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What Are Aging Parents Caring for Adult Children with Disabilities to Do?: A Comprehensive Framework for a Healthy, Stable, Financially Sound Future

Jennifer M. Kirby-McLemore*

INTRODUCTION

As perceptions and treatments of disabilities and people with disabilities have evolved in the modern era, society faces new challenges in providing and maintaining adequate services for individuals living with disabilities. This need for services affects more and more people each year with approximately 52 million caregivers providing care to adults (aged 18+) with a disability or illness.¹ Parents of children with disabilities often find themselves confronting these challenges on a daily basis from the moment the child is born. One such challenge is to prepare a child who needs assistance for life after the parents or primary caregivers are no longer able to do the caretaking. Parents must consider many aspects of caretaking for their children including, but not limited to:

- (1) Who will care for my child when I am gone?

* Jennifer M. Kirby-McLemore, J.D. University of Mississippi School of Law, 2015.

1. J. Coughlin, *Estimating the Impact of Caregiving and Employment on Well-Being*, 2 OUTCOMES & INSIGHTS IN HEALTH MANAGEMENT, no. 1, 1 (June 22, 2010); see also Ellyn S. Kravitz & Carolyn Reinach Wolf, *Who Will Stand in My Shoes? When Adult Children Need Lifelong Support and Supervision*, 83 N.Y. St. B.J. 37, 37 (2011).

- (2) Where will my child live?
- (3) Who will [ensure] my child receives proper medical/mental health treatment?
- (4) Who will manage my child's care?
- (5) Will there be enough money to provide for a good quality of life for my child?²

In order to help children with disabilities transition as seamlessly as possible after the death or incapacitation of a parent/caregiver, those caregivers need to create a stable future for that child through financial and legal means. A stable future can be established by setting aside an appropriate amount of funds or resources or dedicating those funds to a future caregiver and maintaining eligibility for government benefits and programs. Supplement Security Income, one particular government benefit intended to assist people with disabilities, serves approximately 8.4 million people in the United States,³ which accounts for a mere 2.7% of the population.⁴ This, however, does not comport with U.S. Census data, which showed that 9.4% of the population reported living with a “severe” disability.⁵ These statistics suggests that there are over 21 million people who are living with severe disabilities in the United States that are not being served by this government program. Medicaid, another government program that is available to people with disabilities, “served a total of 9,791,456 beneficiaries with disabilities,”⁶ in 2011—a mere

2. Kravitz & Wolf, *supra* note 1, at 37–38.

3. CTR. ON BUDGET AND POLICY PRIORITIES, POLICY BASICS: INTRODUCTION TO SUPPLEMENTAL SECURITY INCOME 1 (2015), http://www.cbpp.org/sites/default/files/atoms/files/PolicyBasics_SocSec-IntroToSSI.pdf [hereinafter INTRODUCTION TO SUPPLEMENTAL SECURITY INCOME]. [perma.cc/Z4UJ-ZSGM].

4. *Disability Status by Sex by Age by Employment Status for the Civilian Noninstitutionalized Population 16 to 64 Years*, U.S. CENSUS BUREAU: FACTFINDER, <http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkm> (last visited January 5, 2016).

5. Press Release, U.S. Census Bureau, Nearly 1 in 5 People Have a Disability in the U.S. (July 25, 2012), <https://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html>. [perma.cc/XKJ2-3YFF].

6. UNIV. OF N.H. INST. ON DISABILITY, 2014 ANNUAL DISABILITY STATISTICS COMPENDIUM 96 (2014), http://www.disabilitycompendium.org/docs/default-source/2014-compendium/2014_compendium.pdf. [perma.cc/R7JE-GEQJ].

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3.1% of the population.⁷ This illustrates yet another gap in either eligibility or accessibility to the country's severely disabled population.

Although eligibility for these services turns on many factors, it appears, at least from the above figures, that significant numbers of people with disabilities are missing out on potentially beneficial government programs. In addition, forthcoming budget cuts and inadequate numbers of "clinical outpatient programs, residential housing, vocational programs and support services" have perhaps created even more urgency in the need for a future care plan for adults with disabilities.⁸ Taking these factors into consideration, this Article presents a comprehensive legal and financial framework for parents of children with disabilities and attorneys to use to ensure a stable, healthy future for these children.

Part I of this Article provides the social and cultural backdrop that created the need for parental guidance concerning the care of adult children with disabilities. Part II introduces the importance of proper planning for adult children with disabilities as well as the key elements for every future care plan. The bulk of this Article is divided into hypothetical situations that would require parents to develop a comprehensive future care plan for their child. These hypotheticals will discuss the various elements included in those plans. Depending on the particular situation, these elements will include: ensuring eligibility for government benefits; establishing an adequate estate plan that contemplates asset distribution and guardianship appointment; and considering alternative options such as purchasing life insurance or gifting the adult child's inheritance to a future caretaker.

The hypothetical in Part III will center on those parents who are financially limited, and caring for a dependent adult child with a disability. Part IV will provide a plan for similarly situated middle class parents, while Part V will detail a plan for a well-to-do family with a partially self-sufficient adult child with a disability. Parents should note that these hypotheticals are meant to be illustrative and therefore do not exhaust all of the possible situations in which they may find themselves. Part VI

7. *See id.* at 98 tbl. 10.2.

8. Kravitz & Wolf, *supra* note 1, at 37.

augments the hypotheticals with a description of additional options that families with moderate to significant resources can use to substitute or supplement some elements of a Future Care Plan.

I. A SHIFTING PARADIGM OF CARE FOR CHILDREN WITH DISABILITIES

Before the United States experienced significant social and cultural changes in the 1960s, parents of children with disabilities were often told that it was “best that [they] put [the child] away and forget about him [or her].”⁹ Similarly, if children began to manifest disabilities as they aged, professionals would suggest institutionalization.¹⁰ Parents and families often lost connections with these children and thus parents did not need to worry over the care of their children after death. These parents, therefore, had no need to prepare a legal and financial framework to support their children with disabilities. Those parents who ignored advice and pressure to institutionalize their children “found that services were almost non-existent” and, veritably, “parents who kept their children at home found that their children were excluded from public education because of their disability.”¹¹

The American Eugenics Movement was partially responsible for this push toward institutionalization.¹² The Movement “argued that all people who were mentally ill, mentally retarded[,] or physically disabled were polluting the gene pool of the country.”¹³ To safeguard the country from this perceived “threat to society,” some states required “mandatory sterilization, incarceration, and[,] in many cases, the castration of persons with disabilities.”¹⁴ By the time research demonstrated the invalidity of the “precepts of the Eugenics movement,” “hundreds of thousands of people with . . . disabilities or mental illness” had been institutionalized.¹⁵

9. Dennis Felty, *A Brief History: As Remembered by Dennis Felty*, KEYSTONE HUMAN SERVS., <https://www.keystonehumanservices.org/about-us/history/default.php/> [perma.cc/8VXY-78MX] (last visited Jan. 6, 2016).

