118, at 4.

## 2. POOLED TRUSTS ARE UNAVAILABLE OR UNATTRACTIVE TO MANY MEDICAID PARTICIPANTS

Pooled trust options are widely underused.<sup>140</sup> For a trust to survive, it must attract a sufficient number of participants in order to establish enough subaccounts for investment purposes, and it must also secure adequate initial fees to meet administrative costs.<sup>141</sup> Because these trusts are primarily derived from those that existed prior to OBRA '93, their basis in organizations benefiting disabled individuals make them visible only to those groups affiliated with or familiar with these organizations, namely, families with disabled loved ones or those who have suffered from a disability for a significant part of their lives. The elderly population constitutes a large pool of eligible participants, and they are unlikely to be familiar with the groups that have historically run (d)(4)(C) trusts. Therefore, many elderly people are unfamiliar with the pooled trust option in planning for their future. Further, once introduced to the option of a pooled trust, potential participants may be discouraged from participating for a number of reasons:<sup>142</sup> disengagement from the mission of the nonprofit organization running the trust; discomfort with the ultimate pay out requirements, which could eliminate the possibility of divesting an inheritance; and mistrust of trustee discretion over disbursements.

As the elderly population's numbers grow, so does their need for Medicaid assistance.<sup>143</sup> While Medicaid was originally intended to benefit only those who were unable to pay for medical expenses due to impoverishment, growing costs of health care and an increasing elderly population has logically expanded the Medicaid-eligible population.<sup>144</sup> A declining mortality rate, increasing life spans, and a decreasing birth rate that has lowered the number of younger Americans have all contributed to a higher proportion of elderly in the overall

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140. Lovelace, *supra* note 52, at 8 ("Pooled trusts, with their nearly miraculous capabilities, are arguably terribly underutilized and underdeveloped.").

141. *Id.* at 6.

142. Mr. Takacs opined that the beneficiaries of (d)(4)(C) pooled trusts are primarily under the age of sixty-five because there are simply more individuals in this demographic. He also indicated that the estate recovery provisions, coupled with state penalties imposed on transfers by people over sixty-five years old, give the elderly population little incentive to invest in these trusts. Takacs Interview, *supra* note 126.

143. See KRUSE, *supra* note 10, at 1 (indicating that longer life spans are accompanied with increases in chronic illnesses and disability).

144. See *id.*

population.<sup>145</sup> The growing elderly population also increases the strain on budgets for public medical and health care assistance programs, such as Medicaid.<sup>146</sup> A report by the Chicago Department of Public Health reveals that “[a]lthough 50.5 percent of those enrolled in Medicaid in 2000 were children, 76.3 percent of all Medicaid funds that year were spent on services for the elderly and people with disabilities. Services to children in 2000 represent only 16.5 percent of all Medicaid spending.”<sup>147</sup> As the percentage of Medicaid funds directed toward an aging population grows, the aging population expands.<sup>148</sup>

An aging population and an increased strain on essential public assistance programs are the subjects of many attempts to reform the country’s health care system.<sup>149</sup> As evidenced by the recent belt-tightening in the Deficit Reduction Act of 2005, the federal government will gradually continue to close opportunities for what is perceived as continued abuse of “entitlement programs.”<sup>150</sup> A growing Medicaid budget, while a concern, should not call for limiting access to these funds, as that would result only in denying needy Americans access to necessary health care. Rather, a provision that works to reimburse the program, such as the payback provision mandatory in (d)(4)(C) trusts, will regenerate funds in Medicaid programs in proportion to amounts spent. Increasing use of (d)(4)(C) trusts by making them accessible, available, and attractive could help solve the problem of Medicaid’s straining budget.

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145. *See id.* at 22 n.2.

146. Chi. Dep’t of Pub. Health, Office of Health Care Access, *Medicaid: An Introduction and Overview*, at 4, June 2004, [http://www.cityofchicago.org/webportal/COCWebportal/COC\\_EDITORIAL/MedicareIntroOvw.pdf](http://www.cityofchicago.org/webportal/COCWebportal/COC_EDITORIAL/MedicareIntroOvw.pdf) (last revised Sep. 2, 2004).

147. *Id.* at 6.

148. *Id.* at 7 (“The federal Congressional Budget Office (CBO) estimated that the federal share of Medicaid spending would increase from \$129.8 billion in FFY 2001 to \$295.4 billion in FFY 2011, an average annual rate of growth of 8.6 percent.”).

149. *See* Hubbard, *supra* note 16, at 639 (outlining previous attempts to correct problems with Medicaid administration).

