

Pooled Special-Needs Trusts: An Exception that Should be the Rule to Protect Adults with Developmental Disabilities

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Introduction

Many parents of developmentally disabled children¹ grow old knowing—and worrying—that their children will always need the sort of care those parents once provided.² James Cumberpatch

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1. Ctrs. for Disease Control & Prevention (CDC), *Developmental Disabilities*, Oct. 29, 2004, <http://www.cdc.gov/ncbddd/dd/dd1.htm>.

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime.

Id. These conditions include what is known as mental retardation, or intellectual disability, "characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities." CDC, *Developmental Disabilities: About Intellectual Disability*, Oct. 29, 2005, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>.

2. See generally Sandra Block, *Special-Needs Trust Helps Disabled Child*, USA TODAY, Aug. 29, 2000, at 3B. According to Block:

Contemplating your own mortality is always scary, but it's particularly frightening if you're the parent of a severely disabled child.

Routine estate planning can be a nightmare. Instead of simply figuring out who gets the house and the mutual fund portfolio, you must wrestle with hard questions about who will care for your grown child when you're no longer around.

Id.; see also Melissa Healy, *Taking the Next Step*, L.A. TIMES, May 5, 2003, at D12 ("[F]or many . . . parents with developmentally disabled sons or daughters, the recognition that a change must be made in the caregiving arrangement brings fear and uncertainty [M]any aging caregivers of now-grown children with mental retardation have nowhere to turn."); Gracie Bonds Staples, *Their Golden Years of Anxiety*, ATLANTA J.-CONST., Oct. 13, 2008, at 1A ("Most parents expect that their children are going to outlive them. It's only those of us who have children with developmental disabilities who worry about it." (quoting Pat Nobbie, Deputy Director of the Governor's Council on Developmental Disabilities)).

lived with this concern for decades.³ His son, Joseph, was born with Down's Syndrome in 1962, the youngest of seven children.⁴ Joseph's last sibling to leave the house did so in 1982, leaving his parents with a bittersweet realization:

Whereas most couples have earned full freedom after all of their children have been raised and left home, we would have to take care of Joseph for the rest of our lives. This was going to be a big job because Joseph is, in most ways, the equivalent of a three- to six-year-old.⁵

Then James Cumberpatch's wife died in 1988.⁶ He struggled: "During the mid-90's, it seemed that I was either working or taking care of Joseph," who lived at home almost exclusively.⁷ In 1998, Joseph moved to a new home, a residential center for adults with developmental disabilities.⁸ Mr. Cumberpatch said:

I am sorry that my wife did not live to feel that same freedom with me and to see Joseph so well situated and happy. . . . I no longer have to worry about what would happen to Joseph if I were to get sick or die. I [w]as [sic] always afraid that my children might inherit this responsibility. They all have spouses and small children of their own, and such a thing should be an unfair and heavy burden.⁹

Joseph's sixtieth birthday falls in 2022. That puts the Cumberpatch family at the crest of a wave, as the number of Americans older than sixty with developmental disabilities is doubling, from 641,161 in 2000 to 1.2 million in 2030.¹⁰ This group is the first generation of developmentally disabled Americans who, by and large, will outlive their parents.¹¹ With

3. *Can We Rest in Peace? Anxiety of Elderly Parents Caring for Disabled Baby Boomers: Testimony Before the S. Select Comm. on Aging*, 105th Cong. 32-34 (1998) [hereinafter *Can We Rest in Peace?*] (statement of James Cumberpatch).

4. *Id.* at 32.

5. *Id.* at 33.

6. *Id.*

7. *Id.*

8. *Id.* at 34.

9. *Id.*

10. *Aging With a Developmental Disability*, 2005 White House Conference on Aging, Dec. 8, 2004, available at

www.whcoa.gov/about/policy/meetings/summary/factortestimony.pdf (testimony of Alan R. Factor, Ph.D., Assoc. Dir., Rehab. Research and Training Ctr. on Aging with Developmental Disabilities, Dep't of Disability and Human Dev., Univ. of Ill. at Chicago). According to Dr. Factor:

The "graying" of the United States population also includes adults with [mental retardation/developmental disabilities] who are part of the large post-World War II baby boom generation. . . . We project this group will nearly double in size to 1.2 million by 2030 when the last of the baby boom generation reaches 60.

Id. at 2 (emphasis removed).

11. The mean age at death for persons with mental retardation was 66.2 in

this change comes a legal problem: those who depend on government benefit programs with strict asset limits risk seeing those benefits cut if their parents die intestate—at least until the inheritance is exhausted by paying for the services that the government had provided.¹² This is counter to the spirit behind intestacy laws, which aim to fulfill the probable intent of deceased persons and to further the preservation of a family's assets from generation to generation.¹³ When the person who receives the inheritance is disabled and receiving public benefits, however, those assets may vanish to the government.¹⁴ Preventing those inherited assets from vanishing requires careful estate planning,¹⁵ a potentially insurmountable barrier for families without the financial ability to plan their estate.¹⁶ Any savings that those parents have accumulated could be at risk.¹⁷

1993, 59.1 in the 1970s, and 18.5 in the 1930s. *Can We Rest in Peace?*, *supra* note 3, at 49 (prepared statement of David Braddock, Ph.D., Head, Dept. of Disability and Human Dev., Univ. of Ill. at Chi.); *see also* Chris Swingle, *Age Challenge*, *ROCHESTER DEMOCRAT AND CHRON.* (N.Y.), Aug. 17, 2008, at A1 (discussing the impacts of the longer life spans of the developmentally disabled).

12. Jennifer Field, *Special Needs Trusts: Providing for Disabled Children Without Sacrificing Public Benefits*, 24 J. JUV. L. 79, 80–81 (2003-2004); *see also* Craig P. Goldman, *Render unto Caesar that Which is Rightfully Caesar's, but Not a Penny More Than You Have to: Supplemental Needs Trusts in Minnesota*, 23 WM. MITCHELL L. REV. 639, 644 (1997). According to Goldman:

Specifically, the concern is whether any money transferred by anyone directly to their son, or even to various third parties for the benefit of their son, would be considered "available assets under either federal or Minnesota medical assistance guidelines, thus potentially disqualifying him from receiving medical assistance benefits. Similarly, the disabled individual . . . must be concerned whether the inheritance from her mother will constitute "available assets," thus disqualifying her from receiving, or continuing to receive, governmental assistance of any sort.

Id.