10. *Id.*

11. *Id.*

12. *Id.*

13. *Id.*

14. *Id.*

15. *Id.* (“In the late 1960s, state institutions across the nation housed almost 156,000 people with intellectual disabilities and 550,000 people

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Fortunately, the tides slowly began to turn in the 1940s as research began to undermine the principles of the Eugenics movement.¹⁶ Following a nationwide study on the “status of the health and well-being of . . . children” initiated by President Herbert Hoover, “[a] Children’s Charter made 19 proposals, calling for increased scientific research to improve child-well being, and public assistance to 10 million mentally and physically ‘deficient’ children.”¹⁷ In the 1950s, Congress began dedicating funds to support special education for children with disabilities.¹⁸ By the 1980s, children with disabilities were guaranteed by law the right to “receive free public education” and, furthermore, found themselves being integrated into regular classrooms.¹⁹ By November of 2010, a nationwide study on the progress toward educating children with disabilities had shown “a 16-point increase in the percentage of students with disabilities graduating from high school since school year 1996–97.”²⁰ Similarly, the same study showed that “[t]he rate at which youths with disabilities enrolled in postsecondary education rose from 14.6[%]

experiencing mental illness. It was common for over 100 people to share a single bedroom. Often, people were naked and lay prostrate on the floors to cool off because the rooms had inadequate ventilation.”)

16. *See id.* (“In the 1940s, new genetic research demonstrated unequivocally that the founding precepts of the Eugenics movement were invalid.”)

17. ANDREW L. YARROW, HISTORY OF U.S. CHILDREN’S POLICY, 1900–PRESENT 5 (2009), <https://firstfocus.org/SiteCollectionDocuments/History%20of%20US%20Children%27s%20Policy%20%28Yarrow%29.pdf.resources/report/history-u-s-childrens-policy/> [perma.cc/LHY2-ZW28].

18. *Id.* at 12.

19. *Id.* at 20; *see generally* 20 U.S.C. §§ 1401 *et seq.* (2014) (governing education of individuals with disabilities). *See also* Mills v. Bd. of Educ., 348 F. Supp. 866 (D.D.C. 1972) (holding that by failing to provide children who had been labeled as behavioral problems, mentally retarded, and emotionally disturbed or hyperactive with publicly supported specialized education, the District of Columbia Board of Education violated controlling statutes and Board’s own regulations and denied due process); Pa. Assoc. for Retarded Children v. Pennsylvania, 343 F. Supp. 279 (E.D. Pa. 1972) (approving as “fair and reasonable” and undertaking a “noble and humanitarian end” a settlement whereby mentally handicapped children would no longer be excluded from a public program of education).

20. U.S. DEP’T EDUC., THIRTY-FIVE YEARS OF PROGRESS IN EDUCATING CHILDREN WITH DISABILITIES THROUGH IDEA, 2 (2010), <http://www2.ed.gov/about/offices/list/osers/idea35/history/idea-35-history.pdf>.

in 1987 to 31.9[%] in 2005.²¹

These progressive strides in the lives of children with disabilities brought additional hurdles. Governmental support and services in conjunction with “advances in medical treatment and improved health care” have dramatically extended the life expectancy of people with disabilities.²² Albeit positive, this change creates new issues related to the care of those people with disabilities, particularly when their parent or caregiver nears the end of his or her own life. Questions and worries arise: Who will care for my disabled child when I am gone? Where will my child live?²³ Who will monitor his/her medical treatments? Who will manage his/her finances? To answer these questions, parents of adult children with disabilities and their legal representatives should consult an expert in the burgeoning field of future care planning. This Article outlines those future care issues and describes the financial and legal methods this planning process entails.

II. CONSTRUCTING A FUTURE CARE PLAN

It is important for parents of children with disabilities and their attorneys to understand that:

Planning for a disabled child’s future involves many disciplines; it requires knowledge of accounting, financial planning, law, medicine, . . . therapy, . . . asset management, guardianship, . . . housing, government entitlements, wills, trusts, . . . and service coordination for all these activities.²⁴

Disability law practitioners and advocates advise parents of adult

21. *Id.*

22. Abraham J. Perlstein, *Comprehensive Future Care Planning for Disabled Beneficiaries*, 27 *EST. PLAN.*, Oct. 2000, at 358.

23. As two scholars have explained, housing is a primary concern for future care planning:

[T]he state will assist the disabled adult to live independently in the community; but because of a perennial shortage of housing, particularly in community-based settings, the adult child for whom no other provision has been made is just as likely to end up in a larger state institution where he or she will not thrive.

LAWRENCE A. FROLIK & MELISSA C. BROWN, *ADVISING THE ELDERLY OR DISABLED CLIENT* ¶ 17.05 (Thomson Reuters 2nd ed., 2015).

24. Perlstein, *supra* note 22, at 358.

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children with disabilities to create a team to design a future care plan that is meant to “optimize the personal and economic security and quality of life of the disabled person, with maximum utilization of available private and public resources.”²⁵ Such a team could be comprised of the parents or caregivers, other involved family members, attorneys specializing in estate planning and disability law, social workers, financial planners, medical professionals, a representative from a local state agency that may take over care for the person, and, if possible, the person the team is assisting.²⁶

When parents begin to work toward establishing a future care plan for their adult child, they must first determine if their resources “will be able to provide enough additional support during his or her lifetime, or whether the child will need some or all of his support from the public sector.”²⁷ For this initial inquiry, a financial planner should review the following:

- (1) The availability of private support;
- (2) The severity of the disability and projected changes in its condition or treatment plans;
- (3) Alternative public benefits, if parents cannot be expected to be the sole support of their child after their death; and
- (4) If necessary, the best possible integration of the parental estate plan with public benefits.²⁸

Once the value of the parental estate is determined, parents must address one of the most critical issues: what portion “of their estate . . . they are prepared to devote to their disabled child at the

25. 2 MAUNSEL W. HICKEY ET AL., *LOUISIANA PRACTICE SERIES* § 5:134 (2015–2016 ed.).

26. See Perlstein, *supra* note 22, at 362.

27. FROLIK & BROWN, *supra* note 23, ¶ 17.06.

28. *Id.* Moreover:

[I]t should be noted that any estate planning can only be effective in the short run. Because the relative size of the parental estate cannot be estimated with any accuracy for more than a few years, the estate plan must be periodically reviewed to ensure that it still makes sense in light of either an increase or a decrease in the estate’s value.

Id.