150. Upon signing the Act, President Bush indicated motivations behind the new restrictions: “These programs are providing vital services to millions of Americans in need—yet the costs of Medicare and Medicaid are straining budgets at both the state and federal level. The bill I sign today restrains spending for entitlement programs, while ensuring that Americans who rely on Medicare and Medicaid continue to get the care they need. . . . The bill tightens the loopholes that allowed people to game the system by transferring assets to their children so they can qualify for Medicaid benefits. Along with governors of both parties, we are sending a clear message: Medicaid will always provide help for those in need, but we will never tolerate waste, fraud, or abuse.” Remarks, *supra* note 87.



### 3. STATUTORY VAGUENESS RENDERS THE (d)(4)(C) POOLED TRUST AN AMBIGUOUS OPTION

The statutory language establishing a pooled trust option for a disabled person is exceptionally simple,<sup>151</sup> but it has left a number of issues unanswered. Changes made to Medicaid through the Deficit Reduction Act have left the vague language creating the (d)(4)(C) trust exception untouched, and, while the Act mercifully left these exempt trusts available to Medicaid beneficiaries, it failed to resolve some of the statutory language that plagues their use by refining and redrafting the language.<sup>152</sup> For example, under the statute, it is unclear whether any additional eligibility conditions other than qualifying as disabled are necessary to establish a (d)(4)(C) trust, when the assets contained within the trust corpus are considered to belong to the beneficiary. Moreover, it is unclear under what circumstances a trust may be established either by the beneficiary himself or by a court and to what extent a trust may retain amounts remaining in the account upon the death of the beneficiary before paying reimbursements to the state. Finally, and perhaps most notably, the proper role of the nonprofit organization in establishing and managing the (d)(4)(C) trust remains unclear,<sup>153</sup> and the sparse legislative history offers little guidance for interpretation.<sup>154</sup> Some of these issues have been addressed either by differing interpretations by state Medicaid agencies

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151. 42 U.S.C.A. § 1396p(d)(4)(C) (West 2003) (reading, “This subsection [which effectively permitted the funds in self-settled trusts to disqualify an individual from Medicaid] shall not apply to any of the following trusts: . . . 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: The trust is established and managed by a nonprofit association. 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. Accounts in the trust are established solely for the benefit of individuals who are disabled by the parent, grandparent, or legal guardian of such individuals, by such individuals, or by a court. 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.”).

152. See Deficit Reduction Omnibus Reconciliation Act of 2005, S1932, 109th Cong. (2006) (enacted) (to be codified as amended at 42 U.S.C.A. § 1396).

153. See *id.* § 1396p(d)(4)(C).

154. See Wiesner, *supra* note 4, at 682–87 (describing the historical context of OBRA ’93). See generally *Hearing on H.R. 2264 Before S. Comm. on Health & the Environment*, 103d Cong. 6 (1993).

or by courts, which leaves the construction of the statute subject to various statutory interpretation techniques.<sup>155</sup>

Some assistance in construing the language of OBRA '93 came with the adoption of the Act by the Centers for Medicare and Medicaid Services (CMS), the administering agency formerly known as the Health Care Financing Administration. As of December 1994, the CMS issued implementing instructions as part of the State Medicaid Manual for interpreting the new treatment of trusts put in place by OBRA '93.<sup>156</sup> The State Medicaid Manual inadequately guides state administering agencies in the treatment of pooled trust accounts by listing the criteria of a (d)(4)(C) trust with the exact language used in the statute and by permitting an applicant already determined to be disabled for the purposes of Social Security benefits to automatically qualify as an acceptable beneficiary of a (d)(4)(C) pooled trust.<sup>157</sup> Further, the State Medicaid Manual confusingly asserts that establishing a (d)(4)(C) trust "may or may not constitute a transfer of assets for less than fair market value."<sup>158</sup> Unfortunately, the implementing instructions do little to clarify some of the questions lingering after enactment of OBRA '93.

As stated, changes and further restrictions in Medicaid enacted through the Deficit Reduction Act of 2005 retained the exempt trusts at § 1396p(d)(4), but some of the changes that *were* made could aid in the interpretation of these exempt trusts. In its Cost Estimate report summarizing provisions of the new Act, the Congressional Budget Office indicated that, while some benefits to a limited group of enrollees would be scaled back, this group would not include disabled or pregnant adults.<sup>159</sup> This preliminary interpretation indicates an intent to retain benefits for disabled people, including the (d)(4)(C) exempt trust option, and hopefully will be an interpretation adopted by state Medicaid agencies.

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155. See, e.g., Del. Op. Att'y Gen. No. 01-IB14 (2001) (written response to questions of the functions and conditions on establishing a qualified (d)(4)(C) pooled trust). But see *In re Kennedy*, 779 N.Y.S.2d 346, 350 (Sur. Ct. 2004) (explaining that an administrative agency's interpretation of a statute is entitled to varying degrees of deference, depending on the provision at issue).