13. *See generally* Susan N. Gary, *Adapting Intestacy Laws to Changing Families*, 18 LAW & INEQ. 1, 6–13 (2000) (explaining that the goals of intestacy statutes are to carry out the probable intent of most testators and to fulfill a societal goal to support the decedent's family, which includes encouraging the accumulation of wealth).

14. *See* Goldman, *supra* note 12, at 644.

15. *See generally* Field, *supra* note 12, at 82–83 (describing how the drafter of a special-needs trust must include provisions to ensure that its assets do not disqualify the child, including irrevocability, clear primary and residual beneficiary designations, and, in some cases, distribution standards); Lawrence A. Frolik, *Estate Planning for Parents of Mentally Disabled Children*, 40 U. PITT. L. REV. 305, 305 (1979) ("Effective estate planning for a mentally disabled beneficiary requires that the lawyer integrate the estate plan with . . . federal and state benefits.").

16. *See* Goldman, *supra* note 12, at 644 ("Certainly, families with the foresight to plan their estates early and carefully are in a vastly superior position *vis-à-vis* those disabled individuals and their families who must deal with these issues after they already have received any assets.").

17. *See* Frolik, *supra* note 15, at 313–14 (discussing the possibility that developmentally disabled children may not be able to manage money left to them);

This Article argues that every State should encourage the creation of pooled supplemental special-needs trusts and then should make such trusts the default option for developmentally disabled citizens who are heirs to an intestate parent. Part I describes the demographic and societal trends that have allowed the population of people with developmental disabilities to flourish, how those Americans rely on Medicaid, and how families with the means and ability to plan can avoid Medicaid's benefit pitfalls. Part II describes the laws of intestacy and the Uniform Probate Code, the vehicle through which state-by-state changes should be sought.

Finally, Part III argues that the Uniform Probate Code should be amended so that states will have a model for a new default rule that presumes that inherited assets passed after an intestate death should go into the sort of pooled trust now allowed under federal law. This change would protect families who lack the financial means necessary to draft a trust or a will to protect benefit eligibility for those with developmental disabilities.

I. Baby Boomers with Developmental Disabilities and Medicaid

A. Medicaid: An Overview

Created in 1965, Medicaid¹⁸ was intended to provide health care to Americans unable to cover the costs themselves.¹⁹ The Federal Department of Health and Human Services oversees Medicaid, which is generally run voluntarily by the States through state agencies.²⁰ Categories of eligibility include "the blind or disabled,"²¹ although potential participants must meet state-designated income thresholds once they are determined to meet

see also Gail C. Eichstadt, *Using Trusts to Provide for the Needs of an Adult Child with a Disability: An Introduction to Family Concerns for Lawyers and a Primer on Trusts for Parents*, 45 S.D. L. REV. 622, 679 (2000) (noting that large gifts or bequests may make a child ineligible for medical benefits, making that gift the only means for the child to pay his/her living and medical expenses).

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

19. See generally Jacqueline D. Farinella, *Come on in, the Water's Fine: Opening up the Special Needs Pooled Trust to the Eligible Elderly Population*, 14 ELDER L. J. 127, 130 (2006) (noting that, after the "relatively modest goal of providing health care to the poor . . . [Medicaid] has grown to become the nation's largest single purchaser of nursing home services, providing for the health care needs of almost forty-four million Americans").

20. *Id.*

21. 42 U.S.C.A. § 1396 (2008).

such a preliminary qualification.²² The Medicaid program dovetails with another program that looks at financial need as a factor in determining eligibility: Supplemental Security Income for the Aged, Blind, and Disabled (SSI).²³ SSI is an entirely federal program that gives qualifying, disabled persons a minimum income.²⁴ Since 1989, SSI eligibility has been limited to those persons with no more than \$2,000 in assets.²⁵ A person who is eligible for SSI is generally deemed eligible for Medicaid.²⁶

Together, Medicaid and SSI provide the “bare essentials” to maintain the health and support of recipients.²⁷ The former provides access to medical and hospital care, prescription medicine, and long-term institutional care.²⁸ The latter provides a meager income aimed to bring the recipient to seventy-five percent of the federal poverty level.²⁹ SSI recipients are generally expected to contribute to the cost of their care, with charges designed so that “the person can only keep a small amount of money as a ‘personal-care allowance’—sometimes as low as \$30 per month—to pay for medical and support expenses not covered by Medicaid, entertainment, or other ‘items and services that would enhance the individual’s quality of life.’”³⁰ Eligibility can be lost by a sudden transfer of assets if a covered person exceeds the asset limit, even after initial qualification.³¹ “Thus, if a parent wishes to leave a disabled child an estate of more than \$2,000, the gift will disqualify the child from receiving SSI and Medicaid

22. Farinella, *supra* note 19, at 131.

23. 42 U.S.C.A. § 1381 (2008); *see also* Farinella, *supra* note 19, at 132 (“At a minimum, the remaining assets must be low enough to qualify for Supplemental and Security Income for the Aged, Blind, and Disabled (SSI), another means-based government benefit program.”); Goldman, *supra* note 12, at 642–43 (discussing coverage of the medically needy under the SSI).

24. *See* Eichstadt, *supra* note 17, at 628.

25. 42 U.S.C.A. § 1382(a)(3)(B) (2008); *see also* Field, *supra* note 12, at 80 (“In 2003, in order to be eligible to receive SSI, a recipient may only own countable assets with a total value of \$2,000.”).

26. *See* CTRS. FOR MEDICAID & MEDICARE SVCS., MEDICAID-AT-A-GLANCE 2005: A MEDICAID INFORMATION SOURCE 1 (2005); *see also* Alicia F. Curtis, *Pooled Supplemental Needs Trusts Help Keep Wolves from Seniors’ Doors*, 21 ME. B. J. 28, 29 (2006) (“Generally, a disabled person who qualifies for SSI will then gain automatic categorical eligibility for Medicaid.”).

27. *See* Field, *supra* note 12, at 81.

28. *See* Curtis, *supra* note 26, at 29 (citing JEFFREY S. CROWLEY & RISA ELIAS, THE KAISER COMMISSION ON MEDICAID AND THE UNINSURED, MEDICAID’S ROLE FOR PEOPLE WITH DISABILITIES 2 (2003)).