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expense of their other children or other possible legatees.”²⁹ Parents may consider dividing the estate equally amongst all children, leaving less to “the disabled child in light of the child’s relative disadvantage [or leaving] . . . a disproportionate allotment to the disabled child” in light of the child’s disability.³⁰

When determining the resources that may be necessary to care for the child, the team should analyze the following four variables:

- (1) The degree of disability the child is expected to experience throughout his or her life;
- (2) The prognosis for recovery;
- (3) The possibility that the disability will become worse over time; and
- (4) The child’s life expectancy.³¹

To best communicate ideas, knowledge, and goals to future caregivers, parents should draft a letter of intent.³² Although this is a non-legal document, it will help instruct family members, trustees, and guardians in their future care of the adult child with a disability.³³ It is important to include in this letter “all . . . pertinent facts about the disabled adult child’s medical history[,] . . . the names and addresses of all the professionals who are involved in [the child’s] life[, and, even,] the names of professionals whom the parents think should be avoided[.]”³⁴ An annual review of this letter to “ensure it remains” up-to-date is of the utmost importance.³⁵

III. FUTURE CARE PLAN FOR PARENTS WITH LIMITED RESOURCES AND A DEPENDENT ADULT CHILD WITH A DISABILITY

Parents with limited financial resources creating a future care

29. *Id.* Another key of financial planning, which financial planners should know to watch out for, is inflation, while also keeping in mind that “[a]s a general rule, the financial needs of the disabled child will be greater than expected, and so it is probably better for the parents to err on the side of generosity.” *Id.*

30. *Id.*

31. *Id.*

32. Perlstein, *supra* note 22, at 361.

33. *Id.*

34. *Id.*

35. *Id.*

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plan for their dependent adult child with a disability will rely heavily on government benefits and programs, like Supplemental Security Income (SSI) and Medicaid. Below is an overview of what a care plan centered on those government benefits might look like.

A. *Future Care Plan for Alan*

Dear Parents of Alan,

This letter is a brief and general overview of the major pieces of Alan's Future Care Plan. You should work out details of this plan (included below) with Alan's Future Care Team.

With your limited financial resources, your child's needs will be best met through SSI and Medicaid. Generally speaking, SSI will cover living expenses including shelter, food, and clothing while Medicaid exists to pay for medical and health related expenses. To create a stable future for Alan, you must ensure that Alan maintains eligibility for SSI and Medicaid. The first step in establishing that eligibility is to ensure that Alan has less than \$2000 in resources and assets. Notably, if Alan's assets include a residential home which you intend to deed to Alan, the home will not exempt Alan from SSI or Medicaid eligibility. However, if you do have over \$2000 that you intend to leave for Alan in a will, please speak with an attorney or financial advisor to distribute those funds (anything over \$2000) either to a designated future caretaker or in a trust that will not make Alan ineligible for government benefits. Please see <http://www.ssa.gov/ssi/text-apply-ussi.htm> for more information regarding the SSI application process and <http://medicaid.gov/> for more information regarding the Medicaid application process.

If one or both of you are currently receiving (or will at some point receive) Social Security benefits, Alan may be eligible to become the beneficiary of those benefits upon the death of the parent(s). Please see <http://www.ssa.gov/planners/disability/dqualify10.html#age22> for more information and consult with an attorney to determine Alan's eligibility for those benefits and to calculate the amount of benefits Alan would be eligible to receive.

If Alan needs constant medical attention or living assistance, seek out a trusted friend or relative who will be willing to sign guardianship papers to assist with and oversee care for Alan. In

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addition, you will need to contact state or privately owned adult care facilities to find a place appropriate for Alan's needs and means.

If Alan can live alone, with less demanding daily attention or assistance, then you may consider other home alternatives. For example, if Alan has a home, the designated guardian could take over the daily care routine at the home. However, if Alan does not have a home or you do not own a home that you intend to bequeath to Alan, contact your local Housing Authority to find out the waiting period and eligibility requirements for a home for a resident with a disability to determine when you will need to apply for the housing program.

B. Details for Alan's Future Care Plan

Adults with disabilities may be eligible for certain government benefits and programs. Parents should understand the perks and limitations of each of those benefits and programs as they consider their estate planning needs.³⁶

Two such benefits disabled children may be eligible to receive, depending on their parents' income and resources, are SSI and Medicaid.³⁷ Fortunately, many states provide Medicaid benefits automatically based on eligibility for SSI.³⁸ Another governmental program parents should consider, but perhaps should not rely on due to the uncertainty of continued government funding, is termed "vocational rehabilitation services." This program is available once the person "reaches working age."³⁹

1. Supplemental Security Income

The Federal Supplemental Security Income Program created SSI in 1972.⁴⁰ These federal benefits intend to provide "a minimum income to . . . qualifying individuals[, including the]

36. *Id.* at 362.

37. *Id.*

38. *Id.*

39. Greg D. Trapp, *Estate Planning: What Parents of Children With Disabilities Should Know*, 14 FUTURE REFLECTIONS, no. 3, Fall 1995, <https://nfb.org/images/nfb/publications/fr/fr14/issue3/f140311.html> [perma.cc/Y826-GKGG].

40. 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 Trust for Parents*, 45 S.D. L. REV. 622, 628 (2000).

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disabled, blind, or [those] age sixty-five or older.”⁴¹ Based on Social Security Administration data from 2014, “the basic monthly SSI benefit is \$721 for an individual.”⁴² Nearly “half of SSI recipients also get SNAP (food stamps), and about one-quarter receive housing assistance.”⁴³

Fortunately, because this program is funded solely by the federal government, “eligibility requirements and payments to recipients are uniform throughout all fifty states.”⁴⁴ Parents seeking eligibility for their adult disabled child should be sure their child fits the federal definition of an “individual with a disability,” which is “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months.”⁴⁵

SSI eligibility “is determined by a complicated formula” which takes into account “earned and unearned income and other support the individual may access.”⁴⁶ Detailed instructions regarding income eligibility for SSI can be found at the Office of Social Security, but generally, eligibility is based on the following: First comes income—which includes wages (including part of spousal income and resources if married and part of parental income and resources if under age 18), Social Security benefits, and “food[] and shelter.”⁴⁷ When determining an individual’s income, his or her residential location is also an important factor that can impact eligibility.⁴⁸ With regard to wages, however, the following monies are not taken into consideration:

- The first \$20 a month of most income . . . receive[d];

41. *Id.*

42. INTRODUCTION TO SUPPLEMENTAL SECURITY INCOME, *supra* note 3, at 2 (stating that SSA reduces these amounts “for recipients who have other sources of income or who live in a Medicaid facility or with someone else who provides support . . . [b]ecause of these reductions the average SSI monthly benefit for individuals was only \$539 in December 2013.”).

43. *Id.*

44. Eichstadt, *supra* note 40, at 628.

45. 42 U.S.C. § 423(d)(1)(A) (2014).

46. Eichstadt, *supra* note 40, at 628.

47. U.S. SOC. SECURITY ADMIN., SUPPLEMENTAL SECURITY INCOME (SSI) 5–6 (2015), <http://ssa.gov/pubs/EN-05-11000.pdf> [perma.cc/2AMY-NEZR].

