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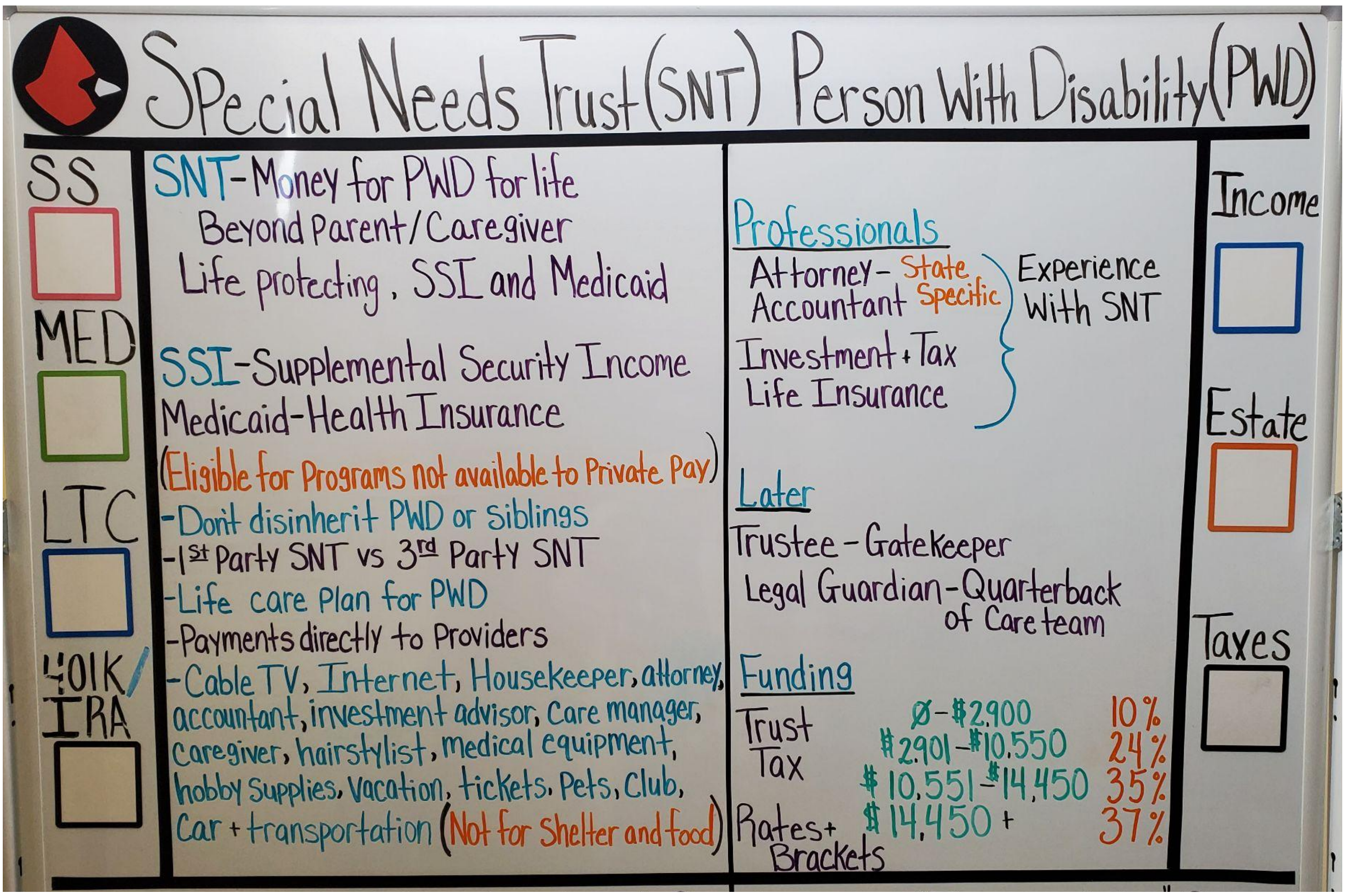
Special Needs Trust (SNT)
Person With Disability (PWD)

Hans and Tom use the following pages to go over this aspect of Estate planning in our video entitled the same.



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PLANNING FOR PERSONS WITH DISABILITIES: RECENT DEVELOPMENTS AND CONTINUED CHALLENGES

By

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Ms. Lewis is nationally recognized for her proficiency in Special Needs Trust planning for persons challenged by disabilities, and is a frequent speaker and author on this topic. She is a Fellow of the American College of Trust and Estate Counsel (ACTEC), and an active member of the Special Needs Alliance, where she has served as Co-Editor of that organization's monthly e-newsletter, *The Voice*. She is also a member of the American Bar Association, the New York Bar Association Elder Law Section, and the State Bar of Georgia Fiduciary Law Section. She is a former Co-Chair of the Long-Term Care, Medicaid and Special Needs Trusts Committee of the Elder Law, Disability Planning and Bioethics Group of the Real Property, Probate and Trust Law Section of the American Bar Association.

Ms. Lewis received her B.A. degree in French and political science, with highest honors, from Wellesley College in 1981. She earned her J.D. degree from Cornell University Law School in 1984. She is admitted to practice law in both New York and Georgia. Ms. Lewis is recognized in the Chambers High Net Worth Guide, Private Wealth Law, individual attorney rankings, and is included in the roster of Georgia Super Lawyers in Estate Planning and Probate. Additionally, she is recognized by Best Lawyers in America® in Trusts and Estates.

Ms. Lewis currently serves as Board Chair of Eagle Ranch, a non-profit residential counseling program for children in northeast Georgia that works to unify troubled families. She also serves on the Board of Wesley Woods Senior Living, which provides affordable housing for Georgia seniors of limited means, and is a consultant to Better Living Together, Inc., which seeks to provide affordable housing in Greater Atlanta for persons with intellectual and developmental disabilities and others of modest means. Ms. Lewis also currently serves on the Boards of the Center for the Visually Impaired and the Bobby Dodd Institute, and previously served as the Board Chair of Georgia Community Supports & Solutions (now InCommunity), all of which support persons with disabilities and their families. She also currently serves on the Board of Cumberland Academy of Georgia, a private school for children with autism. She is also a member of the Children's Healthcare of Atlanta Legacy Advisors Leadership Council. She is a past Chair of the Board of Directors of the Girl Scouts of Greater Atlanta, Inc. and a former Trustee of the Wellesley College Alumnae Association. She is an active member of St. Jude the Apostle Catholic Church in Atlanta, and has been trained as an annulment advocate with the Metropolitan Tribunal of the Archdiocese of Atlanta. She is an active member of the Serra Club of Atlanta, which supports seminarians and religious vocations. In her vast amounts of free time, she volunteers for Canine Assistants, a non-profit based in Milton, Georgia, which raises and trains certified service dogs for recipients with disabilities.

Ms. Lewis has authored an article on "Planning Challenges for Beneficiaries With Special Needs," published in *Estate Planning*, Volume 46, Number 3, March 2019. She has co-authored an article entitled, "Top 15 Tips for Estate Planners When Planning for Special Needs," published in *Probate & Property*, Volume 24, Number 2, March/April 2010, which won the magazine's 2010 Excellence in Writing Award for "Best Overall Article – Trusts & Estates." Her paper on "Planning for Beneficiaries with Special Needs" was included in the Fourth Quarter 2012 edition of the *Journal of Estate & Tax Planning* published by the National Association of Estate Planners & Councils. She has also authored an article entitled "The Crime of the 21st Century: Financial Abuse of Elders," which was published in *Probate & Property*, Volume 28, Number 4, July/August 2014.

Ms. Lewis has lectured frequently on the topics of elder financial abuse and Special Needs Planning for persons with disabilities for ACTEC, the American Law Institute, the Society of Financial Services Professionals, the National Association of Personal Financial Advisors, the American Institute of Certified Public Accountants, the Heckerling Estate Planning Institute, the Special Needs Alliance, the National Academy of Elder Law Attorneys, the Stetson Special Needs Planning and Special Needs Trust National Conference, the Southern Federal Tax Institute, the Federal Tax Institute of New England, the Duke Estate Planning Institute, the Johanson Estate Planning Institute, the Georgia Federal Tax Institute, the Georgia Institute for Continuing Legal Education, the Atlanta Estate Planning Council, and the Georgia Fiduciary Law Institute. Ms. Lewis is a faculty member for the annual American Bankers Association Wealth and Trust School, addressing the complex topic of Special Needs Trust administration. She also regularly presents community workshops on these topics to groups of parents and allied professionals.

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This outline will review the "network" of Special Needs Trusts that serves as the foundation for securing the future of persons challenged by disabilities; the team of "allied professionals" that helps design and implement a comprehensive Special Needs Plan; the types of government benefits and programs that can be accessed and preserved with proper Special Needs Trust planning; the most common challenges (and solutions) encountered in Special Needs Trust planning; and the newest tool in the planner's arsenal: the ABLE account.

I. THE "SPECIAL NEEDS" OF PERSONS WITH DISABILITIES

A. The scope of the population with disabilities

1. An estimated **one billion people** worldwide live with one or more disabilities, according to a ground-breaking report published by the World Health Organization in 2011. *See* World Health Organization & World Bank Group, "World Report on Disability" (2011).[1] This represents 15% of the world's population. Thus, it is not an overstatement to conclude that "Everyone knows someone with a disability." (In March 2018, Apple, Inc. issued a press release regarding its development of new "emojis" to better represent the vast number of individuals with various disabilities.) *The International Classification of Functioning, Disability and Health* uses the terms "disability" as an umbrella for impairments, activity limitations and participation restrictions. Nationally, the seminal report issued by the United States Census Bureau in 2012 concluded that in 2010, approximately **56.7 million of the 303.9 million people in the U.S. civilian non-institutionalized population, representing 18.7% of this group**, reported a disability. *See* Matthew W. Brault, "Americans With Disabilities: 2010," *Current Population Reports*, P70-131, U.S. Census Bureau, Washington, D.C., Issued July 2012 (available at https://www.census.gov/library/publications/2012/demo/p70-131.html. Another 4.1 million institutionalized people (*i.e.* in correctional institutions or nursing homes) have disabilities, but were not included in the Brault report. [Note: a similar in-depth analysis of the data on disabilities gleaned from the 2020 U.S. Census has not yet been released.]

a. The Brault report divided the universe of disabilities into (i) seeing, hearing and speaking limitations, (ii) upper and lower body limitations, (iii) cognitive, mental and emotional functioning limitations, and (iv) difficulties with "Activities of Daily Living" or

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[1] https://www.who.int/publications/i/item/9789241564182.

"Instrumental Activities of Daily Living." Persons age 15 and older with disabilities in these categories were further assigned to one of three "disability domains."

(1) "Communicative" disabilities, including blindness; visual impairments; deafness; hearing impairments; difficulty having speech understood.

(2) "Mental" disabilities, including learning disabilities; intellectual disabilities; developmental disabilities; Alzheimer's disease, senility or dementia; another mental or emotional condition that seriously interferes with everyday activities.

(3) "Physical" disabilities, including required use of a wheelchair, cane, crutches or walker; difficulty walking a quarter of a mile, climbing one flight of stairs, lifting a 10 pound object, grasping objects or getting out of bed; activity imitations caused by arthritis or rheumatism; back or spine problems; broken bones or fractures; cancer; cerebral palsy; diabetes; epilepsy; head or spinal cord injury; heart trouble or atherosclerosis; hernia or rupture; high blood pressure; kidney problems; lung or respiratory problems; missing limbs; paralysis; stiffness or deformity of limbs; stomach or digestive problems; stroke; thyroid problems; tumor, cyst or growth. Brault report, at 2.

b. Another recent report issued by the U.S. Census Bureau, and also authored by Matthew W. Brault, analyzed school-aged children with disabilities. Of the 53.9 million **school-age children** (aged 5 to 17) in the U.S. civilian non-institutionalized population, 2.8 million, or **5.2%, were reported to have a disability** in 2010. *See* Matthew W. Brault, "School-Aged Children With Disabilities in U.S. Metropolitan Statistical Areas: 2010," *American Community Survey Briefs*, U.S. Census Bureau (Nov. 2011).[2]

(1) That report incorporates the definition of "child with a disability" set forth in the **"Individuals with Disabilities Education Act" of 2004 ("IDEA")**, 20 U.S.C. §§ 1400-1482, which includes a child who has "intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance . . ., orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities; and who, by reason thereof, needs special education and related services." 20 U.S.C. § 1401(3)(A).

(2) On December 3, 2021, the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (the "CDC") issued its summary report describing the biennial findings of the CDC's "Autism and Developmental Disabilities Monitoring Network" ("ADDM Network"). Since its creation in 2000, the CDC's ADDM Network has tracked the prevalence of "Autism Spectrum Disorder" ("ASD") in 8 year-old children from multiple states and communities. For the 2018 biennial report, the ADDM Network consisted of communities in Arizona, Arkansas, California, Georgia, Maryland, Minnesota, Missouri, New Jersey, Tennessee,

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[2] http://www.census.gov/library/publications/2011/acs/acsbr10-12.html.

Utah and Wisconsin. The overall ASD prevalence for the 2018 reporting period was one in every 44 children, an increase from one in every 68 children, as summarized in the 2016 report of the ADDM Network.[3] ASD is 4.2 times more common among boys than among girls. *See* Maenner, MJ, Shaw, KA, et al. "Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018."[4] An earlier study in 2018 presaged this marked increase, concluding that the estimated prevalence of children in the U.S. with a "parent-reported" diagnosis of ASD was then one in 40 children.[5] This study has not been updated since these 2018 findings.

B. The "special needs" of persons with disabilities

1. The term **"special needs" has no universally accepted definition**, but this author uses the term to refer to the broad consequences of a person's disabling condition and the resultant life circumstances, challenges and opportunities that ensue therefrom. These needs can range from intensely personal physical requirements, to the consequences of a person's inability to secure employment and wages sufficient to be self-supporting, to occasions for improving the quality of life of the person with the disability. The term thus necessarily means something different for each person with a disabling condition.

a. However, the Medicaid programs of various states are increasingly attempting to limit the scope of the term "special needs" to those that are related solely to the "treatment" of a person's disability. *See, e.g., Lewis v. Alexander*, 685 F.3d 325, 334-35 (3d Cir. 2012). The Court in that decision held that such attempted limitations on the types of "special needs" that can be funded by a Special Needs Trust are constitutionally impermissible and preempted in light of Congress's intent in enacting the federal legislation that blesses the broader use of Special Needs Trusts, as described in Section III, *infra.*

2. Providing appropriately for the special needs of persons with disabilities has emerged as a challenging and complex multidisciplinary task over the past twenty years. Estate planning attorneys and allied professionals have an insatiable appetite for knowledge and direction in this emerging area. Even law students still roaming the hallowed halls of the country's law schools are increasingly eager for academic training in "elder law" and special needs planning. Nevertheless, there are still vast numbers of attorneys and allied professionals who know "just enough to be dangerous" about how best to address the myriad needs of families trying to secure the future of their loved ones with disabilities. This outline will highlight the major challenges, and solutions, which attorneys and allied professionals typically encounter when advising clients with special needs issues.

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[3] MMWR Surveill. Summ. 2021; 70 (No. SS-11): 1-16. DOI: http://dx.doi.org/10.155851/mmwr.ss7011a1.
[4] https://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm.
[5] https://doi.org/10.1542/peds.2017-4161.

II. DO NOT DISINHERIT THE BENEFICIARY WITH SPECIAL NEEDS

A. <u>Disinheritance is an outdated and incorrect approach</u>

1. Estate planners who recommend the disinheritance of a beneficiary with a disabling condition often do so because they are unfamiliar with Special Needs Trust planning. Although they have a vague understanding that it is inadvisable for a variety of reasons to make an outright gift or bequest to a person with a disability, many traditional estate planning professionals are reluctant to develop new expertise in this complex emerging area of the law. Rather than developing a proficiency in this area, or aligning themselves with co-counsel who can provide the necessary expertise, they recommend that the beneficiary with special needs be disinherited and provided for informally by other family members, typically adult siblings.

a. Estate planning attorneys are increasingly held liable for legal malpractice for their lack of proper advice on how best to address the special needs of a beneficiary with a disability. *See, e.g., Board of Overseers of the Bar v. Brown*, Maine Supreme Court Docket No. Bar-01-6 (Oct. 25, 2002).[6]

B. <u>Do not leave the share of the person with special needs to another family member to manage informally</u>

1. Family members may claim that they are willing and able to manage on an informal basis the funds designated for the beneficiary with special needs. However, such a **precatory arrangement** cannot typically be legally enforced. The donee of the funds could maliciously withhold the benefits of the designated funds from the intended beneficiary, leaving the beneficiary with no legal recourse (and no funds to pursue any remedies).

a. Even **well-intentioned** family members may ultimately fail to manage designated funds for the benefit of the intended beneficiary with special needs.

(1) If the donee of the designated funds **commingles the assets** with his own, and thereafter (i) files for bankruptcy, (ii) becomes party to a divorce proceeding and a subsequent equitable division of property, (iii) has a judgment lien recorded against his property, or (iv) fails to pay his tax liabilities and becomes subject to a tax lien, the funds designated informally for the beneficiary with special needs could be dissipated entirely. These are but a few of the most **common creditor traps** that defeat the intention of clients trying to secure the future of beneficiaries with special needs.

(2) A similar result could ensue if the donee of the funds set aside informally for the beneficiary with special needs **predeceases** him and (i) dies intestate with heirs-at-law that include persons other than the intended beneficiary, or (ii) dies testate but fails to make

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[6] http://www.courts.state.me.us/opinions_orders/opinions/documents/Bar-01-6%20Brown.htm

proper arrangements in the Will for the ongoing management of the funds for the benefit of the intended beneficiary. Since an estimated 65% of the population dies intestate, this is another very common flaw in a client's plans to provide informally for beneficiaries with special needs.

III. SPECIAL NEEDS TRUSTS ARE THE CORNERSTONE OF PLANNING FOR A BENEFICIARY WITH A DISABILITY AND RESULTANT SPECIAL NEEDS

A. Types of Special Needs Trusts

1. The universe of Special Needs Trusts can be divided into two main categories: **"first-party" (also sometimes referred to as "self-settled")** Special Needs Trusts (*i.e.* funded with assets belonging to the beneficiary, or to which the beneficiary is legally entitled), and **"third-party"** Special Needs Trusts (*i.e.* funded with assets derived from someone other than the beneficiary).

a. For purposes of drafting Special Needs Trusts, the term "special needs" is often used interchangeably with the terms "supplemental needs" or "supplemental care." Advisors and planners differ widely in their usage of these terms, and there is no generally accepted "best practice" in this regard. As will be discussed below, whichever term is chosen must be **contrasted with providing for the beneficiary's "support" and "maintenance."**

b. The vast majority of Special Needs Trusts are **designed to preserve the beneficiary's eligibility for the various "means-tested" government benefit** programs for which a person with disabilities may qualify (discussed in Section IV, *infra*). This author often uses the term "Supplemental Care Special Needs Trust" to refer to this type of trust. In contrast, a Special Needs Trust could also theoretically be drafted as a "Support Special Needs Trust," but doing so would render the beneficiary ineligible for such "means-tested" programs. Consequently, this outline is devoted to a discussion of how Supplemental Care Special Needs Trusts serve as the cornerstone of securing the future of beneficiaries with special needs.

B. First-Party Special Needs Trusts

1. As part of the OMNIBUS BUDGET RECONCILIATION ACT OF 1993 ("OBRA '93"), Congress specifically authorized the creation of a single-beneficiary Special Needs Trust to be **funded with assets belonging to the beneficiary**, the statutory requirements for which are set forth in 41 U.S.C. § 1396p(d)(4)(A). While several states have statutory provisions that parallel the federal statute authorizing first-party Special Needs Trusts, most do not.

a. In addition to this federal statute, there are two additional primary sources of guidance regarding the validity and effectiveness of Special Needs Trusts: (i) the **Social Security Administration ("SSA") Program Operations Manual System (referred to hereinafter as "POMS")**, and (ii) the various state Medicaid Manuals. The vast majority of POMS provisions relevant to Special Needs Trusts are set forth in POMS SI 01120.200, 01120.201, 01120.202, and 01120.203. (The POMS are available on-line at http://policy.ssa.gov.) **These POMS were substantially updated in April 2018, and all cites thereto in this outline**

reflect those updates. The United States Supreme Court, in *Washington State Department of Social & Health Services v. Guardianship of Keffler*, stated that the POMS "warrant respect." 537 U.S. 371, 385 (2003). A federal district court also recognized and reiterated the proposition that "[a]lthough the POMS is a policy and procedure manual that employees of the Department of Health & Human Services use in evaluating Social Security claims, and does not have the force and effect of law, it is nevertheless persuasive." *Davis v. Secretary of Health and Human Services,* 867 F.2d 336, 340 (6th Cir. 1989). Thus, **practitioners ignore the POMS at their peril.**

2. The **federal statutory requirements**, and related POMS provisions, for a **first-party Special Needs Trust** include the following.

a. First Statutory Requirement. The trust is established by (*i.e.* through the actions of) a **permissible Settlor**, including (i) an adult beneficiary who retains mental capacity notwithstanding his disability (only for trusts established on or after December 13, 2016); (ii) the legal Guardian of the Property or Conservator of the beneficiary, *e.g.* in the case of a minor or an incapacitated adult who meets the relevant threshold under state law for the appointment of a Guardian or Conservator; (iii) a parent or grandparent of the beneficiary; or (iv) a court.

