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# The Growing Need for Third-Party Special Needs Trust Reform

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— Note —

THE GROWING NEED FOR  
THIRD-PARTY SPECIAL NEEDS  
TRUST REFORM

*“The word ‘autism’ still conveys a fixed and dreadful meaning to most people—they visualize a child mute, rocking, screaming, inaccessible, cut off from human contact. And we almost always speak of autistic children, never of autistic adults, as if such children never grew up, or were somehow mysteriously spirited off the planet, out of society.”*

—Oliver Sacks\*

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\* Oliver Sacks, *Foreword to TEMPLE GRANDIN, THINKING IN PICTURES AND OTHER REPORTS FROM MY LIFE WITH AUTISM* xiii, xiii (2006). Oliver Sacks is a British-American writer and Professor of Neurology at New York University School of Medicine. Temple Grandin is an Animal Sciences Professor at Colorado State University, a best-selling author, and an autism activist who was diagnosed with autism at the age of two.

## INTRODUCTION

On July 8, 2011, emergency room nurses at a hospital in Fort Lauderdale, Florida, found a ten-year-old boy named Benjamin wandering around by himself in the hospital. After trying and failing to find his parents, they called the police. Security footage showed a man in a minivan dropping the boy off at the hospital and leaving. The subsequent investigation revealed that the boy's mother had intentionally abandoned him. She said she was "overwhelmed." She had just lost her job and gotten divorced. Her house was being foreclosed on, and she had two other children to care for. Even though she had "tried everything [she] could" to raise her son, she simply "could not handle" his behavioral and medical issues.<sup>1</sup>

In any normal case, this woman's actions would be appalling. But here, even the police seemed to be on her side. They had no intention of prosecuting her or Benjamin's father. "They're not bad parents," the police department reported. "We're talking about parents who tried everything else and got desperate . . . ."<sup>2</sup> Why were the police so seemingly unconcerned about this case of child abandonment? The answer is simple: because Benjamin is autistic. The police turned the boy over to Florida's Department of Children and Families so that he could be placed in a foster home with experience caring for children with special needs.

In April 2013, a couple from Ottawa, Canada, made the "painful decision" to leave their son Philippé at a social services agency because they "could no longer handle him."<sup>3</sup> They said that their decision was "an act of desperation fuelled by 10 years of frustration."<sup>4</sup> Nonetheless, they felt comfortable giving up their child. "I am so sure about what we're doing,"<sup>5</sup> the father said. A camera crew accompanied the mother

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1. Wayne K. Roustan, *Mother of Abandoned Boy with Autism "Overwhelmed,"* SUN SENTINEL (July 9, 2011), [http://articles.sun-sentinel.com/2011-07-09/news/fl-autistic-boy-court-20110709\\_1\\_autism-broward-judge-bad-parents](http://articles.sun-sentinel.com/2011-07-09/news/fl-autistic-boy-court-20110709_1_autism-broward-judge-bad-parents) (last visited Mar. 13, 2014).
  2. *Id.* See also Susannah Bryan, *Autistic Boy Left at Fort Lauderdale Hospital,* SUN SENTINEL (July 8, 2011), [http://articles.sun-sentinel.com/2011-07-08/news/fl-autistic-child-help-20110708\\_1\\_autistic-boy-severe-autism-detective-travis-mandell](http://articles.sun-sentinel.com/2011-07-08/news/fl-autistic-child-help-20110708_1_autistic-boy-severe-autism-detective-travis-mandell) (last visited Mar. 17, 2014) (quoting Mark Riordan, spokesman for the Department of Children and Families, as saying occasions of parents abandoning children at hospitals are "very rare, practically unheard of").
  3. Lesley Ciarula Taylor, *Parents Leave Severely Autistic Son at Ottawa Social Services Agency in "Desperate Act,"* THE STAR (May 1, 2013), [http://www.thestar.com/news/canada/2013/05/01/autism\\_mothers\\_brutal\\_decision\\_to\\_leave\\_19yearold\\_autistic\\_son.html](http://www.thestar.com/news/canada/2013/05/01/autism_mothers_brutal_decision_to_leave_19yearold_autistic_son.html) (last visited Mar. 13, 2014).
  4. *Id.*
  5. *Id.*

as she arrived at the agency's office to drop off her son. The agency fully supported the parents' decision. Philippé—who is also autistic—became one of 393 people with developmental disabilities waiting for a place in a group home in Ottawa.<sup>6</sup>

Parents of disabled children face insurmountable hurdles when attempting what should be simple tasks. They may feel powerless to make their children eat, go to sleep, or even stop hurting themselves. In certain situations, the children require constant care and frequent, expensive medical attention. Some parents are overwhelmed by the continuous work and stress, and some in society accept their decisions to give their children up. Others sincerely want to keep caring for their children but require government assistance to do so. In the United States, the very systems designed to help these parents, Social Security and Medicaid, instead present a whole set of new legal problems. This is especially true for parents who want to leave money for the care of their special needs child after they are gone. One of the difficulties they face is creating a trust for a disabled child without the trust's assets being considered "available" to the beneficiary and depriving him or her of Medicaid and Social Security benefits.

Part I of this Note explains the origins and use of special needs trusts and differentiates between the three types: self-settled, pooled, and third-party special needs trusts. Part II addresses the requirements placed on these trusts by government benefit programs, including lack of beneficiary access, absolute trustee discretion, and limited use of funds. Part II also describes the challenges these restrictions create for attorneys and the additional issues presented by the adoption of the Uniform Trust Code. Part III describes the often conflicting interests of government assistance programs and the families of disabled children, and suggests that recent rises in the diagnosis rate of autism spectrum disorders makes the resolution of this conflict even more pressing. Finally, Part IV discusses why some proposed solutions would not solve the issues faced by third-party special needs trusts. It suggests that the best resolution would involve redrafting Social Security and Medicaid regulations to carve out new exceptions for third-party special needs trusts.

## I. SPECIAL NEEDS TRUSTS

### A. *Definition*

Trusts are legal instruments under which assets are held in the trust's name, managed by a trustee, and distributed for the benefit of

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6. *Id.* Charlotte Wilkinson, spokeswoman for the Ontario Ministry of Community and Social Services, added that placing one person like Philippé in a group home can cost "hundreds of thousands of dollars." *Id.*

a beneficiary.<sup>7</sup> The beneficiary does not own the trust assets, but has an equitable right to derive benefits from them.<sup>8</sup> Consequently, trusts are often used to shield assets from government scrutiny.<sup>9</sup> Special needs trusts are a subset of trusts designed to allow a disabled beneficiary to maintain eligibility for public benefits that cover basic needs, while also receiving resources from his or her family that provide a higher quality of life.<sup>10</sup> Special needs trusts must be established by a parent, grandparent, legal guardian, or court for the sole benefit of a disabled individual under the age of sixty-five.<sup>11</sup> Because many disabled individuals cannot work, they have limited resources and are usually dependent upon their families, the government, or a combination of the two.<sup>12</sup>

### *B. Legislative History*

In the past, due to the strict income-limiting eligibility standards of government assistance programs, families of disabled individuals were often unable to provide support for them without making them ineligible for public benefits. Instead, they would have to choose between retaining eligibility for public assistance, knowing that their loved one would receive only the essentials, or losing government aid and attempting to provide for the disabled individual entirely on their own. Alternatively, they could make the risky choice to disinherit the person and leave the money with another family member in the hopes