156. HEALTH CARE FIN. ADMIN., STATE MEDICAID MANUAL, PART 3—ELIGIBILITY, HCFA Transmittal No. 64 (1994), reprinted in KRUSE, *supra* note 10, at 255.

157. *Id.*

158. *Id.*

159. See CONG. BUDGET OFFICE, COST ESTIMATE: S. 1932 DEFICIT REDUCTION ACT OF 2005, at 41 (2006).

Some of the most notable confusion regards the question of whether this trust is even available to disabled individuals over the age of sixty-five. The (d)(4)(A) trust explicitly states that the qualifying trust is available only to disabled people under the age of sixty-five, but the language establishing the (d)(4)(C) trust is silent on the subject of a qualified beneficiary's age.<sup>160</sup> This ambiguity was unofficially resolved in a Private Letter Ruling from the Department of Health and Human Services (HHS).<sup>161</sup> The recipient of the letter specifically asked for "information with regard to why the age limit applies to this trust, the (d)(4)(A) trust, and, arguably, the (d)(4)(C) trust as well."<sup>162</sup> HHS indicated that, with little insight provided by the conference report accompanying OBRA '93, the agency would not speculate as to the justification for the age limit.<sup>163</sup> However, the letter's drafter, Thomas Hamilton, Director of the Disabled and Elderly Health Programs Group, said, "As a technical point, however, we would note that while an age limit does apply to two of the trusts you cite, the statute does not impose an age limit on the trust cited at 42 U.S.C. 1396p(d)(4)(C)."<sup>164</sup> Although only an unofficial ruling, this language, and subsequent interpretation of the legislation, has the crucial consequence of opening the trust option up to a large and growing class of Medicaid eligible persons—those over the age of sixty-five.<sup>165</sup>

The statute is also unclear about the role of nonprofit organizations that have been granted exclusive authority to establish and manage these exempt trusts. As written, the statute simply states that "[t]he trust is established and managed by a nonprofit association."<sup>166</sup> The language of this statute does not consider the financial hardships

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160. 42 U.S.C.A. § 1396p(d)(4)(A)–(C) (West 2003) (stating that a (d)(4)(A) trust is one "containing the assets of an individual under age 65 who is disabled" where the (d)(4)(C) trust is defined only as a trust "containing the assets of an individual who is disabled" but does not mention a specific age requirement for eligibility of this exempt trust option).

161. Dep't of Health & Human Servs. Priv. Ltr. Rul. (Aug. 9, 2001), reprinted in KRUSE, *supra* note 10, at 328.

162. KRUSE, *supra* note 10, at 329.

163. *Id.* at 328.

164. *Id.*

165. In the same month, the Office of the Attorney General for the State of Delaware issued an equally unofficial letter response to the state's Secretary for the Department of Health and Social Services, offering a similar interpretation of (d)(4)(C) pooled trusts. Del. Op. Att'y Gen. 01-IB14 (2001) (stating "such a trust [an otherwise qualifying (d)(4)(C) trust] is not a resource of the beneficiary [for purposes of Medicaid qualification] regardless of age.").

166. 42 U.S.C.A. § 1396p(d)(4)(C)(i) (West 2003).

that nonprofit organizations must endure to keep these trusts afloat or the conflicts of interest that plague their functioning.<sup>167</sup> By the language, it is unclear whether the nonprofit association must *exclusively* establish and manage the trust, or if it may delegate some of the burdensome tasks to other organizations or corporations, as many organizations currently do.<sup>168</sup> Further, while the statute describes the requirement of pooling the subaccounts and that the subaccounts must be established for the benefit of the disabled individual, it does not reveal any restrictions on the nonprofit organization's role in establishing, managing, and running the trust, on investing the trust's pooled principal, or even on divestment procedures.<sup>169</sup>

The silence in OBRA '93 has led many states to impose restrictions on the operation of (d)(4)(C) trusts.<sup>170</sup> The restrictions imposed on (d)(4)(C) trusts by state law and state Medicaid administering agencies reveal the need for careful administration of the trusts to avoid inadvertent disqualification of a disabled beneficiary from his or her essential Medicaid benefits.<sup>171</sup> For example, by taxing the trust's corpus, limiting disbursements of the trust's corpus to the beneficiary, and imposing transfer penalties at the creation of the trust,<sup>172</sup> state regulations may hinder the administration of these

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167. Lovelace, *supra* note 52, at 6.

168. See discussion *infra* Part III.C.

169. It is important to note that a nonprofit organization will remain bound to the limitations on its activities imposed by the Internal Revenue Code and should be careful that its involvement with the trust does not jeopardize its tax exempt status. See I.R.C. § 501(c)(3) (West 2003).