(1) N.B. **"The Special Needs Trust Fairness Act"** was signed into law on December 13, 2016 to allow a mentally competent, yet disabled, beneficiary to establish his own first-party Special Needs Trust. *See* Title V, Section 5007 ("Fairness in Medicaid Supplemental Needs Trusts") of the 21ST CENTURY CURES ACT, P.L. No. 114-255. The SSA's POMS were updated in April 2018 to reflect this statutory change to 42 U.S.C. § 1396p(d)(4)(A). *See* POMS SI 01120.203.C. If the adult beneficiary has previously granted a Power of Attorney to a third party which authorizes the establishment and funding of a first-party Special Needs Trust with the beneficiary's assets, the SSA will now allow the attorney-in-fact, acting as agent for the beneficiary, to serve as the Settlor of the trust. *See* POMS SI 01120.203.B.9 and C.2.a and 3.

(2) N.B. Prior to December 13, 2016, the SSA took the position that **a mere "agent" of the beneficiary** could *not* serve as the Settlor of a first-party Special Needs Trust. Thus, a person serving as attorney-in-fact for the beneficiary under a Power of Attorney could *not* previously establish a first-party Special Needs Trust for the benefit of the principal, and this was a frequent basis for disqualifying the beneficiary for means-tested government benefit. *Id*.

(3) Notwithstanding the unambiguous provisions of the federal enabling statute regarding the authority of "**a parent or grandparent**" to establish and fund a first-party Special Needs Trust, the SSA has taken the position that a parent or grandparent must also have ***independent legal authority*** over the beneficiary's assets, *e.g.* as a court-appointed Conservator or pursuant to a Power of Attorney. *See* POMS SI 01120.203.B.1.9 and SI 01120.203.C.3. **Absent such authority**, a parent or grandparent may also establish the trust as a "**seed trust**," which is funded with a nominal amount of their own funds, and then subsequently augmented with the beneficiary's assets by someone who has authority over those assets. *See* POMS SI 01120.203.B.1.7, and SI 01120.203.C.2.b.

(4) In the case of a first-party Special Needs Trust established through the actions of a court, the creation of the trust must be ***required*** **by a court order, not merely approved**. *See* POMS SI 01120.203.B.8. The creation of the trust cannot have been completed before the court order is issued. "Court approval of an already created special needs trust is not sufficient . . . The court must specifically either establish the trust or order the establishment of the trust." *Id*,

b. Second Statutory Requirement. The beneficiary of the trust is "disabled" within the meaning of the Social Security Act, 42 U.S.C. § 1382c(a)(3), *i.e.* unable to engage in any **substantial gainful activity ("SGA")** by reason of any medically determinable physical or mental impairment, or combination of impairments, 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. *See* 20 C.F.R. § 416.905. *See* POMS SI 01120.203.B.4. If the beneficiary is under the age of 18, "disability" is defined as a medically determinable physical or mental impairment, or combination of impairments, that causes **marked and severe functional limitations**, and that can be expected to cause death, or that has lasted, or can be expected to last, for a continuous period of not less than twelve months. *See* 20 C.F.R. § 416.906. However, if such a minor is able to engage in SGA, he will not meet the definition of disabled.

(1) For 2022, the **income threshold evidencing a person's ability to engage in SGA** is $1,350/month. For a person who is blind, the SGA threshold is $2,260/month in 2022. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).[7] For purposes of an SGA determination, a person's gross earnings can be reduced by (i) unreimbursed out-of-pocket "impairment related work expenses" (*e.g.* modifications to a vehicle used to transport the person to work), and (ii) the value of any work subsidies or support.

(a) If a person's earnings meet or exceed the SGA threshold, even eliminating their eligibility for a monthly SSI payment, there are various exceptions that allow a working person to maintain eligibility for Medicaid if their earnings are not sufficient to replace the value of their SSI and Medicaid benefits, including publicly-funded attendant or personal care services that enable the person to work. *See* https://www.ssa.gov/redbook.

(2) Until June 26, 2019, the SSA interpreted this statutory element to require the disability determination to be "in-hand" at the time the first-party trust was *established*. Then, in a transmittal dated June 26, 2019 (Transmittal I.D. No. SI 01120 TN 58), the SSA conceded that the beneficiary need not satisfy the definition of "disabled" until he applies for SSI and the trust becomes subject to evaluation as part of the SSI application process, *i.e*. "as of the date on which the trust's resource status could affect the individual's SSI eligibility." POMS SI 01120.203.B.4.

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[7] https://www.socialsecurity.gov/news/press/factsheets/colafacts2022.pdf.

c. Third Statutory Requirement. The trust is irrevocable.

(1) While the federal enabling statute does not expressly require a first-party Special Needs Trust to be irrevocable, both the SSA and state Medicaid programs **require irrevocability**. *See, e.g.*, POMS SI 01120.201.D.2. and SI 01120.200.D.2.

(2) Even if a Special Needs Trust contains an express irrevocability provision, beware the impact of esoteric common law doctrines such as the "Rule in Shelley's Case," the "Doctrine of Worthier Title," the "Doctrine of Merger," or the "Settlor-Sole Beneficiary Rule," the application of which can cause the trust to be deemed *revocable* under state law. *See, e.g.*, POMS SI ATL 01120.201. *See also* Mary F. Radford & Clarissa Bryan, *Irrevocability of Special Needs Trusts: The Tangled Web That is Woven When English Feudal Law is Imported Into Modern Determinations of Medicaid Eligibility*, NAELA Journal, Vol. VIII, No. 1 (Spring 2012).

(3) POMS SI 01120.200.D.3. (as revised in April 2018) added new language to recognize the widespread abolishment of such common law doctrines: "When a trust is established for a beneficiary who is a minor, or if a court has ordered the establishment of a trust for an incompetent beneficiary, assume (absent regional instructions and subject to the NOTE), that it is acceptable for "the estate of the beneficiary" to be named as the residual beneficiary without causing the trust to be considered revocable." [The referenced "NOTE" merely provides that "policies regarding grantor trusts may or may not apply in your particular state."]

d. Fourth Statutory Requirement. The trust is for the ***sole benefit*** of the beneficiary.

(1) While the federal enabling statute uses only the phrase "for the benefit of" the beneficiary, the states and the SSA have effectively required that **a stricter "sole benefit" standard** be utilized when evaluating first-party Special Needs Trusts. *See, e.g.,* POMS SI 01120.203.B.6. This "sole benefit" requirement derives from the "asset transfer rules" which apply to persons who transfer assets as a way of qualifying for means-tested government benefits, including Supplemental Security Income and Medicaid, discussed *infra* in Section IV. The transfer of a person's assets to a first-party Special Needs Trust is an exempt transfer, and not subject to a transfer penalty, only if the trust is "solely for the benefit" of the trust beneficiary. *See* 42 U.S.C. § 1382b(c)(1)(C)(ii)(IV) and § 1396p(c)(2)(B)(iii) and (iv). Thus, POMS SI 01120.203.B.6. and SI 01120.203.I.1., Step 3, assert the position of the SSA that the "sole benefit" standard applies to first-party Special Needs Trusts, notwithstanding the contrary language of the federal enabling statute. The concept of "sole benefit" is further defined in POMS SI 01120.201.F., and currently constitutes a major battleground for those who draft and administer Special Needs Trusts.

e. Fifth Statutory Requirement. **The beneficiary is under age 65** when the trust is established and funded with the beneficiary's assets. *See* POMS SI 01120.203.B.2.

(1) If the trust was established prior to the date that the beneficiary attains age 65, the trust continues to qualify even after he attains age 65. *See* POMS SI 01120.203.B.2.

(2) However, it is **not permissible to make additions** to, or augmentations of, a first-party Special Needs Trust after the beneficiary attains age 65. This does not include interest, dividends or other earnings on trust principal deposited to the trust prior to the beneficiary's 65^{th} birthday. Similarly, annuity payments, support payments, and Survivor Benefit Plan payments (*see infra* at Section IV.A.1.a.(2)(e)(i)) that are payable to a first-party Special Needs Trust pursuant to a court order or an **irrevocable assignment** to the trust prior to the beneficiary's 65^{th} birthday will not constitute "additions" even if the payments continue after age 65. *See* POMS SI 01120.203.B.3.

f. Sixth Statutory Requirement. Upon the death of the beneficiary (or an earlier termination event), medical assistance providers (*i.e.* **Medicaid**, but not the SSA) **will be reimbursed** from any property remaining in the first-party Special Needs Trust (*if* any remains) up to the total amount of medical assistance benefits paid on behalf of the beneficiary under one or more state Medicaid plans during his lifetime. *See* POMS SI 01120.203.B.10.

(1) This last statutory requirement has resulted in the often-used monikers of **"Payback Trust"** or **"Medicaid Payback Trust"** for a first-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A). Such Special Needs Trusts are also often called **"(d)(4)(A) Trusts."**

(2) The **only disbursements** that may be made from a first-party Special Needs Trust after the beneficiary's death and **before satisfaction of the Medicaid payback**, are (i) taxes due from the trust to the state or federal government as a consequence of the beneficiary's death, and (ii) reasonable fees associated with the "administration of the trust estate," including an "accounting of the trust to a court, completion and filing of documents, or other required actions associated with termination and wrapping up of the trust." *See* POMS SI 01120.203.E.1.

(3) Specifically ***excluded*** **as permissible pre-payback** disbursements are taxes due from the beneficiary's estate other than those arising from the inclusion of the trust assets in the beneficiary's gross estate; inheritance taxes due from residual beneficiaries of the trust; payment of debts owed to third parties; **funeral expenses**; and payments to any residual beneficiaries. *See* POMS SI 01120.203.E.2.

(a) Thus, the first order of business for the Trustee of a first-party Special Needs Trust is to secure pre-need, pre-paid arrangements for the beneficiary's burial or cremation and related mortuary, crematory and funerary services to be held as an asset of the trust.

(4) Courts were initially split regarding the scope of the "total amount" that must be paid back to Medicaid. *See, e.g., In the Matter of Ruben N.*, 55 A.D.3d 257 (App.

Div., 2d Dept. 2008), which initially held that Medicaid should be paid back only for assistance paid after the Special Needs Trust was established. *In the Matter of Abraham XX, Deceased v. State of New York*, 11 N.Y.3d 429 (2008), next held that Medicaid should be reimbursed for assistance paid even before the Special Needs Trust was established. Subsequently, the earlier opinion and order in *Ruben N.* were recalled and vacated, citing *Abraham XX*, allowing the state to recover the **cost of care provided over the course of the plaintiff's entire lifetime**. *In the Matter of Ruben N.*, 71 A.D.3d 897 (App. Div., 2d Dept. 2010).

(5) Provisions of the SSA's POMS issued after the decisions noted above take the position (not surprisingly) that Medicaid's payback **"cannot be limited to the period after the establishment of the trust."** *See* POMS SI 01120.203.B.10.

(6) In the **context of a personal injury claim** that yields a recovery (verdict or settlement) for the beneficiary of a (d)(4)(A) Special Needs Trust, before the trust can be funded, Medicaid must first be reimbursed for those medical benefits paid for the beneficiary prior to the establishment of the trust for medical care necessitated by the wrongful acts that generated the recovery. However, the U.S. Supreme Court held in 2006 that this **"pre-trust lien"** may be satisfied only from that portion of the recovery that is specifically allocable to past medical expenses and costs. *See* ***Arkansas Department of Health & Human Services v. Ahlborn***, 547 U.S. 268 (2006).

(a) In 2013, Congress **legislatively overruled the *Ahlborn*** decision in § 202(b) of the BIPARTISAN BUDGET ACT OF 2013 (Joint Resolution, 113th Congress, H.J. Res. 59; Public Law No. 113-67), effective October 1, 2014. However, implementation was delayed twice, most recently by § 220 of the MEDICARE ACCESS AND CHIP REAUTHORIZATION ACT OF 2015 (U.S. House, 114th Congress, H.R. 2; Public Law No. 114-10, § 220, 129 Stat. 87, 154 (2015)), delaying implementation through October 1, 2017.

(b) However, a mere four months later, in February 2018, the **anti-*Ahlborn* legislation** described in Paragraph (a), above, was **"permanently" and retroactively repealed** as part of the BIPARTISAN BUDGET ACT OF 2018 (H.R. 1892, 115TH CONGRESS), Section 53102 ("Third Party Liability in Medicaid and CHIP"). Subsections (b)(1) and (c)(3), provide as follows:

> "(b)(1) REPEAL. Effective as of September 30, 2017, subsection (b) of section 202 of the Bipartisan Budget Act of 2013 (Public Law 113-67; 127 Stat. 1177; 42 U.S.C. 1396a note) (including amendments made by such subsection) is repealed and the provisions amended by such subsection shall be applied and administered **as if such amendments had never been enacted**."

> "(c)(3) EFFECTIVE DATE; TREATMENT. The repeal and amendment made by this subsection shall take effect as if enacted on September 30, 2017, and shall apply with respect to any open claims, including claims pending, generated,

or filed, after such date. The amendments made by subsections (a) and (b) of section 202 of the Bipartisan Budget Act of 2013 (Public Law 113-67; 127 Stat. 1177; 42 U.S.C. 1396a note) that took effect on October 1, 2017, are null and void and section 1902(a)(25) of the Social Security Act (42 U.S.C. 1396a(a)(25)) shall be applied and administered **as if such amendments had not taken effect on such date**."

(7) If a first-party Special Needs Trust will terminate prior to the actual death of the beneficiary, *e.g.* in the event that the beneficiary recovers from his disability and no longer meets the SSA's definition of "disabled," POMS SI 01120.199.F.1. sets forth the following requirements for approved **"early termination"** provisions: (i) the Medicaid payback is satisfied after payment of certain allowable trust administrative expenses (*i.e.* state or federal taxes due as a consequence of the termination of the trust, and reasonable fees and expenses associated with the termination and "wrapping up" of the trust); (ii) the beneficiary (and no other entity or person) receives all remaining trust funds; and (iii) the power to terminate the trust early is held by someone other than the beneficiary.

(8) The Medicaid payback amount (whether paid at the beneficiary's death or some earlier time) is calculated based on the **actual Medicaid rate** for expenditures for the beneficiary during his lifetime (which is significantly lower than private-pay rates for the same services), and does *not* include an "interest" component (which amounts to an **interest-free loan** from the government). The Trustee is well advised to review the details of the alleged payback amount with those persons who were intimately involved in the beneficiary's healthcare plan, as frequent (and significant) errors abound in Medicaid record-keeping.

(9) If the beneficiary during his life has received Medicaid benefits from more than one state, POMS SI 01120.203.B.10. specifies that the **"trust must provide payback for any state(s) that may have provided medical assistance under the state Medicaid plan(s) and not be limited to any particular state(s) . . .."** The 2018 revisions of the POMS now clearly authorize a *pro rata* allocation of the property remaining in a first-party Special Needs Trust if the remaining assets are insufficient to satisfy fully the claims of all of the state Medicaid Plans which have provided medical assistance to the beneficiary during his lifetime. "If the trust does not have sufficient funds upon the beneficiary's death to reimburse in full each state that provided medical assistance, the trust may reimburse the states on a *pro rata* or proportional basis." POMS SI 01120.203.B.10.

g. Additional POMS Requirements. The provisions of POMS SI 01120.203.B. also apply to a first-party Special Needs Trust established on or after December 13, 2016. *See* POMS SI 01120.203.C.4., referencing POMS SI 01120.203.B.2. through SI 01120.203.B.6., SI 01120.203.B.8. and SI 01120.203.B.10. A first-party Special Needs Trust must also pass muster under POMS SI 01120.201. and POMS SI 01120.200.D.1.a., to determine if it is a countable resource. *See* POMS SI 01120.203.A., 01120.203.B.1., 01120.203.C.1., and 01120.200.A.1.

(1) In addition to the issue of irrevocability, discussed at Section III.B.2.C, *supra,* POMS SI 01120.200.D.1.a. and 01120.200.D.1.b.2. effectively require the inclusion in the trust agreement of a **spendthrift clause that is valid under state law**, to preclude the beneficiary from selling his beneficial interest in the trust for cash that can then be used for his food or shelter needs, *i.e.* his "support and maintenance." POMS SI 01120.200.B.13. sets forth the SSA's understanding of a spendthrift clause. Best practice dictates the inclusion of a spendthrift clause prohibiting both voluntary and involuntary transfers of the beneficiary's interest in the first-party Special Needs Trust.

3. In addition to the first-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A), 42 U.S.C. § 1396p(d)(4)(B) authorizes a limited-use trust designed to receive and distribute any income of the beneficiary which exceeds the "income cap" prescribed by a state for Medicaid long-term care eligibility (*i.e.* nursing home Medicaid). *See* additional discussion in Section IV.A.1.c.(3)(a), *infra.* These trusts are also known as **"Miller Trusts"** or **"Qualified Income Trusts."** The requirements for a valid "(d)(4)(B)" trust include the following:

a. The trust must be irrevocable and established for the benefit of the beneficiary by himself, his legal Guardian or Conservator, or an attorney-in-fact acting under a Power of Attorney that grants express authority to establish such a trust.

b. The Trustee may be anyone willing to serve as such (including a nursing home), other than the beneficiary.

c. The trust property can consist solely of the beneficiary's income, such as pension benefits, Social Security benefits, investment income and the like. No other assets or resources may be deposited to the trust.

d. All income deposited to the trust must be fully utilized by the end of the following month for permissible purposes only, including payments for (i) the beneficiary's "share of cost" for nursing home expenses (or the covered expenses of the beneficiary under certain other community-based "classes of assistance" of the state Medicaid program); (ii) the beneficiary's "personal needs allowance;" (iii) approved "diversions" to a community spouse or dependent children; or (iv) medical expenses of the beneficiary or a community spouse that are not covered by Medicaid. Notably *excluded* as permissible expenditures are the fees of professional advisors, bank service fees, or any non-medical living expenses (*e.g.* mortgage or rent).

e. Upon the death of the beneficiary (or other earlier termination events), any funds remaining in the trust must be paid to the state Medicaid program.

f. A Miller Trust/Qualified Income Trust is *not* considered an excluded resource for SSI eligibility purposes. However, some states may exclude these trusts from counting as a resource for Medicaid eligibility purposes. *See* POMS SI 01120.203.F.

C. <u>Third-Party Special Needs Trusts</u>

1. There is **no specific federal statutory authority** for the creation of a third-party Special Needs Trust (*i.e.* one that is funded with assets that do not belong to the beneficiary). However, the POMS published and maintained by the SSA do specifically address third-party Special Needs Trusts. *See, e.g.,* POMS SI 01120.200.A.1.b., POMS SI 01120.200.B.16. **The POMS applicable to first-party Special Needs Trusts, discussed in Section III.B, *supra* (including POMS SI 01120.201. and SI 01120.203.) do not apply to third-party Special Needs Trusts. *See* POMS SI 01120.201.A.2.**

2. Third-party Special Needs Trusts are not subject to most of the federal statutory requirements mandated for first-party Special Needs Trusts, described in Section III.B, *supra.* POMS SI 01120.201.A.2 (among other sections) now clearly states that the POMS which apply to first-party Special Needs Trusts (including POMS SI 01120.203. in its entirety) do not apply to third-party Special Needs Trusts. Thus, most importantly, ***there is no Medicaid payback for a third-party Special Needs Trust*** that is drafted properly from the outset. Consequently, as a general matter, **third-party funds should never be added to a first-party Special Needs Trust, which could unnecessarily subject those funds to the Medicaid payback required for first-party Special Needs Trusts.** Furthermore (i) anyone can serve as the Settlor of a third-party Special Needs Trust; (ii) the beneficiary need not meet any particular definition of "disabled;" (iii) there is no age limitation on the beneficiary or the timing of funding the trust; and (iv) the beneficiary need not be the sole beneficiary of the trust. The POMS do require that the trust be **irrevocable as to the Beneficiary**, *i.e.,* the beneficiary cannot hold the right to revoke or terminate the trust or to use the trust funds for his support or maintenance under the terms of the trust. *See* POMS SI 01120.200.D.1.a., SI 01120.200.D.2. and POMS SI 01120.201.D.1. **"If an individual does not have the legal authority to revoke or terminate the trust or to direct the use of the trust assets for his or her own support and maintenance, the trust principal is not the individual's resource for SSI purposes." *Id.***

a. Drafters are advised to include a **valid spendthrift clause** in the trust agreement that prohibits the beneficiary from transferring or selling his beneficial interest in the trust, and prohibits involuntary transfers (*e.g.* to the beneficiary's creditors), thus precluding those avenues for accessing trust assets for the beneficiary's support and maintenance. *See* POMS SI 01120.200.B.13., and SI 01120.200.D.1.a., and SI 01120.200.D.1.b.2.