29. *Id.*

30. THE ARC, POOLED TRUST PROGRAMS FOR PEOPLE WITH DISABILITIES 3 (2002).

31. *See* Field, *supra* note 12, at 80.

benefits. The child will only be able to re-qualify for benefits when the parent's funds have been exhausted."³²

B. Medicaid and Trusts

A crucial test in determining SSI and Medicaid eligibility is whether an asset is "available" to the developmentally disabled person.³³ A trust set up by a living parent is not considered an asset for Medicaid purposes if the trust contains provisions that require that the trust assets may only be spent to supplement, not replace, government benefits.³⁴ Such provisions qualify the trust as one that aims to fulfill the beneficiary's "supplemental" or "special" needs—those that "provide services and goods above and beyond what Medicaid will provide, but which can greatly enhance a disabled child's life."³⁵ These are the sorts of expenditures beyond the "personal-care allowance" that family members may have provided for the disabled relative.³⁶

Federal law specifically exempts certain additional supplemental-needs trusts, including "pooled" trusts administered by nonprofit organizations, from being taken into account when a disabled person's eligibility is determined.³⁷ These pooled trusts are distinct from a more straightforward supplemental-needs trust

32. *Id.*

33. See Goldman, *supra* note 12, at 643.

34. See *id.* at 647; see also Field, *supra* note 12, at 82 ("Because a parent's estate, if received directly by the disabled child, will disqualify the child from receiving public benefits, it is imperative that the [supplemental-needs trust] not be considered 'available' to the child.").

35. Field, *supra* note 12, at 81.

36. See generally Eichstadt, *supra* note 17, at 634–35 (listing a range of provisions that could be paid for by a supplemental-needs trust, including dental care, psychological support services, furniture, recreation, and transportation).

37. 42 U.S.C.A. § 1396p(d)(4) (West 2006). This statute provides:

This subsection shall not apply to . . .

(c) A trust containing the assets of an individual who is disabled . . . that meets the following conditions:

(i) The trust is established and managed by a nonprofit 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 . . . 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.

Id.

in that they can be funded with the disabled person's assets, not only the assets of a parent or another person.³⁸ A pooled trust also does not require the disabled beneficiary to be under sixty-five, as other trusts allowed under the same statute require.³⁹ These two features are important when a trust's relationship to an intestacy law is concerned. A disabled person who takes from an estate will have those assets considered his or hers immediately, and may receive those assets regardless of age.⁴⁰

The definition of an exempt pooled supplemental-needs trust is codified at 42 U.S.C.A. § 1396p(d)(4)(C), as approved by Congress in 1993 in the Omnibus Budget Reconciliation Act (OBRA '93).⁴¹ In these trusts, each beneficiary's account is maintained individually, although the funds are invested together with many other individual accounts in a pool.⁴² Overall, the legislation aimed to restrict Medicaid eligibility by limiting the use of trusts to shield estates and assets from the Medicaid eligibility determination.⁴³ The legislation does this by mandating that nearly all trusts are considered "resources" of persons being considered for Medicaid, and by requiring that the eligibility calculation take into account asset transfers made by the applicant.⁴⁴ There were three exceptions, two of which applied to persons with disabilities: individual third-party trusts established

38. See *id.*; Goldman, *supra* note 12, at 657–58.

39. See Goldman, *supra* note 12, at 659.

40. RESTATEMENT (THIRD) OF PROPERTY: WILLS & OTHER DONATIVE TRANSFERS § 2.1 (1999) ("A decedent who dies without a valid will dies intestate. . . . The decedent's intestate estate . . . passes at the decedent's death to the decedent's heirs as provided by statute.").

41. The Omnibus Budget Reconciliation Act (OBRA '93), 42 U.S.C.A. § 1396p(d)(4) (2008).

42. See *id.*

43. See Farinella, *supra* note 19, at 136–37. According to Farinella:

In an effort to reduce a growing Medicaid budget, and also in response to growing concern over perceived abuse of the program, Congress tightened the eligibility rules under the Medicaid program. This agenda was put into effect through the Omnibus Budget Reconciliation Act of 1993 (OBRA '93), which effectively extinguished the possibility of qualifying for Medicaid benefits by shielding assets in the most commonly used types of trusts. . . . After [earlier legislation] expanded eligibility for the program's benefits, many otherwise "wealthy" people began to use these benefits, contrary to the program's intended purpose of providing health care to those of limited means. A practice commonly referred to as "Medicaid planning" became prevalent for middle-class elders who faced certain impoverishment either from the costs of health care or the costs of health care insurance. With the help of lawyers or other planning advisers, many elders began to shield their estates in trusts or through asset transfers to family members in order to qualify for Medicaid benefits.

Id.

44. See *id.* at 137–38; Curtis, *supra* note 26, at 30.

for a disabled person by a guardian, parent, grandparent, or court; and pooled trusts.⁴⁵

Goldman points out that pooled trusts have important features:

Pooled trusts offer a number of unique benefits for disabled individuals and their families. For example . . . pooled asset trusts allow disabled individuals to place their own assets into a pooled trust. Moreover . . . [pooled trusts do] not contain any requirement that the disabled individual be under age 65 . . . [and] persons of all ages can avail themselves of this kind of trust. A pooled asset trust is the only method under current law for disabled individuals over the age of 65 to place their own assets into trust without disqualifying themselves from receiving medical assistance benefits⁴⁶

Goldman also notes that pooled asset trusts "do not absolutely require that the state be reimbursed upon the death of the disabled beneficiary for any medical assistance benefits paid to the beneficiary during his or her life."⁴⁷ Rather, the nonprofit agency administering the trust may donate or use the funds to support other beneficiaries.⁴⁸ Pooled asset trusts are available in about thirty-five states.⁴⁹ Where available, they are marketed by advocacy groups as a relatively inexpensive and effective way to provide additional funds for a disabled person without putting benefits at risk.⁵⁰ There is at least one trust established to serve beneficiaries from across the country: The National Pooled Trust, administered by the Center for Special Needs Trust Administration in Florida.⁵¹

45. See Farinella, *supra* note 19, at 138–39.

46. Goldman, *supra* note 12, at 658–59.

47. *Id.* at 659.

48. See *id.*; see also THE ARC, *supra* note 30, at 11 ("Trust programs put the funds that they retain to good use. These funds may be used to assist other beneficiaries whose funds run out prematurely. Funds may also be used to operate the program.").

49. See THE ARC, *supra* note 30, at 13; Curtis, *supra* note 26, at 29 n.6.

50. See generally THE ARC, *supra* note 30, at 2 ("Pooled trust programs enable families or other caregivers, and in some cases individuals with disabilities, to establish relatively inexpensive and effective trust accounts that provide supplemental funds for the person with a disability while protecting him or her from losing important government benefits.").

51. The Center for Special Needs Trust Administration, The National Pooled Trust, <http://nationalpooledtrust.com> (last visited Feb. 26, 2009).