48. *Id.*

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- The first \$65 a month . . . earn[ed] from working and half the amount over \$65;
- Supplemental Nutrition Assistance Program (SNAP) benefits[;]
- Shelter you get from private nonprofit organizations; . . .
- Most home energy assistance.⁴⁹

In addition to the above, “wages . . . use[d] to pay for items or services that help the [individual with a disability] work” are also not counted by Social Security when determining income.⁵⁰

Second come resources—which “include real estate, bank accounts, cash stocks, and bonds.”⁵¹ Generally an individual with resources valued at \$2000 or less would be eligible for SSI.⁵² Certain resources, however, are exempt from consideration including:

- “The home and land where [the individual] live[s];
- Life insurance policies with a face value of \$1,500 or less;
- [the individual’s] car (usually);
- Burial plots for [the individual] and members of [his or her] immediate family;
- Up to \$1,500 in burial funds for [the individual] and up to \$1,500 in burial funds for [the individual’s] spouse.”⁵³

Parents should be relieved to know that “[d]espite the restrictions placed on the amount of allowable income and resources, many families . . . may find that their disabled children are eligible for SSI or Medicaid.”⁵⁴

49. *Id.*

50. *Id.* An example of wages used to help the individual work would be the cost of a wheelchair. *Id.*

51. *Id.* at 6.

52. *Id.*

53. *Id.*

54. Trapp, *supra* note 39.

2. *Medicaid*

Title XIX of the Social Security Act of 1965 created the federal program known as Medicaid.⁵⁵ Medicaid administers “medical assistance on behalf of families with dependent children”⁵⁶ and “long-term health care for those of any age who cannot afford to pay for it.”⁵⁷ Unlike SSI, Medicaid is jointly financed through federal and state monies; therefore, Medicaid may not be available in the same manner for individuals in every state because each state can elect to participate in the program or not.⁵⁸

Eligibility for Medicaid is similar to eligibility for SSI. To be considered eligible for Medicaid, individuals “must have assets of less than \$2,000.”⁵⁹ Like SSI, the “individual’s home, a fund of up to \$1,500 for burial, a car, and a few personal items are excluded from assets.”⁶⁰

Parents and their planning team should review the rules regarding income and resources in their respective states to maintain continued qualification month-to-month. In South Dakota, for example:

[A]n individual’s resources include assets held at the beginning of the month. Income is money acquired during the month by an individual. Resources are not considered income. Any income that is saved instead of being spent will be considered a resource for the individual in the next month.⁶¹

However, there are a number of items that do not qualify as “income for purposes of Medicaid eligibility” including:

- (1) Third-party payments to medical providers;
- (2) County welfare payments to medical providers;
- (3) Money paid by a school district for educational purposes;
- (4) Income tax or sales tax refunds;

55. Eichstadt, *supra* note 40, at 626.

56. *Id.* (citing 42 U.S.C. § 1396 (1994)).

57. *Id.* at 626–27.

58. *See id.* at 627.

59. *Id.*

60. *Id.*

61. *See id.* (citing S.D. ADMIN. R. 67:46:05:41-42 (1998)).

- (5) Unearned irregular income from all sources which totals \$20 or less per month;
- (6) Veterans aid and attendance benefits;
- (7) Life insurance dividends;
- (8) Any benefits received under the provisions of the Older Americans Act of 1965, except wages or salary; and
- (9) Payments to volunteers under the Domestic Volunteer Service Act of 1973, such as from SCORE, VISTA, or the foster grandparent program.⁶²

Parents and the Future Care Plan team should carefully review the rules pertaining to Medicaid in the state where the disabled child resides. Due to each state's ability to opt-in or out of certain Medicaid benefits, careful monitoring of medical treatments and costs is necessary. For example, inpatient and outpatient hospital services, home health services, and physician services are mandatory; while Medicaid benefits, prescription drugs, speech, hearing and language disorder services, optometry services, dental services, prosthetics, private duty nursing services, and services in an intermediate care facility for individuals with an intellectual disability are optional.⁶³

3. *Additional Information on SSI and Medicaid Eligibility*

Many additional exemptions permit SSI and/or Medicaid eligibility. For example, Medicaid, unlike SSI, does not include stepparent income when determining income eligibility.⁶⁴ In addition, if a person is undergoing long-term hospitalization, a large family income may not exclude him or her from Medicaid or SSI benefits.⁶⁵ Most importantly, parents should remember that “[e]ven if [their] income is currently too high to be eligible for SSI, . . . [their] earnings will cease upon . . . death at which point [a] disabled child might then be eligible for SSI.”⁶⁶

62. *See id.* at 627–28 (citing S.D. ADMIN. R. 67:46:04:03 (1998)).

63. *See Benefits, CTR. FOR MEDICAID*, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/medicaid-benefits.html> [perma.cc/VE56-J6DF] (last visited Jan. 3, 2016) (providing a detailed list of mandatory versus optional Medicaid benefits).

64. Trapp, *supra* note 39.

65. *Id.*

66. *Id.*

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In addition, the Social Security Act has created certain exemptions to ensure continued coverage under Medicaid for disabled adult children.⁶⁷

The Social Security Act provides that when a beneficiary loses SSI because of receipt of childhood disability benefits, for purposes of Medicaid eligibility, the [disabled adult child] beneficiary is to be treated as if he or she were still receiving SSI benefits and, thus, eligible for Medicaid “so long as he or she would be eligible for [SSI benefits] in the absence of such child’s insurance benefits or such increase.”⁶⁸

However, the planning team needs to be aware that continued Medicaid eligibility would require the beneficiary to meet the SSI limitations on assets and income outside of the government benefits must be reviewed so as not to disqualify the person for SSI.⁶⁹

4. *Social Security Benefits*

A lesser-known government benefit available to adults with disabilities is Social Security benefits of a parent.⁷⁰ These benefits may be provided to an adult child with a disability “when that parent retires, becomes disabled, or dies.”⁷¹ Eligibility is based on the child applying for the benefits, the child being dependent on the Social Security earner, the child being unmarried, and the child having a disability that began before the age of twenty-two.⁷² To be eligible the adult child “can be a natural child, legally adopted child, stepchild, grandchild, step grandchild, or equitably adopted child of the wage earner.”⁷³

67. Thomas E. Bush, *Disabled Adult Children*, 6 MARQ. ELDER’S ADVISOR 243, 257 (2005).

68. *Id.* (quoting 42 U.S.C. § 1383c(c) (2000)).

69. *Id.*

70. *Id.* at 243–44.

71. *Id.* at 244.

72. *Id.* “Given the odd way the [Social Security Administration] treats people as reaching a birthday on the day before, a childhood disability claimant must become disabled no later than two days before his or her actual twenty-second birthday.” *Id.* at 247.

73. *Id.* at 249. Special considerations, however, should be reviewed. For example:

For a natural child who could not inherit under state law, [an attorney] will need to find out if paternity has been adjudicated by a court, whether a court has ordered the parent to contribute to the

The amount of benefit awarded to the adult child with a disability depends on whether or not the wage-earning parent is alive or deceased.⁷⁴ If alive, “the disabled adult child is entitled to fifty percent of the [parent’s] primary insurance amount.”⁷⁵ However, “[i]f the wage earn[ing parent] is deceased, the disabled adult child receives seventy-five percent of [his or her] primary insurance amount.”⁷⁶

IV. FUTURE CARE PLAN FOR PARENTS WITH MODERATE RESOURCES AND A DEPENDENT ADULT CHILD WITH A DISABILITY

Parents with moderate financial resources creating a future care plan for their dependent adult child with a disability will have more options with respect to the care plan. Below is an overview of what this care plan might look like.