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7. *Lewis v. Alexander*, 685 F.3d 325, 332 (3d Cir. 2012) (citing BLACK'S LAW DICTIONARY 1546 (8th ed. 2004)), *cert. denied*, 133 S. Ct. 933 (2013).
  8. *Id.*
  9. *Id.*; see also AUSTIN WAKEMAN SCOTT, ABRIDGMENT OF THE LAW OF TRUSTS 6 (1960) (explaining that trusts “were created for the very purpose of obtaining . . . flexibility and avoiding the application of the rules of law” and “[t]he trust has often served as a means of evading the law”).
  10. See Kemp C. Scales & Linda M. Anderson, *Special Needs Trusts: Practical Tips for Avoiding Common Pitfalls*, 74 PA. B. ASS'N Q. 169, 170 (2003); see also Amber K. Quintal, *Planning for Individuals with Disabilities: Special Needs Trusts*, THE PRACTICAL TAX LAW. 17, 17 (2008) (stating that “Special needs trusts are means for persons with disabilities to qualify to receive government benefits from needs-based programs while having access to additional funds to pay for supplemental expenses not covered by the government benefits.”).
  11. *ABCD Fact Sheet on Special Needs Trusts*, ALLIANCE FOR THE BETTERMENT OF CITIZENS WITH DISABILITIES, <http://www.abcdnj.org/publications/medicaid/special-needs-trusts/> (last visited Oct. 2, 2014).
  12. *Cf. id.* (noting that, in New Jersey, a special needs trust “must be established by a parent, grandparent, or legal guardian . . . or a court”).

that he or she would use it for the disabled person's benefit.<sup>13</sup> Then, they discovered a third option: special needs trusts. Eventually, the creative use of these trusts to conceal money from Medicaid consideration became common practice.<sup>14</sup>

Congress viewed these trusts as a form of Medicaid abuse and manipulation,<sup>15</sup> calling them "the single most offensive Medicaid estate planning vehicle."<sup>16</sup> It attempted to limit the use of special needs trusts by promulgating a regulation that stated that all trust assets should be considered available to the beneficiary when determining Medicaid eligibility.<sup>17</sup> Under pressure from disability rights activists, Congress repealed the law,<sup>18</sup> but the problems with Medicaid manipulation by trusts persisted. State budgetary crises<sup>19</sup> and an unanticipated and overwhelming increase in the number of Medicaid applicants exacerbated the problem.<sup>20</sup>

In 1993 Congress passed the Omnibus Budget Reconciliation Act ("OBRA '93").<sup>21</sup> Under OBRA '93, Congress created a presumption of "availability" for trust funds; if someone received a personal injury or medical malpractice award and tried to protect that money by placing it in a special needs trust, the funds would be counted as "available" income for determining eligibility for government aid.<sup>22</sup> Although OBRA '93 effectively ended the ability of public benefits recipients to be trust beneficiaries, it appeased disability advocates by codifying two types of special needs trusts as exceptions to the rule: self-settled trusts

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13. Scales & Anderson, *supra* note 10, at 171 (noting that leaving money to a sibling for a disabled child's benefit is "an inherently risky option").
  14. See Quintal, *supra* note 10, at 17 (stating that a common opportunity for using a special needs trust arises "when a person with significant assets becomes disabled and wants to qualify for needs-based government benefits without first spending down his or her own assets").
  15. Ira Stewert Wiesner, *OBRA '93 and Medicaid: Asset Transfers, Trust Availability, and Estate Recovery Statutory Analysis in Context*, 19 NOVA L. REV. 679, 682-83 (1995).
  16. *Id.* at 703.
  17. *Ramey v. Reinertson*, 268 F.3d 955, 958-59 (10th Cir. 2001) (explaining that Congress's regulation was a "condemnation" of the technique of sheltering or shielding assets in an irrevocable trust).
  18. *Id.* at 959.
  19. Wiesner, *supra* note 15, at 683.
  20. *Id.* at 734 ("State Medicaid agencies faced more clients seeking assistance . . . than they had anticipated or were capable of serving.").
  21. Omnibus Budget Reconciliation Act of 1993, Pub. L. No. 103-66, 107 Stat. 312 (codified as amended at 42 U.S.C. § 1396p (2012)).
  22. Jennifer Field, *Special Needs Trusts: Providing for Disabled Children Without Sacrificing Public Benefits*, 24 J. JUV. L. 79, 86 (2003).

and pooled trusts.<sup>23</sup> Through these special needs trusts, relatives of the disabled beneficiary could now supplement basic needs with simple comforts without risking the loss of government assistance.<sup>24</sup> Congress believed it had finally found a solution that could please everyone.

### 1. Self-Settled Special Needs Trusts

The first exception to the “available” trust funds presumption is self-settled trusts, also called (d)(4)(A) trusts because they are defined in 42 U.S.C. § 1396p(d)(4)(A).<sup>25</sup> Self-settled trusts must be funded with the assets of a disabled individual under the age of sixty-five. To be considered “disabled,” the individual “must be 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.”<sup>26</sup> The trust must also be established by someone other than the disabled individual, such as a parent, grandparent, or legal guardian, for the sole benefit of the disabled individual.<sup>27</sup> Finally, it must contain a “payback” provision, stating that all funds left in the trust after the disabled beneficiary dies will be used to repay the state Medicaid agency for the assistance it provided.<sup>28</sup>

### 2. Pooled Special Needs Trusts

The second exception is the pooled, or (d)(4)(C), trust.<sup>29</sup> Pooled trusts are managed by nonprofit associations, which maintain separate accounts for each disabled beneficiary but pool the funds for investment purposes.<sup>30</sup> Unlike regular self-settled trusts, pooled trusts can be established by the disabled beneficiary him or herself, or by a parent,

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23. Scales & Anderson, *supra* note 10, at 171.

24. See Jennifer Brannan, *Third-Party Special Needs Trust: Dead or Alive in a Uniform Trust Code World*, 16 TEX. WESLEYAN L. REV. 249, 250–51 (2010); see also Patricia Tobin, *20/20 Foresight: Planning Ahead for Special Needs Trusts*, 11 PROB. & PROP. 56, 56 (1997) (stating that “[s]pecial needs trusts typically are used so that the beneficiary will have a reserve fund and still qualify for financial means tested public benefits”).

25. 42 U.S.C. § 1396p(d)(4)(A)(2012).

25. 42 U.S.C. § 1382c(a)(3)(A) (2012).

26. 42 U.S.C. § 1396p(d)(4)(A) (2012). See also Quintal, *supra* note 10, at 19 (discussing the requirements of (d)(4)(A) trusts).

27. 42 U.S.C. § 1396p(d)(4)(A) (“[T]he State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a State plan under this subchapter.”); see also Scales & Anderson, *supra* note 10, at 171 (discussing the payback requirement).

28. 42 U.S.C. § 1396p(d)(4)(C) (2012).