C. *A Boom Within the Boom: The Aging Developmentally Disabled Population*

The planning needs of parents of people with developmental disabilities go beyond financial concerns.⁵² An estimated sixty percent of people with mental retardation or developmental disabilities live with their families,⁵³ and one in four of those households have a primary caregiver who is sixty or older.⁵⁴ Parents in these families often face the wrenching realization that they need to start planning for what will happen once they can no longer assist the adult child for whom they have cared for decades.⁵⁵ Often, that means finding the child a placement in a group home or other community-based living facility.⁵⁶ Meanwhile, the number of persons with developmental disabilities living outside of large institutions has grown as families, advocates, and policymakers have sought to increase community placements in smaller-population, intermediate care facilities.⁵⁷

52. See generally Glenn T. Fujiura, *Demography of Family Households*, 103 AM. J. MENTAL RETARDATION 225, 226 (1998) (explaining that the post-World War II generation "may be unprecedented in size, with unanticipated and as yet unrealized demands on state service systems as family caretakers – in particular, aging parents – seek alternatives to family-based support").

53. *Aging with a Developmental Disability*, *supra* note 10, at 2.

54. *Id.*; see Fujiura, *supra* note 52, at 232. According to Fujiura:

The juxtaposition of these three facts – dramatic increases in public sector spending; low to moderate growth in system capacity; and a large, home-based population – brings up critical questions about the character of demographics [regarding people with developmental disabilities]. These are not new questions; the burgeoning attention to residential transitions from the homes of aging caretakers reflects a broad recognition of the aging of the American population and the concomitant aging of family caretakers. . . . In the present analysis over one quarter of those individuals living in family settings (excluding living with a spouse and in one's own residence) were in households headed by a family member 60 years of age or older. Another 35 [percent] were adults in the households of middle-age caretakers, for whom transition issues were near term considerations. The size of the cohort suggests significant and as yet unrealized demands on the states' service systems.

Id.

55. See Fujiura, *supra* note 52, at 226; Staples, *supra* note 2.

56. See *Can We Rest in Peace?*, *supra* note 3; Healy, *supra* note 2; Staples, *supra* note 2.

57. DEWAYNE DAVIS ET AL., NAT'L CONF. STATE LEGIS., DEINSTITUTIONALIZATION OF PERSONS WITH DEVELOPMENTAL DISABILITIES: A TECHNICAL ASSISTANCE REPORT FOR LEGISLATORS (2008), available at <http://204.131.235.67/programs/health/forum/pub6683.htm>; Luana Olivas, *Helping Them Rest in Peace: Confronting the Hidden Crisis Facing Aging Parents of Disabled Children*, 10 ELDER L.J. 393, 399 (2002).

That move was prompted by the courts,⁵⁸ but also followed moves by families and advocates to both improve conditions in large facilities and to make it so that fewer and fewer people with disabilities lived in those institutions.⁵⁹

II. Intestacy Laws and the Uniform Probate Code

Intestacy laws generally have two goals: to fulfill the probable intention of most people who die without a will and to serve societal goals by providing for the support of the decedent's family.⁶⁰ They do this by governing the transfer of wealth and assets from the decedent to his or her heirs when the decedent has not expressed intentions for that transfer.⁶¹ Laws vary from state to state, but all states have a model to follow: the Uniform Probate Code (UPC), drafted by the National Conference of Commissioners on Uniform State Laws (NCCUSL).⁶² Under intestacy laws, an heir's interest in a decedent's estate becomes possessory at the time of death.⁶³

A. Intestacy: The "Statutory Will" that Does Not Fit All⁶⁴

Intestacy laws are a State's attempt to set a default for what should happen when a person dies without having made a will—rendering the laws a mass-produced solution fitted to a myriad of families with a myriad of problems. But no "one-size-fits-all" approach will fulfill the needs of all American families.⁶⁵ This has prompted commentators to propose statutory changes that work to

58. See, e.g., *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999) (holding that States are required to provide community-based treatment for persons with mental disabilities "when the [s]tate's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities").

59. See DAVIS ET AL., *supra* note 57, at 13 (discussing "Opportunities for State Action" in improving institutions for the developmentally disabled").

60. See Gary, *supra* note 13, at 3 ("[T]he goal behind intestacy statutes is to give the decedent's property to the decedent's family."); *id.* at 9 ("The most commonly identified goal of intestacy statutes is to create a dispositive scheme that will carry out the probable intent of most testators.").

61. *Id.*

62. See *id.*

63. RESTATEMENT (THIRD) OF PROP.: WILLS & OTHER DONATIVE TRANSFERS § 2.1 (1999) ("A decedent who dies without a valid will dies intestate. . . . The decedent's intestate estate . . . passes at the decedent's death to the decedent's heirs as provided by statute.")

64. See Gary, *supra* note 13, at 1 (coining the term "statutory will" and defining it as "a will in which the government, rather than the individual, determines the dispositive terms").

65. *Id.* at 1-2.

provide a better answer to the needs of more people. For example, Gary advocates for a statutory change that, "for intestacy purposes, expands the definition of parent and child to include a person who can establish that a parent-child relationship existed between that person and the decedent."⁶⁶ Such a change, Gary argues, creates a functional definition of family that best reflects the fact that the "form of American families has changed and . . . continue[s] to change."⁶⁷

Gary is one of many commentators and advocates who have examined intestacy statutes when evaluating how society has adapted to changing family structures and relationships.⁶⁸ Some take a critical view of how inheritance laws codify societal attitudes: "Inheritance law, which at first seems to be a fortress of the legitimate family, appears on closer inspection to be more like a museum."⁶⁹ For her part, Gary's proposal will influence, and be influenced by, other changes already taking place in society,

66. *Id.* at 6.

67. *Id.* at 80–81 (proposing statutory language be added to the portion of a state's intestate code describing the parent-child relationship). According to Gary, state legislatures should add the following language to their intestate code:

(a) For purposes of intestate succession, an individual is the child of another individual and an individual is the parent of another individual if the person seeking to establish the relationship proves by clear and convincing evidence that a parent-child relationship existed between the two individuals at the time of the decedent's death. This section shall not create inheritance rights for any person other than the individuals for whom a parent-child relationship is established pursuant to this section.

(b) [Factors.] Although no single factor or set of factors determines whether a relationship qualifies as a parent-child relationship, the following factors are among those to be considered as positive indications that a parent-child relationship existed . . . [factors range from objective considerations, such as whether the relationship began during the child's minority, to subjective ones, such as whether the child's treatment by the parent was comparable to the parent's treatment of his or her legal children].

Id.

