

# JACOB’S LADDER TO A HIGHER QUALITY OF LIFE\*: SPECIAL NEEDS FINANCIAL PLANNING FOR PRACTITIONERS AND CAREGIVERS

*by Richard Stebbins* \*\*

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\* Based on research conducted by the Social Security Administration, “Jacob” was the most common name for males born from 1999 to 2010. *Popular Baby Names*, SOCIAL SECURITY ONLINE, [www.socialsecurity.gov/OACT/babynames/top5names.html](http://www.socialsecurity.gov/OACT/babynames/top5names.html) (last modified Mar. 11, 2011).

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## I. INTRODUCTION

More than 36 million<sup>1</sup> United States citizens live with a disability.<sup>2</sup> Thanks to medical advances, individuals with disabilities live longer and more active lives than in the past, while caregivers tend to delay planning for the future of their disabled children.<sup>3</sup> Due to the changing needs of the special needs population, understanding the strategies that can help these individuals is especially important for practitioners.

This article provides guidance for caregivers and practitioners that are “supporting independence and promoting involvement in all aspects of society”<sup>4</sup> for loved ones and clients with special needs using Jacob, a hypothetical child growing up with Down syndrome, living in Anytown, USA.<sup>5</sup> Part II of the article addresses financial, strategic, and educational benefits available to Jacob as he becomes an adult.<sup>6</sup> Part III examines several types of special needs trusts and illustrates how these trusts can provide a benefit without endangering government entitlements.<sup>7</sup> Parts IV and V provide practical strategies that caregivers and practitioners can use

1. See *Disability Characteristics: 2010 American Community Survey 1-Year Estimates*, U.S. CENSUS BUREAU, [factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS\\_10\\_1YR\\_S1810&prodType=table](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_10_1YR_S1810&prodType=table) (last visited Mar. 20, 2012) (including only the civilian noninstitutionalized—not inpatient in a nursing facility—population to reach this number).

2. “Special needs” will be used interchangeably with the technically correct “disability” throughout the article. “Disability” is the common term used on government benefit program literature and in the tax code, while support groups favor the term “special needs.” See generally SPECIAL NEEDS SUPPORT CENTER, <http://www.sns-cuv.org/> (last visited Mar. 20, 2012); *Special Needs Support Groups: Advice for Families and Caregivers*, CARE.COM <http://www.care.com/special-needs-special-needs-support-groups-p1167-q227944.html> (last visited Mar. 20, 2012); MEETUP.COM, <http://splneedsparents.meetup.com/> (last visited Mar. 20, 2012); PARENT SUPPORT GROUP, <http://www.parentsupportgroup.org/> (last visited Mar. 20, 2012).

The United States Code defines disabled as follows:

[A]n individual shall be considered to be disabled . . . if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months. . . . [A]n individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy. . . . An individual under the age of 18 shall be considered disabled . . . if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and 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 12 months.

42 U.S.C.A. § 1382c(a)(3)(A)–(C)(i) (West 2005).

3. Harriet P. Lefley & Agnes B. Hatfield, *Helping Parental Caregivers and Mental Health Consumers Cope with Parental Aging and Loss*, 50 PSYCHIATRIC SERVICES, 369, 369–73 (1990).

4. See *Overview*, U.S. CENSUS BUREAU, <http://www.census.gov/hhes/www/disability/overview.html> (last updated Sept. 21, 2009).

5. See discussion *infra* Parts II–V.

6. See discussion *infra* Part II.

7. See discussion *infra* Part III.

to ensure that Jacob, now grown, continues to enjoy a high quality of life even after his parents pass away.<sup>8</sup>

## II. BENEFITS AVAILABLE

### A. Financial

Throughout Jacob's life, the government may provide financial support through different programs such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare.<sup>9</sup> The inner workings of these entitlement programs are complex; thus, caregivers and practitioners need to understand the rules for each program.

#### 1. Supplemental Security Income

While Jacob is under the age of eighteen, he may be ineligible for benefits if his parents hold resources in excess of \$3,000; this amount makes SSI difficult to obtain for most families, as those resources are "deemed" available to Jacob.<sup>10</sup> "Resources" are things the parents own with exceptions for their home, household goods and personal effects, life insurance policies under \$1,500 face value, educational funds, and one vehicle.<sup>11</sup> SSI can be paid to a child with a disability<sup>12</sup> who is under the age of eighteen and earns less than \$1,010 a month, provided that the disability is expected to result in death, has lasted twelve months, or is expected to last at least twelve months.<sup>13</sup> A full time student with a disability under the age of twenty-two may exclude up to \$1,700 of their monthly earnings.<sup>14</sup>

The government will assess Jacob's assets on a monthly basis, which means the benefit could be denied in one month and granted the next month.<sup>15</sup> Once an application is made for benefits, the state typically takes three to five months to make a final decision regarding disability.<sup>16</sup> Payments (which can vary by state, as some states will add to the SSI payment) may begin immediately and last for six months while the state

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8. See discussion *infra* Parts IV–V.