3. Third-party Special Needs Trusts may be established ***inter vivos*** (*i.e.* during the Settlor's life), including as part of his estate plan (*e.g.* under a Revocable Living Trust that serves as a Will substitute), or under the Settlor's Will as a **testamentary** trust.

a. However, if the Settlor's spouse is the intended beneficiary of a third-party Special Needs Trust, 42 U.S.C. § 1382b(e) requires that the trust be created under the Settlor's Will (and *not* pursuant to a Will substitute such as a Revocable Living Trust) in order to be disregarded as an "available" or "countable" resource to the spouse for purposes of eligibility for means-tested government benefits (discussed in more detail in Section IV, *infra*).

D. <u>"Pooled" Special Needs Trusts</u>

1. In addition to the single-beneficiary first-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A), described in Section III.B., *supra*, OBRA '93 also authorized the concept of a "pooled" Special Needs Trust, with a separate first-party sub-account established for the sole benefit of a beneficiary with a disability. 42 U.S.C. § 1396p(d)(4)(C) (and related POMS provisions) set forth the following **statutory requirements for a first-party sub-account with a pooled Special Needs Trust (often also referred to as a "(d)(4)(C)" Special Needs Trust).**

a. First Statutory Requirement. A pooled Special Needs Trust must be **"established and managed by a non-profit association."** POMS SI 01120.203.D.1. POMS SI 01120.203.D.3. defines a non-profit association as "an organization established and certified under a state nonprofit statute." As of January 2011, tax-exempt status is no longer required of the non-profit association.

b. Second Statutory Requirement. A first-party sub-account with a pooled Special Needs Trust must contain the assets of an individual who is **"disabled"** as defined by 42 U.S.C. § 1382c(a)(3) (discussed in Section III.B.2.b, *supra*). Prior to June 26, 2019, the SSA required proof of a qualifying disability at the time a sub-account was established. POMS SI 01120.203.D.2. Since June 26, 2019, POMS SI 01120.203.D.2. now requires the beneficiary to satisfy the SSA's definition of disabled "as of the date on which the trust's resource status could affect the individual's SSI eligibility."

c. Third and Fourth Statutory Requirements. The pooled Special Needs Trust must maintain a **separate first-party sub-account** for the **sole benefit** of each beneficiary with a disability, but may pool the assets of the separate sub-accounts for purposes of investment and management. *See* POMS SI 01120.203.D.1., 4. and 5.

d. Fifth Statutory Requirement. A separate first-party sub-account with the pooled Special Needs Trust must be **established by** (i) the beneficiary's legal Guardian of the Property or Conservator; (ii) the beneficiary's parent or grandparent; (iii) a court; or (iv) the beneficiary himself (or his attorney-in-fact acting under a Power of Attorney). (In contrast, as noted in Section III.B.2.a., *supra*, only since December 13, 2016 has it been permissible for the beneficiary of a first-party (d)(4)(A) Special Needs Trust to serve as the Settlor of his trust.) POMS SI 01120.203.D.1. and 01120.203.D.6.

e. Sixth Statutory Requirement. To the extent that the pooled Special Needs Trust does not retain any amounts remaining in a separate first-party sub-account upon the beneficiary's death, such assets must be used to **reimburse Medicaid** (but not the SSA) up to the total amount of medical assistance benefits paid on behalf of the beneficiary during his lifetime under one or more state Medicaid Plans, *i.e.* not just after the sub-account is established. *See also* POMS SI 01120.203.D.8. "If the trust does not have sufficient funds upon the beneficiary's death to reimburse each state that provided medical assistance, the trust may reimburse the states on a *pro rata* or proportional basis." *Id.* POMS SI 01120.203.E.1. describes the few permissible pre-payback expenses that are allowable.

(1) POMS SI 01120.199.F.2. sets forth modified requirements for an acceptable **"early termination"** provision applicable to a beneficiary's first-party sub-account with a pooled Special Needs Trust. The requirements described in Section III.B.2.f.(7), *supra* (*i.e.* for first-party Special Needs Trusts), need not be satisfied in the context of a pooled Special Needs Trust if the early termination provision only allows for the transfer of an account from one qualified pooled Special Needs Trust to another. However, no funds may be retained by the first pooled Special Needs Trust if the termination of the beneficiary's account occurs during his life rather than by virtue of his death.

f. There is **no express statutory limitation on the age** of a beneficiary of a first-party sub-account with a pooled Special Needs Trust, *i.e.* a first-party sub-account may theoretically be established with a pooled Special Needs Trust even if the beneficiary is 65 or older (in contrast to a (d)(4)(A) Special Needs Trust, as described in Section III.B.2.e., *supra*). However, many states choose to impose a **penalty for the uncompensated transfer** of the beneficiary's assets to the pooled Special Needs Trust after the age of 65 if the beneficiary wishes to qualify for Medicaid long-term care (*i.e.* nursing home) coverage, or for certain long-term care services rendered in the community. *See* 42 U.S.C. § 1396p(c)(1)(B)(i)-(ii), (c)(1)(G), (e)(1), (f); POMS SI 01120.203.D.1. and POMS SI 01150.121.

(1) The United States Court of Appeals for the Third Circuit has held that the attempt by the Commonwealth of Pennsylvania to impose an age limitation on the persons who can establish an account with pooled Special Needs Trusts authorized by 42 U.S.C. § 1396p(d)(4)(C) (*i.e.* prohibiting beneficiaries who are 65 years of age or older) violates federal law and is thus preempted. *See Lewis v. Alexander*, 685 F.3d 325 (3d Cir. 2012).

g. Additional POMS Requirements. A first-party sub-account with a pooled Special Needs Trust must also pass muster under POMS SI 01120.200.D.1.a. to determine if it is a countable resource. POMS SI 01120.203.D.1.

h. A separate sub-account with a **pooled Special Needs Trust** may also be established with assets derived from a **third-party**. While the beneficiary of a third-party sub-account with a pooled Special Needs Trust must still satisfy the government's definition of "disabled" (which is not required for the beneficiary of a third-party Special Needs Trust, as described, *supra*, in Section III.C.2), (i) there is no restriction on who can establish the third-party account; (ii) the beneficiary's age does not limit the timing of the establishment or funding of the account; and (most importantly) (iii) **there is no Medicaid payback with a third-party sub-account.**

i. A pooled Special Needs Trust is typically governed by a **"Master Trust Agreement"** that applies to all of the separate sub-accounts. A separate sub-account is established by completing a **"Joinder Agreement,"** which usually does not require the involvement of an attorney (one of the most popular aspects of this option). This is a very cost-effective option for a beneficiary who has too many assets to maintain his eligibility for means-tested government benefits, but not enough to warrant the expense of creating or maintaining a custom-drafted first-party or third-party Special Needs Trust.

j. Prior to December 13, 2016, a first-party sub-account with a pooled Special Needs Trust was often **the only option** for a beneficiary who (i) had no living parents or grandparents, (ii) was "disabled" but mentally competent and thus could not qualify for a legal Guardian or Conservator under state law, (iii) could not convince a court to serve as the Settlor of a (d)(4)(A) Special Needs Trust, and/or (iv) was age 65 or older.

2. Supreme Court Review? On June 12, 2012, the United States Court of Appeals for the Third Circuit held that the Medicaid program administered in the Commonwealth of Pennsylvania could not impose additional criteria for the exemption of pooled Special Needs Trusts authorized by 42 U.S.C. § 1396p(d)(4)(C). *See Lewis v. Alexander*, 685 F.3d 325 (3d Cir. 2012). Pursuant to the federal preemption doctrine, the Court struck down the following elements of a Pennsylvania statute that purported to impose additional qualification criteria over and above those set forth in the federal statute: (i) a restriction on the amount of funds in a deceased beneficiary's account that can be retained by the pooled Special Needs Trust; (ii) a requirement that expenditures from a beneficiary's account must be "reasonably related" to the beneficiary's needs; (iii) a requirement that the beneficiary's special needs could not be met without the funds in the beneficiary's account; (iv) a definition of "special needs" that limits permissible disbursements to "items, products or services . . . related to the treatment of the beneficiary's disability;" and (v) a restriction limiting beneficiaries of a pooled Special Needs Trust to those under 65 years of age.

a. The Court held that "Congress intended that special needs trusts be defined by a specific set of criteria that it set forth and no others. We base this upon Congress' choice to provide a list of requirements to be met by special needs trusts. The venerable canon of statutory construction— *expressio unius est exclusio alterius*—essentially says that where a specific list is set forth, it is presumed that items not on the list have been excluded . . .. Absent an explicit statement or a clear impression that states are free to expand the list, *expression unius* leads us to conclude they are not." *Id.* at 347.

b. Earlier in its decision, the Court concluded that "in determining Medicaid eligibility, states are **required to exempt any trust meeting the provisions** of 42 U.S.C. § 1396p(d)(4)." *Id.* at 344. The Third Circuit's holding that "42 U.S.C. § 1396p(d)(4) imposes mandatory obligations upon the states" is contrary to the position of the Second Circuit in *Wong v. Doar*, 571 F.3d 247 (2d Cir. 2009), and the Tenth Circuit in *Keith v. Rizzuto*, 212 F.3d 1190 (10th Cir. 2000), which held that 42 U.S.C. § 1396p(d)(4) **does not mandate that the states exempt Special Needs Trusts meeting its criteria**. *Id.* 343. On January 14, 2013, the United States Supreme Court denied a Petition for Writ of Certiorari, thus leaving intact the Third Circuit's decision. *See* 133 S.Ct. 933 (2013). This issue is thus **ripe for a review by the United States Supreme Court.**

E. <u>"Sole Benefit" Trusts</u>

1. 42 U.S.C. § 1396p(c)(2)(B)(iii) and (iv) (Medicaid) and § 1382b(c)(1)(C)(ii)(IV) (Supplemental Security Income) exempt from transfer penalties (for purposes of *the transferor's* eligibility for Medicaid and SSI) any amounts transferred to a trust "solely for the benefit of" (i) the transferor's child (of any age) who is blind or "disabled" (within the meaning of the Social Security Act), or (ii) any person under the age of 65 who is "disabled." *See also* POMS SI 01150.121.A.2 and 3. While a so-called "Sole Benefit Trust" ("SBT") is usually drafted as a Special Needs Trust so that it does not count as an "available" or "countable" resource to a beneficiary who receives means-tested government benefits, the states are split on whether a SBT must contain a Medicaid payback provision (as required of first-party "(d)(4)(A)" and "(d)(4)(C)" Special Needs Trusts), or whether the trust agreement can instead mandate that all trust property must be paid out on an "actuarially sound" basis over the beneficiary's estimated life expectancy (which might be a viable option for beneficiaries who do not receive means-tested government benefits). The states are further split on the definition of "sole benefit" distributions, both in the context of SBTs and the other types of Special Needs Trusts discussed in this Section III, *supra*.

F. <u>Special Needs Trusts are not "available" or "countable" for purposes of most "means-tested" government benefits</u>

1. Special Needs Trusts (whether first-party or third-party) that are ***properly drafted*** **are not considered "available" or "countable"** resources for purposes of the beneficiary's eligibility for most "means-tested" government benefits, including Medicaid and Supplemental Security Income (discussed in Section IV, *infra*).

a. A properly drafted Special Needs Trust (whether first-party or third-party) will specify that the Trustee is not obligated, and cannot be compelled by the beneficiary, a court, or anyone else, to use the assets of the trust to provide for the beneficiary's "support" or "maintenance." **In most jurisdictions, the use of the "support" or "maintenance" distribution standards with respect to disbursements for a beneficiary who is otherwise eligible for means-tested government benefits typically results in the trust assets being deemed "available" or "countable" to the beneficiary, thus jeopardizing such eligibility.**

(1) Thus, the last two of the **classic "h-e-m-s" ascertainable standards** for trust distributions found in most testamentary "Bypass/Credit Shelter Trusts" (*i.e.* "health, education, ***maintenance*** and ***support***") will generally render the assets of those trusts **"available" or "countable"** resources to a beneficiary seeking to maintain his eligibility for means-tested government benefits. *See* POMS SI 01120.200.D.1.a. and 2.

(2) While some practitioners utilize a **fully discretionary distribution** standard for Special Needs Trusts, unadorned by any descriptive standard whatsoever, many professional Trustees prefer an **illustrative listing of permissible types** of distributions that can be made from a Special Needs Trust without adversely impacting the beneficiary's means-tested benefits. The following are a few of **the most common types of permissible disbursements.**

(a) As noted *supra* at Section III.B.2.d, the administration of first-party Special Needs Trusts must be guided by the "sole benefit rule" imposed by the SSA. The **April 2018 revisions to the POMS attempt to soften the SSA's previously strict construction of the sole benefit rule.** The "kinder, gentler" construction of this rule (which, as noted above, generally does not apply to third-party Special Needs Trusts) is currently espoused in POMS SI 01120.201.F.3.a., requiring simply that the beneficiary derive "primary benefit" from a trust disbursement. Drafters and administrators of first-party Special Needs Trusts are well advised to review and understand these new provisions, and the examples illustrating the significant "thaw" in the SSA's previously intractable position on the sole benefit rule as applied to first-party Special Needs Trusts.

(b) Permissible disbursements include payments **directly to the providers of services** for the benefit of the beneficiary, including services not covered by Medicaid; household services, including cable TV, internet, telephone, security alarm, housekeepers; professional services, including those of attorneys, accountants, care managers, life care planners, benefits advocates, special education advocates, investment advisors; personal care services, such as dry cleaning, laundry, hairstylists, massage therapists, acupuncturists, personal attendants; companion/sitter services; counseling and therapies.

(c) Permissible disbursements include payments **directly to the providers of goods** for the benefit of the beneficiary (excluding food and shelter), including medical equipment and supplies, household appliances, furniture and furnishings; clothing and personal effects; camera and computer equipment; musical instruments; fitness and sporting equipment; hobby supplies; magazine and newspaper subscriptions; holiday decorations and cards; linens and towels; stationery and stamps; tickets to recreational or entertainment events.

(d) Also permissible are **"quality of life"** expenditures, such as appropriate vacations; educational opportunities and supplies; club memberships; a pet or service animal and its required supplies and veterinary care.

(e) Frequent requests for payment of **transportation** costs, (including an appropriate private vehicle) and the fuel, maintenance and insurance therefor; taxi or private driver; ride-share transportation options, such as Uber and Lyft; public transportation passes; bicycle, moped or golf cart; helicopter or private airplane, are also permissible, as long as no cash exchanges hands.

(f) Permissible disbursements also include **non-food** grocery and household items; personal care and hygiene items; over-the-counter medications.

(g) Finally, it is permissible for the trust to pay the beneficiary's **credit card bill** for items other than shelter or food (*e.g.* no payment for groceries, restaurant dining or catered meals).

(h) The 2018 POMS revisions make it clear that the Trustee of a first-party or third-party Special Needs Trust may permissibly use trust assets to fund an ABLE account (discussed in detail in Section VII, *infra*) for the beneficiary. *See* POMS SI 01120.201.I.1.c. and h.

b. A properly drafted Special Needs Trust (whether first-party or third-party) will specify the Settlor's intention that **the trust should "supplement, not supplant" any public or private benefits** for which the beneficiary may be eligible as a consequence of his disability.

(1) Nevertheless, the Trustee should also be given the latitude to **"opt out" of such benefits** if they are not "reasonably available" to the beneficiary (*e.g.* the expense of obtaining the benefits exceeds the value thereof), or if the benefits are insufficient or otherwise inadequate to provide fully for the beneficiary's needs.

2. Special Needs Trusts that are ***properly administered*** **are not considered "available" or "countable"** for purposes of the beneficiary's eligibility for most "means-tested" government benefits, including Medicaid and Supplemental Security Income (discussed in Section IV, *infra*).

a. In general, the Trustee of a Special Needs Trust must make disbursements **directly to the provider** of goods and services for the benefit of the beneficiary with the disability, for purposes ***other than the beneficiary's food or shelter needs*** (*i.e.*, the two categories of disbursements that the government includes in a person's **"support" and "maintenance"**). *See* POMS SI 01120.201.I. for an overview of how to minimize the potential adverse impact of trust distributions on the beneficiary's means-tested benefits.

(1) Nevertheless, a Special Needs Trust **should not specifically prohibit** the Trustee from using the assets of the trust for the beneficiary's **food or shelter** needs, notwithstanding a possible reduction in the beneficiary's means-tested government benefits for such use, if to do so would serve the best interests of the beneficiary.

(a) The classic example of a situation where it would be in the beneficiary's best interests to use the assets of a Special Needs Trust to provide for his shelter is where his monthly cash benefit from the Supplemental Security Income program (maximum Federal Benefit Rate for 2022 is $841 per month) is insufficient to cover his rent or mortgage payment. If the Trustee of the Special Needs Trust either (i) "makes up the difference" between the SSI payment and the actual rent or mortgage payment that is due, or (ii) pays the entire rent or mortgage payment that is due, this will in turn nominally reduce the beneficiary's SSI payment for that month. *See infra*, at Section IV.A.1.a.(2)(f). As long as the Trustee is cognizant of the impact on the beneficiary's means-tested benefits of such disbursements, any potentially adverse impact on the beneficiary's overall living situation can generally be managed in the best interest of the beneficiary.

(2) Disbursements of cash or cash equivalents (including funds accessible via the beneficiary's personal unrestricted bank debit card, the beneficiary's credit card with cash advance features, or items that can be converted to cash, *e.g.* **a gift card or gift certificate) should never be distributed directly to the beneficiary**, as this will result in a dollar-for-dollar reduction in the beneficiary's means-tested benefits. POMS SI 01120.201.I.1.a. and f.

(a) A distribution of **cash (or cash equivalents) to the beneficiary's Guardian, Conservator**, or legal representative, or other person "acting on his behalf," will be deemed made to the individual beneficiary directly. *See* POMS SI 01120.201.D.3.a. In contrast, **reimbursements paid to a third party** for funds expended on behalf of the beneficiary are not considered made to the beneficiary. *See* POMS SI 01120.201.I.g. Similarly, payments from a trust to pay off a credit card belonging to a third party for purchases (other than food or shelter) made by that person for the trust beneficiary are not deemed to be made directly to the beneficiary. *Id.*

(b) A practical tool to afford the beneficiary with limited access to appropriate purchasing power is an **"administrator-managed prepaid card"** such as the True Link debit card. *See* www.truelinkfinancial.com. The updated POMS that were issued in April 2018 specifically mention the True Link card in POMS SI 01120.201.I.1.e., and provide a step-by-step analysis on how to utilize this tool without jeopardizing the beneficiary's eligibility for means-tested government benefits. **Required elements of the effective use of a True Link card** include: (i) the Trustee is the owner of the prepaid card account, and the beneficiary is merely a cardholder; (ii) the card is not used to obtain cash; and (iii) the card is not used to pay for food or shelter items. The True Link card can be programmed by the administrator (*i.e.* the Trustee) to block its acceptance at specified types of vendors for specified categories of items. The administrator determines the amount of purchasing power pre-loaded onto the card, *i.e.* it is not attached directly to the trust assets.