29. Scales & Anderson, *supra* note 10, at 172.

grandparent, or legal guardian.<sup>31</sup> Lastly, the trust must contain a provision stating that when the beneficiary dies, the remaining funds in the account will either be distributed to other members of the pooled trust or used to pay back state Medicaid agencies.<sup>32</sup> Pooled trusts are most commonly used when the family of the disabled individual cannot choose a trustee or afford to hire a professional trustee. A family that prefers to see the funds go to other disabled people rather than the state may also choose a pooled trust.<sup>33</sup>

### 3. Third-Party Special Needs Trusts

OBRA '93 failed to create an exception for third-party special needs trusts. These trusts differ from self-settled and pooled trusts in that they are funded with the assets of someone other than the disabled beneficiary.<sup>34</sup> Because the beneficiary of a third-party trust never owned the assets prior to the creation of the trust, OBRA '93 does not apply at all. Third-party trusts are usually established by a parent, grandparent, or legal guardian of a disabled individual. They can be either inter vivos trusts established during the grantor's life or testamentary trusts created through a will.<sup>35</sup> Inter vivos trusts allow the parents or grandparents of a disabled child to put funds into the trust and ensure that the trust functions properly before they die.<sup>36</sup> Third-party trusts are also exempt from the payback requirements of self-settled and pooled trusts, which means the grantor can designate

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30. Brannan, *supra* note 24, at 252.

31. 42 U.S.C. § 1396p(d)(4)(C)(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."). This payback provision is slightly different from the one in (d)(4)(A) because the remaining trust funds may be distributed to other beneficiaries of the pooled trust instead of the state.

32. Brannan, *supra* note 24, at 252 ("A Pooled trust would most likely be created when the family . . . prefers that the amount remaining in the trust after the beneficiary's death be passed to disabled individuals rather than be given back to the state.").

33. *Id.* Self-settled and pooled trusts can be funded with damages awarded to the beneficiary through personal injury or medical malpractice suits. *See id.* at 251-52. Third-party special needs trusts are typically funded by family members. The significant difference is that beneficiaries of third-party special needs trusts are more likely to have been born with their disability.

34. *E.g., id.* at 252.

35. Brannan, *supra* note 24, at 253.



that the funds should pass to remainder beneficiaries, such as the disabled individual's siblings, after the disabled beneficiary dies.<sup>37</sup>

The lack of payback requirements for third-party special needs trusts takes some pressure off of parents who have both disabled and non-disabled children. Instead of trying to estimate their disabled child's lifespan to decide how much money to place in the trust, the grantors know that their other children will ultimately receive any remaining money left in the trust. While third-party special needs trusts may, at first glance, appear to be more flexible than self-settled trusts, they suffer from many complexities in drafting and administration that make maintaining eligibility for government assistance difficult.

## II. THE PROBLEM OF MAINTAINING MEDICAID ELIGIBILITY

For disabled individuals, the two most important government benefits are Supplemental Security Income ("SSI") and Medicaid.<sup>38</sup> In response to concern over the rising costs of health care,<sup>39</sup> Congress created Medicaid under Title XIX of the Social Security Act in 1965.<sup>40</sup> Medicaid is a jointly funded state and federal program that provides medical assistance to people who could not otherwise afford medical care.<sup>41</sup> The program is now the nation's largest health insurer, with a combined federal-state cost of \$400 billion annually.<sup>42</sup> The cost is expected to increase even more with the implementation of Affordable

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36. *E.g.*, Scales & Anderson, *supra* note 10, at 171. For many trust grantors and their relatives who may qualify for self-settled or pooled trusts, third-party special needs trusts are attractive options precisely because they do not include a payback provision.
37. Tobin, *supra* note 24, at 56.
38. Mary F. Radford & Clarissa Bryan, *Irrevocability of Special Needs Trusts: The Tangled Web That Is Woven When English Feudal Law Is Imported into Modern Determinations of Medicaid Eligibility*, 8 NAT'L ACAD. ELDER L. ATT'YS J. 1, 5 (2012).
39. Social Security Amendments of 1965, Pub. L. No. 89-97, 79 Stat. 286 (1965) (current version at 42 U.S.C. § 1396 (2012)).
40. *Harris v. McRae*, 448 U.S. 297, 301 (1980) ("The Medicaid program was created in 1965, when Congress added Title XIX to the Social Security Act . . . for the purpose of providing federal financial assistance to States that choose to reimburse certain costs of medical treatment for needy persons.").
41. Jeffrey R. Grimyser, *Missing the Forest for the Trees: Why Supplemental Needs Trusts Should Be Exempt from Medicaid Determinations*, 89 CHI.-KENT L. REV. 438, 442 (2014) (citing John D. Blum & Gayland O. Hethcoat II, *Medicaid Governance in the Wake of National Federation of Independent Business v. Sebelius: Finding Federalism's Middle Pathway, from Administrative Law to State Compacts*, 45 J. MARSHALL L. REV. 601, 610 (2012)).

Care Act expansions.<sup>43</sup> SSI is a federal program that pays for basic living expenses of disabled individuals, such as food, clothing, and shelter.<sup>44</sup> The eligibility rules for SSI are similar across the nation, and in most states, SSI is linked to Medicaid so that a recipient of one qualifies for the other.<sup>45</sup> Both SSI and Medicaid are “needs-based” or “means-tested” public benefit programs meant for low-income individuals, so incomes and resources below a specified level are necessary in order to qualify.<sup>46</sup> Generally, a person loses eligibility for SSI and Medicaid if he possesses more than \$2,000 in countable assets. He would have to spend down those assets in order to requalify.<sup>47</sup>

To determine eligibility, SSI breaks income down into three categories: earned, unearned, and in-kind.<sup>48</sup> While most disabled individuals do not have earned income, distributions from trusts may be counted as unearned income if they are not made in the correct way.<sup>49</sup> Also, if someone buys food or rents an apartment for the disabled individual, it would be considered in-kind income and could make the disabled beneficiary ineligible for government assistance.<sup>50</sup> Money received in the current month is “income,” and any money left over on the first day of the next month is an “asset.”<sup>51</sup> Some assets, including the beneficiary’s home, one vehicle, furniture, life insurance, and personal items, are not considered “countable” for eligibility purposes.<sup>52</sup> But improper trust distributions run the risk of being counted as income and disqualifying the disabled beneficiary for SSI and Medicaid eligibility. For example, if the trust paid for basic repairs to the beneficiary’s only home or vehicle, the value of those repairs would be

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42. *Id.* at 442 n.18.

43. *See* Scales & Anderson, *supra* note 10, at 170.

44. Tobin, *supra* note 24, at 56.

45. Scales & Anderson, *supra* note 10, at 170; *see also* Univ. of Wash. Med. Ctr. v. Sebelius, 634 F.3d 1029, 1031 (9th Cir. 2011) (explaining that Medicaid eligibility rules require that a person have “income and resources [that] are insufficient to meet the costs of necessary medical services”).

46. DISABILITY RIGHTS WASHINGTON, SPECIAL NEEDS TRUSTS 1 (2007) (available at <http://www.disabilityrightswa.org/special-needs-trusts-0>) [hereinafter *Disability Rights*]; *see also* Quintal, *supra* note 10, at 18 (noting the distinction between countable and noncountable assets).

47. Brannan, *supra* note 24, at 254.

48. *See id.* at 254–55.