9. See discussion *infra* Part II.

10. See *Understanding Supplemental Security Income*, SOCIAL SECURITY ONLINE, <http://www.ssa.gov/ssi/text-resources-ussi.htm> (last visited Mar. 20, 2012).

11. *Id.*

12. See *supra* text accompanying note 2.

13. U.S. SOC. SEC. ADMIN., BENEFITS FOR CHILDREN WITH DISABILITIES, SSA Publication No. 05-10026 (2012), available at <http://www.ssa.gov/pubs/10026.html>.

14. *Id.* The \$1,700 amount is contingent on being a full-time student and is subject to an annual earnings limit of \$6,840 for 2012. *Id.* If the child is not a full-time student, then the \$1,700 amount drops to \$1,010. *Id.*

15. See *id.*

16. *Id.*

makes the determination.<sup>17</sup> After Jacob is initially deemed disabled for SSI purposes, reviews will be conducted periodically to ensure Jacob still qualifies.<sup>18</sup> Keeping current medical and school records will help make the application and review process go as smoothly and quickly as possible.<sup>19</sup>

## 2. Social Security Disability Insurance

If eligible, SSDI will be paid to a “child” with a disability that began prior to age twenty-two, and payments will continue as long as the individual is disabled.<sup>20</sup> For Jacob to be eligible one of his parents must be receiving Social Security benefits or, if deceased, have worked long enough at a Social Security covered job, or Jacob must have been receiving benefits prior to age eighteen.<sup>21</sup> The Social Security Administration determines SSDI benefit amounts based on the Social Security earnings records of the parents.<sup>22</sup> Jacob’s benefit can be up to 50% of the Social Security payment his parents receive.<sup>23</sup> After receiving benefits for twenty-four months, Jacob will be eligible for Medicare.<sup>24</sup>

## 3. Medicare

Medicare is a health insurance program that helps disabled individuals who are under the age of sixty-five—the fact that Medicare is an insurance program means beneficiaries will pay a deductible and possibly a premium.<sup>25</sup> Medicare, including Medigap coverage, comes in parts A through L but is most commonly known for Parts A, B, and D.<sup>26</sup> The costs of Medicare are adjusted annually; the numbers provided below are accurate for 2012.<sup>27</sup>

Medicare Part A provides coverage for medically necessary inpatient care in hospitals and only charges a premium in cases like Jacob’s where

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17. *Id.*

18. *Id.*

19. *Id.*

20. *Id.*

21. *Id.*

22. *Id.*

23. *Id.*

24. U.S. SOC. SEC. ADMIN., WHAT YOU NEED TO KNOW WHEN YOU GET SOCIAL SECURITY DISABILITY BENEFITS, SSA Publication No. 05-10026 (2011), available at <http://www.ssa.gov/pubs/10153.html#2>.

25. See Overview, CENTERS FOR MEDICARE & MEDICAID SERVICES, <http://www.cms.gov/MedicareGenInfo/> (last updated Dec. 14, 2005, 12:00 AM). Medicare also benefits people over the age of sixty-five and anyone with End-Stage Renal Disease. See *id.*

26. COLLEGE FOR FINANCIAL PLANNING, CURRENT ISSUES IN RETIREMENT PLANNING, 87–89 (2008).

27. See Original Medicare Costs in 2012, MEDICARE INTERACTIVE, [www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide\\_id=1728](http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide_id=1728) (last updated Nov. 1, 2011).

the beneficiary has not fully contributed to the system.<sup>28</sup> The deductible for Part A is \$1,156 per year, and coinsurance costs will vary based on the length of time spent in the hospital.<sup>29</sup>

Medicare Part B charges an annual deductible of \$140 and an annual premium that will typically be \$99.90, and Part B covers physician and outpatient expenses.<sup>30</sup> Medicare Part B is optional; those enrolling after turning sixty-five, however, will be assessed a penalty on their premium of 10% for each 12-month period they delay.<sup>31</sup>

Medicare Part D is open to anyone who is covered by Medicare and offers help with prescription drug costs.<sup>32</sup> After paying a \$320 deductible, the individual pays only 25% of prescription drug costs until the combined cost of both Medicare and the individual reaches \$2,930.<sup>33</sup> At this point, the individual will have spent \$320 plus \$652.50 (25% of \$2,610) for a total of \$972.50 out of pocket.<sup>34</sup> The individual has now reached what is known as the “donut hole” and is responsible for all costs until he or she spends a total of \$4,700 out of pocket on prescription drugs.<sup>35</sup> If the individual can make it out of the donut hole, he or she is responsible for only 5% of all subsequent purchases.<sup>36</sup> These costs are annual and begin again each year.