170. See David J. Correia, *Disability Trusts That Allow a Client to Qualify for Medicaid*, EST. PLAN., May 2003, at 233–40 (identifying a number of state attempts to limit federal assistance eligibility through the state Medicaid administering agency rules, tax treatment of trusts, and subsequent case law interpreting the appropriate scope of state authority in this area); see also *Keith v. Rizzuto*, 212 F.3d 1190, 1193 (10th Cir. 2000) (court interpretation of OBRA '93, holding that the language of 42 U.S.C.A. § 1396p(d) did not only permit states to count trusts toward Medicaid eligibility; it required states to do so, and thus, while income trusts were exempt from that requirement, states were left free to decide whether and under what conditions to recognize such trusts). Note that this outcome may be due to the fact that the trust at issue was an "income-trust," as opposed to a more general disability trust, but it still illustrates the consequences of vague statutory language in subsequent court interpretation.

171. See Correia, *supra* note 170, at 233–40 (identifying a number of state attempts to limit federal assistance eligibility through the state Medicaid administering agency rules, tax treatment of trusts, and subsequent case law interpreting the appropriate scope of state authority in this area).

172. *Id.*; Rosenberg, *supra* note 33, at 123–27 (describing different state statutory models authorizing trusts for people with disabilities).

trusts.<sup>173</sup> One author has argued that application of pre-OBRA '93 laws should be invalid as a violation of federal preemption.<sup>174</sup>

Other than court interpretation when a case or controversy gives the judiciary the opportunity to review state restrictions,<sup>175</sup> the only substantial check on state rules is federal preemption, which, as reinforced in the federal Medicaid statutes, keeps states from implementing requirements that are more restrictive than federal rules.<sup>176</sup> Many state rules, however, are likely permissible due to the vague language of the statute.

### C. Current Trends in the (d)(4)(C) Trust

The (d)(4)(C) pooled trusts are essentially models of special needs trusts, operating for decades to benefit people with disabilities, and established either by family members wishing to provide for the beneficiary after their own death<sup>177</sup> or by courts after lawsuit settlements.<sup>178</sup> The operation of (d)(4)(C) trusts today varies widely, which is a consequence of the vague language of the enabling legislation. The different functioning structures can be attributed to the state in which the trust operates, the demographics of the trust's beneficiaries, and, most notably, the nature and intentions of the nonprofit organization that runs the (d)(4)(C) pooled trust.

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173. See Correira, *supra* note 170, at 238. For example, in Massachusetts, the Supreme Judicial Court found that the corpus of three trusts were to be deemed available to the beneficiaries for purposes of Medicaid eligibility by applying the federal law to pre-OBRA '93 trusts, a consequence a trust administrator drafting the trust could not have anticipated.

174. *Id.*

175. Note that some courts have interpreted the statute to give full effect to disability trust exemption. See, e.g., *Saenz v. Roe*, 526 U.S. 489 (1999) (where the Supreme Court struck a California statute limiting maximum welfare benefits available to citizens who had resided in the state for less than twelve months); see also Correira, *supra* note 170, at 233–40.

176. 42 U.S.C.A. § 1396a(r)(2)(B) (West 2003) (providing guidelines for any state plan for medical assistance in determining income and resource eligibility by requiring that the methodology in determining eligibility be less restrictive and no more restrictive than provisions included in the federal Medicaid statute); see Correira, *supra* note 170, at 233.

177. Luckenbach, *supra* note 9, at 7 (“For decades, parents of children with disabilities and nonprofit organizations had been using ‘pooled’ or ‘umbrella’ trusts to hold assets for the benefit of their disabled children.”).

178. See Johns, *supra* note 48, at 65.

**1. LIFE'S PLAN—OPERATING A (d)(4)(C) PRIVATE POOLED TRUST**

Life's Plan, Incorporated is a nonprofit organization in Downer's Grove, Illinois, that administers two pooled trusts, a Third Party Supplemental Trust and a Life's Plan Self-Funded Payback Trust.<sup>179</sup> An examination of this organization's general functions, specifically in managing a Self-Funded Payback Trust that operates as a (d)(4)(C) exempt trust, reveals the extraordinary expense necessary to start, manage, and sustain a pooled (d)(4)(C) trust.<sup>180</sup> Life's Plan programs essentially consist of a trust agreement between a beneficiary, a Board of Trustees, and Life's Plan, whose stated purpose is providing education on life care planning and trust options to disabled individuals and their families.<sup>181</sup> The Board consists of representatives of disabled people's families, legal and banking professionals, and members of organizations dedicated to the interests of disabled people.<sup>182</sup> Trustees are compensated for reasonable expenses incurred in performing the responsibilities of their positions.<sup>183</sup> In addition to the Board of Trustees, Life's Plan employs a number of additional staff members to manage the trust.<sup>184</sup>