(3) In exercising its fiduciary discretion to make (or not) a disbursement for the benefit of the beneficiary of a Special Needs Trust, the Trustee must first consider (i) the impact of a proposed distribution on the beneficiary's eligibility for means-tested programs and services, and (ii) the consequent benefit to the beneficiary of the proposed distribution, *i.e.* is the proposed disbursement in the best interest of the beneficiary. Only after both of these factors have been ***reviewed, considered*** and ***documented*** should the Trustee make (or not) a distribution for the benefit of the beneficiary of a Special Needs Trust. This deliberative process will help avoid a claim that the Trustee "has abused its discretion by acting in bad faith or beyond the bounds of reasonable judgment."[8] For a suggested list of additional considerations to be assessed by the Trustee of a discretionary trust (not just a Special Needs Trust) in response to a distribution request, and a discussion of how to establish a process for exercising a Trustee's discretionary power to make disbursements (or not) for the benefit of a trust beneficiary, *see*

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[8] *See* Edward V. Wilcenski and Tara Anne Pleat, *Administration of Special Needs Trusts: Development of an Improved Approach*," N.Y.S. Bar Journal (March 2019), at 20, citing *Trust of Frederick Brockway Gleason, Jr.* 1999/4582A, N.Y.L.J. 1202629074611, AT #1 (Sur. Ct., New York Co., 2013).

Christian S. Kelso, *"Get HEMS Straight: Tailor the Right Distribution Standard*," Estate Planning, November 2015 (Vol. 42, No. 11).

3. As noted in Section III.B.2.d.(1), *supra*, transfers by a beneficiary under age 65 of his assets to a first-party Special Needs Trust that is *properly drafted and properly administered* are **not penalized as "uncompensated transfers"** for purposes of the beneficiary's eligibility for means-tested benefits. *See* 42 U.S.C. §§ 1396p(c)(2)(B)(iii) and (iv); 42 U.S.C. § 1382b(c)(1)(C)(ii)(IV); POMS SI 01150.121.A.3.

a. However, as noted in Section III.D.1.f, *supra*, numerous states do choose to penalize the funding of a (d)(4)(C) pooled Special Needs Trust account by a beneficiary who is **65 years of age or older** at the time of the funding transfer.

b. In general, **transfer penalties** for purposes of **Supplemental Security Income** apply to uncompensated transfers during a **36-month "look-back period,"** which starts from the date of the transfer or the date of the application for SSI, whichever is later. 42 U.S.C. § 1382b(c)(1)(A)(iv). To calculate the period of ineligibility, the amount transferred is divided by the transferor's monthly SSI benefit, rounding up or down to the nearest whole number. Uncompensated transfers to trusts that are not safe harbor "(d)(4)(A)" or (d)(4)(C)" Special Needs Trusts (or a "Sole Benefit Trust," as described, *supra*, in Section III.E.) are generally treated as available resources if there are *any* circumstances under which the Trustee could make distributions for the benefit of the transferor or his spouse. POMS SI 01120.201.D.2.

c. In general, **transfer penalties** for **Medicaid** purposes include a maximum **"look-back period" of 60 months**. The penalty period is determined by dividing the value of the transferred assets by the statewide average private-pay rate for nursing home services. *See* 42 U.S.C. § 1396p(c)(1)(E) and POMS SI 01730.046.

IV. GOVERNMENT BENEFITS THAT ARE "MEANS-TESTED" AND THOSE THAT ARE BASED ON A WORKER'S EMPLOYMENT HISTORY

A. "Means-tested" government benefits for persons with disabilities

1. The two most relevant means-tested government benefits programs that persons with disabilities typically wish to maintain are **Supplemental Security Income ("SSI")**, a monthly cash benefit intended to cover a person's food and shelter needs, and Medicaid. In 2022, the maximum Federal Benefit Rate ("FBR") for SSI is $841 per month, although some states provide "state supplements" to this base amount. **Medicaid** is the means-tested program which provides basic health care and medical services. Financial eligibility for means-tested government benefits is determined by reference to the applicant's "available" or "countable" income and resources. **Properly drafted, established, funded and administered Special Needs Trusts do not count against the beneficiary in determining financial eligibility for these means-tested benefits.**

a. **SSI** is authorized by Title XVI of the Social Security Act, 42 U.S.C. §§ 1381-1383f, and Title 20, Part 416 of the Code of Federal Regulations. The **SSI eligibility requirements** include:

(1) The applicant is aged **65 or older, blind or "disabled"** (*i.e.* unable to engage in "substantial gainful activity," as described in Section III.B.2.b., *supra*). If the applicant is under the age of 18, disability is defined by reference to "marked and severe functional limitations," as described in Section III.B.2.b., *supra*.

(2) The applicant has **minimal earned and unearned income and resources** to pay for his food and shelter needs.

(a) Resources include the applicant's cash or other assets that he owns and can convert to cash and **use for his support and maintenance.** Resources are either "excluded" (*e.g.* a home, one automobile, normal household items and personal effects, certain burial funds and funerary services) or "countable." *See* POMS SI 01130.050. ("Guide to Resource Exclusions"). **Countable resources cannot exceed $2,000** for an individual, or $3,000 for a couple.

(b) Special Needs Trusts that are properly drafted, established, funded and administered are considered "unavailable" or "not countable" to the beneficiary for purposes of his financial eligibility for SSI.

(c) An applicant's **income may be either "earned" or "unearned,"** and if it is "countable" will reduce the amount of his monthly SSI cash payment. There are limited income exclusions, which include the first $20 of general income in a month (other than "In-Kind Support and Maintenance" ("ISM"), discussed *infra*); $65 of earned income in a month, plus half of the remaining earned income in a month, and for a person who is disabled but not blind, the first $780 per year. **"Earned income" only reduces the SSI payment by 50 cents for each dollar earned, while "unearned income" reduces the SSI payment dollar-for-dollar (with special rules for ISM,** discussed *infra*).

(d) "Earned" income includes wages; net earnings from self-employment; payments for participating in a sheltered workshop or other supported employment; royalties; and honorariums.

(e) "Unearned" income is all income that is not earned, and includes ISM; private pensions and annuities subject to the Employee Retirement Income Security Act ("ERISA") (29 U.S.C.A. § 1056(d)), as well as periodic payments, such as Social Security Disability Income payments, worker's compensation, veterans benefits, unemployment benefits (most of which are **non-assignable to a Special Needs Trust,** *see, e.g.*, POMS SI

01120.200.G.1.c. and POMS SI 01120.201.J.1.c.); life insurance proceeds or other death benefits; gifts and inheritances; support and alimony; dividends and interest; and rents and royalties.

(i) There is one recent notable exception to the general rule that veterans benefits are non-assignable and thus constitute unearned income to the recipient: the **military "Survivor Benefits Plan" ("SBP")** retirement annuity option for the benefit of a "disabled dependent child." For purposes of this program, a "dependent child" is defined in 10 U.S.C. § 1447(11), and "disabled" is defined in 42 U.S.C. § 1382c(a)(3). The "Disabled Military Child Act" (Public Law 113-291, amending Title 10, U.S.C. §§ 1448, 1450 and 1455), signed by President Obama on December 19, 2014, authorized a **military parent to elect (during the parent's lifetime) to *irrevocably assign* to a *first-party* Special Needs Trust the SBP annuity for a disabled dependent never married child.** (*See* discussion, *supra*, at Section III.B., for the requirements of a first-party Special Needs Trust.) The Department of Defense ("DOD") issued initial implementation guidance on December 31, 2015 in the form of a "Memorandum" to the Deputy Assistant Secretaries of the Army, Navy and Air Force, captioned "Enabling Payment of Survivor Benefit Plan Annuities to a Special Needs Trust." POMS SI 01120.201.J.1.e., part of the April 2018 POMS updates, expressly recognizes that the SBP annuity is assignable to a first-party Special Needs Trust. *See also* POMS SI 01120.200.G.1.d. The original DOD guidance was superseded by DOD Instruction 1332.42 ("DOD Instruction") on December 30, 2020 (available at https://www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodi/133242p.pdf. Section 6.4.b. of the DOD Instruction provides that a covered participant may, during life, irrevocably elect to designate a first-party Special Needs Trust for the sole benefit of their dependent child with a disability to receive the child's SBP annuity payments. If the covered participant failed to do so prior to their death, then the dependent child's surviving parent, grandparent, or court-appointed legal guardian or fiduciary may establish and irrevocably designate a first-party Special Needs Trust to receive the child's SBP annuity payments. *See* Section 6.4.c. of the DOD Instruction. Section 6.4.f. of the DOD Instruction outlines the requirements of, and the procedure for, designating a compliant first-party Special Needs Trust to receive SBP payments after the death of the covered participant.

(f) "In-Kind Support and Maintenance" ("ISM") consists of food or shelter provided directly to the applicant and paid for by a third person, including a Special Needs Trust. This category of unearned income does not result in a dollar-for-dollar reduction of the SSI benefit, but is generally limited to a maximum reduction equal to one-third of the maximum SSI Federal Benefit Rate (plus $20, in some cases), regardless of the actual value of the food and shelter provided. **"Shelter" includes only the following items: mortgage payments (including any property insurance required by the mortgage holder); real property taxes; rent; heating fuel; gas; electricity; water; sewer; and garbage removal.** *See* POMS SI 00835.465.D.1. The dollar value of these items is added and divided by the number of people living in the home to determine each person's *pro rata* share. If a person is not paying at least this amount towards his *pro rata* share (*e.g.* with his monthly SSI benefit), his SSI benefit will be reduced in one of two ways, depending on his living arrangement. *See* POMS SI 01120.200.E.1.b. and POMS SI 01120.200.F.3.c.

(i) The **"Value of One-Third Rule" ("VTR")** applies if the SSI recipient lives in the household of another person throughout the month and receives both food and shelter from someone inside that household. The VTR reduces the SSI benefit by one-third of the FBR.

(A) In 2022, the FBR is $841 per month, so the VTR reduction is $280 per month ($841÷3). (For the current FBR and VTR amounts, *See* POMS SI 00835.901.)

(B) If the VTR applies, the SSI payment is reduced by the full VTR amount, regardless of how "short" the recipient is towards paying his *pro rata* share of the household food and shelter expenses. For example, if his *pro rata* share is $900 per month, and he can only pay $841 per month towards his *pro rata* share, his **SSI payment will be reduced by the full VTR** of $280 rather than just the deficit of $59.

(ii) In contrast, the **"Presumed Maximum Value Rule" ("PMV")** applies to all other living arrangements to which the VTR does not apply. The PMV rule applies when a person outside the household, including the Trustee of a Special Needs Trust (whether first-party or third-party), pays for the food or shelter of an SSI recipient.

(A) If the PMV Rule applies, the SSI recipient's SSI payment is reduced by the lesser of (A) one-third of the FBR plus the $20 general income exclusion (*i.e.* $300 in 2022, calculated as follows: $841÷3 plus $20), or (B) the actual value of the food and shelter received by the SSI recipient from the person outside the household.

(B) For example, if the Trustee of a Special Needs Trust pays $4,000 per month towards the beneficiary's food and shelter expenses, his SSI payment is reduced by no more than $300 per month. If, on the other hand, the Trustee pays only $100 per month towards those expenses (*e.g.* because the beneficiary's other income and resources are sufficient to pay for the balance of his *pro rata* share of the household expenses), then his SSI payment is only reduced by $100, not by $300. (In contrast, if the VTR were applicable, as explained above, the SSI payment would be reduced by the full $280 per month, not just by $100 per month.)

(iii) Warning: If the SSI recipient's monthly SSI payment is $280 or $300, as the case may be, or less (*e.g.* because of other countable income, including government benefits), then a trust distribution for his food or housing expenses that results in a VTR or PMV reduction could "zero out" his SSI payment, resulting in the consequent loss of SSI-linked Medicaid.

(iv) In contrast, distributions from an "ABLE account" for the food or shelter-related expenses of the "designated beneficiary" do not constitute ISM income to him if utilized for such purposes in the month of receipt. *See* POMS SI 01130.740.C.4. However, if a distribution for those purposes is not spent in the month of receipt, *i.e.* it is retained by the beneficiary into the month following the month of receipt, it will be counted as a "resource" subject to the normal SSI counting rules. *See* POMS SI 01130.740.D.2. For a full discussion of ABLE accounts, *see* Section VII, *infra*.

(g) In certain circumstances, the income or resources of other persons may be **"deemed" to be available** to the applicant for purposes of financial eligibility for SSI, including from a parent who is not eligible for SSI to an unmarried minor child who is applying for SSI, and from a spouse who is not eligible for SSI to a spouse who is applying for SSI. *See* POMS SI 01310.001. and SI 011320.001.

(3) Finally, the SSI applicant must be a **U.S. citizen, U.S. national or a "qualified alien,"** as defined in 8 U.S.C. § 1641(b).

(4) The SSA has the authority to designate a third party (an individual, an institution or an organization) as a **"Representative Payee" to receive and manage monthly SSI payments** for the benefit of a beneficiary who is incapacitated. These monthly payments to a Representative Payee do not become part of the beneficiary's Special Needs Trust or conservatorship estate; rather, the Representative Payee has independent authority to expend these payments for the beneficiary, and must separately report to the SSA how the benefits have been expended for the beneficiary during the annual reporting period. If the Representative Payee bank account to which the SSI benefits are direct-deposited each month has a balance that exceeds $2,000 for an individual (or $3,000 for a couple), the beneficiary will generally be considered "over-resourced," thus jeopardizing his ongoing eligibility for SSI. **SSI payments received by a beneficiary should never be added to a third-party Special Needs Trust, and it is not recommended that SSI payments be added to a first-party Special Needs Trust.**

b. Medicaid is governed by Title XIX of the Social Security Act, 42 U.S.C. §§ 1396-1396w-5. **Medicaid eligibility requirements** and benefits can vary from state to state, as it is a program that is jointly administered and funded by the federal government and the states. Medicaid eligibility is often **inextricably linked to SSI eligibility**. In this regard, there are three main classifications of state Medicaid programs.

(1) "SSI criteria states," in which the eligibility criteria are the same for SSI and Medicaid, but which require a separate application process for each benefit. Seven States (and the Northern Mariana Islands) fall into this category (Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon and Utah). *See* POMS SI 01715.010.A.2.

(2) "§ 209(b) states," in which at least one of the Medicaid eligibility criteria is more restrictive than the SSI eligibility criteria, and which require a separate application process for each benefit. Nine states fall into this category (Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Oklahoma and Virginia). *See* POMS SI 01715.010.A.1. In determining a person's eligibility for Medicaid, the states in this category may not use a methodology that is more restrictive than that used by the SSI program on January 1, 1972. *See* 42 U.S.C. §§ 1396a(a)(10)(C)(i)(III) and 1396a(r)(2).

(3) "§ 1634 states," in which SSI recipients automatically qualify for, and are enrolled in, the state Medicaid program. The thirty-four states not mentioned in (1) and (2), above, as well as the District of Columbia, fall into this category. *See* POMS SI 01715.010.A.3.

c. There are three main types of Medicaid eligibility:

(1) "Categorically needy" persons qualify for Medicaid if they also qualify for certain other government benefits programs, typically SSI. All states are required to cover the categorically needy. *Ramey v. Reinertson*, 268 F.3d 955, 960 (10th Cir. 2001), citing *Herweg v. Ray*, 455 U.S. 265, 268 (1982).

(a) In working with families who have adult children with disabilities, practitioners will find that many of these persons obtain their Medicaid coverage by virtue of their **eligibility for at least $1 of SSI**. Thus, it is critical that Special Needs Trusts for such individuals be administered in such a way that disbursements do not totally eliminate the beneficiary's monthly SSI payment. This might happen, for example, if the Special Needs Trust pays for the beneficiary's shelter costs, which constitutes ISM, which can reduce the beneficiary's SSI payment by up to one-third of the maximum Federal Benefit Rate at the time of reference. If the beneficiary's monthly SSI benefit amount is less than this one-third amount before the reduction for ISM (*e.g.* because of other earned or unearned income), and is thus reduced to zero after the reduction, his SSI-linked Medicaid coverage is lost.

(2) "Optionally categorically needy" persons with limited resources can qualify for Medicaid if their monthly incomes are not more than 300% of the Federal Benefit Rule (*i.e.* $2,382 in 2021).

(3) "Medically needy" persons with limited resources can qualify for Medicaid even if their incomes are over 300% of the Federal Benefit Rate, if their monthly medical expenses exceed their income and they agree to "spend-down" their excess income on their medical expenses.

(a) In 2017 [the last year for which the author could verify this information], **"Spend Down" states** included California, Connecticut, Hawaii, Illinois, Kansas, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New York, North Carolina, North Dakota, Ohio, Pennsylvania, Rhode Island, Utah, Vermont, Virginia, Washington, West Virginia and Wisconsin.

(b) Some states, known as **"Income Cap" states**, do not allow the "medically needy" to qualify for Medicaid by means of a "spend-down" of excess income. However, any excess income may be transferred to a Qualified Income Trust authorized by 42 U.S.C. § 1396p(d)(4)(B), discussed in Section III.B.3, *supra*. In 2017 [the last year for which the author could verify this information], the Income Cap states included Alabama, Alaska, Arizona, Arkansas, Colorado, Delaware, Florida, Georgia, Idaho, Indiana, Iowa, Kentucky, Louisiana, Mississippi, Nevada, New Jersey, New Mexico, Oklahoma, Oregon, South Carolina, South Dakota, Tennessee, Texas and Wyoming.[9]

(4) "Dual eligibles" are persons who qualify for both Medicaid and Medicare (discussed below). By virtue of their Medicare eligibility, these persons qualify for state Medicaid programs that will help them pay their Medicare premiums, co-payments or deductibles (*e.g.* the "Qualified Medicare Beneficiaries" program and the "Specified Low-Income Beneficiaries" program), and their prescription drug premiums or costs (*e.g.* the "Low-Income Subsidy" program run by the federal government). *See* additional discussion at Subsection B.1.e, *infra*.

d. Eligibility for SSI and Medicaid is also required for numerous community-based programs and services, *e.g.* group home residential arrangements and "life skills" programs. Access to these programs is limited to those persons whose financial affairs have been arranged so that they are eligible for SSI and Medicaid, and some will only accept SSI benefits as payment for program services, *i.e.* **private pay is not an option. A family's private wealth cannot guarantee access to these beneficial programs, contrary to the belief of many wealthy clients** who are accustomed to doing business on a "money talks" basis. Thus, even families of great wealth are engaging in Special Needs Trust planning for their beneficiaries with disabilities in order to gain access to these programs.

B. Employment-based government benefits for persons with disabilities

1. Many persons with disabilities are eligible for employment-based government benefits **determined by reference to the employment history of a worker**. The applicant's income and resources generally do not adversely impact these benefits, *i.e.* ***these benefits are not means-tested***. Under Title II of the Social Security Act, the "Old Age, Survivors and Disability Insurance" program ("OASDI"), the SSA affords certain benefits for workers, and their families, when the worker retires, becomes disabled or dies. *See* 42 U.S.C. §§ 401-434; 20 C.F.R. §§ 404.1-404.2127.

a. Social Security Retirement benefits provide monthly cash payments to eligible workers who have attained at least 62 years of age, and who have worked, and paid FICA taxes on sufficient earnings, and have earned at least 40 "credits" (a maximum of four credits each year) (formerly referred to as "quarters of coverage"). *See* 42 U.S.C. § 414(a)(2). In **2022, the amount of earnings needed to earn one credit is $1,510** (or $6,040 to earn the maximum of four credits for the year). Credits are based on total wages (or self-employment income) during the

[9] http://payingforseniorcare.com/longtermcare/resources/medicaid.html.

entire year, no matter when during the year the actual work was performed. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).[10]

b. Social Security Disability Insurance ("SSDI") benefits are monthly cash payments to a worker whose mental or physical disability renders him incapable of "Substantial Gainful Activity," as defined, *supra*, in Section III.B.2.b. The required number of "credits" (formerly referred to as "quarters of coverage") to secure this benefit varies depending on the age at which the worker became disabled. *See* https://www.ssa.gov/planners/credits.html. The SSA uses a "sequential evaluation process" to determine if the claimant's disability is sufficiently medically severe, and whether he can engage in *any* type of work available in the national economy taking into account his age, education, work experience and functional capacity.

c. The **SSDI** program also pays a monthly cash benefit to a person over the age of 18 (i) whose disability began prior to the age of 22, (ii) who is consistently unable to engage in "Substantial Gainful Activity," and (iii) who is unmarried, or is married to another similarly situated person. *See* 20 C.F.R. § 404.350(a)(5) and POMS DI 10115.001. This category of benefits is currently called the **"Childhood Disability Beneficiary"** benefit **("CDB")**, but it was formerly known as **"Disabled Adult Child" ("DAC")** benefit. This benefit is payable to the adult child of his parent based on *the parent's* work and earnings record.