#### 4. Medicaid

Medicaid is a health care program that pays money directly to health care providers for people with low income and limited resources.<sup>37</sup> In most

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28. Forty quarters of coverage with a quarter equaling \$1,130 in 2012 and no more than four quarters earned in a year result in an individual being fully covered for Medicare Part A purposes and thus not subject to premiums. *See id.* Those subject to a premium may pay up to \$451 per month. *See id.* The premium can be adjusted based on age and the number of quarters the individual worked. *See id.* Further discussion of the topic is beyond the scope of this article. *See Automatic Determinations*, SOCIAL SECURITY ONLINE, <http://www.ssa.gov/OACT/COLA/QC.html> (last updated Oct. 19, 2011); *Program Development Research*, SOCIAL SECURITY ONLINE, <http://www.ssa.gov/disabilityresearch/wi/medicare.htm> (last modified Feb. 9, 2011); *Medicare Part A*, CENTERS FOR MEDICARE & MEDICAID SERVICES, [https://www.cms.gov/MedicareGenInfo/02\\_Part%20A.asp#TopOfPage](https://www.cms.gov/MedicareGenInfo/02_Part%20A.asp#TopOfPage) (last modified Dec. 14, 2005).

29. *See Original Medicare Costs in 2012*, MEDICARE INTERACTIVE, [http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide\\_id=1728#top](http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide_id=1728#top) (last updated Nov. 1, 2011).

30. *See Medicare premiums and coinsurance rates for 2012*, MEDICARE.GOV (Oct. 27, 2011, 11:48 AM), [https://questions.medicare.gov/app/answers/detail/a\\_id/2309/kw/2012%20PREMIUM](https://questions.medicare.gov/app/answers/detail/a_id/2309/kw/2012%20PREMIUM). This premium is tied to the annual income of the individual. *See id.*

31. *See Medicare Part B late enrollment penalty*, MEDICARE ONLINE, [http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide\\_id=316#top](http://www.medicareinteractive.org/page2.php?topic=counselor&page=script&slide_id=316#top) (last updated Jan. 3, 2012).

32. *See Medicare Prescription Drug Coverage (Part D)*, MEDICARE.GOV, <http://www.medicare.gov/navigation/medicare-basics/medicare-benefits/part-d.aspx> (last visited Mar. 21, 2012).

33. *See 2012 Medicare Part D Outlook*, Q1MEDICARE.COM, <http://www.q1medicare.com/PartD-The-2012-Medicare-Part-D-Outlook.php> (last visited Mar. 21, 2012).

34. *See id.*

35. *See id.*

36. *See id.*

37. *See MEDICAID.GOV*, <http://www.cms.gov/MedicaidGenInfo/> (last visited Mar. 21, 2012).

states, those who are eligible for SSI are also eligible for Medicare.<sup>38</sup> Income and resource limits vary by state, but for a single individual, income generally cannot exceed \$2,094 per month and resources cannot exceed \$2,000.<sup>39</sup> Medicaid can retroactively cover medical bills up to three months prior to application and will continue until the individual's circumstances change.<sup>40</sup>

### B. Planning

The early years of caring for a child with special needs can be overwhelming. The National Early Childhood Technical Assistance Center (NECTAC) works to help infants and toddlers with disabilities and their families on a state-by-state basis and should be the first stop for a new parent.<sup>41</sup> This program serves as a resource for parents to coordinate and implement appropriate services such as speech therapy, physical therapy, and occupational therapy for children with special needs.<sup>42</sup> NECTAC creates a comprehensive plan that assesses the child's current development and family goals, as well as a plan of action to access the services needed to achieve those goals.<sup>43</sup>

In addition, any child eligible for SSI is eligible for a special provision of SSI Children with Special Health Care Needs (CSHCN).<sup>44</sup> State health departments administer CSHCN, which generally provides specialized health services to special needs children through arrangements with a variety of health providers.<sup>45</sup> Once basic financial and health needs have been met, parents should begin considering their child's future.<sup>46</sup>

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38. *Ramey v. Rizzuto*, 72 F. Supp. 2d 1202, 1207 (D. Colo. 1999), *aff'd sub nom*, *Ramsey v. Reinertson*, 268 F.3d 955, 959–60 (10th Cir. 2001); *Reames v. Oklahoma*, 411 F.3d 1164, 1169–70 (10th Cir. 2005).

39. See ELDER LAW ANSWERS, [http://www.elderlawanswers.com/Elder\\_Info/Elder\\_Article.asp?id=2751](http://www.elderlawanswers.com/Elder_Info/Elder_Article.asp?id=2751) (last visited Mar. 21, 2012). There are additional and more generous provisions for married couples regarding the income and resources of the healthy spouse, but this article will focus as close as possible on limitations and benefits for the hypothetical Jacob. See *id.*

40. See MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Eligibility.html> (last visited Mar. 21, 2012).

41. See NECTAC: THE NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER, <http://www.nectac.org/default.asp> (last visited Feb. 12, 2012).