49. *Id.* at 254; *Understanding Supplemental Security Income: SSI Income*, SOCIAL SECURITY, <http://www.socialsecurity.gov/ssi/text-income-ussi.htm> (last visited Oct. 2, 2014).

50. Micah Huff & Martha Brown, *Special-Needs Trusts: Drafting and Administration Issues*, 56 ST. LOUIS B. J. 10, 13 (2010).

51. *Id.*

considered income because they would normally be covered by SSI. Third-party special needs trusts are highly susceptible to this danger. Because they are not listed as exceptions to OBRA '93, third-party special needs trusts depend on courts' interpretations of trust language to decide whether the trust is a support trust or a supplemental trust. Beneficiaries of supplemental trusts are eligible for Medicaid, but beneficiaries of support trusts are not. As a result, grantors and drafters of special needs trusts have to carefully consider the factors courts will access in defining the trust: the (1) beneficiary's access to the funds; (2) level of trustee discretion; and (3) use of the funds.

#### A. *Beneficiary Access*

Countable assets for determining SSI and Medicaid eligibility include only assets that are considered "available" to the disabled beneficiary.<sup>53</sup> Thus, the key to a successful special needs trust is keeping the funds unavailable. Funds are "available" "[i]f the individual has the right, authority or power to liquidate the property or his or her share of the property."<sup>54</sup> To ensure trust assets are considered unavailable, the disabled beneficiary must have no control over the trust, including the power to remove or replace trustees or compel distributions.<sup>55</sup> Discretionary trusts accomplish this by using permissive language to describe distributions: "may" instead of "shall."<sup>56</sup> This language creates a "mere expectancy" of a distribution, giving the beneficiary no enforceable property rights in the trust.<sup>57</sup> Because the beneficiary cannot bring claims against a trustee who refuses to distribute trust funds, he or she has no property right in the trust, and the trust assets are considered unavailable for government assistance purposes.<sup>58</sup> The Social Security Administration also suggests making the trust irrevocable because that prevents the beneficiary from terminating the trust and gaining access to the funds.<sup>59</sup> In order to function, third-party special needs trusts must take control over the trusts funds away from the beneficiary and give it instead to the trustee; however, this creates a new problem—the potential for abuse.<sup>60</sup>

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52. Quintal, *supra* note 10, at 18.

53. 20 C.F.R. § 416.1201(a)(1) (2014).

54. Quintal, *supra* note 10, at 23.

55. Brannan, *supra* note 24, at 263.

56. *Id.*

57. *Id.* at 263–64.

58. Field, *supra* note 22, at 82.

59. WORLD INSTITUTE ON DISABILITY, *Special Needs Trusts: Problems and Solutions*, EQUITY E-NEWSLETTER (Apr. 2006), <http://wid.org/center-on-economic-growth/programs-of-the-center-on-economic-growth/access->

B. *Trustee Has Absolute Discretion*

1. Trustee Power and Duties

Creators of a special needs trust have to select a trustee to manage the investment and distribution of trust funds. The trustee should use the funds to pay the expenses of the disabled beneficiary but should never give him or her funds directly.<sup>61</sup> Normally, the trustee assumes a “fiduciary duty” to act in the best interest of the person with disabilities and can be sued for violating this duty.<sup>62</sup> But in the case of a third-party special needs trust, where a key element is the inability of the beneficiary to demand distribution, winning a case against the trustee for breach of fiduciary duty could result in the loss of government benefits.

Special needs trusts often sacrifice the beneficiary’s legal protection by giving the trustee full or “absolute” discretion over the timing, purpose, and amount of distributions.<sup>63</sup> This type of discretion is broader than usually found in trusts.<sup>64</sup> Under this standard, the trustee can deny any request from the beneficiary, even if it is entirely reasonable and essentially has the ability never to make a single distribution.<sup>65</sup> Courts usually refuse to intervene when the trustee has absolute discretion.<sup>66</sup> Furthermore, it is hard to prove that the trustee does not have a good motive for withholding distributions. As a result, if there is any plausible reason for the trustee’s actions, he will win the case and not be required to distribute any trust funds.<sup>67</sup> The creation of checks and balances within the trust documents can help prevent this sort of situation, but the complexity of special needs trusts means

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to-assets/equity/equity-e-newsletter-april-2006/special-needs-trusts-problems-and-solutions/.

60. *Disability Rights*, *supra* note 46, at 2.

61. *Id.*

62. Stephen W. Dale, *Choosing the Ideal Trustee of Your Child’s Special Needs Trust*, THE SPECIAL NEEDS ALLIANCE, 1, 1 <http://www.wrightslaw.com/info/ideal.trustee.dale.pdf> (last visited Sept. 28, 2014).

63. Lisa Nachmias Davis, *Absolute Discretion: Understanding the Trustee Provisions in Your Child’s Special Needs Trust*, EP MAG., June 2008, at 52.

64. Dale, *supra* note 62, at 1 (“When parents create a Special Needs Trust for their son or daughter, they are creating a contract that is empowering the trustee with the ability to never make a single distribution if the trustee so desires.”); *see also* Davis, *supra* note 63, at 52 (“A Special Needs Trust gives the Trustee enormous power to help—or not help—your child. The Trustee has absolute discretion.”).

65. Davis, *supra* note 63, at 52.

66. *Id.*

that even well-intentioned human error can completely deprive a beneficiary of public benefits.<sup>68</sup>

## 2. Choice of Trustee

Because the trustee will have absolute discretion over the special needs trust, the choice of trustee is extremely important. For grantors with special needs children, choosing a trustee can be extremely difficult. The most common and convenient choice for trustee is a responsible family member or close friend who is acquainted with and cares about the beneficiary.<sup>69</sup> Unfortunately, many trusts fail because the family member who was well intentioned and willing to become trustee was ill equipped to handle the associated responsibilities.<sup>70</sup> Some may even change their mind about accepting the position after discovering what fiduciary duties and recording requirements are placed upon trustees.<sup>71</sup> This is especially true for special needs trusts because of the added complexities. If a family member trustee accepts the position initially and then decides to give it up, finding a replacement becomes even more difficult.<sup>72</sup> Also, even if a trustee is willing and able to handle the responsibility, her relationship with the disabled beneficiary can cloud her judgment. Circumstances and emotions may pressure a trustee to make distributions for the immediate well-being or happiness of the disabled individual that will ultimately result in loss of government benefits.

On the other hand, banks or private professional trustees like lawyers or accountants tend to be very knowledgeable and responsible and usually outperform family members as trustees.<sup>73</sup> They have experience performing the investment, management, accounting, and tax services required of a trustee.<sup>74</sup> But they may not be an option for some families because they charge an annual fee, often 1 percent of the value of the trust.<sup>75</sup> They may also require a minimum trust fund

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67. *Id.* at 53.