(1) In order to be eligible for the CDB benefit, the adult child's parent (i) must be receiving Social Security retirement or disability benefits, or (ii) must have died with sufficient earned "credits" (formerly known as "quarters of coverage"). **Payments under the CDB program count as "unearned income"** to the adult child for purposes of the SSI program, thus reducing the SSI benefit dollar-for-dollar (after a $20 general income exclusion), and often eliminating the SSI benefit entirely, as well as eligibility for SSI-linked Medicaid.

(2) If the adult child is determined to be eligible for the CDB, it cannot be declined in favor of SSI eligibility. If a person who is receiving SSI payments (and is thus eligible for SSI-linked Medicaid) loses his eligibility for both SSI and SSI-linked Medicaid when he becomes eligible for CDB benefits, he will nevertheless be able to maintain his Medicaid eligibility under a different "class of assistance," aptly named "Disabled Adult Child Medicaid." That's the good news. The bad news: neither the SSA nor Medicaid will volunteer this information, and **there are likely millions of eligible people who have not re-established their Medicaid eligibility under the DAC class of Medicaid assistance.**

d. There are various ways for a person to become eligible for **Medicare**, a federal insurance program with no income or resource limitations. *See* Title XVIII of the Social Security Act, 42 U.S.C. §§ 1395-1395kkk-1. Workers who have attained age 65, and are eligible for Social Security retirement benefits, are also eligible for Medicare. In addition, once a person

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[10] http://www.socialsecurity.gov/news/press/factsheets/colafacts2022.pdf.

has received **SSDI benefits (including CDB benefits) for 24 months**, he can become eligible for Medicare coverage, which includes the following elements.

(1) "Part A" providing hospital insurance.

(2) "Part B" providing medical insurance.

(3) "Part C" is an alternative option to traditional Part A and Part B coverage, and provides access to various managed care programs.

(4) "Part D" providing prescription drug coverage.

e. Once a person becomes eligible for Medicare, there are additional programs available to persons with low income, that may be administered through the state Medicaid program (known as **"Medicare Savings Programs")**. Such programs include (i) the "Qualified Medicare Beneficiary" ("QMB") program, which pays the premiums for Part A and Part B Medicare coverage, as well as Medicare co-insurance payments and deductibles; (ii) the "Specified Low Income Medicare Beneficiary" ("SLMB") program, which pays for the Part B premium; and (iii) the "Low Income Subsidy" (or "Extra Help") program, which helps pay for prescription drug coverage under Medicare Part D. As noted in Section A.1.c.(4), *supra*, these programs **are means-tested**, and may require the payment of premiums determined with reference to the person's countable income. Each of these programs has separate income and resource limits. *See* www.medicare.gov.

V. SPECIAL NEEDS TRUST TAX CONSIDERATIONS

A. First-Party Special Needs Trusts

1. A first-party Special Needs Trust typically qualifies as a "grantor trust" for federal income tax purposes. Regardless of who serves as the Settlor, the sole beneficiary is almost always treated as the "grantor" for income tax purposes. Thus, the income and gains generated by the assets of a first-party Special Needs Trust that is a grantor trust are taxed to the beneficiary of the trust under IRC § 671, whether or not actually distributed to, or for the benefit of, the beneficiary.

a. IRC § 677 supports grantor trust status for a first-party Special Needs Trust with a "non-adverse party" serving as Trustee (*i.e.* because trust income is, or may be, payable to the beneficiary in the discretion of a non-adverse party, or held or accumulated for future distribution to the beneficiary). PLR 200620025 (May 19, 2006) held that a first-party (d)(4)(A) Special Needs Trust was a grantor trust with respect to the beneficiary under IRC § 677(a)(1) and (2), since the income of the trust was to be used, or accumulated, for the benefit of the grantor-beneficiary in the discretion of a Trustee who was not an adverse party. IRC § 672(a) defines "adverse party" as any person having a substantial beneficial interest in the trust which would be adversely affected by the exercise or non-exercise of the power he possesses. IRC

§ 672(b) defines "non-adverse party" as any person who is not an adverse party. Thus, a Trustee who has no beneficial interest in a first-party Special Needs Trust, *e.g.* as a remainder beneficiary, would be a non-adverse party. *See also* Rev. Rul. 83-25, 1983-1 C.B. 116.

b. Other mechanisms for assuring grantor trust status for a first-party Special Needs Trust include vesting the beneficiary with a non-testamentary special power of appointment over the trust corpus remaining at death after the Medicaid payback is satisfied. *See* IRC § 674.

(1) Even if the beneficiary is not capable of exercising the power of appointment due to his disabling condition, the mere possession of the power has been held sufficient. *See, e.g.*, Rev. Rul. 55-518, 1955-2 C.B. 384.

c. Granting the sole beneficiary of a first-party Special Needs Trust the administrative "power to reacquire the trust corpus by substituting other property of an equivalent value" under IRC § 675(4)(C) will also assure grantor trust status.

(1) In some regions, the SSA has held that a beneficiary's power to substitute property under IRC § 675(4)(C) is tantamount to an impermissible right to revoke the Special Needs Trust. As discussed in detail *supra*, at Sections III.B.2.c. and III.C.2, a power of revocation held by the beneficiary of a Special Needs Trust is grounds for disqualification.

d. If a first-party Special Needs Trust is a grantor trust for income tax purposes, it cannot qualify as a "Qualified Disability Trust" under IRC § 642(b)(2)(C)(ii), discussed *infra*, in Section V.B.2.

2. It is generally **beneficial for a first-party Special Needs Trust to be taxed as a grantor trust with respect to the beneficiary** for income tax purposes, inasmuch as many trust beneficiaries are in a lower income tax bracket than the compressed tax brackets that would otherwise apply to an irrevocable non-grantor trust. In 2022, an unmarried individual taxpayer reaches the 37% bracket at $539,900 of taxable income, while an irrevocable non-grantor trust reaches the 37% bracket at $13,450 of taxable income. *See* Rev. Proc. 2021-45, IRB-2021-48 (11/10/21). These figures reflect the provisions of "AN ACT TO PROVIDE FOR RECONCILIATION PURSUANT TO TITLES II AND V OF THE CONCURRENT RESOLUTION ON THE BUDGET FOR FISCAL YEAR 2018" (Pub. L. 115-97, 131 Stat. 2504), formerly informally known as "The Tax Cuts and Jobs Act of 2017" (referred to hereafter as "the 2017 Tax Act"). A grantor trust is not subject to the so-called "Medicare Tax" on undistributed net investment income imposed by IRC § 1411.

a. If the beneficiary is a minor under the age of 19, the so-called **"Kiddie Tax" under IRC § 1(g) may also apply**. Threshold requirements for the application of the Kiddie Tax are (i) the child beneficiary has not yet attained 19 years of age prior to the end of the taxable year (or 24 years of age, if he is a student), (ii) the child beneficiary has at least one parent alive as of the last day of the taxable year, and (iii) the child beneficiary does not file a joint return for the taxable year. IRC § 1(g)(2)(A), (B) and (C). Under the 2017 Tax Act, for the years 2018 and 2019, the Kiddie Tax was no longer imposed at the highest marginal rate of the child's parents, but rather at the (generally) more confiscatory rates applicable to trusts and estates. *See* IRC § 1(j)(4)(B).

b. Since the typical beneficiary of a first-party Special Needs Trust will have no access to assets to enable him to satisfy his personal income tax liability with respect to the income and gains generated by the trust, it is advisable to include in the trust agreement a provision that allows the Trustee to utilize the assets of the trust to satisfy that income tax liability directly.

c. "Income" for income tax and trust accounting purposes can be a vastly different concept from "income" for purposes of means-tested benefits. *See* Section IV.A.1.a.(2)(c), (d), (e) and (f), *supra*, for a discussion of the latter. For example, if the Trustee of a Special Needs Trust uses trust principal to pay the beneficiary's rent, this constitutes "income" as "In-Kind Support and Maintenance" ("ISM") to the beneficiary for purposes of his means-tested government benefits, but it does not constitute income for income tax purposes. If the Trustee uses trust principal to pay for the beneficiary's education, the disbursement would not constitute income for purposes of either the income tax or means-tested benefit programs.

(1) This **definitional distinction** can cause tremendous issues for the beneficiary of a first-party Special Needs Trust, especially as the computer systems of the IRS and state revenue divisions communicate electronically with the computer systems of the Social Security Administration and the state Medicaid programs. Thus, after the beneficiary of a first-party Special Needs Trust (which is a grantor trust for income tax purposes) files his individual income tax returns properly reporting the income and gains attributable to the property with which his trust is funded, the state Department of Revenue computer is likely to send an "Alert" to the state Medicaid computer that the Medicaid-eligible beneficiary has reported $XXX of "income" for income tax purposes (which, of course, always exceeds the amount of "income" that a recipient of means-tested benefits can have and still retain eligibility). A benefits termination letter to the beneficiary from Medicaid, issued by an "auto-attendant," often ensues without any opportunity to speak with a live person about the critical distinctions between these definitions of "income." Occasionally, even a discussion with a live person is insufficient to convince the state Medicaid program that **the beneficiary remains eligible notwithstanding the proper income tax reporting of the income and gains** generated by the assets of the first-party Special Needs Trust. This is when one or more of the numerous "allied professionals" on the beneficiary's Special Needs Team must leap into action to prevent the erroneous termination of his means-tested benefits. *See, infra*, in Section VI.E.

d. If a first-party Special Needs Trust is a grantor trust with respect to the beneficiary, and the Trustee uses trust assets to pay for the beneficiary's medical expenses, the taxable income reportable by the beneficiary on his personal tax return may be offset by those **trust-funded medical expenses** if they exceed 7.5% of the beneficiary's Adjusted Gross Income. (N.B. If the unmarried beneficiary claims the standard deduction of $12,950/year in 2022 (under IRC § 63(c)(2)), the medical expense deduction will not help to reduce his tax liability unless it, combined with all other remaining permissible deductions (*e.g.* charitable, state and local taxes, etc.), exceeds that standard deduction amount). IRC § 213(d)(1)(A) (and the regulations thereunder) defines deductible "medical expenses" to include the costs of "diagnosis, cure, mitigation, treatment or prevention of disease," and the costs of treatments "affecting any structure or function of the body." This definition would include:

(1) Premiums for health and medical insurance, amounts paid for qualified long-term care services, and limited amounts paid for a qualified long-term care insurance contract.

(2) Prescribed medicine and drugs.

(3) The costs of transportation to obtain medical care, and the travel costs of a companion for a person who cannot travel alone.

(4) The cost of rendering a vehicle wheelchair accessible.

(5) Medically necessary caregiver services, even if not rendered by a licensed medical professional, as long as they are of a type generally performed by a nurse.

(6) Certain long-term care services for the "chronically ill," as defined in IRC § 7702B(c)(2). Payments to family members for long-term care services are not deductible unless the person is a "licensed professional with respect to such service."

(7) Meals and lodging for a caregiver rendering nursing or long-term care services.

(8) The cost of care in an assisted living facility, nursing home or other institution (including meals and lodging), if the principal reason for the placement is to obtain medical care.

(9) The entire cost of a skilled nursing home facility.

(10) The costs of living in a transitional group residence pursuant to the recommendation of a psychiatrist.

(11) The costs of a special education school that trains a child to overcome learning disabilities, including tuition, meals and lodging, if recommended by a doctor and if the principal reason for attending the school is to overcome the child's learning disabilities.

(12) Doctor recommended tutoring by a teacher who is specially trained and qualified to work with children who have learning disabilities caused by mental or physical impairments.

(13) Admission and travel to medical conferences that address the illness or condition of the patient.

(14) The cost to maintain medically necessary equipment.

(15) The cost of special equipment installed in a home, or improvements made for medical purposes (deductible only to the extent that the reasonable cost exceeds the increased value of the property, if any, that results from the improvement), including entrance and exit ramps; widening doorways; installing railings or support bars; installing lifts; modifying stairways; grading the property to provide ready wheelchair access to the residence.

(16) For more examples of deductible medical expenses, consult IRS Publication 502, "Medical and Dental Expenses" (available at www.IRS.gov/pub/irs-pdf/p502.pdf). *See also* IRS Publication 907, "Tax Highlights for Persons with Disabilities" (available at www.IRS.gov/pub/irs-pdf/p907.pdf).

In contrast, if the Trustee of a non-grantor Special Needs Trust (*i.e.* most *inter vivos* third-party Special Needs Trusts) makes such disbursements for the beneficiary's medical expenses, the trust may not deduct them as medical expenses. However, the trust may be entitled to a distribution deduction under IRC §§ 651 and 661 (and a corresponding amount will constitute income to the beneficiary reportable on his individual income tax return).

3. If a first-party Special Needs Trust is a grantor trust for income tax purposes, it is permissible to **use the grantor-beneficiary's Social Security Number**, rather than a separate Federal Employer Identification Number ("FEIN"), to report the trust's income and gains on the beneficiary's individual Form 1040. However, professional Trustees generally do **obtain a separate FEIN** for a first-party Special Needs Trust to help reinforce the notion that the trust and the beneficiary are not the same for purposes of the beneficiary's ongoing eligibility for means-tested government benefits. This optional approach is permitted by Treas. Reg. § 301.6109-1(a)(2)(i)(B). Even if the trust does have a separate FEIN, it would not be proper for the Trustee to file a full Form 1041 for the trust. Instead, the Trustee should file a simple "informational return" on Form 1041 notifying the IRS that the trust's income and gains will be reported on the grantor-beneficiary's personal individual return. The beneficiary should simply receive a copy of this filing; a Schedule K-1 should *not* be used for this purpose.

4. Since the Trustee of a first-party Special Needs Trust retains discretion to use the *entire* corpus and income contributed to the trust by the beneficiary, for the *sole benefit* of the beneficiary, there should be **no gift tax consequences to the beneficiary** upon funding.

a. The gift tax consequences of a transfer of the beneficiary's assets to a first-party Special Needs Trust were tangentially addressed in PLR 9437034 (Sept. 16, 1994). The beneficiary of a first-party Special Needs Trust funded with a personal injury settlement retained a testamentary special power of appointment over any property remaining in the trust after the Medicaid payback. This power was duly exercised in the beneficiary's Last Will and Testament prior to his death. The requested ruling concerned the includability of the trust corpus in the beneficiary's gross estate for federal estate tax purposes. In holding that the trust corpus remaining at the beneficiary's death was includable in his gross estate under IRC §§ 2038 and 2036(a), the Service also noted in passing that the beneficiary's retained right to alter the disposition of the trust corpus at his death through the exercise of the special testamentary power of appointment rendered the funding transfer an incomplete gift under Treas. Reg. § 25.2511-2(b). *Query* whether it would be possible to value any alleged gift of a remainder interest in a first-party Special Needs Trust, considering (i) the unpredictable impact of a disability on the beneficiary's life expectancy, (ii) the Trustee's complete discretion to disburse the entire trust corpus, and income, for the beneficiary's special needs, and (iii) the Medicaid payback obligation.

5. The estate tax consequences to the beneficiary of a first-party Special Needs Trust are generally well-settled. IRC § 2036(a)(1) will operate to cause **inclusion in the beneficiary's gross estate** of any property remaining in the trust at the time of his death. *See also* PLR 9437034, *supra*.

a. The value of the trust property that is properly includable in the beneficiary's gross estate could be significantly reduced by virtue of the **"payback" claim** against the trust held by any Medicaid program(s) which provided medical assistance to the beneficiary during his lifetime. *See* IRC § 2053(a)(3). Furthermore, there may be a **"stepped-up basis"** available for any assets remaining in a first-party Special Needs Trust at the death of the beneficiary under IRC § 1014(b)(9), thus minimizing any capital gains tax payable upon the liquidation of the assets to satisfy the Medicaid payback.

(1) POMS SI 01120.203.E.1. permits the payment from the assets of a first-party Special Needs Trust remaining at the death of the beneficiary any state and federal estate or inheritance taxes attributable to the inclusion of the trust assets in his gross estate, prior to satisfying the Medicaid payback interest.

b. To the extent that a first-party Special Needs Trust has been funded by means of guaranteed annuity payments consequent to a personal injury claim (often referred to as a **"structured settlement")**, the present value thereof is also fully includable in the beneficiary's gross estate under **IRC § 2039**. Annuity contracts do not typically provide for the acceleration of future guaranteed payments to pay the annuitant's estate tax liability unless a "commutation right" has been purchased when the annuity is procured (for a hefty charge of 5% or more of the total premium paid for the annuity).

B. Third-Party Special Needs Trusts

1. An *inter vivos* third-party Special Needs Trust is most typically drafted as a **non-grantor "complex trust"** that is not required to distribute all of its income. Thus, such a trust would file its own income tax returns under **its own FEIN**, and be subject to the compressed tax brackets applicable to irrevocable non-grantor trusts. As noted, *supra*, in Section V.A.2., in 2022, complex trusts become subject to the 37% bracket at just $13,450 of taxable income. IRC § 1(e). Nevertheless, if the trust's **Distributable Net Income ("DNI")** (as defined under IRC § 643(a)) is "carried out" to the beneficiary in a given tax year, it is taxable to, and reportable by, the beneficiary. The trust then issues the beneficiary a Schedule K-1 showing the taxable income properly reportable on his personal income tax return. If the beneficiary is a minor, the **"Kiddie Tax"** under IRC § 1(g) may also apply to "unearned" income from the trust reportable on his return. Furthermore, a third-party Special Needs Trust that is not a grantor trust may also be subject to the so-called **"Medicare Tax"** on its undistributed net investment income under IRC § 1411.

a. It is certainly possible, however, to draft an *inter vivos* third-party Special Needs Trust so that it is a "grantor trust" with respect to (typically) the person who establishes and funds the trust (*e.g.* the beneficiary's parent during that person's lifetime) by invoking one or more of the grantor trust rules set forth in IRC §§ 671-679, *e.g.* the "power of substitution" under IRC § 675(4). In this fashion, the parent would be responsible for paying the income taxes on the trust's income and gains, leaving the trust property undiminished by the amount of the income tax payments and reducing the parent's potential taxable estate by a similar amount.

2. "Qualified disability trust" ("QDT") status may be available to a third-party Special Needs Trust that is **not a grantor trust** for income tax purposes. *See* IRC § 642(b)(2)(C).

a. Even though the 2017 Tax Act eliminated the personal exemption for individuals previously afforded by IRC § 151(d)(5)(A), new IRC § 642(b)(2)(C)(i) provides that a QDT is still entitled to an exemption of $4,450 for the 2022 tax year, as opposed to the $100 exemption under IRC § 642(b)(2)(A) allowed to an irrevocable non-grantor complex trust. This new exemption is indexed for inflation in future years. IRC § 642(b)(2)(C)(iii)(II). The requirements for a QDT are as follows.

(1) The trust must be **irrevocable**.

(2) The trust must be established for the **sole lifetime benefit** of a **person who is "disabled."** (Thus it is not possible for a QDT to provide for secondary permissible beneficiaries during the lifetime of the beneficiary, but it is permissible to designate remainder beneficiaries upon the death of the beneficiary with the disability.)

(3) The beneficiary with a disability is **under the age of 65** when the trust is established and funded.

(4) The beneficiary has been **"determined by the Commissioner** of Social Security to have been **disabled** (within the meaning of Section 1614(a)(3) of the Social Security Act, 42 U.S.C. 1382c(a)(3)) for some portion of the year."

(a) Thus, if the beneficiary is receiving Supplemental Security Income or Social Security Disability Income, the requisite disability determination will have been made. However, there are circumstances where the beneficiary with a disability is not receiving those benefits, and the QDT statute requires that the necessary disability determination be obtained through alternate means (*e.g.* as authorized by POMS SI 01150.121., or by similar provisions of a state's Medicaid program).

b. For a discussion of how the income of a QDT for the benefit of a minor is exempt from the "Kiddie Tax" under IRC § 1(g), *see* Stephen J. Silverberg, *A Clear Winner in the Tax Cuts and Jobs Act of 2017: Qualified Disability Trusts*, NAELA News Online, June 2018.