42. See *id.*

43. See NECTAC: THE NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER, <http://www.nectac.org/topics/families/families.asp> (last visited Mar. 21, 2012).

44. See 42 U.S.C.A. § 701(a)(1)(d) (West 2010).

45. See UF INSTITUTE FOR CHILD HEALTH POLICY, <http://www.ichp.ufl.edu/ichp> (last updated Mar. 19, 2012).

46. See SPECIAL NEEDS FIN. PLAN, <http://specialneedsplanning.com/> (last visited Mar. 21, 2012).

### C. Education

Educational success can be difficult for individuals with special needs. Only 72% of people at the age of twenty-five or older with special needs have a high school diploma or the equivalent, while 88% of people over the age of twenty-five without special needs have at least a high school diploma.<sup>47</sup> In 1990, Senator Tom Harkin successfully introduced amendments to transform the Education of the Handicapped Act into the Individuals with Disabilities Education Act (IDEA), a robust program designed to provide early intervention and education strategies for children with disabilities.<sup>48</sup> IDEA charges each state and local school district with the responsibility to provide every child free and appropriate education.<sup>49</sup> IDEA takes effect when Jacob turns three and will last until he turns twenty-one.<sup>50</sup>

## III. SPECIAL NEEDS TRUSTS

### A. Overview

Thanks to the benefits and support services available to him as a disabled U.S. citizen, Jacob is able to maintain a life with a basic comfort level.<sup>51</sup> However, a limit exists on how far these disability benefits can be stretched, and Jacob's parents want him to enjoy the best life possible.<sup>52</sup> The problem is, while Jacob might have expenses that exceed the benefits he receives, he would not qualify for certain entitlements if his monthly income exceeded \$1,010<sup>53</sup> or if his personal assets exceeded \$2,000.<sup>54</sup> If

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47. See U.S. CENSUS BUREAU, at "Education" (May 26, 2010), [http://www.census.gov/newsroom/releases/archives/facts\\_for\\_features\\_special\\_editions/cb10-ff13.html](http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb10-ff13.html).

48. See STEVEN R. ALEMAN, CONG. RESEARCH SERV., ED 343318, EDUCATION OF THE HANDICAPPED ACT AMENDMENTS OF 1990, 7 (1991), available at <http://www.eric.ed.gov/PDFS/ED343318.pdf>.

49. See 20 U.S.C. § 1412(a)(1)(a) (2005).

50. See *id.*

51. See §§ 1400–45.

52. See *Update 2012*, SOCIAL SECURITY ONLINE, (Feb. 2012) <http://www.ssa.gov/pubs/10003.html> (follow "Information for people who receive Social Security benefits" hyperlink).

53. See *id.* This \$1,010 limit applies to "Substantial Gainful Activity (Non-blind)" and increases to \$1,690 for a blind individual. See *id.* Please note that these limits apply only to Social Security Income and not Social Security Disability Income. See *id.*

54. See *Supplemental Security Income (SSI)*, SOCIAL SECURITY ONLINE, <http://www.socialsecurity.gov/ssi/text-resources-ussi.htm> (last visited Feb. 12, 2012). For the purposes of Social Security Income and Medicaid, this \$2,000 limit counts the following assets as "resources": cash, money in a savings or checking account, cash value in life insurance over \$1,500, stocks and bonds, household goods and personal effects over \$2,000, motor vehicles (except for one), and real estate other than a home. See *id.* The following items do *not* count as resources: the individual's home, car, wedding ring, Plan for Achieving Self-Support savings (the individual sets money aside to pay for costs to return to work), Individual Development Account (matched savings account used to for, typically, purchasing a home, tuition, or starting a business), burial funds up to \$1,500 and burial plots, and certain support payments.

Jacob's parents give him money to pay rent or buy groceries, his benefits will be reduced. A special needs trust (SNT) can, without reducing government benefits, provide Jacob with the assets needed to travel to a family reunion; have a cell phone, Internet access, and cable television; go to the dentist; enjoy a night out with friends; and even further his education.<sup>55</sup>

An SNT achieves these goals by placing assets for the benefit of the individual with special needs into a trust and giving a trustee limited discretion on the purpose of distributions along with language that the distributions should supplement government benefits.<sup>56</sup> These trusts are particularly useful with advance planning, and one can even manage an unexpected financial windfall for an individual with special needs.<sup>57</sup> The initial cost to create a trust and the maintenance costs will vary depending on the complexity and size of the trust.<sup>58</sup> A typical SNT with a \$500,000 corpus could result in an initial setup cost of \$5,000 along with a 2%-6% annual maintenance fee.<sup>59</sup> These costs can vary widely, so comparison shopping is in order.<sup>60</sup>

The following special needs trusts will preserve SSI and Medicaid benefits, can provide benefits now, and can last beyond the death of Jacob's parents.<sup>61</sup> Each trust overview features a scenario that illustrates how the trust could be used for Jacob's benefit.