68. See generally *id.* (advocating for change in intestacy laws to take into account functional parent-child relationships in addition to biological relationships); Raymond C. O'Brien, *Domestic Partnership: Recognition and Responsibility*, 32 SAN DIEGO L. REV. 163, 217 (1995) (stating that "[t]he Uniform Probate Code, because of its purpose to make uniform the law among the various jurisdictions, is a good vehicle from which to discuss provisions in the law of intestate and testate succession that could change in providing for domestic partners" (citations omitted)); Jennifer Seidman, *Functional Families and Dysfunctional Laws: Committed Partners and Intestate Succession*, 75 U. COLO. L. REV. 211, 213–14 (2004) (analyzing "the notable absence of provisions for surviving partners of committed relationships" in the Uniform Probate Code and proposing amendments to the Code "to increase equity in intestate succession").

69. Seidman, *supra* note 68, at 211 (quoting MARY ANN GLENDON, *THE TRANSFORMATION OF FAMILY LAW: STATE, LAW, AND FAMILY IN THE UNITED STATES AND WESTERN EUROPE* 289–90 (1989)).

making it so that intestacy laws “encompass the children of the new families such as stepchildren, children of gay and lesbian families, and children in families headed by opposite-sex, unmarried partners.”⁷⁰ She contends that her proposed changes could “make intestacy statutes more inclusive and more useful,” and that “intestacy laws should approximate the intent of the decedent and provide support, both economic and psychological, for all families.”⁷¹

Although Gary focuses on the changing definition of family, a change in intestacy laws for the benefit of heirs with developmental disabilities is not based on a new understanding of the parent-child relationship. Instead, it furthers the probable intention of most parents who die without a will and leave children with developmental disabilities.

B. A Model for the States: The Uniform Probate Code

The UPC is one of dozens of codes drafted by the NCCUSL, which was founded in 1892 in order to promote uniformity among the states.⁷² These uniform acts include the widely adopted Uniform Commercial Code.⁷³ The NCCUSL is a nonprofit organization made up of commissions from each state, the District of Columbia, Puerto Rico, and the United States Virgin Islands.⁷⁴ Commissioners must be lawyers; most are practitioners, judges, or law professors.⁷⁵

Each uniform act takes years to develop, as proposals are investigated, reported, examined, revised, and revised again.⁷⁶ Final drafts are presented to all commissioners for approval, and then are voted on by representatives from each state.⁷⁷ The uniform or model acts that are approved are then presented to state legislatures, which are urged to adopt them as-is; the goal is

70. Gary, *supra* note 13, at 80.

71. *Id.*

72. The National Conference of Commissioners on Uniform State Laws, *Introduction*, <http://www.nccusl.org/Update/DesktopDefault.aspx?tabindex=0&tabid=11>, (last visited Apr. 3, 2009) [hereinafter NCCUSL, *Introduction*].

73. The National Conference of Commissioners on Uniform State Laws, *UCC Information*, <http://www.nccusl.org/Update/DesktopModules/NewsDisplay.aspx?ItemID=89> (last visited Feb. 15, 2009).

74. NCCUSL, *Introduction*, *supra* note 72.

75. *Id.*

76. *Id.*

77. *Id.*

to provide "guideline legislation, which states can borrow from or adapt to suit their individual needs and conditions."⁷⁸

The UPC is one such act. The American Bar Association (ABA) prepared the first version, the Model Probate Code, in 1946.⁷⁹ Subsequently, the ABA and NCCUSL worked together to put forward the jointly approved UPC in 1969.⁸⁰ Its primary purposes were:

- (1) to simplify and clarify the law concerning the affairs of decedents, missing persons, protected persons, minors and incapacitated persons;
- (2) to discover and make effective the intent of a decedent in distribution of his property;
- (3) to promote a speedy and efficient system for liquidating the estate of the decedent and making distribution to his successors;
- (4) to facilitate use and enforcement of certain trusts;
- (5) to make uniform the law among the various jurisdictions.⁸¹

Intestacy provisions are "designed to provide suitable rules for the person of modest means who relies on the estate plan provided by law."⁸² Updating the UPC, a model for all states, is an ideal method of addressing unintended effects on persons with disabilities, particularly when they relate to intestate wealth transfers that, if automatic, would put a disabled person's eligibility for needed governmental benefits at risk.⁸³

III. Pooled Trusts Should be the Default Option for Intestate Transfers Involving Persons with Developmental Disabilities

There is an "inherent societal conflict" between the policies of providing for persons who cannot care for themselves and those ensuring that persons who can care for themselves do not receive

78. *Id.*

79. Stephanie J. Willbanks, *Parting is Such Sweet Sorrow, but Does it Have to be so Complicated? Transmission of Property at Death in Vermont*, 29 VT. L. REV. 895, 900 (2005).

80. *Id.*

81. UNIF. PROBATE CODE § 1-102 (amended 2003), 8 U.L.A. 26 (1998).

82. *Id.* art. II, pt. 2, general cmt. (identifying the purpose of the pre-1990 UPC and stating that the revised version retains the same goals); cf. Willbanks, *supra* note 79, at 901 (asserting that the UPC provisions are "designed . . . to reflect the probate intent of the average decedent, and to accommodate modern family structures").

83. Cf. Willbanks, *supra* note 79, at 949 (arguing that States that adopt the UPC benefit from uniform provisions, which are augmented by reporter's notes and legal decisions from other jurisdictions, and intestacy provisions, which reflect decedents' probable intent).

public funds.⁸⁴ Persons with developmental disabilities should not be disqualified from receiving SSI and Medicaid because a parent or other relative has died intestate. Supplemental special-needs trusts protect those persons, but only do so fully when their family members have already created such trusts for their benefit.⁸⁵ Pooled trusts should be the default for those persons with disabilities for whom such trusts are not already in place.

A. Supplemental Special-Needs Trusts Are the Best Way for Parents to Ensure that an Inheritance Does Not Disrupt the Services that Their Developmentally Disabled Children Receive

1. Other Options are Insufficient

The intersection of intestacy laws and Medicaid and SSI asset limits leaves those families able to plan for an asset transfer with several undesirable options: disinheriting developmentally disabled children; transferring assets to other adult children or third parties to care for developmentally disabled children; or transferring assets to trusts of which disabled children are the beneficiaries.⁸⁶

Disinheritance is a difficult emotional prospect, as Goldman explains: while the move has the effect of ensuring a disabled child's eligibility for medical assistance, it comes "at the emotional cost of excluding their [child]" from a share of the parents' estate.⁸⁷ "This cost is too high for many families, since the utter lack of funds designated to enhance the disabled child's quality of life usually creates an uneasy and dissatisfied feeling in the parents."⁸⁸ Disinheritance is only effective in ensuring that a disabled heir does not become disqualified from his or her SSI or Medicaid benefits; it is not effective in making it so that parents' intentions to support their children in even a supplemental manner are carried out.⁸⁹ Parents may then couple disinheritance

84. See Field, *supra* note 12, at 89.

85. See *id.* at 79-80 (explaining how special-needs trusts, when properly drafted, enable disabled individuals to receive public assistance and trust funds for additional assistance, while individuals without trusts run the risk of poverty and depending exclusively on state support).