The Board of Trustees is solely responsible for distributing the funds and is subject to a number of standards it must meet for participants to maintain access to federal benefits.<sup>185</sup> The trust transfer agreement, a legal document drafted by an attorney, states that the purpose of the trust is "to only supplement and not to replace earnings and governmental benefits, if any, and not to pay for food, lodging, medical, dental, and hospital expenses which can otherwise be claimed from other sources including governmental agencies, pursuant to the life care plan of the Participant."<sup>186</sup> Examples of supplement-

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179. All materials obtained from Life's Plan, Inc., 2801 Finley Road, Downer's Grove, Ill. 60515, used with permission of the Trust's management (on file with *The Elder Law Journal*), available at Life's Plan Inc., <http://www.lifesplaninc.org> (last visited Mar. 10, 2006).

180. See generally SELF FUNDED, *supra* note 118 (describing the purposes of, and other aspects regarding a (d)(4)(C) trust).

181. *Id.*

182. LIFE'S PLAN, INC., WHAT IS THE DIFFERENCE BETWEEN THE SELF FUNDED PAYBACK TRUST AND A PRIVATE "PAYBACK" TRUST? (2004) [hereinafter DIFFERENCE BETWEEN SELF FUNDED AND PRIVATE] (on file with *The Elder Law Journal*).

183. SELF FUNDED, *supra* note 118.

184. *Id.* at 3.

185. *Id.* at 4.

186. LIFE'S PLAN, INC., LIFE'S PLAN SELF FUNDED PAYBACK TRUST TRANSFER AGREEMENT (2004) [hereinafter TRUST AGREEMENT] (on file with *The Elder Law Journal*).

tal expenses that are appropriate for disbursement of trust funds include membership in a health club, supportive equipment including hearing aids and glasses, travel, personal and living expenses, hiring an advocate or guardian, and medical services that are not provided by state and federal benefits.<sup>187</sup> Trustees have significant discretion over disbursement of the funds.<sup>188</sup> The initial transfer agreement indicates that both participants and trustees agree to a number of criteria that must be considered in making disbursement decisions; these criteria include the age and physical condition of the participant, the nature and extent of governmental assistance or benefits, the life expectancy of the participant, and the needs and ability for care, support, maintenance, and education for the participant.<sup>189</sup> Use of these criteria indicates that disbursement decisions are made on a subjective and individual basis.<sup>190</sup>

The trust's operating budget is derived from three principle sources of funds.<sup>191</sup> First, the trust transfer agreement requires payment of an initial enrollment fee of \$775, an annual fee of \$750, an annual asset value fee of 1% of the subaccount, and an annual bank management fee of 1% of the subaccount.<sup>192</sup> These fees are attributed to "usual and customary services including administration of the account, investment management, securities processing and custody, record keeping and other fiduciary services."<sup>193</sup> The second and most significant source of funds is the money from the pay-over provision of a (d)(4)(C) trust, which requires 10% of the principal that is left after the subaccount is terminated to be paid to the trust.<sup>194</sup> Once this payment is satisfied, the remaining funds are secured to the typical pay-

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187. LIFE'S PLAN, INC., EXAMPLES OF SUPPLEMENTAL OPPORTUNITIES WHICH MAY BE PROVIDED (2004) [hereinafter SUPPLEMENTAL OPPORTUNITIES] (on file with The Elder Law Journal).

188. See SELF FUNDED, *supra* note 118 ("If at any time the Trustees believe that continued payment of principal and net income or any portion thereof on behalf of a Participant would be contrary to the best interests of such Participant, or the account itself lacks the funds necessary to carry out its purposes, . . . then the Trustees may pay or apply such principal and/or net income to or for the benefit of the Participant in such manner as the Trustees believe advisable . . .").

189. SELF FUNDED, *supra* note 118.

190. *Id.*

191. LIFE'S PLAN, INC., TRUST INCORPORATION AGREEMENT (2004) [hereinafter INCORPORATION AGREEMENT] (on file with The Elder Law Journal).

192. LIFE'S PLAN, INC., FEE SCHEDULE (2004) [hereinafter FEE SCHEDULE] (on file with The Elder Law Journal).

193. *Id.*

194. INCORPORATION AGREEMENT, *supra* note 191.

back provision to reimburse the state for benefits paid to the participant.<sup>195</sup> Fifteen percent of any remaining principal in the subaccount, after both the pay-over and the pay-back provisions are met, is then directed toward Life's Plan, Inc.<sup>196</sup> Finally, funds remaining in the trust after these divestments are assigned to a source indicated by the participant in the initial agreement or in his will.<sup>197</sup> Depending on factors such as the size of the subaccount at transfer, life of the subaccount, extent of disbursements over the life of the subaccount, and rate of accruing interest during the life of the subaccount, these divestments may either not occur or could be a fairly insignificant contribution to the operating costs of the Life's Plan trust.