### 1. Family Special Needs Trust

If drafted properly, a family special needs trust will contain the provisions needed to ensure that Jacob preserves his access to government entitlements and protect the assets from creditors.<sup>62</sup> There are no age restrictions, but there is a Medicaid lien reimbursement requirement that requires the trust to reimburse Medicaid for any costs paid if assets remain

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*See id.* An in-depth discussion of these assets and their interaction with entitlements is beyond the scope of this article.

55. *See SI 01120.200 Trusts—General, Including Trusts Established Prior to 1/1/00, Trusts Established with the Assets of Third Parties and Trusts Not Subject to Section 1613(e) of the Social Security Act*, SOCIAL SECURITY ADMINISTRATION, 9–10, available at <http://www.floridaspecialneeds.org/uploads/file/2009%20poms%20on%20trusts%20p%20200,201,203.pdf> (last visited Mar. 21, 2012).

56. *See id.*

57. *See id.*

58. *See Estate Planning: Is a Trust Beneficial?*, CNN MONEY, <http://money.cnn.com/magazines/moneymag/money101/lesson21/index6.htm> (last visited Mar. 21, 2012).

59. *See* Patrick L. Thimangu, *Special Needs Trusts a Must for Children with Disabilities*, ST. LOUIS BUS. J. (Dec. 16, 2007, 11:00 PM), <http://www.bizjournals.com/stlouis/stories/2007/12/17/focus1.html?page=all>.

60. *See id.*

61. *See infra* Part III.A.1–5.

62. *See* 42 U.S.C. § 1396p(d)(4)(A) (2010).



in the trust upon Jacob's death.<sup>63</sup> The family special needs trust can be created today by a parent, grandparent, guardian, or the court, and can be used as the beneficiary for family member's life insurance policies, bequests, and gifts.<sup>64</sup> Any assets given directly to Jacob affect his benefits.<sup>65</sup> A term life insurance policy can be the ideal solution for a family with minimal assets to care for their special needs child from beyond the grave.<sup>66</sup> Additionally, Crummy trust provisions allow parents to pay the premiums without incurring gift tax liability in extreme cases where the policy premiums exceed \$26,000 annually.<sup>67</sup>

*a. Family SNT Scenario: Funding a Special Needs Trust*

Jacob's parents both have full-time jobs where the employer provides \$50,000 of a group term life insurance policy to employees. An attorney is hired to create the SNT shortly after Jacob's birth, and Jacob's father designates the trust as the beneficiary of his \$50,000 group term policy from work. Jacob's mother does the same with her policy for a total of \$100,000 that will eventually go to the trust. Jacob's parents also make the trust the residuary beneficiary of their estates and are careful to leave nothing directly to Jacob.

*2. Pooled Special Needs Trust*<sup>68</sup>

Owning even minimal assets can cause issues with entitlements.<sup>69</sup> The pooled SNT allows a person to set aside his or her own money without losing Social Security Income or Medicaid benefits.<sup>70</sup> An individual has the

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63. See *id.* § 1369p(d)(4)(B)–(C).

64. See *id.* § 1369p(d)(4)(c)(iii).

65. See Thimangu, *supra* note 59.

66. See Chad Fish, *A Guide to Life Insurance for Special Needs Children*, TERM LIFE INS. BLOG (Feb. 8, 2011), <http://www.termlifeinsurancenews.com/blog/guide-life-insurance-special-children>.

67. See Arden Dale, *Crummey Trusts Still Smart, Say Advisors*, WALL ST. J. (Sept. 24, 2011), <http://online.wsj.com/article/SB10001424053111904563904576586974079779298.html>.

68. See 42 U.S.C. § 1396p(d)(4)(C) (2010).

69. See *supra* Part II.

70. See 42 U.S.C. § 1396p(d)(4)(C).

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

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

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

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

(iv) To the extent that amounts remaining in the beneficiary's account upon the death of the beneficiary are not retained by the trust, the trust pays to the State from such remaining amounts in the account an amount equal to the total amount of medical assistance paid on behalf of the beneficiary under the State plan under this subchapter.

ability to use his own funds for the pooled SNT.<sup>71</sup> This is a big advantage for someone with considerable wealth because the amount of the individual's assets would otherwise restrict or deny the individual's access to government entitlements.<sup>72</sup> In addition, the pooled SNT does not require that the trust repay the costs incurred by the government for the benefit of the individual if the trusts retain the assets.<sup>73</sup>