86. See, e.g., Goldman, *supra* note 12, at 644-47 (describing the "most common, most effective, and least desirable options" for families faced with providing for disabled family members).

87. *Id.* at 644.

88. *Id.* at 645.

89. See Eichstadt, *supra* note 17, at 637.

with the next option, in which they leave an estate to others with the direction that they provide for the disabled child.⁹⁰

While they are living, or after death through a will, parents may also choose to give money to a non-disabled child or other third person to spend in caring for the parents' disabled child.⁹¹ While apparently simple, this option is "extremely unadvisable in virtually all circumstances."⁹²

First and foremost, there is no legal duty whatsoever for the third party or parties to act in accordance with the transferor's instructions; they are free to dispose of the assets as they see fit. In other words, there is nothing beyond a moral obligation and a faith in the character of the third party to ensure that the third party will honor the transferor's wish that the transferred assets be used for the benefit of the disabled individual. All too often, such faith in family members is simply misplaced.⁹³

There are several other potential problems with this option. The third party chosen to provide for the disabled person may not be able to fulfill that informal responsibility.⁹⁴ Moreover, it is possible that the transferred sum could be deemed a "constructive trust."⁹⁵ This determination could potentially leave the disabled person in the same situation he or she would be in otherwise: "[I]f such an argument were successful, the assets in the constructive trust would likely be 'available assets' of the disabled individual for medical assistance purposes and would have to be 'spent down' before the individual would become eligible for . . . benefits."⁹⁶ A further problem with such a transfer is that the transferred sums are considered the third party's assets, which leaves the assets at risk of depletion through divorce, transfer at the death of the third party, or acquisition by the third party's creditors.⁹⁷

Finally, an improperly defined trust may also be deemed a disabled person's available asset for the purpose of determining Medicaid eligibility.⁹⁸ In fact, one goal of the Omnibus Budget

90. *Id.*

91. Goldman, *supra* note 12, at 645.

92. *Id.* at 646.

93. *Id.*

94. See Field, *supra* note 12, at 83 (asserting the need to appoint alternate trustees in case the original trustee "cannot, or will not, act").

95. Goldman, *supra* note 12, at 646.

96. *Id.*

97. *Id.* at 646-47.

98. See Farinella, *supra* note 19, at 129 (blaming careless drafting for failure to properly exclude special-needs trust assets from restrictive provisions, as envisioned in federal statutory language); cf. Field, *supra* note 12, at 82-83 (detailing Social Security Administration guidelines to follow in drafting special-

Reconciliation Act of 1993 was to limit individuals' ability to "shield" assets from these determinations and make themselves eligible for Medicaid.⁹⁹ Key questions in determining whether a trust is an available asset include whether the trust is revocable or irrevocable, and whether it is funded with the individual's own money or with money from others.¹⁰⁰ The focus, then, is on how

needs trusts so that the trust assets will not be considered available to a disabled person).

99. See Farinella, *supra* note 19, at 128.

100. 42 U.S.C.A. § 1396p (2008). According to the statute:

(d) Treatment of trust amounts

(1) For purposes of determining an individual's eligibility for, or amount of, benefits under a State plan under this subchapter, subject to paragraph (4), the rules specified in paragraph (3) shall apply to a trust established by such individual.

(2)(A) For purposes of this subsection, an individual shall be considered to have established a trust if assets of the individual were used to form all or part of the corpus of the trust and if any of the following individuals established such trust other than by will:

(i) The individual.

(ii) The individual's spouse.

(iii) A person, including a court or administrative body, with legal authority to act in place of or on behalf of the individual or the individual's spouse.

(iv) A person, including any court or administrative body, acting at the direction or upon the request of the individual or the individual's spouse.

(B) In the case of a trust the corpus of which includes assets of an individual (as determined under subparagraph (A)) and assets of any other person or persons, the provisions of this subsection shall apply to the portion of the trust attributable to the assets of the individual.

(C) Subject to paragraph (4), this subsection shall apply without regard to—

(i) the purposes for which a trust is established,

(ii) whether the trustees have or exercise any discretion under the trust,

(iii) any restrictions on when or whether distributions may be made from the trust, or

(iv) any restrictions on the use of distributions from the trust.

(3)(A) In the case of a revocable trust—

(i) the corpus of the trust shall be considered resources available to the individual,

(ii) payments from the trust to or for the benefit of the individual shall be considered income of the individual, and

(iii) any other payments from the trust shall be considered assets disposed of by the individual for purposes of subsection (c) of this section.

(B) In the case of an irrevocable trust—

(i) if there are any circumstances under which payment from the trust could be made to or for the benefit of the individual, the

the trust instrument itself is drafted and constructed.¹⁰¹

2. Supplemental-Needs Trusts Are a Superior Alternative

There are two general categories of supplemental-needs trusts: self-settled trusts, which include pooled trusts; and trusts settled by a parent, guardian, relative, or other third party.¹⁰² Trusts in the latter group offer many advantages to families that have the time and resources to draft and establish them.¹⁰³ As their name implies, these trusts are established to provide benefits that “supplement, but do not supplant,” government benefits.¹⁰⁴ This keeps the trust assets from being considered “available” to the disabled person; these trusts will not, therefore, disqualify him or her from medical assistance benefits.¹⁰⁵ By their terms and drafting, then, supplemental special-needs trusts specifically direct their trustees to only spend trust assets on things that do not replace benefits provided by a government services agency.¹⁰⁶ Acceptable purchases can include leisure items, but also certain types of medical care that are not covered by Medicaid, including over-the-counter medication, nurses, private rehabilitation services, and other advanced care.¹⁰⁷

portion of the corpus from which, or the income on the corpus from which, payment to the individual could be made shall be considered resources available to the individual, and payments from that portion of the corpus or income—

(I) to or for the benefit of the individual, shall be considered income of the individual, and

(II) for any other purpose, shall be considered a transfer of assets by the individual subject to subsection (c) of this section; and

(ii) any portion of the trust from which, or any income on the corpus from which, no payment could under any circumstances be made to the individual shall be considered, as of the date of establishment of the trust (or, if later, the date on which payment to the individual was foreclosed) to be assets disposed by the individual for purposes of subsection (c) of this section, and the value of the trust shall be determined for purposes of such subsection by including the amount of any payments made from such portion of the trust after such date.