3. The gift tax consequences to donors of transfers to a third-party Special Needs Trust depend on whether any of the beneficiaries possess a **"right of withdrawal"** with respect to the contributed funds, commonly referred to as "Crummey powers." *See Crummey v. Commissioner*, 397 F.2d 82 (9th Cir. 1968). Because a gift to a trust does not generally qualify as a "present interest" for purposes of the annual gift tax exclusion under IRC § 2503(b)(1) (in 2022, $16,000 per donee), *Crummey* powers have been used for decades to convert a future interest gift to a trust into a present interest that qualifies the gift for the annual gift tax exclusion. However, **it is inadvisable to give a *Crummey* power to a beneficiary who receives means-tested government benefits**, such as SSI and Medicaid, inasmuch as the value of the property that is subject to the power could well be considered "income," or an "available" or "countable" resource, to the beneficiary, thus jeopardizing his continued eligibility for those benefits. *See e.g.*, O.C.G.A. § 53-12-83.

a. Nevertheless, it is certainly possible to **grant a right of withdrawal to a secondary permissible beneficiary** of a third-party Special Needs Trust, under the rationale of *Estate of Cristofani v. Commissioner*, 97 T.C. 74 (1991). Thus, a common approach is to grant a *Cristofani* right to a secondary beneficiary who does not have a disability, and who (i) may receive discretionary distributions during the lifetime of the primary beneficiary with a disability (typically for a limited purpose such as "emergency health care"), and (ii) is a remainder beneficiary upon the death of the primary beneficiary with a disability. If the holder of the *Cristofani* right fails to exercise it, the property subject to the right remains in trust for the primary benefit of the beneficiary with the disabling condition, thus preserving his ongoing eligibility for his means-tested government benefits.

b. Granting a *Crummey* power or *Cristofani* right of withdrawal to a beneficiary who receives means-tested government benefits is a frequent **planning *faux pas*** that can be remedied by means of a judicial (or non-judicial) modification of the trust. *See* discussion, *infra*, in Section VI.D.4.

4. The estate tax consequences to the beneficiary of a third-party Special Needs Trust will depend upon whether he is vested under the trust agreement with rights or powers that cause includability for estate tax purposes (*e.g.* a general power of appointment). A third-party Special Needs Trust that is not designed to implement generation-skipping transfer tax planning will typically be drafted to **avoid estate tax includability** in the gross estate of the beneficiary. This is especially so since the beneficiary may be subject to Medicaid "estate recovery" at the time of his death under the provisions of one or more state Medicaid plans which have provided medical assistance benefits to him after the age of 55. Furthermore, most third-party Special Needs Trusts are drafted so that contributions thereto qualify as completed gifts by the donor, who typically retains no beneficial interests or powers that would cause estate tax inclusion.

VI. CHALLENGES (AND SOLUTIONS) IN SPECIAL NEEDS PLANNING

Estate planning attorneys, and the myriad allied professionals with whom they work, must address numerous challenges when advising families trying to secure the future of a beneficiary with a disability and consequent special needs. Although every family is unique, there are several predictable challenges (and viable solutions) presented by each special needs planning engagement.

A. <u>"Person-first" terminology</u>

1. For those estate planning attorneys and allied professionals who have little experience advising families with special needs issues, one of the biggest challenges is learning, appreciating and using "person-first" terminology when referencing the beneficiary with a disability and his consequent special needs. It does not matter how technically proficient an advisor may be if he or she **alienates the client by utilizing outdated and disparaging terminology** to refer to the person with the disabling condition. Just as the "N-word" offends most people of good will, so too does the "R-word" ("retard" or "retarded"), which has only recently gained a similarly offensive status. In 2010, "Rosa's Law" (Pub. L. 111-256, 124 Stat. 2643) mandated the use of the term "intellectual disability" (instead of "mental retardation") in federal health, education and labor statutes. State statutes are increasingly being amended to replace all forms of the "R-word" with more respectful terminology.

a. Many years ago, a new client with the patience of Job illustrated the concept of person-first terminology for the author, as follows: "I don't have a disabled daughter; I have a daughter with a disability. She isn't wheelchair-bound; she uses a wheelchair to get around. She is not an Autistic child; she's a child who has Autism. She's not mentally retarded; she has a cognitive disability. Her siblings without disabilities aren't normal; they are neuro-typical."

b. Using person-first terminology will seem cumbersome and unnatural at first. Clients, however *do take notice* of those who successfully integrate this concept into normal parlance. In time, the old terms that emphasized the disability first, instead of the person first, will become as offensive to the attorneys, and to the other allied professionals with whom they work, as they have been to these families. This may be the easiest challenge to overcome, and will completely transform the way a family relates to, and communicates with, their professional advisors. For a "cheat sheet" on the proper terminology to use when referring to individuals with disabilities, *see "Guidelines: How to Write and Report about People with Disabilities*," 9th Edition (2020), published by the University of Kansas Research and Training Center on Independent Living (available at <u>www.rtcil.org/guidelines</u>).

B. <u>Determining an appropriate allocation of assets among beneficiaries with and without disabilities</u>

1. Families often agonize over the issue of **how to divide their estates** between beneficiaries with disabilities and those who are "neuro-typical," *i.e.* without disabilities. The notion of a **"fair"** allocation collides with that of an **"appropriate"** allocation, considering that the beneficiaries with disabilities will likely never be fully self-supporting.

a. One extreme option, that can usually be discarded after a thoughtful discussion, is that of **leaving a family's entire estate**, including probate and non-probate assets, in trust for the sole lifetime benefit of the child with a disability, allowing the neuro-typical siblings to inherit only upon that child's death. This option is usually neither fair nor appropriate.

(1) Delaying the inheritance of the neuro-typical siblings until the death of their sibling with a disability will **inevitably lead to resentment** in the very people who would serve as the primary social and support network for the child with a disability after the parents are deceased. Such resentment can range in intensity from mildly dysfunctional to pathologically aberrant. The last thing that the estate planning attorney should do is to facilitate a plan that is doomed to failure on a relational level.

b. Although disinheriting the beneficiary with special needs is generally inadvisable, as discussed, *supra*, in Section II, it might be an appropriate (and fair) option to consider if that beneficiary has a very large first-party Special Needs Trust funded with the proceeds of a settlement or verdict. However, many families believe that no amount of money will be sufficient to provide fully for the special needs of their children with disabilities. This is where a "Life Care Plan" can meet the challenge.

2. **Developing a "Life Care Plan" for the beneficiary with special needs** is an indispensable element of a realistic estate plan. Rather than just guessing as to the amount of money that will be needed to fully fund the special needs of a child with disabilities, a **Life Care Plan represents an objective, arm's length assessment of the estimated cost**. As the name implies, a Life Care Plan itemizes those medical and non-medical services, products, equipment, housing options, educational options and life-enhancing experiences from which the child with special needs will derive benefit during his estimated life expectancy, along with an economic analysis of the likely expenses and cost of same, indexed for inflation.

a. A Life Care Plan also provides an **indispensable road-map for the Trustee** of any Special Needs Trust. If there is no Life Care Plan in place at the inception of the trust, the Trustee is advised to procure one as the first order of business. If the beneficiary of a first-party Special Needs Trust has received a verdict or settlement as part of a personal injury lawsuit, the trial attorney will have obtained one or more Life Care Plans as part of that process. However, for families who have children with disabilities that are no one's fault, *e.g.* Autism or Down Syndrome, they typically have never heard of a Life Care Plan.

(1) A Life Care Plan is developed by an allied professional known as a "Life Care Planner," who frequently has a medical background as a nurse, physician, or rehabilitation therapist, or as a social worker. (This author prefers to collaborate with a Nurse Life Care Planner. *See* American Association of Nurse Life Care Planners at www.aanlcp.org.) There are several national associations that purport to "certify" Life Care Planners, but it is a generally unregulated emerging specialty without consistent standards. Nevertheless, a good Life Care Planner plays a critical role in answering the question **"How much is enough to leave in a Special Needs Trust** for my child with a disability?" which in turn informs the discussion about how to allocate a client's estate between beneficiaries with and without disabilities.

3. Consider **an equal allocation of probate assets coupled with an augmentation of non-probate assets** for the beneficiary with special needs. Clients are often concerned about memorializing (in their Wills or Revocable Living Trusts) an unequal allocation of assets among their children. They perceive that these documents are preserved in black and white for all eternity, and for all to see and read (and re-read) for decades. An easy solution to this concern is to **augment the equal probate share of the child with special needs** by means of non-probate assets that pass pursuant to a beneficiary designation, which typically is not preserved for posterity in the same fashion as a Will or Revocable Living Trust. Using life insurance (possibly owned by and payable to an Irrevocable Life Insurance Trust with embedded Special Needs Trust provisions) to fund an appropriate augmentation of the beneficiary's share of probate assets is a viable solution for many clients.

C. <u>Coordinating gifts, bequests and distributions for a beneficiary: the "network" of Special Needs Trusts</u>

1. As noted above, utilizing third-party Special Needs Trusts is the cornerstone of securing the financial future of a beneficiary who is receiving means-tested benefits to help fund the cost of his care and other needs. **A special needs estate plan will typically include a network of several third-party Special Needs Trusts** for the beneficiary with a disability, each of which is designed to receive funding from different sources, at different times, including the following.

a. A **testamentary** third-party Special Needs Trust under the Will or Revocable Living Trust of each parent may be the foundation of a Special Needs Plan.

b. Since a testamentary Special Needs Trust cannot be designated to receive gifts or bequests from others if the testator is still alive, an ***inter vivos*** third-party Special Needs Trust **designed to receive bequests** from other family members or friends who wish to help secure the financial future of the beneficiary is an indispensable element of an effective Special Needs Plan. These generous third parties are advised of this option by means of a "Dear Family and Friends Letter."

(1) The **"Dear Family and Friends Letter"** will describe the Special Needs Planning that has been undertaken for the benefit of the beneficiary, and the ultimate goal of preserving his means-tested government benefits. The letter will then provide the **precise verbiage necessary to "incorporate by reference"** the provisions of the *inter vivos* third-party Special Needs Trust that is ready and waiting to receive "pour-over" testamentary bequests or other post-death transfers for the benefit of the beneficiary. The letter will also include a strong caveat that any potential benefactor should seek independent legal or tax advice from his professional advisors prior to implementing any proposed transfer to the trust.

c. Many families also wish to include an *inter vivos* third-party Special Needs Trust **designed to receive lifetime gifts that will qualify for the gift tax annual exclusion** by vesting *Cristofani* rights of withdrawal in persons who are permissible secondary beneficiaries and remaindermen, but *not* in the primary beneficiary receiving means-tested benefits. *See* discussion, *supra*, in Section V.B.3.a. A "Dear Family and Friends Letter" should also be prepared for this type of gifting trust, with specific instructions about how the right of withdrawal process works.

(1) Drafting attorneys may need to engage in creative drafting designed to accommodate the increasingly complicated wishes of clients regarding the disposition of any assets remaining in the trust at the death of the beneficiary with a disability. To avoid a multiplicity of trusts to accommodate the wishes of different donors regarding their preferred remainder beneficiaries, it is possible to draft provisions that require **"tracking" the contributions from different donors** so that any remainder passes solely to persons designated by that donor. The success of such an approach may also require the drafting attorney to prepare instructions to the Trustee that generally require *pro rata* usage of the various internal "funds" (all with different remainder beneficiaries) established within the trust (although exceptions might be considered, *e.g.*, if necessary to minimize the transfer tax consequences to the trust beneficiaries).

d. Almost every family will need an *inter vivos* third-party Special Needs Trust for an individual with a qualified disability or chronic illness who also qualifies as a "Designated Beneficiary" and as an "Eligible Designated Beneficiary" of a trust that also qualifies as a "see-through" "accumulation" trust that also qualifies as a "Type II" "Applicable Multi-Beneficiary Trust" for the lifetime benefit of that individual. If the third-party Special Needs Trust satisfies all of the relevant provisions of the Code and Treasury Regulations, including the "SECURE" Act and the Treasury Regulations thereunder, then that individual's life expectancy may be used in calculating required minimum distributions from third-party retirement accounts payable to the said third-party Special Needs Trust. The SECURE Act is set forth in § 401 of Title V, Revenue Provisions of "Division O" of the "Further Consolidated Appropriations Act of 2019," Pub. L. No. 116-94, 133 Stat. 2534 (2019). Designing the trust so that it also constitutes a "Qualified Disability Trust" (discussed in Section V.B.2., *supra*) can afford significant income tax benefits to the beneficiary. *See* Stephen J. Silverberg, *A Clear Winner in the Tax Cuts and Jobs Act of 2017: Qualified Disability Trusts*, NAELA News Online, June 2018.

e. Many families also need a **Life Insurance Trust with embedded third-party Special Needs Trust provisions** designed to own, and be the designated beneficiary of, one or more single life or second-to-die policies insuring (typically) the parents of the beneficiary with special needs. Although the beneficiary with special needs should not hold a *Crummey* power, secondary permissible beneficiaries (and remaindermen) can hold *Cristofani* rights of withdrawal to facilitate the gift tax-efficient funding of the premiums for any policies owned by the Trust. N.B. In light of the historically high estate tax exemption afforded by the 2017 Tax Act (*i.e.* $12.06

million per person in 2022, indexed for inflation through January 1, 2026), fewer families are now electing an *irrevocable* Life Insurance Trust.

f. It is possible to **facilitate charitable planning** by designating a third-party Special Needs Trust as the income beneficiary of a Charitable Remainder Trust ("CRT") (either a Charitable Remainder Annuity Trust ("CRAT") or a Charitable Remainder Unitrust ("CRUT")) with a stated term not exceeding 20 years. The CRT would be funded ideally with appreciated property during the donor's lifetime, or at death with a retirement account. **Under IRC § 7701(a)(1), a third-party Special Needs Trust would qualify as a permissible CRT income beneficiary.** At the end of the CRT term (not to exceed 20 years), the remainder could pass to a charitable organization which may have provided meaningful support to the family of the beneficiary, or which is devoted to the specific disabling condition with which the beneficiary is challenged.

(1) Designing the third-party Special Needs Trust as a "Qualified Disability Trust" (discussed in Section V.B.2., *supra*) can help ameliorate the income tax consequences of annual CRT distributions to the Special Needs Trust, as will those distributions from the Special Needs Trust for the benefit of the beneficiary which will "carry out" to the beneficiary for income tax reporting purposes income that would otherwise be taxable to the Special Needs Trust at its compressed rates (as discussed in Section V.B.1., *supra*).

2. A Special Needs Estate Plan should also include one or more first-party Special Needs Trusts. Notwithstanding the best efforts of the estate planning attorney and allied professionals to utilize the above-described network of third-party Special Needs Trusts to coordinate financial benefits for the beneficiary with special needs, something *always* slips through the cracks that results in the beneficiary becoming legally entitled to receive property that jeopardizes his eligibility for means-tested benefits. Following are some of the more common scenarios.

a. The **well-intentioned generosity of a friend or family** member who (i) leaves an outright bequest to the beneficiary, (ii) makes an outright lifetime gift to the beneficiary, (iii) dies intestate with the beneficiary entitled to share in the estate as an heir-at-law, or (iv) designates the beneficiary as a direct payee of a non-probate asset, can wreak havoc on a beneficiary's eligibility for means-tested government benefits.

b. If the **beneficiary becomes legally entitled to receive benefits** as a contingent or default taker of a non-probate asset when the primary beneficiary predeceases the owner of the asset, this can jeopardize his means-tested benefits.

(1) If a beneficiary receiving means-tested government benefits is legally entitled to receive any of the property described in a. or b., above, **a "Qualified Disclaimer"** under IRC § 2518 by, or on behalf of, the beneficiary is ***not effective*** to avoid an interruption or termination of those benefits. *See* POMS SI 01150.110.E. Although the disclaimer may be effective for transfer tax purposes, and valid under state law to convey title to the disclaimed asset to another person, the disclaimant's means-tested benefits will be adversely impacted.

c. If the beneficiary with special needs **wins the lottery** or another significant cash prize, the value of this windfall often pales in comparison to the value of the means-tested government benefits that can be lost as a consequence thereof.

d. If the beneficiary becomes legally entitled to receive court-ordered **child support or alimony** payments as a consequence of divorce, this may disqualify him from ongoing eligibility for means-tested benefits if not properly coordinated with his Special Needs Planning.

(1) Although the property described in c. and d. may be excluded as a resource once deposited to a first-party Special Needs Trust, such payments may constitute unearned income to the beneficiary (as discussed, *supra*, in Section IV.A.1.(2)(e)) unless such payments are **irrevocably assigned** to the first-party Special Needs Trust, including by court order. *See* POMS SI 01120.200.G.1.d. and SI 01120.201.J.1.d.

e. The balance in a beneficiary's Representative Payee account (*i.e.* which receives direct deposits of his SSI, SSDI or CDB cash payments each month) may occasionally exceed the $2,000 resource limit for means-tested benefits, resulting in his being "over-resourced" and thus jeopardizing ongoing eligibility for such benefits (*see* discussion, *supra*, at Section IV.A.1.a.(2)(a)). POMS GN 00602.075.C.1. would allow the **transfer of such "excess" funds in the Representative Payee account to a first-party Special Needs Trust** for the sole benefit of the beneficiary "established exclusively for the use and benefit of the beneficiary to meet the beneficiary's current and reasonably foreseeable needs."

f. In each of the above situations, having a **first-party Special Needs Trust available on "stand-by," on a pre-need basis**, provides a ready solution for handling the asset to which the beneficiary is legally entitled in a manner that will help preserve his eligibility for means-tested government benefits. As discussed, *supra*, in Section III.B.2.a., the permissible Settlors of a first-party Special Needs Trust now include the beneficiary (after December 13, 2016), if the beneficiary, though disabled, is a mentally competent adult; the beneficiary's parents, grandparents, legal Guardian or Conservator; or a court. A beneficiary's parent (or grandparent) may also establish a first-party Special Needs Trust as a "seed trust" (authorized by POMS SI 01120.203.B.7. and SI 01120.203.C.2.b.) as part of their estate planning as an elegant pre-need solution to an inevitable problem.

(1) If the beneficiary is, in fact, an incapacitated adult (or a minor) when he becomes legally entitled to financial benefits such as those listed above, and which would otherwise be subject to a Conservatorship, it is likely that a **court procedure will be necessary to authorize the transfer** of those assets into a first-party Special Needs Trust established on a pre-need basis. Furthermore, any assets that remain in a **Conservatorship are considered "available" or "countable" resources** for purposes of the ward's eligibility for means-tested government benefits. *See* POMS SI 01140.215.B.1.

(2) In PLR 200620025 (May 19, 2006), an adult child with a disability, and receiving means-tested government benefits, was designated as the direct beneficiary of a share of his deceased father's IRA. In order to preserve his means-tested government benefits, the son's legal Guardian petitioned a court of competent jurisdiction for authority to (i) **create a first-party Special Needs Trust, and (ii) fund it with the beneficiary's share of the inherited IRA**. The Service held that the first-party Special Needs Trust was a "grantor trust" for federal income tax purposes under IRC § 677(a). Thus, since a grantor trust is disregarded for income tax purposes, the Service held that the funding of the trust with the beneficiary's share of the inherited IRA was not a transfer for purposes of IRC § 691(a)(2). This conclusion remained the same even after the beneficiary's share of the inherited IRA was transferred, by means of a trustee-to-trustee transfer, to a new IRA set up and maintained in the name of the deceased IRA owner to benefit the son through his first-party Special Needs Trust. Finally, the Service held that required minimum distributions from the new IRA to the first-party Special Needs Trust could be calculated using the son's life expectancy.

(3) If the beneficiary of a first-party Special Needs Trust which is established by his parents or grandparents on a pre-need basis as part of their estate plan happens to have testamentary capacity at that time, consider seeking input from the beneficiary as to who he would like to receive any assets remaining in the trust after any Medicaid "payback" is satisfied.

g. Rev. Rul. 2002-20, 2002-1 C.B. 794 (4/26/02), holds that a CRUT is qualified under IRC § 664 if the unitrust amount is paid to a separate first-party Special Needs Trust for the lifetime benefit of an individual who is "financially disabled" as defined in IRC § 6511(h)(2)(A), and that individual has a testamentary general power of appointment over the balance remaining in the Special Needs Trust after the Medicaid payback. Thus, the 20-year term limitation required for a CRT when a third-party Special Needs Trust is designated as the income beneficiary (discussed, *supra*, in Section VI.C.1.f) does not apply to such a first-party Special Needs Trust unitrust recipient. "Financially disabled" is defined as "unable to manage [the individual's] financial affairs by reason of a medically determinable physical or mental impairment of the individual which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." The Ruling holds that the use of the assets in such a first-party Special Needs Trust "is consistent with the manner in which [the beneficiary's] own assets would be used. [The beneficiary], therefore, is considered to have received the unitrust amounts directly" from the CRUT for purposes of IRC § 664(d)(2)(A). "Accordingly, the term of the [CRUT] may be for the life of [the beneficiary of the first-party Special Needs Trust] and is not limited to a term of years. The same result would apply if the [CRUT] were a charitable remainder annuity trust."