A. *Future Care Plan for Beth*

Dear Parents of Beth,

This letter is a brief and general overview of the major pieces of Beth’s Future Care Plan. You should work out details of this plan (included below) with Beth’s Future Care Team. With your moderate financial resources, you will likely be able to provide Beth with more than her basic necessities. However, in order to ensure the longevity of Beth’s Future Care Plan, you should consider maintaining Beth’s eligibility for SSI and Medicaid so that any additional support funds for Beth can be put into an

support of the child, or whether the father has acknowledged, in writing, that the child is his. . . . For an adopted child, an attorney will need to look at when the child was adopted, how old the child was when adoption proceedings were started, whether the adoption took place in the United States, when the wage earner became entitled to benefits or died, and whether the child was the insured’s stepchild before adoption. For a stepchild, determine the date of the wage earner’s marriage to the child’s parent and the length of the marriage before the wage earner became entitled to benefits or died. For a grandchild, examine not only the relationship between the child and grandparent, but also whether the parent, that is, the child of the grandparent, was deceased or disabled.

Id. at 250.

74. *See id.* at 253.

75. *Id.* at 254.

76. *Id.*

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appropriate trust for the additional comforts in life. Owing to the newly enacted Achieving a Better Life Experience (ABLE) Act of 2014, appropriating money for the care of your child while maintaining eligibility for government benefits has become easier. Outside of financial and estate planning, you will need to consider setting up a guardianship plan for Beth.

To ensure financial stability, you should proceed with establishing eligibility for SSI and Medicaid. Generally speaking, SSI will cover living expenses including shelter, food, and clothing while Medicaid exists to pay for medical and health related expenses. The major requirement for eligibility is to ensure that Beth has less than \$2000 in resources and assets. Notably, if Beth's assets include a residential home which you intend to deed to Beth, the home will not exempt Beth from SSI or Medicaid eligibility.

Following the enactment of the ABLE Act, you will be able to accumulate a limited amount of funds in a savings account for your child's care and needs while maintaining eligibility for government benefits without establishing a trust. The Act limits the use of those funds to "qualified disability expenses" and exempts the first \$100,000 in ABLE accounts from the SSI \$2000 resource limit.

If one or both of you are currently receiving (or will at some point receive) Social Security benefits, Beth may be eligible to become the beneficiary of those benefits upon the death of the parent(s). Consult with an attorney to determine Beth's eligibility for those benefits and to calculate the amount of benefits Beth would be eligible to receive under Social Security.

Once eligibility for government benefits has been established, you should allocate the remainder of your estate, which you intend to leave to Beth, into an appropriate trust. There are several different types of trusts useful in your situation. The go-to trust for parents with adult children with disabilities are often the Supplemental (or Special) Needs Trust. The perk of this trust is that as long as the trust clearly states that funds are only meant for supplemental needs and those funds are properly managed to only purchase and cover needs not covered under SSI and Medicaid, then the trust will not interfere with SSI and Medicaid eligibility. Parents prefer these trusts because any additional funds over and above \$2000 can be set aside to provide the

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comfortable life the child may have enjoyed while the parents were still alive. For example, the funds can be used for entertainment, additional nursing or living assistance, and recreation. The key to this and any other kind of trust is to select a trustworthy and knowledgeable trustee to manage the trust on Beth's behalf.

A trust you could set up during your lifetime to benefit Beth is a living trust. This would be helpful if you would prefer that during your lifetime someone else manages the resources necessary to provide supplemental support for Beth.

If you are limited in the amount of support funds you will have to leave to Beth, but have at least \$5000, you should inquire about the benefits of a pooled trust. These trusts are helpful because, as the name suggests, parents pool their funds into a larger trust account which can accrue greater interest dividends, while often having the added advantage of being managed by a non-profit organization specializing in care for people with disabilities.

If Beth needs constant medical attention or living assistance, seek out a trusted friend or relative who will be willing to become Beth's legal guardian to assist with and oversee Beth's care. Of utmost importance, the guardian and trustee of any trust you may have set up for Beth should not be the same person. This will create an extra level of protection for Beth, as the guardian and trustee can hold each other accountable to monitor Beth's care and expenses. It is best if the guardian is the same age or younger than Beth, to increase the chance that Beth will have the same caregiver for the duration of her life after you can no longer provide the care.

If housing for Beth is a concern, you will need to contact state or privately owned adult care facilities to find a place appropriate for Beth's needs and means. If Beth can live alone, with less demanding daily attention, then you may consider other home alternatives. For example, if Beth has a home, the designated guardian could take over the daily care routine at the home. However, if Beth does not have a home or you do not own a home that you intend to bequeath to Beth, contact your local Housing Authority to find out the waiting period and eligibility requirements for a home for a resident with a disability to determine when you will need to apply for the housing program.

B. *Details for Beth's Future Care Plan*

1. *Wills and Guardianship Matters*

Your Future Care Plan Team may want to begin the plan by creating a will. The cost of executing a will is generally nominal; however, “the presence of a disabled child might . . . add significantly to the cost of acquiring a proper estate plan” with a will being only the first step of many in creating an appropriate future care plan.⁷⁷

Besides the division of assets to beneficiaries of the estate, a major component of a will meant as part of a future care plan should include a “nomination . . . of a guardian of the person . . . to take effect upon the death of the surviving parent.”⁷⁸ Furthermore, to add protections to the future care of the child the parent should choose “[d]ifferent persons . . . should serve as guardian [as stated in the will] and trustee [as stated in a trust].”⁷⁹ Under most care plans the guardian would be “responsible for the child’s general wellbeing, for determining his or her place of residence, and for consenting to medical treatment.”⁸⁰ And this may go without saying, but, “[i]deally, the guardian should be someone of the same generation as, or younger than, the disabled adult child” to guarantee continuity of care through the child’s lifetime.⁸¹

If the adult child with a disability has the mental capacity to make certain major life decisions on his or her own, then a formal guardian may not be necessary.⁸² But in that case, the individual could “sign a health care proxy and appoint a health care agent for

77. Trapp, *supra* note 39; see also 6 ANNE E. MELLEY, TEXAS FAMILY LAW SERVICE § 49:15 (2007).

78. *Id.*; see also Kravitz & Wolf, *supra* note 1, at 37. Frolik and Brown further explain that guardians should really only be recommended for a disabled adult child “who has . . . been declared mentally incapacitated.” FROLIK & BROWN, *supra* note 23, ¶ 17.05. “In many instances, the substitute decision making for the child can be provided by more informal arrangements.” *Id.* However, if a child “is severely disabled and living in an institution or has significant medical problems, guardianship is probably necessary.” *Id.* ¶ 17.06.