Id.

101. See Frolik, *supra* note 15, at 305–07 (arguing that estate planning for parents of individuals with disabilities requires careful drafting and an attorney’s familiarity with the complicated laws and situations their families face).

102. Field, *supra* note 12, at 80.

103. See Goldman, *supra* note 12, at 660–61.

104. *Id.* at 660.

105. *Id.*

106. *Id.*

107. Field, *supra* note 12, at 82.

In contrast, pooled trusts are a form of self-settled trusts,¹⁰⁸ meaning that they can include assets belonging to the disabled individual.¹⁰⁹ As their name implies, these trusts pool the assets of a number of sub-trusts together for investment and administrative efficiency.¹¹⁰ Pooled trusts differ in one important respect from the other trust forms provided for in the OBRA '93 statute: "A pooled asset trust is the only method under current law for disabled individuals over the age of 65 to place their own assets into trust without disqualifying themselves from receiving medical assistance benefits."¹¹¹ This is critical when assessing the needs of the aging developmentally disabled population and the intersection of trusts with intestacy laws, as those laws make an heir's interest in a decedent's estate possessory at the time of death.¹¹²

*B. Pooled Special-Needs Trusts Should be the Default
Under Intestacy Laws*

Intestacy statutes should be rewritten to trigger an individual review whenever a person with a developmental disability is determined to be an heir to a person who dies without a will. That review should examine whether the developmentally disabled person is already the beneficiary of a special-needs trust. If there is no existing special-needs trust, then the default recipient of the developmentally disabled person's inheritance should be the pooled trust that is designated to handle intestate situations in that state. The funds should then be disbursed in compliance with federal law, so that they supplement, but do not supplant, government benefits.

While families who have the financial means to draft and settle a special-needs trust in advance of the parents' death should consider establishing third-party trusts, that recommendation can only go so far for families that lack the resources to follow it.¹¹³ More protection is needed. The NCCUSL should revise the UPC to

108. *Id.* at 88.

109. Goldman, *supra* note 12, at 659.

110. Field, *supra* note 12, at 88.

111. Goldman, *supra* note 12, at 659.

112. RESTATEMENT (THIRD) OF PROP.: WILLS AND OTHER DONATIVE TRANSFERS § 2.1 (1999) ("A decedent who dies without a valid will dies *intestate* The decedent's intestate estate . . . passes at the decedent's death to the decedent's *heirs* as provided by statute." (emphasis added)).

113. See Paula A. Monopoli, *Nonmarital Children and Post-Death Parentage: A Different Path for Inheritance Law?*, 48 SANTA CLARA L. REV. 857, 857-59 (2008) (arguing that low-income families are often unable to opt out of default rules).

protect these families' interests and enable the UPC to accommodate the needs of the growing population of developmentally disabled seniors. Such responsive changes are part of the UPC's history.¹¹⁴

The UPC should be changed to reflect the needs of families that include persons with developmental disabilities. The proposed change should be incorporated in Article III of the UPC, the provisions of which include:

[d]esigned to be applicable to both intestate and testate estates and to provide persons interested in decedents' estates with as little or as much by way of procedural and adjudicative safeguards as may be suitable under varying circumstances, this system is the heart of the Uniform Probate Code.

The organization and detail of the system here described may be expressed in varying ways and some states may see fit to reframe parts of this Article to better accommodate local institutions.¹¹⁵

The change should draw upon the definition found in Section 5-102 of the UPC, which defines an "incapacitated person" as "an individual who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance."¹¹⁶ Drafters would achieve this change by adding new subsections (c) and (d) to Section 2-101 of the UPC, which would then read in full:

Section 2-101. Intestate Estate.

(a) Any part of a decedent's estate not effectively disposed of by will passes by intestate succession to the decedent's heirs as prescribed in this Code, except as modified by the decedent's will.¹¹⁷

(b) A decedent by will may expressly exclude or limit the right of an individual or class to succeed to property of the decedent passing by intestate succession. If that individual or a member of that class survives the decedent, the share of the decedent's intestate estate to which that individual or class would have succeeded passes as if that individual or each member of that class had disclaimed his [or her] intestate share.¹¹⁸

114. See Willbanks, *supra* note 79, at 900–01 (describing the number of times that the UPC has been amended).

115. UNIF. PROBATE CODE art. III, gen. cmt. (1968), 8 U.L.A. 26.

116. UNIF. PROBATE CODE § 5-102 (amended 2008), 8 U.L.A. 96 (Supp. II 2008).

117. UNIF. PROBATE CODE § 2-101(a) (amended 2008), 8 U.L.A. 79 (Supp. I. 2008).

118. *Id.* § 2-101(b).

(c) When an heir of a decedent is an incapacitated person under Section 5-102 of this Code, or when an heir of a decedent is a person with a disability or impairment who receives Medicaid assistance, then the part of the estate that would pass to that heir shall be held in trust for the heir and used solely to supplement, and not supplant, the services and benefits received by the heir, according to the provisions of subsection (d).

(d) If the incapacitated person is the beneficiary of a supplemental special-needs trust, then the part of the decedent's estate that would pass to the person will pass to the trustee according to the terms of the trust. If the incapacitated person is not a beneficiary of a supplemental special-needs trust at the time the estate would pass, then the person appointed to supervise the disabled person's care shall accept that part of the estate until it can be deposited in either an individual or pooled special-needs trust.

The change could be made using existing procedures of the NCCUSL.¹¹⁹ It would be similar to other changes made and proposed regarding intestacy laws that needed revision in order to reflect changes in society.¹²⁰

C. *Parallels to Other Suggested Changes*

In recent years, many commentators have advocated for changes to intestacy laws to make them properly reflect both a decedent's intent when that person is in a committed, same-gender relationship and changing ideas of parental relationships.¹²¹ Paula Monopoli, law professor at the University of Maryland, described the reasoning behind such proposed changes in relation to children born after a biological parent's death, outside of a marriage:

The significant demographic shift in the number of nonmarital births makes the issues surrounding nonmarital children critical ones for society and inheritance law. Most of these

119. See NCCUSL, *Introduction*, *supra* note 72 (describing the way in which the NCCUSL drafts and proposes new statutes).