## 2. CENTRALIZING MANAGEMENT OF THE (d)(4)(C) POOLED TRUST

As many organizations have begun to simultaneously recognize the potential benefits of running a (d)(4)(C) pooled trust and the difficulty of establishing and running these trusts, a few have begun to provide services to nonprofit organizations.<sup>198</sup> The Center for Special Needs Trust Administration, Inc., a nonprofit organization based in Clearwater, Florida, states that its purpose is to offer solutions to the administrative difficulties of special needs trusts by providing specialized administration services.<sup>199</sup> The Center essentially takes over the administration side of running a (d)(4)(C) trust or other special needs trust.<sup>200</sup> This organization acts as a bridge between the individual, the trust, and various professionals who can assist in proper management of the trust, including investment advisors, a law firm with experience navigating the qualifying rules for Medicaid, and various public assistance programs. By linking these essential components and guiding trusts through the minefield of state regulations, the Center can save substantial costs in running a special needs trust and ultimately ensure that administration of the trust does not lead to loss of benefits for the beneficiary.<sup>201</sup>

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195. *Id.*

196. *Id.*

197. *Id.*

198. The Ctr. for Special Needs Trust Admin., Inc., Homepage, at <http://www.sntcenter.org> (last visited Mar. 10, 2006).

199. *Id.*

200. *Id.*

201. *Id.*



The most significant assistance offered by the Center, and similar organizations, is to provide trustee services and act as the beneficiary's liaison, thus taking on the more sensitive functions of running (d)(4)(C) trusts.<sup>202</sup> Putting these tasks in the hands of a third party can ensure that the needs of the disabled beneficiary are not overlooked by overworked and underqualified nonprofit staff. The Center promises "that trust beneficiaries' needs are preeminent and that each special needs trust is administered for the sole benefit of each individual trust beneficiary."<sup>203</sup>

An organization like the Center offers many benefits. It can relieve a nonprofit organization's burden of handling many of the difficult, sensitive, and demanding tasks involved in running a (d)(4)(C) trust. More importantly, however, taking over some of the more sensitive tasks eliminates some of the conflicts of interest inherent in (d)(4)(C) trust management. One current problem with an organization like the Center, however, is that it is not specifically accounted for in the statutory language creating (d)(4)(C) trusts and is, therefore, subject to virtually no regulation. Without any guidelines for handling beneficiary requests, managing disbursements, or setting the fees it charges a hiring nonprofit organization, an unregulated consulting agency has the potential of causing more problems than it may solve. To ensure that a third-party manager truly makes a (d)(4)(C) trust more viable, responsible, and utilized, there must be clear standards.

### 3. DELAWARE CAREPLAN—A STATE MODEL FOR THE (d)(4)(C) POOLED TRUST

In 1998, the state of Delaware instituted an innovative approach to special needs trust treatment under the state's Medicaid rules with the Delaware CarePlan Trust Act.<sup>204</sup> Codified in Title 12 of the Delaware Code, the Delaware CarePlan Trust Act is a model trust for nonprofit, nongovernmental organizations administering trusts for persons with disabilities in the state of Delaware, and its stated purpose is to "provide a method to assure ongoing individualized support for a person with a disability."<sup>205</sup> The Act requires these organizations to provide a number of services with the purpose of maintaining a focus

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202. *Id.*

203. *Id.*

204. DEL. CODE ANN. tit. 12, §§ 4001–4012 (2001).

205. *Id.* § 4002(a).

on caring for the disabled trust beneficiary, including comprehensive care planning, guardianship for those who are incompetent, and advice and counsel for appointed guardians.<sup>206</sup> The Act sets forth its general purpose through eight stated goals: (1) encourage the orderly establishment of the trust for the benefit of disabled beneficiaries; (2) ensure that the trust is administered properly and is free from conflicts of interest; (3) facilitate contributions on behalf of beneficiaries and pooling of the funds; (4) provide families with assurance that the beneficiary is supported and the trust is efficiently managed; (5) ensure that guardians are available to beneficiaries; (6) encourage the availability of trust resources for supplemental needs not met by government programs; (7) encourage the inclusion of indigent beneficiaries when funds are available; and (8) encourage families to set aside funds for persons with disabilities to ensure that the trust principal is not considered an asset or income that could disqualify the beneficiary from government programs.<sup>207</sup>