79. 6 MELLEY, *supra* note 77, § 49:15.

80. *Id.*; see also FROLIK & BROWN, *supra* note 23, ¶ 17.05; Kravitz & Wolf, *supra* note 1, at 39.

81. FROLIK & BROWN, *supra* note 23, ¶ 17.06.

82. See Kravitz & Wolf, *supra* note 1, at 38.

themselves.”⁸³ If this is the case, the team advising the family “should evaluate specifically the adult child’s capacity to execute such a document.”⁸⁴ The adult child should be informed as to the “purpose of this document and . . . of making his or her wishes known to the person who is appointed as agent.”⁸⁵

For individuals who lack “capacity to appoint a health care agent,” the Family Health Care Decisions Act (FHCDA) has created a “hierarchy of decision makers” who are permitted to “decide on a proposed treatment or to withhold or withdraw treatment under specific circumstances and when the patient is in a hospital or residential health care facility.”⁸⁶ Other legal alternatives available for end-of-life decisions that are necessary are living wills and do not resuscitate orders.⁸⁷

2. *Achieving a Better Life Experience Act Accounts*

Before the end of 2015, “individuals with significant disabilities” whose disability emerged before the age of 26 will be able apply to establish one ABLE savings account per individual.⁸⁸ Particulars of these accounts are still being worked out by the states, but generally the following limitations and policies apply.⁸⁹ Annual contributions, in total, may not exceed \$14,000.⁹⁰ Limitations on the total accumulation over time will be determined on a state by state basis.⁹¹ For example, “[m]any states have set [a] limit at more than \$300,000 per plan.”⁹² Regarding SSI eligibility, “[t]he first \$100,000 in ABLE accounts would be exempted from the SSI \$2,000 individual resource limit.”⁹³ Funds accumulated in excess of \$100,000 will deem the

83. *Id.*

84. *Id.*

85. *Id.*

86. *Id.* As an added protection under the FHCDA, “neither a health care agent nor a surrogate . . . may involuntarily commit a person or override the person’s objection to treatment on an inpatient psychiatric unit.” *Id.*

87. *Id.*

88. *Congress Passes ABLE Act: Major Victory for Persons with Disabilities and Their Families*, NAT’L DISABILITY INST. (Dec. 17, 2014), <http://www.realeconomicimpact.org/news/?id=460>. [perma.cc/Y8XW-FGBH].

89. *Id.*

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.*

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individual ineligible for SSI, but Medicaid eligibility will continue.⁹⁴ However, states could “recoup some expenses through Medicaid upon the death of the [individual].”⁹⁵

Beyond the limitations on funds, the Act also limits qualifying expenses that may be charged to the ABLE accounts.⁹⁶ Qualifying expenses “include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services” as they relate to the individual living with his or her disability.⁹⁷

When determining if an ABLE account is the right option for a particular individual, the family should consider one major advantage of these accounts over the trust options described below. This advantage is that the individual is in charge of the account, rather than a designated trustee, thereby creating more flexibility for the family and individual as well as providing more control over the funds.⁹⁸

3. *Trusts*

There are many different types of trusts that can be used to plan for future care of a child with a disability. However, the parent must be aware of the implications of and restrictions on each type of trust.⁹⁹ For example, not all trusts “will protect eligibility for SSI and Medicaid.”¹⁰⁰ In addition, a spendthrift clause should be included in a support trust to prohibit creditors from making reimbursement claims from the trust.¹⁰¹

When addressing the financial management and oversight of the assets of an adult child with a mental illness or developmental disability, an aging parent may want to consider offering the adult child, if he or she has the requisite capacity, the opportunity to execute a power of attorney. Unlike a health care proxy, which goes into effect only when the person loses capacity to make

94. *Id.*

95. *Id.*

96. *Id.*

97. *Id.*

98. *Id.*

99. See Eichstadt, *supra* note 40, at 633–36.

100. Trapp, *supra* note 39.

101. Eichstadt, *supra* note 40, at 636–37.

health care decisions, a power of attorney authorizes the agent, previously called the “attorney-in-fact,” to make financial decisions either while the person has capacity but chooses not to act or loses capacity to make financial decisions. A power of attorney can be as broad or narrow as the individual would like, authorizing the agent to make all or only some financial decisions.¹⁰²

a. *Living Trusts*

Living trusts function exactly as they sound—“tak[ing] effect during the lifetime of the creator of the trust.”¹⁰³ The property in trust is “managed for the benefit of the” beneficiary.¹⁰⁴ When the trust creator dies, the property in trust “automatically transfers to the person named as the successor trustee.”¹⁰⁵ Living trusts do have the disadvantage of initially costing more than a will.¹⁰⁶ Moreover, the creator of the living trust will still need to draft a will to transfer property not titled in the trust at the time of death.¹⁰⁷

b. *Special or Supplemental Needs Trusts*

Special needs trusts are the only trusts that automatically “preserve SSI and Medicaid eligibility.”¹⁰⁸ Because these trusts prohibit the disabled beneficiary from “access[ing] or control[ing] the trust property,” the Social Security Administration does not consider such property as a “resource.”¹⁰⁹ Funds in a special

102. Kravitz & Wolf, *supra* note 1, at 38.

103. Trapp, *supra* note 39.

104. *Id.*

105. *Id.* One advantage of this automatic transference is the avoidance of probate. *See id.*

106. *Id.*

107. *Id.*

108. *Id.* “[A] special needs trust can be a testamentary trust. However, a special needs trust does not have to be a testamentary trust. A special needs trust can also be used to protect a gift or legal settlement.” *Id.* Only certain disabilities “allow for a supplemental needs trust.” Perlstein, *supra* note 22, at 366. Those disabilities include: “developmental disabilities, mental illness, physical disabilities, mental retardation, injuries such as traumatic brain injuries (for which personal injury awards have been received), and neurological impairments such as Alzheimer’s and other old-age-related diseases.” *Id.*

109. Trapp, *supra* note 39; *see also* Eichstadt, *supra* note 40, at 636.

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needs trust can be used to “pay for items such as college tuition, medical care, home improvements, entertainment, certain types of insurance, transportation, or even vacations.”¹¹⁰ Examples of benefits and advantages of supplemental needs trusts, include the ability to pay for: (1) a full-time private duty nurse not covered by government funding; and (2) a designated recreational coordinator to take the individual out for pizza and bowling once a week.¹¹¹

Although cash can be used to pay for items listed above, any cash provided to the beneficiary from the trust will be considered income, which may cause a “reduction or elimination of SSI benefits.”¹¹² Furthermore, payments for “food, utilities, and shelter will also be counted as income” affecting SSI benefits.¹¹³

Parents, financial planners, and attorneys need to exert extra caution when creating these trusts. To maintain Medicaid eligibility, a special needs trust “must limit the amount . . . the trustee is allowed to distribute to a level below the maximum income amount allowed by Medicaid.”¹¹⁴ To further this goal, the trust should designate a trust purpose—à la “to supplement state and federal entitlement programs and to pay only for those items or services not paid for by the entitlement programs.”¹¹⁵ The

110. Trapp, *supra* note 39; *see also* Perlstein, *supra* note 22, at 367 (“Monies from a supplemental needs trust may be used for items that provide the beneficiary with a better quality of life, such as additional medical treatment, insurance, individualized therapy, special medical equipment, advocacy, case management, entertainment, recreation, and any other goods, services or activities that enhance the beneficiary’s life.”).