68. Brannan, *supra* note 24, at 257.

69. Dale, *supra* note 62, at 2.

70. Tobin, *supra* note 24, at 60.

71. *Id.*

72. Dale, *supra* note 62, at 3.

73. Field, *supra* note 22, at 83.

74. *Id.* at 84.

amount of \$250,000 to \$500,000,<sup>76</sup> whereas assets in special needs trusts commonly range from only \$10,000 to \$150,000.<sup>77</sup>

Professional trustees also lack the personal touch that many families desire in a trustee. They do not have a relationship with the beneficiary or knowledge of his or her needs and preferences.<sup>78</sup> Depending on the nature of the beneficiary's disability, he or she may have very specific or unique needs, or may be completely self-sufficient in some areas and totally helpless in others. Without knowledge of these details, the trustee may make some completely unnecessary distributions while neglecting to cover other important needs.

The choice of trustee is one of the most important elements of a successful special needs trust. Because of the atypical situations they are put in, trustees of special needs trusts must be both compassionate and vigilant. Consequently, attorneys who fail to advise the grantor about the inherent dangers of choosing the wrong trustee are often liable for malpractice.<sup>79</sup>

### C. *Use of Funds*

Any distribution from a special needs trust made directly to the disabled beneficiary or spent on support rather than supplemental benefits could make the beneficiary ineligible for need-based government benefits.<sup>80</sup> While attorneys are responsible for drafting a trust with appropriate distribution standards to prevent loss of eligibility, trustees must also be prepared to carefully consider the consequences of each distribution they make.<sup>81</sup> Special needs trusts may be classified as either supplemental trusts (often called "discretionary trusts") or support trusts, depending on the kind of expenses for which the trust funds are used. Support trust assets can be used to pay for the beneficiary's food, clothing, and shelter.<sup>82</sup> Conversely, supplemental trusts are used only

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75. Brannan, *supra* note 24, at 257; Field, *supra* note 22, at 84.

76. 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, 97 n.27 (2000).

77. Brannan, *supra* note 24, at 257.

78. *Disability Rights*, *supra* note 46, at 2.

79. Quintal, *supra* note 10, at 22.

80. Scales & Anderson, *supra* note 10, at 176 ("With even the best-drafted trusts, problems almost inevitably arise in their administration, especially by trustees unfamiliar with the way various government agencies view 'income.' Improper administration can result in the loss of public benefits to the beneficiary and therefore liability to the trustee, and the attorney advising the trustee. Once the special needs trust has been drafted and funded, it is important that the attorney provide explicit guidance to the trustee regarding administration of the trust.").

81. Field, *supra* note 22, at 81.

to provide for the beneficiary's needs not already covered by public benefits.<sup>83</sup> Such needs are often called "luxuries," but they simply allow the disabled beneficiary to maintain a standard of life above basic survival,<sup>84</sup> since public benefits like SSI and Medicaid are designed to provide only the "bare necessities."<sup>85</sup>

For example, the SSI definition of "food and shelter" covers payments for "food, mortgage . . . , real property taxes, rent, heating fuel, gas, electricity, water, sewer, and garbage removal."<sup>86</sup> If the trust attempts to pay any of these expenses on the beneficiary's behalf, it will jeopardize SSI eligibility. Supplemental trusts should provide other goods and services important for daily life: help with shopping and errands, transportation, vacations, entertainment, computer equipment, toiletries, personal hygiene assistance, and companionship.<sup>87</sup> The trusts can also provide medical care beyond what Medicaid covers, such as over-the-counter medication, experimental treatments, private nurses, and rehabilitation services.<sup>88</sup>

Another issue for third-party special needs trusts is that there are no clear rules on what qualifies as a supplemental trust versus a support trust. Courts ultimately decide whether a disputed trust is supplemental or supportive. The best way to ensure that a trust is supplemental is to include a limiting distribution standard in the trust instrument. This language cannot generally force the trustee to make distributions, but it can prohibit him or her from distributing funds for certain purposes. SSI and Medicaid regulations do not recognize a specific standard, but some states do.<sup>89</sup> Ohio, for example, requires a supplemental trust to contain a strict distribution standard that explicitly prohibits payments for food, clothing, and shelter.<sup>90</sup> While broad trust language like "health, maintenance, education, and

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82. *Id.*

83. *Id.*; see also Tobin, *supra* note 24, at 56–58 (“[D]isabled individuals . . . may need services or goods that could be considered luxuries for those in good health but are necessities for impaired individuals.”).

84. Field, *supra* note 22, at 81.

85. Huff & Brown, *supra* note 50, at 14.

86. *Id.* at 14–15; see also Tobin, *supra* note 24, at 58 (listing “necessary luxuries” that a supplemental trust may provide).

87. Tobin, *supra* note 24, at 56.

88. Field, *supra* note 22, at 82–83.

89. *Id.* at 83; see also Quintal, *supra* note 10, at 22 (“[M]any practitioners . . . expressly prohibit distributions for basic needs such as food, clothing, and shelter.”); Scales & Anderson, *supra* note 10, at 174–75 (“An alternative distribution standard is the strict “SSI standard” prohibiting any distributions for food, clothing, or shelter . . . . While this is the safest and most conservative standard for a special needs trust, it is also the most inflexible.”).

support” is common and provides more flexibility, it may put the trust in danger of being considered a support trust and causing the beneficiary to lose eligibility for SSI and Medicaid.<sup>91</sup> On the other hand, a rigid standard will also prevent the trustee from making payments that would temporarily reduce the beneficiary’s benefits but would benefit the disabled individual overall.<sup>92</sup>

The trust document can also spell out that the grantor’s intent was to “supplement and not supplant” public benefits.<sup>93</sup> The benefit of this “intent clause” is illustrated in four cases reviewed by the Pennsylvania Supreme Court between 1987 and 1996.<sup>94</sup> All four cases involved trusts with similar distributions standards. In two of the cases, the court decided that the trust assets were protected by inferring the trust settlor’s intent to create a supplemental trust from the trust language and the circumstances surrounding its creation.<sup>95</sup> In *Lang v. Commonwealth, Department of Public Welfare*,<sup>96</sup> the trust document instructed the trustee to support the beneficiary only to the extent not already covered by public assistance and to invest the remainder.<sup>97</sup> The court held that this showed that the testator’s intent was to “set up a discretionary support trust rather than a mandatory form of trust or a ‘pure’ support trust.”<sup>98</sup> In *Snyder v. Commonwealth, Department of Public Welfare*,<sup>99</sup> the court held that the grantor intended to only supplement her son’s needs because she explicitly instructed the trustee not to support her son if it would result in the loss of aid.<sup>100</sup>

In the other two cases, the court decided that the trust assets were not protected. The court in *Commonwealth Bank & Trust Co. v. Commonwealth, Department of Public Welfare*<sup>101</sup> held that a trust was clearly meant for support when it mandated the trustee to make

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90. Quintal, *supra* note 10, at 23; *see also* Huff & Brown, *supra* note 50, at 14 (“Some attorneys that draft SNTs mistakenly believe that the ascertainable standards of ‘health, education, maintenance, and support’ are necessary, or that the standards should be inserted for good measure. This is an incorrect assumption, and usually, a costly mistake that can harm a beneficiary on public benefits.”).

91. Quintal, *supra* note 10, at 23.

92. Huff & Brown, *supra* note 50, at 13.

93. Scales & Anderson, *supra* note 10, at 174.

94. *Id.*

95. 528 A.2d 1335 (Pa. 1987).

96. *Id.* at 1345.

97. *Id.* at 1343.

98. 598 A.2d 1283 (Pa. 1991).