These goals are met through a number of guidelines that govern the functioning of a Delaware CarePlan Trust.<sup>208</sup> First, the trust must be administered by a Board that includes family members or public representatives, but no one with voting power may also provide services to disabled individuals through another organization, nor shall any Board member receive fees or commissions for their services to the trust.<sup>209</sup> Second, once an applicant becomes eligible as a participant, the trust must develop a comprehensive care plan that identifies the date for delivery of services and determine the conditions, nature, and criteria for the services provided.<sup>210</sup> While these guidelines, which attempt to preserve government benefits by outlining the rules for disbursements in advance, may appear strict, the Act provides the beneficiary the opportunity to make a special disbursement request if an emergency arises, so long as the requests are consistent with the Act's stated purposes.<sup>211</sup> The Act more effectively ensures the maintenance of a beneficiary's eligibility in government benefits at section 4009, which states

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206. *Id.* § 4001(2).

207. *Id.* § 4002(b)(1)–(8).

208. *Id.* §§ 4003–4011.

209. *Id.* § 4003(a)–(b).

210. *Id.* § 4004(c)(1)–(3).

211. *Id.* § 4005(a).

Notwithstanding any other provision of law, a participant's interest in the Delaware CarePlan Trust shall be disregarded in assessing financial eligibility and liability under any program of government benefits or assistance. No government agency shall reduce the benefits or services available to any individual because that person is a participant.<sup>212</sup>

An advantage of codifying a model for a trust is apparent in the Delaware CarePlan Act's provision that requires the trust to report and itemize all funds collected and any operating costs incurred over the course of the year.<sup>213</sup> The trust must make the report available to the public and provide the report to beneficiaries and their representatives.<sup>214</sup> This provision provides a clear benefit by holding trust fund managers accountable, which, in turn, provides peace of mind for beneficiaries and their families and eases the trustee conflict of interest.

One area in which the Delaware CarePlan Act does not provide much guidance is in the disbursement of the trusts' funds at the termination of the subaccount. The Act simply requires the Board to develop standards and procedures to follow when a beneficiary's subaccount is withdrawn.<sup>215</sup> While clear guidelines for the treatment of surplus funds are missing, the Act does permit the Board to release the funds from the trust and use those surplus funds to enroll an otherwise qualifying indigent participant into the trust.<sup>216</sup> Overall, the Delaware CarePlan Trust Act is an exceptional approach to guiding nonprofit organizations in establishing qualifying trusts because it avoids conflicts of interest and ensures that the interests of the disabled beneficiary remain paramount.

#### IV. Resolution

Twelve years have passed since Congress codified approval of the special needs pooled trust in the U.S. Code. While changes to Medicaid since OBRA '93 indicate a commitment to limiting the use of trusts by Medicaid beneficiaries,<sup>217</sup> the (d)(4)(C) trusts remain an available option for disabled people, and interpretation of this new

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212. *Id.* § 4009.

213. *Id.* § 4006(a).

214. *Id.* § 4006(a)-(d).

215. *Id.* § 4007(a).

216. *Id.* § 4007(b)-(c).

217. *See* Deficit Reduction Omnibus Reconciliation Act of 2005, S1932, 109th Cong. (2006) (enacted) (to be codified as amended at 42 U.S.C.A. § 1396).

legislation should not restrict the use of these trusts by any disabled person, regardless of age. As discussed above, the statute's current language, notably left untouched by the Deficit Reduction Act of 2005, must be retooled to address a number of important needs that have arisen over the past decade. First, new statutory language and more specific instructions to state Medicaid agencies are necessary to ease the effect of restrictive state laws and to permit centralization or delegation of trust management. Redrafting the language at (d)(4)(C) should also mandate an adherence to the fundamental purposes of the trusts—to support and benefit disabled people. These goals may be accomplished both through redrafting the statutory language and by providing state Medicaid administering agencies with a model trust, which could be set forth in the State Medicaid Manual. These changes will aid state agencies in regulating (d)(4)(C) trusts within their jurisdictions and guide the formation of new (d)(4)(C) trusts by nonprofit organizations.

#### A. Statutory Language

The following changes to the statutory language at (d)(4)(C) will improve its effectiveness. First, to codify the availability of this trust option to disabled individuals over the age of sixty-five, the statutory language should be amended at (d)(4)(C) to read, "A trust containing the assets of an individual who is disabled (as defined in section 1382c(a)(3) of this title), *regardless of the individual's age*, that meets the following conditions: . . ."