(1) Caveat: Rev. Rul. 2002-20 does not mention the provisions of IRC § 6511(h)(2)(B), which states that "An individual shall not be treated as financially disabled during any period that such individual's spouse or any other person is authorized to act on behalf of such individual in financial matters." *Query* whether the mere existence of a court-appointed Conservator for the individual or an attorney-in-fact under the individual's Durable Power of Attorney for financial matters (which many beneficiaries of first-party Special Needs Trusts do indeed have) would render this charitable planning opportunity unavailable.

D. <u>Existing trusts with "support" or "maintenance" standards for distributions to the beneficiary with a disability</u>

Inasmuch as special needs estate planning is a relatively new sub-specialty, practitioners are frequently confronted with **older irrevocable trusts** that utilize the classic "h-e-m-s" ascertainable standards of "health, education, *maintenance* and *support*" for all beneficiaries. As noted, *supra*, in Section III.F.1.a., if a trust beneficiary is receiving means-tested government benefits, such as SSI and Medicaid, the **"support" and "maintenance" distribution standards typically result in the trust assets being deemed "available" or "countable"** to the beneficiary, thus jeopardizing those benefits. The inclusion of the "maintenance" and "support" distribution standards for a beneficiary who receives means-tested government benefits (found in most "Bypass/Credit Shelter" Trusts and in many "Dynasty/Generation-Skipping" Trusts) threatens to disqualify the beneficiary with a disability from ongoing eligibility for those benefits. Options to deal with this challenge may include the following.

1. If the original trust grants the **power to amend** the trust provisions, the exercise of that power (by someone other than the beneficiary with special needs) is an unexpectedly easy solution.

2. The exercise of a **power of appointment** (by someone other than the beneficiary with special needs) in favor of a newly-created third-party Special Needs Trust can often solve the problem if the provisions allow for the appointment of trust assets to, "or for the benefit of," the beneficiary, including "in further and separate trust."

3. A **"decanting" encroachment** by the Trustee into a newly-created third-party Special Needs Trust is another frequently utilized solution. Although not all states currently have decanting statutes, well-respected practitioners who have thoroughly considered this topic have concluded that the "common law of every state likely confers decanting authority on trustees." *See* Jonathan G. Blattmachr, Jerold I. Horn & Diana S.C. Zeydel, *An Analysis of the Tax Effects of Decanting*, 47 Real Prop. Tr. & Est. L.J. 141, 170 (Spring 2012).

4. A **judicial modification** of the original trust which replaces the "support" and "maintenance" standards with Special Needs Trust provisions with respect to any distributions for the benefit of the beneficiary receiving means-tested government benefits is an expensive and labor-intensive option. State law typically provides specific procedures for the judicial modification of irrevocable trusts, which are designed to uphold the intent of the person who established the trust and to effectuate the purpose of the trust. It is typically necessary to craft and support the position that **had the creator of the trust known** that its original provisions for the beneficiary with the disability would disqualify him from ongoing eligibility for a significant source of funding his special needs (*i.e.* means-tested government benefits) the creator would have taken the steps needed to modify those provisions accordingly by replacing them with Special Needs Trust provisions. The trust modification petition **typically addresses the following issues.**

a. A statement of proper jurisdiction and venue.

b. A complete list of all interested parties, including the Trustee(s), the trust beneficiaries (both current and remainder), and any Guardian ad Litem who may need to be appointed to represent the interests of any unknown or unborn trust beneficiaries, or the beneficiary with the disability if he is not mentally competent.

c. A complete description of the original trust provisions in favor of the beneficiary with special needs (and the other trust beneficiaries).

d. A description of the facts and circumstances surrounding the creation of the trust, supported by appropriate affidavits of those persons with actual knowledge of same.

e. A discussion of the beneficiary's disabling condition, and whether the person who created the original trust was aware of the disabling condition and the consequent special needs of the beneficiary.

f. The exact type of government benefits for which the beneficiary is eligible, which would be reduced or eliminated if the original "support" and "maintenance" distribution standards are not replaced with Special Needs Trust provisions. Note: insist on seeing the actual "benefits award letter" from the Social Security Administration and the state Medicaid plan which describes the beneficiary's government benefits, since many families do not know or appreciate the difference between means-tested and employment-related benefits.

g. Citations to the relevant state and federal law that supports the proposition that the "support" and "maintenance" standards in the original trust will disrupt or eliminate the beneficiary's means-tested government benefits.

h. A discussion of the intent of the creator of the original trust to benefit the beneficiary with special needs by creating the trust, and how that intent, or the accomplishment of the purpose of the original trust, would be defeated, or substantially impaired, if the original provisions remain unmodified, supported by affidavits of persons familiar with the creator's intent and/or an affidavit from an attorney, or other allied professional, who routinely works with similarly-situated clients.

i. A discussion of how the proposed trust modification will uphold the intent of the person who created the original trust, and the accomplishment of the purpose of the trust, by (i) allowing the beneficiary's eligibility for means-tested government benefit programs to continue, and (ii) allowing the modified trust to supplement, and not supplant, those government benefits.

j. An analysis of the beneficiary's life expectancy; the insufficiency of the assets of the original trust to fund fully all of his health care and disability-related special needs for the balance of his lifetime, or that beneficial programs and services are not available on a private pay basis but only if the beneficiary is eligible for the government benefit programs; and the need for government benefit programs to supplement the trust assets to fund fully those needs.

k. A discussion of **whether the state's Medicaid plan will require a "payback" provision** to be included in the modified trust, notwithstanding the status of the original trust as a third-party trust (which would normally not be required to include a Medicaid payback provision, as discussed, *supra*, in Section III.C.2). Some states take the position that a trust which would have been considered an "available" or "countable" asset as originally drafted must include a payback provision in the modified version only if the creator made no reference whatsoever to the beneficiary's disabilities. The states are reportedly very inconsistent with regard to requiring the inclusion of a Medicaid payback provision in a modified third-party Special Needs Trust.

(1) If a Medicaid payback provision is required in the modified trust, and if there are other current or remainder beneficiaries of the trust whose beneficial interests would be adversely impacted by the satisfaction of the payback from the property remaining in the trust upon the death of the beneficiary with special needs, then the family should consider other available sources of liquidity **(*e.g.* life insurance covering the beneficiary)** for satisfying the payback. Medicaid cares only that its payback right is satisfied, not the source of the funds with which it is satisfied. This is also especially problematic if the major asset of the modified trust is illiquid or otherwise "sacred" to the beneficiaries, such as the family homeplace or some other sentimental asset which they do not wish to liquidate upon the death of the beneficiary with special needs to satisfy the Medicaid payback.

5. The Trustee of an irrevocable trust that contains problematic distribution standards for a beneficiary who receives means-tested government benefits could also consider a **complete encroachment to the beneficiary** of the entire trust corpus, followed by an **immediate funding of a first-party Special Needs Trust** with that property. This approach would necessarily entail subjecting the property to a Medicaid payback; however, if the corpus is likely to be depleted entirely (or in large part) during the beneficiary's lifetime, the payback prospect is of little consequence. If the beneficiary is a minor or an incapacitated adult under relevant state law, it would be necessary to obtain court approval for the transfer of the encroached assets into the first-party Special Needs Trust. Furthermore, every effort should be made to time the encroachment to the beneficiary and the immediate funding of the first-party Special Needs Trust with the encroached trust property in the same month so that his eligibility for means-tested benefits is adversely impacted for only a single month.

E. Lack of a team of "allied professionals"

Families trying to secure the future of beneficiaries with disabilities already realize that this requires a team effort. The estate planning attorney is ideally suited to help the client assemble this Special Needs Team as part of the estate planning process. The members of a typical Special Needs Team should include, at a minimum, the following allied professionals.

1. An **estate planning attorney** who is familiar with the myriad issues involved in advising families with special needs, or who is willing to obtain and work with co-counsel who is experienced in this area. There are two national organizations whose members are proficient in the special needs space: the Special Needs Alliance[11] and the Academy of Special Needs Planners.[12]

2. A **Life Care Planner**, discussed, *supra*, in Section VI.B.2.a.(1).

3. A **Care Manager**, who prepares a personal care plan for the beneficiary, coordinates the beneficiary's caregivers and oversees the implementation of the plan, and personally periodically verifies the quality of care being rendered to the beneficiary.

4. A **government benefits specialist** who can assist the family with applying for the various programs for which the beneficiary may be eligible as a consequence of his disability. Many benefits applications are derailed because of a family's unfamiliarity with the forms or the process, or because of the failure to adequately document the beneficiary's disabling condition from a medical or functional limitation standpoint. This professional can often also advise the Trustee of a Special Needs Trust as to whether any proposed trust disbursements will adversely impact the beneficiary's means-tested benefits.

5. If the beneficiary with special needs is of school age, a **special education advocate or attorney** can help the family obtain the "free and appropriate public education" ("FAPE") in the "least restrictive environment" ("LRE") to which he is legally entitled. Under the federal "Individuals with Disabilities Education Act" ("IDEA") (previously known as the "Education for All Handicapped Children Act" from 1975 to 1990), the educational program for a child with a disability must be designed to prepare him or her for further education, employment and independent living, as outlined in an "Individualized Education Program" ("IEP") tailored to the child's specific and unique needs. *See* 20 U.S.C. § 1400 *et seq*. There is a small, but growing, cadre of attorneys who limit their practice to advising and representing parents in special education hearings under the IDEA, since many public school systems fail or refuse to provide the FAPE guaranteed by IDEA. An increasing number of students with Autism Spectrum Disorder (or other disorders with consequent disruptive or self-injurious behaviors) are the victims of physical abuse at the hands of their teachers, who have not been properly trained in the management of such behaviors. Civil remedies and criminal penalties are available for redress of such abuse.

6. **Accountants** who are well-versed in preparing income tax returns for Special Needs Trusts, the beneficiaries thereof, and the parents or legal guardians of the beneficiaries who are funding the costs of their medical care and other needs. Many accountants are unfamiliar with Special Needs Trust taxation rules, or with the myriad expenditures that qualify as medical expenses. *See supra* Section V.A.2.c.

a. In addition to income tax returns for Special Needs Trusts, numerous States require **annual accountings to the state Medicaid plan** which detail the receipts and disbursements of a Special Needs Trust, both first-party and third-party. For example, the Georgia Medicaid plan has established a first-of-its-kind "Trust Review and Accounting Unit" currently

[11] http://www.specialneedsalliance.org/.
[12] http://www.specialneedsplanners.com/.

administered by Gainwell Technologies (a publicly-traded national corporation that provides healthcare cost containment services to both state and federal agencies). This program has already been replicated in Iowa, Mississippi, North Carolina and Wyoming (with several others pending). Reviews of these annual trust accountings focus on **potential violations of the "sole benefit rule"** applicable to first-party Special Needs Trusts (*see* Section III.B.2.d.(1), *supra*) as well as disbursements from first-party and third-party Special Needs Trusts that constitute **"In-Kind Support and Maintenance"** that adversely impact the beneficiary's Supplemental Security Income monthly payment (*see* Section IV.A.1.a(2)(f), *supra*). Most accountants and attorneys are not ideally suited for the preparation of these annual accountings, which can be prepared more cost-effectively by a paralegal or bookkeeper.

7. **Investment advisors** who are sensitive to the generally low risk tolerance of beneficiaries with disabilities, and understand how a beneficiary's specific disability impacts a portfolio allocation, *e.g.* a compromised life expectancy and the costs of funding his Life Care Plan. Many persons with disabilities have a normal life expectancy, and their assets must be invested so that inflation does not erode their purchasing power over the long term.

8. **Life insurance professionals** who understand the process of determining the expected cost of a Life Care Plan, and can recommend creative strategies for funding that cost taking into account all of the other resources available to the beneficiary, including his parents, siblings or other support network, as well as the various government benefit programs for which he may be eligible as a consequence of his disabilities. Increasingly, the beneficiaries of Special Needs Trusts find it desirable or advisable to obtain life insurance on their own lives, which may be possible (with a specialty underwriter) **if their disabilities do not adversely impact their insurability.**

9. An **appropriate Trustee**, and successors, for the network of Special Needs Trusts that will form the cornerstone of the beneficiary's financial security. Serving as the Trustee of a Special Needs Trust is not for the faint-of-heart. Even well-intentioned, motivated family members risk sabotaging a perfect Special Needs Plan if they improperly administer the Special Needs Trusts for which they are responsible. If those family members also happen to be the remainder beneficiaries of the Special Needs Trusts, then (human nature being what it is), it is quite possible that the beneficiary will not benefit as the client intended. Thus, an independent or professional Trustee is highly recommended for Special Needs Trusts.

a. Unfortunately, many professional or corporate Trustees have **very high minimums** for all trust accounts (and perhaps even higher minimums for Special Needs Trusts in recognition of the labor-intensive nature of their administration) which often preclude this option for many clients. Even more regrettable are the increasing numbers of corporate Trustees that categorically refuse to accept Special Needs Trusts of any size. Increasingly, attorneys, accountants, former trust officers and other allied professionals are offering **private fiduciary services** for Special Needs Trust administration with no, or a relatively low, minimum account threshold. These "allied professionals" are also often available to serve as **"distribution advisors"** to those Trustees (individual or corporate) who are not well-versed in the myriad rules and restrictions applicable to disbursements from Special Needs Trusts.

10. Last, but not least, the **legal Guardian** of a beneficiary with special needs will eventually serve as the **"quarterback" of the Special Needs Team,** after the beneficiary's natural parents are deceased. Many clients are paralyzed with fear by the prospect that (i) no one will agree to serve as Guardian for their children with disabilities because of the monumental task it represents, and (ii) anyone who does agree to serve will not do it as well as they have done. Assembling the Special Needs Team as part of the estate planning process provides a solution to both of these concerns. (It is also advisable to secure the appointment of a Conservator at the same time to take responsibility for the actions described, *supra*, at Section VI.C.2.f.)

a. If a person nominated under the client's Will to serve as Guardian of the client's child with a disability believes that he must personally undertake the responsibilities of all of the Team members listed above, the client's fear would be justified. However, if the nominated Guardian were able to view his role as the "quarterback" of those allied professionals, with a **division of labor agreed upon in advance**, then serving as Guardian would not seem nearly as daunting.

b. If the members of the Special Needs Team are identified and assembled while the parents of the beneficiary are still living, then the parents can take an active role in communicating their expectations so that, working together, the Team members may indeed do as well as the parents have done. Each Team member can be given appropriate opportunities to interact with the beneficiary, his parents, and each other, before the parents' demise. Instead of losing the history of care and love which the parents have left as part of their legacy, the **Team members are made a part of that history**.

c. Assembling the members of the Special Needs Team while the parents of the beneficiary are still living can also facilitate a more **accurate analysis of the cost** of procuring the services of the Team members in the future. If, as is often the case, the likely cost exceeds the clients' wildest nightmares, steps can be taken to bridge any funding gap that may exist.

d. For various reasons, the natural parents of adult children with disabilities often **fail or refuse to secure the appointment of a legal Guardian** for them. Psychologically, such parents simply cannot bear the thought of a process that necessarily emphasizes the areas in which their adult children remain vulnerable and unable to take care of their own health and personal safety. Such parents have spent their whole lives emphasizing their children's abilities (however modest), and refuse to focus realistically on their vulnerabilities, which is the primary focus of a guardianship hearing. Third parties (especially long-standing health care providers) often enable this "head-in-the-sand" approach as long as one of the natural parents of the adult child with a disability is still living, operating on a "wink-wink" basis (and often violating the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") in the process). Needless to say, this is an imprudent approach which can risk the health and well-being of the adult child with the disability if, for example, a catastrophic health care emergency were to arise and a doctor unfamiliar with the family insisted on Letters of Guardianship before taking any directions regarding the child's course of care.

VII. ABLE ACCOUNTS

A. Background Information

1. The "STEPHEN BECK, JR. ACHIEVING A BETTER LIFE EXPERIENCE ACT OF 2014" (the "ABLE Act") (Public Law 113-295) was signed on December 19, 2014 by President Obama as part of the Tax Increase Prevention Act of 2014. This new legislation aims to "provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits" otherwise available to such persons through private sources, employment, public programs, or otherwise. ABLE Act § 101(1). The ABLE Act **adds new § 529A to the Internal Revenue Code** of 1986 (the "Code"), as well as numerous amendments to related provisions of the Code (*e.g.* IRC §§ 2501, 2503, 2511, 2642 and 2652 with respect to gift and generation-skipping taxes). Similar to § 529 Qualified State Tuition Program accounts, a qualified § 529A ABLE account is funded with after-tax dollars, all earnings on the account assets are tax-deferred, and distributions for **"Qualified Disability Expenses" ("QDEs")** are not includable in the income of the designated beneficiary.

2. On March 23, 2015, the IRS issued Notice 2015-18 setting forth limited guidance for states eager to establish ABLE Programs without the benefit of even proposed regulations. A few days later, the Social Security Administration ("SSA") issued **new POMS SI 01130.740. pertaining to ABLE accounts**. On June 22, 2015, the Department of the Treasury published proposed regulations expanding on the provisions of the ABLE Act. On November 20, 2015, in response to hundreds of comments on the proposed regulations submitted by individuals and organizations, the Internal Revenue Service issued Notice 2015-81, "Interim Guidance Regarding Certain Provisions of Proposed Regulations Relating to Qualified ABLE Programs." On September 7, 2017, the Department of Health and Human Services Centers for Medicare and Medicaid Services, issued further guidance, SMD#17-002, "Implications of the ABLE Act for State Medicaid Programs." In **March 2018, SSA issued a revised version of POMS SI 01130.740.**, followed by another update in February 2022**.** Finally, on November 19, 2020, the IRS published **final treasury regulations** for the ABLE Act in the Federal Register (Vol. 85, No. 224) (available at federalregister.gov/documents/ 2020/11/19/2020-22144/guidance-under-section-529a-qualified-able-programs). The final regula-tions are generally applicable to calendar years beginning on or after January 1, 2021. (Note: As of May 23, 2022, POMS SI 01130.740. had not yet been updated by the SSA to reflect the substance of the final treasury regulations.)

B. General Requirements for a Qualified State ABLE Program

In order to qualify for tax-exempt status pursuant to IRC § 529A(a) and Treas. Reg. § 1.529A-1(a), a qualified state ABLE program described in IRC § 529A, the final regulations, and POMS SI 01130.740., must comply with the following requirements.

1. The program is established and maintained by a state, or a state's agency or instrumentality (*e.g.* private company), pursuant to state statute, regulations or other action.

2. The program permits the establishment of an ABLE account only for a "designated beneficiary" who is an "eligible individual" when the account is established.

3. The program permits the establishment of only one ABLE account, by specified persons in a specified order, for an "eligible individual" who becomes the designated beneficiary.

4. The program requires that the designated beneficiary be disabled or blind (as defined by the SSA) prior to his 26th birthday, and to establish such disability or blindness in accordance with certain prescribed procedures, both upon the initial establishment of the ABLE account and periodically thereafter until its termination.

5. The program must limit the nature and amount of contributions by all persons to an ABLE account, including an annual limitation based on the annual gift tax exclusion under IRC § 2503(b), and a cumulative, aggregate limitation keyed to the state's limit for § 529 Qualified State Tuition Program accounts under IRC § 529(b)(6).

6. The program must limit distributions from an ABLE account to the QDEs of the designated beneficiary during a tax year that he satisfies the above disability requirements.

7. The program must require a separate accounting for an ABLE account to the designated beneficiary thereof, and additional annual and other periodic reports to the IRS and the SSA.

8. The program must limit the designated beneficiary to two opportunities each calendar year to provide investment direction regarding the assets in his ABLE account.

9. The program must prohibit the assignment, sale or exchange of an interest in the ABLE account.

10. The program must provide that, upon the death of the designated beneficiary, the state's Medicaid plan may file a claim against the ABLE account for the total amount of medical assistance paid for the designated beneficiary under the state's Medicaid plan after the establishment of the account.