111. Perlstein, *supra* note 22, at 367.

112. Trapp, *supra* note 39. If the trust creator intends to deposit a large sum of money to the special needs trust on behalf of the beneficiary—for, say, an insurance payment or damages award—such a sum must be diverted prior to receiving the payment, otherwise it may affect Medicaid of SSI eligibility. *Id.*

113. *Id.*

114. *Id.*

115. *Id.* *See also* Eichstadt, *supra* note 40, at 633 (describing that third parties may establish “a supplemental needs trust to provide for items to increase the comfort, pleasure, and happiness of a person with a disability”); *id.* at 629 (“[The] intention [of the trust] is to provide for items only to improve the quality of life for the child with a disability and not to provide for the child’s support.”). If the requirements detailed above are not met in the drafting of the trust and if assets of the individuals are a source for the trust, then “the government may be entitled to reimbursement for Medicaid expenditures for the individual from any funds remaining in the trust after the death of the child.” *Id.* at 630.

trust:

[M]ust clearly state that no trust funds will be used to provide for food, shelter, and clothing for the beneficiary with a disability. It must also be clear that the income is not available to the beneficiary and that the trustee has complete discretion in disbursing the trust funds. The trustee must be empowered with complete discretion in making payments on behalf of the beneficiary from the trust or not spending funds from the trust.¹¹⁶

These trusts are “most appropriate for families who have a financial need for the SSI payment or who need Medicaid to cover medical expenses.”¹¹⁷ However, if a disabled child carries few medical expenses, a relatively small monthly payment from SSI may not be worth securing if a large inheritance would adequately protect and care for the child.¹¹⁸

Notwithstanding the above limitations regarding the use of the trust funds, the only other concern that arises with using special needs trusts is designating a trustworthy and dedicated trustee since the beneficiary will have no access or control over the funds.

c. *Pooled Trusts*

States have implemented the use of pooled trusts for the care of people with disabilities.¹¹⁹ Parents and caregivers interested in this trust option need to be aware of their particular state’s laws regarding the creation and maintenance of these trusts. Pooled trusts can be managed by non-profit agencies or other experienced and dedicated trustees.¹²⁰ Under these pooled trust accounts,

116. *Id.* at 633–34.

117. Trapp, *supra* note 39.

118. *Id.*

119. *See, e.g.*, Eichstadt, *supra* note 40, at 637–38. For example, South Dakota implemented pooled trusts through the South Dakota Guardianship Program Trust in the summer of 1997. *See id.* This action followed the Omnibus Budget Reconciliation Act of 1993, which created the Guardian Pooled Trust. *See What Law Allows for Special Needs Trusts?*, GUARDIAN TR., <http://www.guardiantrusts.org/faqs/> [perma.cc/2QL4-UEY4] (last visited Nov. 22, 2015); *see also* 42 U.S.C. § 1396p (d)(4)(C) (2014).

120. *See* Perlstein, *supra* note 22, at 365. “After the death of the disabled person, the nonprofit is the first distributee, if so designated; Medicaid is the second distributee, whether designated or not; and then designated family

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“[p]arents of persons with disabilities pool their assets into one trust under the direction of” trustees or a non-profit agency.¹²¹ Then, “[e]ach beneficiary receives a pro rata share based on the assets included . . . in his account.”¹²²

There are several benefits of pooling accounts in this type of trust program.¹²³ First, the parents need only \$5,000 to establish such a trust.¹²⁴ Second, by joining the assets of several small trusts, the comingled trust receives a higher return on the investment.¹²⁵ Furthermore, “[t]he initial cost and set up fees for the [parents] are less than the fees that would be charged by the trust department of a bank for one small individual trust.”¹²⁶ Moreover, the beneficiary remains “eligible to receive assistance from federal programs because this trust is a discretionary supplemental needs trust.”¹²⁷ Perhaps most importantly, pooled trusts allow families “to rely on . . . the leadership and guidance of an agency with experience in this field.”¹²⁸

V. FUTURE CARE PLAN FOR PARENTS WITH PLENTIFUL RESOURCES
AND A PARTIALLY INDEPENDENT ADULT CHILD WITH A DISABILITY

Parents with plentiful financial resources creating a future care plan for their partially independent adult child with a disability will have more options with respect to care plan. Below is an overview of what this care plan might look like.

members receive distributions from any remaining money.” *Id.* at 366.

121. Eichstadt, *supra* note 40, at 638. Accounts are separate and distinct, and are pooled only for investment purposes. Perlstein, *supra* note 22, at 365–66.

122. Eichstadt, *supra* note 40, at 638.

123. The beneficiary is not the only one who can benefit from the trust: “The nonprofit organization can be named as one of the beneficiaries to receive any funds remaining in the trust when the disabled beneficiary dies.” Perlstein, *supra* note 22, at 366. As a result, the state can be “repaid for the medical assistance Medicaid provided . . . from any funds remaining in the disabled person’s trust account which are not retained by the nonprofit as a beneficiary.” *Id.*

124. Eichstadt, *supra* note 40, at 638.

125. *Id.*

126. *Id.*

127. *Id.*

128. Perlstein, *supra* note 22, at 365.

70 *ROGER WILLIAMS UNIVERSITY LAW REVIEW* [Vol. 21:45]A. *Future Care Plan for Caleb*

Dear Parents of Caleb,

Fortunately, due to your assets and resources, you and the Future Care Team can create a plan for Caleb that will be unencumbered by the eligibility requirements of government benefits like Supplemental Security Income and Medicaid. This sort of Future Care Plan, covered by total private support, should include a will, creation of a support trust, and/or designation of a conservator to manage the funds. If you have multiple children, you should decide whether you want to distribute your estate to them equally, or weighted more heavily to Caleb for the additional support Caleb may need, or weighted more heavily to the other child(ren) if he/she/they intend to help care for Caleb.

If you leave more of your assets to Caleb, be sure to designate a trustworthy and knowledgeable conservator to properly monitor Caleb's use of those assets. Use caution when deciding to leave more assets to Caleb's sibling for Caleb's care, as the sibling's future could be determinative to Caleb's care. For example, if the sibling lost half of his/her assets in a divorce settlement or lost all assets to creditors during a bankruptcy, Caleb's care could be significantly altered for the worse.