Second, the statute should explicitly permit a nonprofit organization to utilize a central advising or administering organization in its start-up and management and a financial organization in the trust investment. Allowing delegation of certain functions will not only ensure proper management of the trust, but will also ease the conflict of interest inherent in running a trust under which the trust's corpus is available to the nonprofit trustee at the death of the beneficiary. Specifically, the statutory language should be amended at (d)(4)(C)(i) to read, "The trust is established and managed by a nonprofit organization. *Nothing in this statute shall prohibit an outside organization established with the purpose of centralizing the management of special needs trusts from assisting in the management of the trust in conjunction with the nonprofit organization. Nothing in this statute shall prohibit the nonprofit*

*organization from delegating the investment of the trust's corpus to a certified financial institution."*

Third, to ensure responsible management of the trust that will not result in the loss of financial benefits for the disabled beneficiary, the statutory language should specify that the disbursements adhere to guidelines in the model trust, as outlined below. Thus, the statutory language at (d)(4)(C)(ii) should be amended to read, "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. *Disbursements of the separate accounts that adhere to requirements provided by the State agency, and do no more than supplement the beneficiary's quality of life and health care, must not result in the loss of the beneficiary's government benefits eligibility.*" The statutory language at (d)(4)(C)(iii) should also be amended to read, "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. *The source or amount of these funds must not result in the loss of the individual's government benefits eligibility.*"

Finally, borrowing from the Delaware CarePlan Trust Act, the federal statutory language that codifies the exemption of special needs pooled trusts should mandate that the management of the trust remain focused on the best interests of the disabled beneficiary. Thus, if a nonprofit organization is able to establish and run a financially viable special needs pooled trust, the interests of the beneficiary will not be overshadowed by this financial interest. This goal can be met by establishing accountability. The statutory language should be amended to add (d)(4)(C)(v), reading, "*The managing nonprofit association shall prepare a report annually, itemizing all funds collected for the year, income earned, salaries, other expenses incurred, and the opening and final trust balances. This report shall include itemized lists of disbursement requests made by beneficiaries and of disbursements made during that year. Annual accountability reports will be reviewed by the State agency to ensure proper administration of the trust free from conflicts of interest.*"

**B. A Model (d)(4)(C) Trust<sup>218</sup>**

The current State Medicaid Manual provides minimal guidance on state treatment of special needs pooled trusts. A model trust can ensure more clarity and certainty, however, by guiding the establishment and management of these trusts. A model trust should be developed by professionals in the field, and it should incorporate the following important provisions.

First, like the Delaware CarePlan Trust Act, the model (d)(4)(C) trust should establish in its articles of incorporation the purpose, scope, and organization of the trust. It should also state that its purpose is to ensure the care and support of the disabled beneficiary through adequate supplemental disbursements that can increase the quality of life and improve the health care of the beneficiary. Establishing this principle will ensure that the management of the trust does not deviate from the purpose of providing for a disabled beneficiary.

Second, in order to ensure that the trust beneficiaries do not lose eligibility for federal benefits, the model (d)(4)(C) trust should include standard form transfer agreements that set guidelines for the subaccount's disbursements and rules governing disbursement frequency and amounts. This form should include dates and frequency of disbursements, require clear reasons for the amounts, and provide a comprehensive list, approved by the state agency, of possible supplemental needs that can be met by disbursements.

Third, the model (d)(4)(C) trust should provide clear procedures for terminating the trust, which outline the minimum percentage of the account balance that must be paid to the state and nonprofit organization before divested according to the beneficiary's will.

Finally, to alleviate the conflict of interest inherent in the management of the trust, the model (d)(4)(C) trust should mandate the separation of the trust management and disbursements of the subaccounts. This may be achieved by requiring a separate board that is able to responsibly meet disbursement requests and judge their adequacy to supplement the beneficiary's financial and medical needs.

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218. The suggestion to create a model trust in order to guide nonprofit organizations in establishing and managing (d)(4)(C) trusts was first made to the author of this note by Ms. Renée Colwill Lovelace, MBA, JD, CELA, of the Lovelace Law Firm, P.C. in Austin, Texas, during a telephone interview in January 2005. The author of this note would like to extend her thanks to Ms. Lovelace for her suggestions, ample advice, and generous support. Lovelace Interview, *supra* note 127.

This board could serve multiple (d)(4)(C) trusts at a time, ensuring that nonprofit organizations without prior experience in providing services for disabled people are able to run (d)(4)(C) trusts without undertaking this sensitive responsibility. Delegating this responsibility to an outside entity will eliminate many of the administrative costs of dealing with subaccount disbursements.

## **V. Conclusion**

The special needs pooled trust is an exceptional planning option available to people facing a future of high medical expenses and a number of difficult choices. Twelve years after the trust was exempted from harsh transfer penalties in OBRA '93, and after surviving subsequent increases in those penalties in the Deficit Reduction Act of 2005, it remains widely underused by elderly people, many of whom are unaware of its existence or their own eligibility. Making minor changes to the statutory language and providing states with a model trust will make this trust a more visible and viable option for many people planning for their future.