Similar to a mutual fund, many individuals combine their assets in a pooled SNT, which saves them administration and investment costs.<sup>74</sup> The act of pooling funds into one trusts is usually more cost-effective than an individual SNT for windfalls under \$100,000.<sup>75</sup> A nonprofit organization will administer the trust as a pooled account, and then distributions for each individual's benefit during his or her lifetime will be based on that individual's contribution.<sup>76</sup> Any assets left after the individual's death will either remain in the trust to benefit other individuals with disabilities or will be used to reimburse the state, depending on the setup of the trust.<sup>77</sup>

*a. Pooled SNT Scenario: Handling a Windfall*

Jacob's wealthy uncle passes away and absentmindedly leaves \$100,000 directly to Jacob as opposed to leaving the money for the family SNT. Please note that Jacob's uncle could also leave this money to a pooled SNT for Jacob's benefit. Jacob cannot receive SSI and Medicaid until his resources once again drop below \$2,000.<sup>78</sup> Luckily, Jacob's church has an existing pooled special needs trust for the benefit of church members with special needs. Jacob cannot receive an SSI or Medicaid payment this month, but once the inheritance is placed in the church trust his benefits will begin again.<sup>79</sup> Furthermore, Jacob will receive additional

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*Id.*

71. See § 1396p(d)(2)(A).

72. See, e.g., *Understanding Supplemental Security Income*, SUPPLEMENTAL SECURITY INCOME, <http://www.socialsecurity.gov/ssi/text-income-ussi.htm> (last visited Mar. 21, 2012); Sandra L. Smith, *What is a Pooled Trust, and When Should You Use One?*, LEXIS NEXIS COMMITTEES (Oct. 21, 2011, 12:18 PM), <http://www.lexisnexis.com/community/estate-elderlaw/blogs/specialneedstrusts/archive/2011/10/21/what-is-a-pooled-trust-and-when-should-you-use-one.aspx>.

73. See Smith, *supra* note 72.

74. See, e.g., *id.*; Dennis A. Fordham, Esq., *Estate Planning For Family Member with Special Needs*, DENNIS A. FORDHAM, <http://www.dennisfordhamlaw.com/articles/h/estateplanning-12-09-09.php> (last visited Feb. 12, 2012).

75. See Smith, *supra* note 72. Multiple experts on the subject in the past have agreed that \$100,000 is the breakpoint due to the cost of setting up a trust and the ongoing administrative expenses. See *id.* The author feels that this number is low due to an inflation of cost in legal services.

76. § 1396p(d)(4)(C)(i)–(ii).

77. § 1396p(d)(4)(C)(iv).

78. See *supra* text accompanying note 39.

79. See Smith, *supra* note 72.

benefits from both the family SNT and the pooled SNT.<sup>80</sup> Coordination of these benefits will be crucial in providing Jacob with the greatest possible quality of life.

### 3. Third Party

A third-party SNT is used in situations when unrelated third parties make donations to a trust for the benefit of others.<sup>81</sup> This type of trust does not always include the specific SNT language needed to preserve benefits, so care should be taken to ensure the needs of the individual will be met.<sup>82</sup> If the trust does not work in coordination with government entitlements, someone should determine whether Jacob would receive a greater benefit from the trust or from the guaranteed government entitlements. If the trust provides a greater overall benefit, even if for a short period of time, Jacob should enjoy the greater benefit from the trust until the funds run out, and then he should apply for government entitlements. However, if the trust benefits combined with government entitlements do not provide Jacob with a greater benefit than government entitlements alone, Jacob should take only government entitlements and leave the trust benefits for someone who might not have access to government entitlements.

The tragic events of 9/11 spawned two large funds meant to benefit victims of the coordinated 9/11 attacks on the World Trade Center and the Pentagon.<sup>83</sup> The Columbine tragedy led to the creation of both the Healing Fund for the benefit of the victims and a separate third-party fund created by the victims themselves to renovate the site of the tragedy into a beautiful memorial and benefit victims of violence in Colorado.<sup>84</sup>

A third-party SNT should contain the specific language needed to preserve benefits and should be created for a specific group of people.<sup>85</sup> There are no age restrictions on the beneficiaries of a third-party SNT, and there is no requirement that the fund reimburse the government for any entitlements the government paid to the beneficiaries.<sup>86</sup>

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80. Bernard A. Krooks & Andrew Hook, *What Attorneys Need to Know About Special Needs Trust*, ALI-ABA EST. PLAN. COURSE MATERIALS J., 2 (Oct. 2005), available at [http://files.ali-aba.org/thumbs/datastorage/lacidoirep/articles/EPCMJ\\_EPCMJ0510-KROOK\\_thumb.pdf](http://files.ali-aba.org/thumbs/datastorage/lacidoirep/articles/EPCMJ_EPCMJ0510-KROOK_thumb.pdf).