99. *Id.* at 1287.

100. 598 A.2d 1279 (Pa. 1991).



quarterly payments to the beneficiary, regardless of her other sources of assistance.<sup>102</sup> Also, in *Estate of Rosenberg v. Department of Public Welfare*,<sup>103</sup> the court held that the grantor of a spousal support trust whose wife had never needed public assistance could not have intended for the trust to become supplemental at some future time.<sup>104</sup> To summarize, when the grantor knows that the beneficiary would be eligible for government assistance and intends the trust funds to only supplement other aid, the trust is supplemental. If not, the court will likely classify the trust as a support trust and disqualify the beneficiary from receiving Medicaid benefits.<sup>105</sup>

As a general guideline, trustees of special needs trust should never distribute cash directly to the beneficiary because it will reduce the beneficiary's SSI benefit dollar-for-dollar.<sup>106</sup> The trust and family members of the beneficiary may choose to make in-kind distributions of food or clothing to the beneficiary. Under SSI rules, these will reduce the disabled individual's benefits, but the amount of the reduction is capped.<sup>107</sup> If planned correctly, large in-kind distributions of food or clothing will outweigh the loss of SSI benefits and have a net positive impact. The trustee can also get around SSI and Medicaid regulations through creative distributions that are not quite support.<sup>108</sup> For example, the trust cannot purchase medical services, but it could hire domestic caregivers or personal assistants.<sup>109</sup> It cannot pay rent, but it can fund renovations to the beneficiary's home for accessibility.<sup>110</sup> Finally, the trust could pay for the professional services of lawyers and accountants.<sup>111</sup>

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101. *Id.* at 1282.

102. 679 A.2d 767 (Pa. 1996).

103. *Id.* at 772.

104. Rosenberg, *supra* note 76, at 120 (“[A] trust that clearly expresses the creator’s intent to supplement and not to replace government benefits will not be considered an available resource” but “[a]mbiguous language gives a court the opportunity to utilize its own concept of public policy or fairness to achieve a certain result.”).

105. Scales & Anderson, *supra* note 10, at 176.

106. *Id.* at 177.

107. *Id.* at 176; *see also* Brannan, *supra* note 24, at 255–56 (discussing alternative expenditures, like caregiver services or attorney’s fees).

108. Brannan, *supra* note 24, at 255. As another example, the trust could pay for a wheelchair accessible van and its maintenance, repair, and insurance costs. *Id.*

109. *Id.* at 255–56.

110. *Id.* at 256. The trust funds could also be used to pay for “luxuries” that would benefit the disabled child emotionally, mentally, or socially. Recreation, vacations, education, and training would all be included. *Id.*

*D. Effects of the Uniform Trust Code*

The Uniform Trust Code (“UTC”) was drafted using the trust statutes of several different states along with the Restatement (Third) of Trusts.<sup>112</sup> It attempted to codify trust law as a response to the increased use of trusts in estate planning and growing awareness of lack of substantial state trust laws.<sup>113</sup> In 2000, the National Conference of Commissioners on Uniform State Laws approved the UTC.<sup>114</sup> It serves mostly as a default statute to be applied when the trust document is silent, and it can be largely overridden by language in trust instruments.<sup>115</sup> In the case of third-party special needs trusts, the terms of the UTC that cannot be overridden, such as the duty of the trustee to act in good faith, create problems.<sup>116</sup> Despite its attempt to make trust creation easier, the UTC may hurt third-party special needs trusts more than it helps.<sup>117</sup> As a result, fewer than half of the states have adopted the UTC, and many of these applied substantial revisions.<sup>118</sup>

Critics of the UTC point to two main problems it presents for third-party special needs trusts: (1) the “good faith” requirement for trustees, and (2) the elimination of the distinction between discretionary and support trusts.<sup>119</sup> The “good faith” requirement implemented by the UTC in section 804(a) states that the trust beneficiary may demand distribution if the trustee abuses power.<sup>120</sup> But if the beneficiary of a special needs trust took advantage of this ability, the trust assets would be reclassified as “available” income to the beneficiary, leading to loss of Medicaid benefits.<sup>121</sup>

The second problem with the UTC is the reversal of long-established common law distinctions between discretionary and

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111. *Id.* at 261. Drafters of the UTC also had to consider and cooperate with the Restatement (Third) of Property, Wills and Other Donative Transfers, and the Restatement of Restitution. They spent seven years on the final version. *Id.*

112. *Id.*

113. *Id.*

114. *Id.* at 262.

115. *Id.*

116. *Id.*

117. For example, when Ohio adopted the UTC, it modified exceptions to spendthrift provisions that make it more difficult for creditors to access trust funds left to spouses and children. *See* OHIO REV. CODE ANN. §§ 5805.02(C), 5805.03, 5805.04(D) (West 2007) (modifying UTC §§ 503–04).

118. Brannan, *supra* note 24, at 263.

119. *Id.* at 265–66.

120. *Id.* at 264–65.

support trusts.<sup>122</sup> If a trust that is used only for supplemental purposes is now treated the same as one used for support, then the standard for distributions that end eligibility for SSI and Medicaid regulations may become blurred. Previously acceptable distributions may now be considered countable “support” to the beneficiary and make the beneficiary ineligible for needs-based government aid.<sup>123</sup> As a result, attorneys drafting special needs trusts are forced to explicitly waive parts of the UTC that would otherwise afford clients protection against abuse. Thus, in its attempts to reform and simplify trust creation, the UTC actually further complicated the trust creation and management processes for families with disabled children.

### III. POLICY

At first glance it may seem that the government and Medicaid beneficiaries have opposing interests when it comes to trusts. Beneficiaries presumably want to conceal their assets in trusts while taking advantage of government programs, while the government wants to avoid giving out unnecessary aid. But, upon closer inspection, it becomes clear that many disabled individuals cannot maintain an adequate quality of life without relying on both government aid and trust funds. This is especially true of beneficiaries of third-party special needs trusts. Medicaid and SSI are designed only to help maintain a basic standard of health and quality of life for those who cannot entirely afford their own support—a situation in which many parents with disabled children inevitably find themselves.

#### A. *Government Versus Family Interests*

The government has obvious interests in protecting its programs from abuse, so concern about overreliance on Medicaid and Social Security comes as no surprise. The initial distrust of special needs trusts in particular was based on the belief that people who were disabled but still wealthy could draw on government funds they did not need instead of spending their own money.<sup>124</sup> There was also fear that expanding public assistance would lessen the incentive for communities to create informal support networks and create even more reliance on the government.<sup>125</sup> When Congress passed OBRA '93, it achieved its goal

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121. *Id.* at 265 (stating that discretionary and support trusts have been treated differently under common law for more than 125 years).

122. *Id.*

123. Rosenberg, *supra* note 76, at 145 (“The obvious critique of SNTs is that they allow people with private resources to utilize the SSI and Medicaid programs at the expense of people who are truly indigent.”).

124. *Id.* at 144 (quoting Bruce C. Vladek et al., *Confronting the Ambivalence of Disability Policy: Has Push Come to Shove?*, in *DISABILITY: CHALLENGES FOR SOCIAL INSURANCE, HEALTH CARE FINANCING &*

of limiting trust beneficiaries' access to government aid and mitigated some of these fears. However, by failing to include third-party special needs trusts as an exception to the rule, Congress created unreasonable restrictions that do more harm than good, particularly to third-party special needs trusts.