To avoid these sorts of risks, it may be best to ask a financial planner and/or attorney to assist you in creating a support trust to care for Caleb through the end of Caleb's life. A support trust may best secure the financial stability of Caleb's Future Care Plan as it will be managed by a trustee with the financial expertise to ensure the longevity of the funds.

B. *Details for Caleb's Future Care Plan*

If parents and families have the financial resources, they may choose to care for any adult children with disabilities through support trusts or conservatorships funded entirely by those resources.¹²⁹ This plan for care:

[E]liminates governmental intrusions into private family matters, avoids disputes about eligibility for government benefits during the life of the adult child with a disability,

129. Eichstadt, *supra* note 40, at 636–37.

does not require an understanding of Medicaid and SSI, and allows parents to fulfill what they may view as their moral obligation to provide for their child.¹³⁰

If parents or caretakers have the means to follow this pathway of care, they should hire an attorney with estate planning experience to weigh the pros and cons and “handle the legal intricacies.”¹³¹

VI. ALTERNATIVES AND SUPPLEMENTS TO TRUSTS FOR *BETH'S* AND *CALEB'S* PARENTS

Parents with moderate or significant resources and assets should also consider alternatives to trusts. Alternatives may include: disinheriting the child, granting a gift to a future caretaker, developing a plan to achieve self-sufficiency, purchasing a non-countable resource. The following discussions will describe the advantages and disadvantages of each of these options.

A. *Disinheriting the Adult Child with a Disability*

One possible alternative to establishing a trust is to disinherit the child and subsequently request in the will that certain beneficiaries or legatees “provide for the child with a disability and leave specific instructions as to their wishes.”¹³² Although it may sound heartless, this alternative can be in the best interest of a child with a disability as it makes the child eligible for Medicaid and SSI.¹³³ The obvious downside to this alternative is that after the death of the parent there is no one around to make sure the designated beneficiary actually cares for the child.¹³⁴

130. *Id.* at 637.

131. *Id.*

132. *Id.*; see also FROLIK & BROWN, *supra* note 23, ¶ 17.07 (“[D]isinheritance may be the only sensible way to ensure that the child will receive his full allotment of public benefits, and thus proper care.”); 6 MELLEY, *supra* note 77, § 49:15 (“Clients who are the parents of a developmentally disabled child may want to ensure that the child will remain eligible for SSI and Medicaid, and therefore may want to disinherit the child.”).

133. See 6 MELLEY, *supra* note 77, § 49:15; see also Eichstadt, *supra* note 40, at 637.

134. See Eichstadt, *supra* note 40, at 637.

B. *Gift to Future Caretaker*

An alternative similar to disinheriting the child and appointing a beneficiary to care for the child is to give a financial gift to a trusted family member, like a sibling, with the same intentions.¹³⁵ However, major flaws exist in this plan. For example, death, divorce, or other major financial disasters could have dire effects on the ability to care for the adult child. Divorce could lead to cutting caretaking funds in half if the funds were deemed marital property and, thus, subjected to equitable distribution.¹³⁶ Death of the family member would mean the funds might pass on to a spouse or children rather than to the disabled person.¹³⁷ Bankruptcy could drain all the funds earmarked for the child as creditors put liens on the monies.¹³⁸

C. *Develop a Plan for Achieving Self-Sufficiency*

Although this trust alternative will be limited to only those individuals capable to work toward some manner of independence, parents may want to look into an SSI work incentive called the Plan For Achieving Self-Support, or PASS.¹³⁹ This program “allow[s] income and resources to be exempted, in order to achieve the goal of becoming self-supportive.”¹⁴⁰ The advantages of PASS allow the child to remain eligible for SSI and Medicaid while being flexible in that the funds can be drawn “from assets already in [the parents] possession or in [the] child’s possession.”¹⁴¹ Additionally, PASS can be used simultaneously with a special needs trust.¹⁴²

D. *Purchase of a Non-Countable Resource*

Another alternative to trust is for the parent to purchase a non-countable resource such as a home. Like PASS, the purchase of non-countable resources can be completed simultaneously with

135. Perlstein, *supra* note 22, at 365.

136. *Id.*

137. *Id.*

138. *Id.*

139. Trapp, *supra* note 39.

140. *Id.*

141. *Id.*

142. *Id.*

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a special needs trust.¹⁴³ Before such a purchase is made, the parent should consult his or her attorney to ensure the item falls in a category of resource exemptions for SSI and Medicaid eligibility.

E. *Life Insurance*

Parents may want to purchase life insurance as a method of providing for their disabled child. The most useful type of life insurance for parents planning for the care of their disabled child would be permanent life insurance.¹⁴⁴ Although permanent life insurance is more expensive than a term life insurance, which covers short-term expenses, this sort of insurance would better “provide for . . . [the] disabled child, regardless of the [parent’s] age at death.”¹⁴⁵

One of the most important policy concerns is: Which parent does the life insurance policy cover?¹⁴⁶ For example, “[i]f one spouse is the child’s primary caregiver, and the other spouse works outside the home,” the primary caregiver should be insured.¹⁴⁷ This way “[p]roceeds of this policy could be used to pay for continuing care of an adult disabled child if the caregiver spouse passes away and the surviving spouse must continue to work outside the home.”¹⁴⁸ In addition, parents should invest in a second-to-die policy, which “could be used to care for the child even if the child outlives both parents.”¹⁴⁹

The final concern regarding life insurance policies is the beneficiary designations.¹⁵⁰ In order to maintain eligibility for SSI and Medicaid, the policy must state: “proceeds pass to [a]

143. *Id.*

144. Webber B. Roscher, *Providing for Adult Children with Disabilities in a Traditional Estate Plan: Looking Beyond the Special Needs Trust*, 27 *PROB. & PROP. MAG.* no. 6, November–December 2013, http://www.americanbar.org/publications/probate_property_magazine_2012/2013/november_december_2013/2013_aba_rpte_pp_v27_6_article_roscher_adult_children_with_disabilities.html.

145. *Id.* (“[In addition,] permanent . . . life insurance . . . will prevent the [parent] from having to qualify for life insurance each time a term policy lapses, which can become more difficult as time passes.”).

146. *Id.*

147. *Id.*

148. *Id.*

149. *Id.*

150. *Id.*

special needs trust, rather than [directly] to the adult special needs child.”¹⁵¹

CONCLUSION

Creating and annually reviewing a Future Care Plan is essential to providing a stable and healthy future for adult children with disabilities. By implementing the greatest diversity in financial resources available to the child and establishing alternatives and fall-back plans, parents can protect their children in death as best they did in life. This Article should stand as an introductory guidebook for parents beginning the planning process. However, to create the best care plan, parents should work with a team, as described previously, to analyze all of the possibilities available for their child’s particular situation and their financial means.¹⁵²

151. *Id.*

152. One great resource parents may consider is the Academy of Special Needs Planners. See ACAD. SPECIAL NEEDS PLANNERS, <https://attorney.elderlawanswers.com/home/index/org/asnp> (last visited Jan. 8, 2016).