81. *Id.*

82. *Id.*

83. See, e.g., *Archive of September 11th Victim Compensation Fund of 2011*, DEPARTMENT OF JUSTICE, <http://www.justice.gov/archive/victimcompensation/> (last visited Feb. 4, 2012); *THE SEPTEMBER 11TH FUND FINAL REPORT*, available at <http://www.nycommunitytrust.org/Portals/0/Uploads/Documents/September11thFundFinal.pdf> (last updated Feb. 12, 2012).

84. HOPE COLUMBINE, [www.hopcolumbine.org](http://www.hopcolumbine.org) (last visited Feb. 12, 2012).

85. See *Special Needs Planning*, THEMCMMASTERLAWFIRM.COM, [www.themcmasterlawfirm.com/specialneeds.html](http://www.themcmasterlawfirm.com/specialneeds.html) (last visited Feb. 12, 2012).

86. *Supplemental Needs Trust*, FERNFINKEL.COM (Feb. 4, 2012), [www.ferninkel.com/supneed.html](http://www.ferninkel.com/supneed.html).

*a. Third-Party SNT Scenario: Jacob's Grandfather Dies in 9/11*

While Jacob's grandparents vacation in New York City, flying debris resulting from the terrorist attack on the World Trade Center kills Jacob's grandfather. The loss devastates Jacob and his mother. People all over the world donate money to the September 11th Fund to help the loved ones of those injured or killed in the attack. Jacob and his mother both receive funds from the trust, which contains the language needed to preserve Jacob's entitlements. Jacob's grandfather wisely designated the family SNT created earlier as the beneficiary of a term life policy.<sup>87</sup> The additional funds now available for Jacob allow him to live the highest quality of life possible and do not affect his government benefits.<sup>88</sup> SSI and Medicaid will continue to cover Jacob's basic needs, while the additional funds allow Jacob to travel to the site of his grandfather's demise and say goodbye.<sup>89</sup>

#### 4. Settlement

A settlement trust is usually for a disabled individual as the result of a personal injury action that results in either a judgment in favor of the plaintiff or an out-of-court payment on behalf of the plaintiff.<sup>90</sup> The defendant should make the proceeds out directly to the trust rather than the plaintiff to avoid onerous tax liability and possible disruption of current entitlements.<sup>91</sup> If drafted correctly, the Omnibus Budget Reconciliation Act of 1993 (OBRA)<sup>92</sup> gives these trusts the power to work in conjunction with government entitlements.

*a. Settlement Trust Scenario: Trucker Collides with Jacob the Pedestrian*

A truck driver for a major company smashes into Jacob while he is walking down the sidewalk. Jacob's injuries are temporary but severe. The company fires the driver and reaches a settlement agreement with Jacob for \$500,000. Jacob's attorney wisely requires the company to pay the settlement to a settlement trust, which is, in essence, an annuity contract with an insurance company, in order to preserve Jacob's government entitlements.<sup>93</sup>

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87. See Krooks & Hook, *supra* note 80, at 6.

88. See *id.*

89. See *id.*

90. See Jay J. Sangerman, Esq., *Supplemental Needs Trusts for the Settlement of Tort Claims, Estate Planning and Protection of Inheritances*, SANGERMAN.COM (2007), [www.sangerman.com/html/supplemental\\_needs\\_trusts\\_-\\_a.html](http://www.sangerman.com/html/supplemental_needs_trusts_-_a.html).

91. See, e.g., 42 U.S.C. § 1396p(d)(4)(A) (2003).

92. See Jeffery H. Minden, Esq., *Supplemental Needs Trusts: Some Frequently Asked Questions*, NAT'L SPECIAL NETWORK, INC., [www.nsn.com/frequently.htm](http://www.nsn.com/frequently.htm) (last visited Mar. 21, 2012).

93. See Sangerman, *supra* note 90.

### 5. Income Only “Miller” Trust

A Miller trust exempts the individual’s income (including SSI and pension income) from calculations of income and resources if the state is reimbursed from the trust for Medicaid expenses.<sup>94</sup> An individual could use this trust if the individual’s income exceeds the income cap but is still lower than the average cost of a nursing home in the region where the individual will receive care.<sup>95</sup> The individual assigns all nonexempt income to the trust, the trust directly pays the nursing home the maximum allowable amount, and Medicaid pays the nursing home the remainder of the bill.<sup>96</sup>

#### a. Miller Scenario: Jacob in a Nursing Home

Jacob turns sixty-six and moves into a nursing home to receive care from qualified nurses. Jacob’s combined SSI and pension benefits from his work at a small grocery store give him an income of \$3,000 per month. This exceeds the income cap but remains below his region’s average of \$3,500 per month cost of care in a nursing home. Jacob directs his SSI and pension benefits directly to a Miller trust, the Miller trust pays a portion of the nursing home bill, and Medicaid picks up the tab for the remainder.<sup>97</sup> When Jacob passes away, the Miller trust reimburses the state.<sup>98</sup> This allows Jacob to stay in a nursing home close to his friends and family in Anytown, USA.