As previously discussed, self-settled special needs trusts are usually funded with damages from personal injury or medical malpractice suits. Money is awarded to a plaintiff for the purpose of paying the plaintiff's medical expenses but then is set aside in a trust so that it can be used for other things. The plaintiff can then rely on government aid for basic needs and medical care, even when he should be able to cover those costs himself. Conversely, third-party special needs trusts are funded primarily by family members of the beneficiary. The money going into the trust is not specially designated for medical care, and it never belonged to the beneficiary.

The beneficiaries of third-party special needs trusts are often disabled children who will always be dependent on someone else for their care due to their severe physical or mental disabilities.<sup>126</sup> If they qualify for Medicaid, gifts or inheritances could disqualify them. Without third-party special needs trusts, they have no way of supplementing their income. Government aid provides them with a low quality of life, limited to the bare necessities. Families who cannot afford to fully support the child must become reliant on Medicaid coverage, even if it means depriving their child of certain comforts to maintain eligibility.<sup>127</sup> Third-party special needs trusts are not meant to needlessly drain resources from government programs. Rather, their purpose is to “mitigate[] the inadequacies of government benefit programs” by covering non-medical needs of disabled dependents.<sup>128</sup>

The government also faces public interest and health problems associated with the limited resources of Medicaid. Many disabled individuals get their health insurance through Medicaid, but the focus of the program on health care neglects other areas of life in which disabled individuals need extra assistance.<sup>129</sup> For example, Medicaid does not provide “adequate mental health services, community based

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LABOR MARKET POLICY 83, 87–88 (Virginia P. Reno et al. eds., 1997) (stating that proposals to expand government program eligibility or services are often met with concern that “additional people will emerge ‘out of the woodwork’ to take advantage of the services”).

125. *Id.* at 109.

126. Grimyser, *supra* note 42, at 467 (explaining how third-party special needs trust grantors face “a catch-22: either receive Medicaid and be prohibited from using SNTs; or use a SNT and [risk] becom[ing] ineligible for Medicaid”).

127. Rosenberg, *supra* note 76, at 94.

128. *Id.* at 147.

services, or access to assistive technology.”<sup>130</sup> Allowing special needs trusts to supplement Medicaid may allow the beneficiary to live more independently or become more involved with family and the community. The ability to take advantage of these other resources could reduce costly hospital or institutional care.<sup>131</sup>

Overall, the possible benefits of letting families supplement Medicaid and SSI without losing the benefits entirely are unexplored because the regulations have always been focused on cutting off aid to anyone who might drain the system. A change in policy and perspective could help government aid programs save money while also improving the benefits that their recipients experience.

*B. Scientific Evidence of Rise in Diagnosis  
of Autism-Spectrum Disorders*

Government assistance programs now face the growing challenge of providing for young, mentally disabled individuals. Many of these children have been diagnosed with autism spectrum disorder (“ASD”), which includes autism and Asperger disorders.<sup>132</sup> Diagnosing children with ASD is complex and time consuming because it is based on “comprehensive behavioral evaluations.”<sup>133</sup> There is no medical detection system.<sup>134</sup> Instead, children must be evaluated for “impairments in social interaction and communication along with restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities.”<sup>135</sup>

Scientific studies suggest that the diagnosis rate of ASD and other mental disorders in children is increasing.<sup>136</sup> The Center for Autism reports that autism now affects one in sixty-eight children.<sup>137</sup> In addition, autism is the fastest-growing serious developmental disability

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129. *Id.*

130. *Id.*

131. Stephen J. Blumberg et al., Center for Disease Control and Prevention, *Changes in Prevalence of Parent-Reported Autism Spectrum Disorders in School-Aged Children: 2007 to 2011–2012*, 65 NAT’L HEALTH STAT. REP. 1 (2013).

132. *Id.*

133. *Autism Fact Sheet*, CENTER FOR AUTISM, <http://www.thecenterforautism.org/news/autism-fact-sheet> (last visited Sept. 5, 2014) [hereinafter *Fact Sheet*].

134. Blumberg, *supra* note 131, at 1.

135. See Lorna Wing & David Potter, *The Epidemiology of Autism Spectrum Disorders: Is the Prevalence Rising?*, 8 MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES RES. REV. 151, 151 (2002); see also Blumberg, *supra* note 131, at 1 (noting “a significant increase” in parent-reported autism).

136. *Fact Sheet*, *supra* note 133.

in the United States.<sup>138</sup> For example, the Center for Disease Control and Prevention (“CDC”) recently reported that the rate of ASD in children between the ages of six and seventeen rose from 1.16 percent in 2007 to 2 percent in 2011–2012.<sup>139</sup> It is unclear whether the increase is due to a rising occurrence rate or more awareness and better diagnosis methods.

Currently, the American Academy of Pediatrics recommends a developmental screening of all children for ASD by the age of twenty-four months.<sup>140</sup> Still, many children go undiagnosed until they reach school age, when their parents and teachers are more likely to notice their unusual difficulty in making friends or inability to interact normally with other children.<sup>141</sup> In addition, diagnosis becomes more common once children reach school age because children must have a named disability to qualify for special education under the Individuals with Disabilities Act.<sup>142</sup> Many experts believe that the increase in the rate of diagnosis can be attributed to greater public knowledge about ASD and its symptoms.

The CDC’s data support the idea that the number of diagnoses of ASD is rising but not the actual occurrence rate. Its recent phone survey revealed that 30 percent of children between ages ten and thirteen and 14 percent of children between ages fourteen and seventeen were first diagnosed at age seven or older.<sup>143</sup> At that point, they were well past the age when symptoms of their ASD would have been noticeable. Furthermore, more than half of the same children had only “mild” ASD. According to the CDC:

Together, these findings suggest that the increase in prevalence of parent-reported ASD may have resulted from improved ascertainment of ASD by doctors and other health care professionals in recent years, especially when the symptoms are

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137. *Id.*

138. Blumberg, *supra* note 131, at 2. These data were taken from the 2007 and 2011–2012 versions of the National Survey of Children’s Health—a telephone survey—which received more than 63,000 responses in 2007 and more than 65,000 responses in 2011–2012. *Id.*

139. *Id.* at 1; *see also* Chris Plauché Johnson & Scott M. Myers, *Identification and Evaluation of Children with Autism Spectrum Disorders*, 120 PEDIATRICS 1183, 1198–99 (2007) (discussing current screening protocols).

140. Blumberg, *supra* note 131, at 1; *see also* Johnson & Myers, *supra* note 139, at 1202 (“Older children who first present with symptoms of AS after school entry often are first recognized and evaluated by the school district’s educational diagnostic team.”).

141. Blumberg, *supra* note 131, at 1–2; Individuals with Disabilities Education Act Amendments, Pub. L. No. 101–476, 104 Stat. 1103 (1990).