120. See, e.g., Gary, *supra* note 13 (arguing for change in intestacy law to broaden ideas of parent-child relationships); Seidman, *supra* note 68 (advocating for changes in intestacy laws regarding committed partners); Willbanks, *supra* note 79, at 900-01 (listing amendments made to the UPC).

121. See generally Gary, *supra* note 13 (advocating for change in the intestacy laws to take into account functional parent-child relationships in addition to biological relationships); O'Brien, *supra* note 68, at 217 (stating that the UPC is "a good vehicle from which to discuss provisions in the law of intestate and testate succession that could change in providing for domestic partners"); Seidman, *supra* note 68, at 213-14 (analyzing "the notable absence of provisions for surviving partners of committed relationships in the UPC" and proposing amendments to the UPC "to increase equity in intestate succession").

children do not stand to inherit vast fortunes. They are often born into middle income and low-income families. Their parents and grandparents are the least likely segment of the population to seek estate planning services and to opt out of the default system of intestacy to draft an inclusive will. This is the very reason why the rules of intestacy—the default or off-the-rack rules of inheritance law—should be streamlined to make it as easy for nonmarital children to inherit as possible. The impact of what might appear to be a small inheritance often proves very significant in the lives of nonmarital children, both as minors and adults.¹²²

Similarly, a change in intestacy laws—the “off-the-rack rules of inheritance law”—would benefit persons with developmental disabilities by protecting their eligibility to receive governmental benefits. As with the proposal for nonmarital children, the impact of what appears to be a small inheritance could prove to be very significant for people with developmental disabilities.

D. Implementation and Advantages

The NCCUSL process for amending the UPC and implementing the changes can take years.¹²³ That time could allow the NCCUSL commissioners to advocate at their respective state legislatures for passage of the amendment once it is completed.¹²⁴ While the National Pooled Trust could be an option

122. Monopoli, *supra* note 113, at 857–59; see also E. Gary Spitko, *An Accrual/Multi-Factor Approach to Intestate Inheritance Rights for Unmarried Committed Partners*, 81 OR. L. REV. 255, 255–59 (2002) (discussing the relationship between intestacy law and non-marital children). According to Spitko:

As cohabitation among unmarried couples becomes more common in the United States, a most pressing challenge facing inheritance law scholars, practitioners, and others who concern themselves with the development of inheritance law is to craft reforms that would, if implemented, better serve non-marital families while at the same time maintaining a reasonable ease of administration of estates. One area in urgent need of such reform is intestacy law. Current intestacy law generally does not reflect as well as it could the way Americans today structure their family lives. For example, the intestacy statutes of forty-seven states make no provision for the survivor of a non-marital committed partnership. . . .

I have argued elsewhere in favor of revising Article II of the Uniform Probate Code to grant intestate inheritance rights to the intestate decedent's surviving committed but non-marital partner. Reform of the Uniform Probate Code to provide such intestate inheritance rights would further Article II's principal goal of promoting the donative freedom of the decedent. Further, such reform could be undertaken without unreasonably undermining Article II's expressed subsidiary goals including a desire for simplicity and certainty in the administration of estates.

Id.

123. NCCUSL, *Introduction*, *supra* note 72.

124. See *id.* (discussing the role of commissioners in persuading legislatures to

for all persons, legislatures may want to examine the trusts offered in their states to ensure that persons with disabilities have adequate and trustworthy choices.¹²⁵

Pooled trusts are not without disadvantages.¹²⁶ Even with those disadvantages, however, pooled trusts are superior to the loss of eligibility that would follow when a disabled person comes into possession of a share of inheritance without protection from benefit disqualification.¹²⁷ Additionally, these disadvantages are minimized by adequate competition among nonprofit organizations, whether national or state-based, to provide good service and low operating fees.¹²⁸

Conclusion

States should encourage the creation of pooled supplemental special-needs trusts and then make such trusts the default option for developmentally disabled citizens who are heirs to an intestate parent. This new default is needed for families without the means and ability to plan a way to avoid Medicaid's benefit pitfalls through a third-party special-needs trust or other methods. The demographic and societal trends that have allowed the population of people with developmental disabilities to flourish have also made this change more and more necessary.

adopt the proposed changes after the draft is completed).

125. See generally THE ARC, *supra* note 30, at 7 (discussing pooled trust programs). Specifically:

Pooled trust programs vary in their operations. It is important to examine the specific details about any program you are considering using. Before signing any papers, or investing in a trust, review written information on the particular program that you are considering, consult with your attorney and speak with other families who use the program. Meet with the people who operate the trust to ask questions and insist on clear answers. Carefully explore whether or not the program is a good and solid option for you and your family member.

Id.

126. See *id.* at 12 (describing the lack of control family members have over disbursements; the generally conservative and uniform investment strategies of the trusts; policies that may direct the fate of funds left in beneficiaries' accounts at their deaths that may differ from family wishes; and the risk that the combination of a trust program's ability to decide how funds are spent and its ability to establish a policy allowing it to retain a portion of funds may create an incentive not to spend funds for beneficiaries—although “[t]rustees are required to exercise fiduciary responsibility precisely because of this kind of concern”).

127. See THE ARC, *supra* note 30, at 4 (describing how important it is that parents be able to plan for their children without jeopardizing benefits); Farinella, *supra* note 19, at 130 (outlining the importance of government benefits in providing health care to the poor).

128. See THE ARC, *supra* note 30, at 12 (noting the expertise of trust providers in providing high quality, low-cost services).

An amended UPC would give states a model for how to approach this problem. Since the Code addresses guardianships, intestate transfers, and wills, it is an ideal vehicle for promoting a process in which state lawmakers could establish a pooled supplemental-needs trust as the default for intestate transfers affecting persons with developmental disabilities. Designing the approach as voluntary rather than mandatory allows States to ensure that an appropriate nonprofit-administered pooled trust has been identified prior to the statute's enactment.

In the end, the change in the default rule would alleviate worry for parents who are not able to take the step that seventy-one-year-old Lorraine Sheehan did.¹²⁹ In 2008, Sheehan established a special-needs trust for her son, John, because she wanted to make sure that the autistic forty-three-year-old could stay in the house and neighborhood where he grew up.¹³⁰ "Nobody wants to think they are going to die," Sheehan said of her planning.¹³¹ "But it certainly is a relief and comfort to know you . . . have a fighting chance to keep John as happy as he is now."¹³²

129. Eileen Ambrose, *Plan Ahead for Special-Needs Child*, THE BALT. SUN, Sept. 14, 2008, at 1C.

130. *Id.*

131. *Id.*

132. *Id.*