The following table offers a comparison of the funding and reimbursement options for the different SNT types.<sup>99</sup>

| Special Needs Trust Summary |              |               |
|-----------------------------|--------------|---------------|
|                             | Self Funding | Reimbursement |
| Family                      | Maybe        | Yes           |
| Pooled                      | Yes          | Maybe         |
| Third Party                 | No           | No            |
| Settlement                  | No           | Yes           |
| Miller                      | Yes          | Yes           |

94. See 42 U.S.C. § 1396p(d)(4)(B); *Miller v. Ibarra*, 746 F. Supp. 19, 20 (D. Colo. 1990).

95. See Raymon B. Harvey, *Miller Trust: Are You Trapped in the Gap?*, ELDERLAWANSWERS.COM, [www.elderlawanswers.com/resources/article.asp?id=659&Section=7&state=AR](http://www.elderlawanswers.com/resources/article.asp?id=659&Section=7&state=AR) (last visited Mar. 21, 2012).

96. John J. Campbell, § 3.18 *Medicaid’s treatment of trusts*, WEST’S COLO. PRACTICE SERIES: ELDER LAW (Catherine Anne Seal, ed., 2011).

97. *Id.*

98. *Id.*

99. See discussion *supra* Part III.

## IV. RECOMMENDATIONS

Planning ahead is the best strategy to ensure that Jacob will enjoy the best life possible. His parents should consult a practitioner versed in the financial maze of options available to Jacob. All applicable benefits (NECTAC, IDEA, SSI, SSDI, and Medicare) should be used in coordination with a special needs trust to care for Jacob.<sup>100</sup>

Relatives should all be aware of the existence of a SNT and the need to leave nothing directly to Jacob.<sup>101</sup> A letter of intent for the trustee detailing the goals of the parents (or grantors) will help the trustee better understand which discretionary expenses should be covered by the trust. The trustee has a degree of latitude in certain expenses, and a guideline, while not legally binding, will help the trustee to administer the trust as close to the wishes of the grantors as legally possible.<sup>102</sup>

It may also be wise to designate multiple trustees for a SNT: one trustee to handle the investments, one to ensure no payments that will unnecessarily reduce benefits are made, and a third trustee (a parent or guardian might be a good choice here) that is close enough with the beneficiary to know what is needed to maximize the quality of life for the beneficiary.<sup>103</sup>

Estate planning can be difficult when there are multiple siblings, and Jacob's parents might want to sit down with those siblings to discuss why they are taking the actions they are; this can help to avoid costly and time-wasting will contests in the future. A guardian, if needed, should be considered for Jacob, and that guardian should be both fully aware of and accept the possibility of helping to care for Jacob.<sup>104</sup> An unwilling or unappointed guardian will result in a court-appointed guardian that the judge feels will best meet the needs of the child; this appointment might not be the same choice the parents would have made.<sup>105</sup> A letter of intent that includes simple things, such as the breakfasts that Jacob enjoys, to the more serious issues such as a list of doctors, therapists, and medications needed, will help the guardian know how to best care for Jacob.

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100. See discussion *supra* Part II.

101. Lefley & Hatfield, *supra* note 3.

102. See Miller, v. Ibarra, 746 F. Supp. 19, 33 (D. Colo. 1990).

103. See Bob Carlson, *Trustee Strategy for the 21st Century*, INVESTORSINSIGHT.COM (Jan. 16, 2009, 12:04 PM), [http://www.investorsinsight.com/blogs/retirement\\_watch/archive/2009/01/16/trustee-strategies-for-the-21st-century.aspx](http://www.investorsinsight.com/blogs/retirement_watch/archive/2009/01/16/trustee-strategies-for-the-21st-century.aspx).

104. See Celeste Holder Kling, *Estate Planning for Parents of Minor Children*, COLO. STATE UNIV. EXTENSION, CONSUMER SERVICES, Finance 9.102, 1 (2008), <http://www.ext.colostate.edu/pubs/consumer/09102.pdf>.

105. *Id.*

## V. CONCLUSION

Caring for a special needs child can be complicated, but planning early will help the child enjoy a high quality of life. Educating caregivers and practitioners can create a better life for hundreds of thousands of people who might otherwise have lived a poor quality of life, an issue that can become more pressing, as medical advances mean these children will outlive their parents.

Planning ahead and educating others helps Jacob and everyone in his situation live the best quality of life possible.