142. Blumberg, *supra* note 131, at 5.

mild. Changes in the ascertainment of ASD could occur because of changes in ASD awareness among parents or health care professionals, increased access to diagnostic services, changes in how screening tests or diagnostic criteria are used, or increased special education placements in the community.<sup>144</sup>

As a result, some would suggest that the rise in the number of ASD diagnoses does not reflect an increase in the number of ASD cases. One blogger noted that activist organizations might try to scare people by declaring an “epidemic” but clarified that “the numbers of people born with autism aren’t necessarily increasing dramatically. It’s just that we’re getting better and better at counting them.”<sup>145</sup>

However, for the SSI and Medicaid programs, the distinction does not matter. Once a child is diagnosed with ASD, his or her family can apply for benefits. The increasing diagnosis rate will result in more government aid expenditures even without an increase in the actual rate of the disorder. Families with children who have ASD spend an average of \$60,000 a year on care.<sup>146</sup> Many of these families will be forced to apply for aid. Because the children meet the disability criteria but are still likely to live longer thanks to advances in medicine and technology, they may be able to collect Medicaid disbursements over their entire lifespans. Medicaid and other government assistance programs will struggle to keep up with the increased demand, but third-party special needs trusts could be a highly effective tool in balancing the cost between the government and families of the disabled children.

#### IV. SOLUTION

Third-party trusts cannot continue to function if their definition as either a supplemental or support trust is left up to the interpretation of trust language by state courts. They differ from self-settled and pooled trusts in several significant ways that only make the need for a bright-line rule even more imperative. They are created to provide a higher quality of life using funds that never belonged to the beneficiary, not to shield funds that the beneficiary received from personal injury or medical malpractice settlements. They can be set up *inter vivos* to provide for the disabled child while his or her parents are still alive. They are more likely to involve a beneficiary who is incapable of demanding distributions from the trust, even if that would not lead to ineligibility for SSI and Medicaid. These individuals have lived and will continue to live with disabilities throughout their entire lives, and they

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143. *Id.*

144. Emily Willingham, *Autism Prevalence Is Now at 1 in 50 Children*, FORBES (Mar. 20, 2013, 2:04 PM), <http://www.forbes.com/sites/Emilywillingham/2013/03/20/autism-prevalence-is-now-at-1-in-50-children> (last visited Sept. 5, 2014).

145. *Fact Sheet*, *supra* note 133.

may be to varying degrees dependent on their families and the government for support.

Unlike self-settled trusts, for which the family may make no expenditure for the care of a disabled individual, the funds in third-party trusts come entirely from the family. Consequently, the creation and effective use of third-party special needs trusts tend to have more of an impact on the family of the disabled individual than other types of trusts. Because these differences are widely overlooked by SSI, Medicaid, and the UTC, families with permanently disabled children have to undertake the complicated task of creating trusts that even their attorneys may not understand, even though they are not usually capable of committing the kind of abuse that regulations creating the complications are meant to prevent. One-time changes to the SSI and Medicaid regulations could fix this problem and remove the burden from thousands of families.

The government should design a way for parents of disabled children to supplement Medicaid and other basic support through third-party special needs trusts without losing their benefits. In order to offset the inescapable increase in demand for government aid, the new system should reduce the amount of aid given based on the level of support parents or other benefactors are willing and able to provide, both during their lives and after their deaths through the trust. However, a revised system needs to realistically rebalance the amount of aid withdrawn versus the assets available. A mere \$2,000 in assets should not be enough to completely disqualify a disabled beneficiary from receiving his government aid. While \$2,000 may be enough to provide a disabled individual with extra care, it is nowhere near sufficient to cover his or her medical, housing, and other basic costs for even a single month.

The best way to implement this change would be to give supplemental third-party special needs trusts their own exception in 42 U.S.C. § 1396p(d)(4), but an exception that is less limited than the exceptions for self-settled and pooled trusts. The exception would not need to allow the beneficiary to have access to the funds. In fact, many disabled beneficiaries of third-party special needs trusts lack the capacity to use the assets themselves. Instead, it should do away with the reliance on court interpretations of third-party special needs trusts by giving clear criteria for when a trust is supplemental. The criteria could be laid out as follows: when a trust (1) is established by a parent, grandparent, or legal guardian of a disabled person who qualifies for Medicaid; (2) is funded by the parents, grandparent, or legal guardian; and (3) states an intent to supplement, not supplant, government aid, it is presumed to be a supplementary trust that cannot disqualify the beneficiary from need-based governmental programs.<sup>147</sup>

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146. Going a bit further, Joseph A. Rosenberg suggests that a presumption should be created that “[a]bsent a clear expression of intent that the trust should be used to replace government benefits, the trust should not be



The more lenient distribution standards would allow family members and the trust to make some contributions that overlap with SSI and Medicaid without fear of losing benefits. The exception would also need to include a way to calculate how much aid to withhold based on how much money the trust distributed. For instance, if the trust is routinely able to give the beneficiary more each month than he would receive from Medicaid and SSI, the government aid provided should be greatly reduced. But if the trust can usually only give 10 percent of what the government provides, the beneficiary's aid should not be reduced at all. Because the purposes of the two sources differ, the reduction in benefits should never match the trust distributions dollar for dollar. One provides necessities, while the other offers comforts. For instance, if the trust makes a large expenditure to renovate the beneficiary's house for accessibility, it should not result in a loss of medical benefits equal to the cost of the renovations.

Proponents of the Medicaid program may argue that this new exception would drain its already-stretched funds, but that argument is flawed. Generally, any change that adds new recipients to the program would cost it money; however, the supplemental third-party special needs trust exception would not add new recipients. People who use these trusts have already found a way to collect the full amount of their government aid through loopholes in the Medicaid regulations, albeit by sacrificing many legal protections. Instead of costing Medicaid more, the trust expenditures sanctioned by the new exception would actually let Medicaid decrease the amount given to some recipients. They would also restore the rights of the trust beneficiaries, who would no longer have to rely on the absolute discretion of trustees and court inquiries into the subjective nature of the grantor's intent.

## CONCLUSION

It is never easy to take the first steps down the long road toward amending regulations, but in the case of third-party special needs trusts, the destination is worth it. Parents or guardians of special needs children would be relieved of a major mental and emotional burden if they had a reliable means of securing their children's long-term well-being. The Medicaid and Social Security programs would no longer be caught in a tug-of-war between assisting the beneficiaries of third-party special needs trusts and accusing them of cheating the system. Attorneys and the courts would have fewer complex and time-

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considered an available asset for purposes of eligibility for government benefits." Rosenberg, *supra* note 76, at 149. I believe this might make it too easy for trusts to make distributions for support (e.g., buying a house) under the guise of being a supplemental trust. Some court interpretation will always be necessary, and the distribution types and amounts are the most difficult element to clearly label either support or supplement.

consuming cases on their hands, and the interests of justice, social welfare, and economy would be served.

The increasing rate of ASD diagnoses creates additional legal concerns across the board. While this Note focuses only on estate planning aspects of special needs care, undoubtedly changes are needed in the medical, education, labor, housing, and civil rights fields to cope with a rising number of disabled individuals. Disability issues are often ignored by legislators—pushed to the side to make way for topics deemed more pressing. But the problems will not simply disappear. Now more than ever, thanks to medical and social innovations, disabled children have the opportunity to grow up in an environment that strives to understand their needs and unlock their potential. The law needs to catch up.

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