C. State Action to Establish an ABLE Program

1. The ABLE Act authorizes (but does not require) the states to establish ABLE programs. Any state which elects to establish an ABLE program must do so through legislation or regulations. *See, e.g.,* O.C.G.A. §§ 30-9-1 *et seq.,* for the "GEORGIA ACHIEVING A BETTER LIFE EXPERIENCE (ABLE) ACT."

a. On December 18, 2015, a provision of the Consolidated Appropriations Act of 2016 (Public Law 114-113, H.R. 2029, December 18, 2015), amended the original ABLE Act **to permit an individual to enroll in the ABLE program of any state**, whether it be the state of that individual's residence or another state with a valid ABLE program that accepts out-of-state residents. *See* http://www.ablenrc.org/about/what-are-able-accounts. *See* Treas. Reg. § 1.529A-2(b)(2)(B)(ii).

(1) The ABLE National Resource Center maintains an updated roster of states that offer active ABLE programs. *See* http://www.ablenrc.org/state-review. However, as of May 23, 2022, only four states did not offer an active ABLE program to their residents: Idaho, North Dakota, South Dakota and Wisconsin.

2. According to the Deputy Director of the STABLE Program (which administers the first and largest ABLE program, offered by the states of Arizona, Georgia, Kentucky, Missouri, New Hampshire, New Mexico, Ohio, Oklahoma, South Carolina, Vermont, West Virginia, and Wyoming), as of December 31, 2021, there were more than 112,131 ABLE accounts nationwide, with assets under management of over $1 billion. Thus, a mere 1.4% of the nearly 8 million people with disabilities who would qualify for an ABLE account have actually established one.

D. Eligibility Requirements for a "Designated Beneficiary"

1. The "designated beneficiary" of an ABLE account, who is also **considered to be the owner** of the account, must be an "eligible individual." IRC § 529A(e)(1) and (3); Treas. Reg. § 1.529A-1(b)(3) and (8); POMS SI 01130.740.B.3.

2. An **"eligible individual"** must qualify as blind or disabled, as defined by the SSA, and **the onset of the blindness or disability must have occurred prior to the individual's 26th birthday**. [Note: The "ABLE Age Adjustment Act," introduced on February 22, 2021, as H.R. 1219/S.331 in the 117th Congress, would increase from 26 to 46 the age threshold for ABLE accounts.] A qualified ABLE program must require that the individual be: (i) eligible for Supplemental Security Income (SSI) based on disability or blindness that began before age 26; (ii) entitled to Disability Insurance Benefits (DIB), Childhood Disability Benefits (CDB), or Disabled Widow's or Widower's Benefits (DWB) based on disability or blindness that began before age 26; (iii) an individual who has certified (or whose specified agent has certified) that he: (A) has a medically determinable physical or mental impairment that results in "marked and severe functional limitations" (*i.e.* the standard for children claiming SSI benefits) that can be expected to result in death, or has lasted (or can be expected to last) for a continuous period of at least 12 months, without regard to age or whether the individual engages in substantial gainful activity, or (B) is blind, and the onset of the disability or blindness occurred before age 26; or (iv) satisfies one of the conditions listed in the "Compassionate Allowances List" maintained by the SSA (*see* https://www.ssa.gov/compassionateallowances/conditions.htm). While an individual may file a disability certification meeting specific requirements in order to prove eligibility for an ABLE account, no inference regarding disability for purposes of eligibility for other government benefits may be drawn from such a certification. IRC § 529A(e)(1) and (2)(B); Treas. Reg. §§ 1.529A-1(b)(8)(i) and (ii), and 1.529A-2(e)(1), (2), (3) and (5); POMS SI 01130.740.B.3.

a. An **eligibility determination applies for the entire taxable year**. Treas. Reg. § 529A-2(d)(1)(i). Periodic recertification of the disability is required in accordance with Treas. Reg. § 1.529A-2(d)(2).

b. Treas. Reg. §§ 1.529A-2(d)(1)(ii)(D) and (e) eliminate one particularly problematic element of the disability certification requirements set forth in IRC §

529A(e)(2)(A)(ii), *i.e.* that a disability certification include a copy of the individual's diagnosis related to his impairment, signed by a physician meeting the criteria of 42 U.S.C. § 1395x(r). The individual must retain the written, signed and dated physician's diagnosis and make it available to the state's ABLE Program "upon request."

3. The Code and final regulations require program administrators to **collect and maintain records regarding the types of disabilities reported** by the designated beneficiaries of ABLE accounts. For this purpose, disabilities are divided into seven categories: developmental disorders; intellectual disabilities; psychiatric disorders; nervous system disorders; congenital anomalies; respiratory disorders; and other. IRC § 529A(d)(2) and Treas. Reg. §§ 1.529A-2(d)(1)(ii)(E) and (e), and 1.529A-5(c)(2). This information is reported on IRS Form 5498-QA.

E. Contributions to and Disbursements from an ABLE Account

1. Any person (as defined by IRC § 7701(a)(1)), including the designated beneficiary, **may contribute** to an ABLE account, *i.e.* an individual, trust (including a Special Needs Trust), estate, partnership, association, company, non-profit entity, or corporation. *See also* Treas. Reg. § 1.529A-2(a)(3), and POMS SI 01130.740.B.2. However, the **annual cap on total contributions** to an ABLE account **from all sources** is limited by reference to the federal annual gift tax exclusion amount under **IRC § 2503(b)** (which is $16,000 in 2022). IRC § 529A(b)(2)(B)(i) and Treas. Reg. §§ 1.529A-2(g)(2)(i) and 1.529A-1(b)(9); POMS SI 01130.740.B.2. A qualified ABLE program may accept contributions only **in the form of U.S. dollars**, including a check, cashier's check, money order, credit card payment, electronic transfer, wire transfer, after-tax payroll deduction, or other similar method of payment. IRC § 529A(b)(2)(A) and Treas. Reg. § 1.529A-2(g)(1).

a. The final regulations provide that a qualified ABLE program must require the return of all contributions to an ABLE account in excess of the annual contributions limit, along with all net income attributable to those excess contributions, to the contributors on a last-in, first-out basis. Treas. Reg. § 1.529A-2(g)(4).

b. Qualified contributions also include certain rollover distributions from one ABLE account to a different ABLE account for the same designated beneficiary, or to an ABLE account for a successor designated beneficiary who is an eligible individual and a "family member" of the original designated beneficiary. IRC § 529A(c)(1)(C); Treas. Reg. §§ 1.529-1(b)(12) and (16). For rollover purposes, a qualified member of the designated beneficiary's family is limited to a sibling only, by blood, marriage, or adoption, including step-siblings and half-siblings. IRC § 529A(e)(4); Treas. Reg. § 1.529A-1(b)(12); POMS SI 011130.740.B.5.

c. A **penalty-free rollover from a traditional 529 Plan** account (owned by the designated beneficiary or a family member) to an ABLE account is permissible until January 1, 2026. Treas. Reg. §1.529A-1(b)(2). However, the rollover is subject to the annual contribution limit *from all sources* applicable to an ABLE account, described above.

d. Until January 1, 2026, the designated beneficiary of an ABLE account who earns income from a job may **contribute an additional amount to his ABLE account**, if he does not contribute to, or participate in, a defined contribution plan under IRC § 414(i), an annuity contract under IRC § 403(b), or a deferred compensation plan under IRC § 457(b). The funds contributed may be derived from his compensation or from his other assets (but not directly from the assets of a third party). Treas. Reg. § 1.529A-2(g)(2)(ii). The amount that may be contributed is **the lesser of** (i) the designated beneficiary's compensation (as defined in IRC § 219(f)(1) for the taxable year), or (ii) an amount equal to the "applicable poverty line" for a one-person household for the calendar year preceding the calendar year in which the designated beneficiary's taxable year begins, *to wit*, as set forth in the poverty guidelines updated periodically in the Federal Register by the U.S. Department of Health and Human Services under 42 U.S.C. § 9902 (2), for the state of residence of the employed designated beneficiary. Treas. Reg. § 1.529A-2(g)(2)(ii)(B). On January 21, 2022, the latest poverty guidelines (*i.e.* from the prior year, 2021) reported $13,590 as the relevant poverty guideline for the forty-eight contiguous states and the District of Columbia; $15,630 for Hawaii; and $16,990 for Alaska. Federal Register, Vol. 87, No. 14, Friday, January 21, 2022, at page 3315. *See also* POMS HI 03001.020.C.3.

e. While there is no federal income tax deduction for contributions to an ABLE account, the designated beneficiary of an ABLE account may be entitled to claim a non-refundable tax credit for "qualified retirement savings contributions" to the ABLE account (also known as the "saver's credit") for tax years beginning in 2018 through 2025), as well as the refundable "earned income tax credit." Some states also allow a modest income tax deduction (*e.g.* Ohio allows a maximum $2,000 deduction against the donor's Ohio income tax liability).

2. If distributions made from an ABLE account for the designated beneficiary's QDEs do not exceed the total QDEs of the designated beneficiary paid during his tax year (or, at the election of the designated beneficiary, within sixty days of the end of his tax year), then **no amount so distributed shall be included** in the designated beneficiary's gross income. POMS SI 01130.740.C.4., IRC § 529A(c)(1)(B)(i) and Treas. Reg. §§ 1.529A-3(a)(1) and (2). Earnings generated within an ABLE account are excluded from the income of the designated beneficiary. POMS SI 01130.740.C.2. However, the earnings attributable to non-QDE distributions will be includable as ordinary income in the designated beneficiary's taxable income. Treas. Reg. § 1.529A-3(d) imposes an additional tax of ten percent of the income tax imposed on the includable in the gross income of the designated beneficiary.

a. A well-respected Special Needs Planning tax attorney known to the author has explained the inclusion as follows. "The income taxation of non-qualified ABLE distributions under IRC § 529A(c)(1)(A), by its reference to IRC § 72 (regarding annuity taxation), attempts to **tax only the *gain* related to the non-qualified distributions,** not the entirety of the distribution. IRC § 529A(c)(3) then requires the tax imposed by IRC § 529A(c)(1)(A) to be increased by 10%, and includable in the gross income of the designated beneficiary. It's framed in the nature of *a surcharge on the tax*, not a separate penalty."

3. The term **"qualified disability expenses"** means those incurred while the designated beneficiary is an eligible individual, that **"relates to"** the designated beneficiary's blindness or disability, and that are made **"for the benefit of"** the designated beneficiary to maintain or improve his health, independence, or quality of life. ABLE Act § 101(1); IRC § 529A(e)(5); Treas. Reg. §§ 1.529A-1(b)(15) and 1.529A-2(h)(1); POMS SI 01130.740.B.8. "Qualified disability expenses" should be broadly construed to include basic living expenses, and should not be limited to expenses for items for which there is a medical necessity or which provide no benefits to others in addition to benefitting the eligible individual. Treas. Reg. § 1.529A-2(h)(1).

a. IRC § 529A(e)(5), Treas. Reg. § 1.529A-2(h)(1), and POMS SI 01130.740.B.8. provide an initial list of **types of QDEs:** education, housing, transportation, employment training and support, assistive technology and related services; personal support services; health, prevention and wellness; financial management and administrative services; legal fees; expenses for ABLE account oversight and monitoring; funeral and burial expenses; and basic living expenses (*e.g.* food and special dietary items).

(1) Both the ABLE Act and the proposed regulations initially required a qualified ABLE program to establish "safeguards" to distinguish between distributions used to pay QDEs and other non-qualified distributions, and to facilitate the identification of **amounts distributed for the designated beneficiary's "housing expenses"** including mortgage payments (as well as insurance required by the mortgage holder); real property taxes; rent; heating fuel; gas; electricity; water; sewer; and garbage removal. POMS SI 01130.740.B.9. These items are also included as elements of "In-Kind Support and Maintenance" attributed to an SSI recipient in the context of calculating the amount of his monthly cash benefit. *See* discussion, *supra*, at Section IV.A.1.a.(2)(f). The proposed regulations provided no guidance or suggested methodology to accomplish such required classification or tracking.

(a) In response to hundreds of negative comments regarding this aspect of the proposed regulations, the Treasury Department and the IRS agreed in Notice 2015-81 that **"the final regulations will not require a qualified ABLE program to identify or record whether distributions were made for housing expenses."** Furthermore, that Notice also confirms that "the final regulations will not require, for any federal income tax purpose, a qualified ABLE program to establish safeguards to distinguish between distributions used for the payment of qualified disability expenses and other distributions." Cf. Treas. Reg. § 1.529A-3(a)(1), regarding the includability in the gross income of the designated beneficiary of an ABLE account if distributions from the ABLE account exceed his QDEs paid during the taxable year (regardless of when incurred).

(b) However, ABLE programs are required to effectuate a **monthly "data exchange" with the SSA** regarding the first-of-the-month balance in an ABLE account, and disbursements from an ABLE account during the month, including funds transferred from an ABLE account onto the designated beneficiary's "prepaid debit card." POMS SI 01130.740.E.1., and SI 01130.740.G. The designated beneficiary must be prepared to **categorize distributions** from his ABLE account in order to properly determine his federal income tax obligations, and **for purposes of the "resource" analysis** required of SSI recipients. POMS SI 01130.740.C.5.b. and SI 01130.740.D.2. and 3.

(2) The designated beneficiary of an ABLE account, or another person with "signature authority" over the account (as discussed in Section H.1., below), has the authority to withdraw funds from an ABLE account for the benefit of the designated beneficiary. POMS SI 01130.740.B.4. Reportedly, the vast majority of distributions from ABLE accounts are effectuated by means of SSA-approved "prepaid debit cards," which are accepted wherever Visa is accepted. POMS SI 01130.740.G. The prepaid debit card offered by True Link Financial has been approved by the SSA for use with ABLE accounts. The designated beneficiary, or other person with signature authority, "pre-loads" purchasing power from the ABLE account onto the card for later spending, *i.e.* the debit card is *not* attached directly to the account as with a traditional bank debit card. Purchasing power transferred from an ABLE account to a prepaid card is considered a qualified distribution. POMS SI 01130.740.G. Other options for withdrawing funds from an ABLE account include paper checks and electronic transfers.

F. ABLE Accounts and Means-Tested Government Benefits

1. Generally, the balance in a designated beneficiary's **ABLE account is disregarded** as a resource for purposes of determining his eligibility for means-tested federal and state benefits. ABLE Act § 103(a). Thus, the ABLE Act allows individuals with disabilities to retain their eligibility for means-tested government benefits while controlling assets in excess of the general $2,000 resource limit for SSI and Medicaid, discussed, *supra*, at Section IV.A.1.a.(2)(a).

a. The SSA POMS state that contributions to, distributions from, and earnings on, an ABLE account are not considered income to the designated beneficiary for purposes of his means-tested government benefits. *See* POMS SI 01130.740.C.1. and 4. Distributions from an ABLE account are deemed to be conversions of resources from one form to another. *See* POMS SI 01130.740.C.4. **Distributions from an ABLE account are not counted as income (including "In-Kind Support and Maintenance," discussed, *supra* at Section IV.A.1.a.(2)(f)) to the designated beneficiary regardless of whether they are used for non-housing QDEs, housing QDEs, or non-qualified expenses**. POMS SI 01130.740.C.4.

b. Although the POMS acknowledge that distributions from an ABLE account are not *income* to the designated beneficiary (including income that constitutes "In-Kind Support and Maintenance") if spent in the same month received, there are numerous provisions of the POMS that address **an ABLE account, and distributions therefrom, as an available *resource*** to the designated beneficiary.

(1) A distribution from an ABLE account for a QDE *other than housing* is excluded from the designated beneficiary's countable resources if it is retained by him beyond the month received, as long as the designated beneficiary maintains, makes contributions to, or receives distributions from, the ABLE account; the distribution remains unspent; the distribution is identifiable; and the designated beneficiary intends to use the distribution for a QDE unrelated to housing. POMS SI 01130.740.C.5.a.

(2) In contrast, a distribution from an ABLE account for a *housing-related* QDE, or for an expense that is not a QDE, that is retained by the designated beneficiary in a month following the month of receipt is includable in the designated beneficiary's countable resources under the normal resource counting rules. POMS SI 01130.740.D.2. and 3.

c. Additionally, once the value of an **ABLE account exceeds $100,000,** the designated beneficiary's **eligibility to receive SSI payments is suspended**, but not terminated. ABLE Act § 103(b)(1). POMS SI 01130.740.C.3. Additional consequences of exceeding this threshold depend on the following.

(1) If the balance in an SSI recipient's ABLE account exceeds $100,000 by an amount that causes the recipient to exceed the SSI resource limit, whether alone or when combined with his other resources, the recipient enters into a **special SSI suspension period** where: (i) the SSA suspends the recipient's SSI payments without time limit (as long as the designated beneficiary remains otherwise eligible to receive SSI); (ii) the recipient maintains his underlying SSI-linked Medicaid eligibility; and (iii) the recipient's SSI eligibility does not terminate after twelve continuous months of suspension. The SSA will reinstate SSI payments for any month in which the designated beneficiary's ABLE balance no longer exceeds the resource limit and he is otherwise eligible. POMS SI 01130.740.D.1.a.

(a) If the balance in the ABLE account exceeds $100,000 by an amount that causes the recipient to exceed the SSI resource limit, but the recipient's other resources (*i.e.* other than the ABLE account) also exceed the SSI resource limit, then (i) the SSA will suspend the recipient's SSI payments; (ii) the recipient loses his underlying SSI-linked Medicaid eligibility; and (iii) the recipient's SSI eligibility will terminate after twelve continuous months of suspension. The SSA will reinstate the recipient's SSI eligibility and Medicaid benefits for any month in which the recipient's ABLE account balance, combined with his other resources, do not cause the individual to exceed the resource limit. POMS SI 01130.740.D.1.b.

(2) If an individual is ineligible for SSI for any reason other than excess resources in an ABLE account, the special suspension status rules will not apply. The SSA will suspend the individual's SSI eligibility using normal procedures. POMS SI 01130.740.D.1.c.

d. The **total cumulative "aggregate" value of an ABLE account is capped** at the **state's limitation for § 529 Qualified State Tuition Program accounts** (a/k/a "529 Plans"), currently ranging from $235,000 to $555,000. The final regulations mandate the return to contributors of excess aggregate contributions (and the net income attributable to those contributions) which cause an ABLE account balance to exceed the state's maximum limitation for § 529 Plans. IRC § 529A(b)(6), and Treas. Reg. §§ 1.529A-1(b)(10) and 1.529A-2(g)(3) and (4). The Code and regulations do not specify if a designated beneficiary would lose his Medicaid eligibility solely because the value of his ABLE account exceeds the IRC § 529(b)(6) limit.

e. It is not entirely clear whether a transfer to an ABLE account by a designated beneficiary of his own assets when he is 65 or older would constitute a penalty transfer for purposes of means-tested government benefits eligibility, as discussed, *supra*, at Section

III.B.2.d. and Section III.D.1.f. However, some well-respected practitioners insist that the designated beneficiary may continue to fund his ABLE account even after he attains 65 years of age, since the definition of "designated beneficiary" does not include any upper age limitation. POMS SI 10030.740.B.3. (In contrast, no contributions to a first-party Special Needs Trust may be added after the beneficiary's sixty-fifth birthday, as discussed, *supra*, at Section III.B.2.d.)

G. ABLE Accounts May Be Subject to a Medicaid Payback Claim

1. IRC § 529A(f) states that upon the death of the designated beneficiary of an ABLE account, subject to any outstanding payments due for qualified disability expenses, all funds remaining in the ABLE account **"shall be distributed to [the state Medicaid program] upon filing of a claim** for payment by such state," up to an amount equal to the total medical assistance paid for the designated beneficiary from and after the date the ABLE account was established. Treas. Reg. § 1.529A-2(o) elaborates on this statutory provision as follows:

> "A qualified ABLE program must provide that a portion or all of the balance remaining in the ABLE account of a deceased designated beneficiary **must be distributed to a state that files a claim** against the designated beneficiary or the ABLE account itself with respect to benefits provided to the designated beneficiary under that state's Medicaid plan . . . The payment of such claim (if any) will be made only after providing payment from the designated beneficiary's ABLE account of the designated beneficiary's funeral and burial expenses (including the unpaid balance of a pre-death contract for those services) and all outstanding payments due for his or her other qualified disability expenses, and shall be limited to the amount of the total medical assistance paid for the designated beneficiary after the establishment of the ABLE account . . .."

2. "Upon the death of the designated beneficiary, funds remaining in the ABLE account, after payment of all outstanding qualified disability expenses, must be used to reimburse the state(s) for Medical Assistance (Medicaid) benefits received by the designated beneficiary, if the state(s) file(s) a claim for reimbursement." POMS SI 01130.740.A.2.

a. Thus, **even third-party funds contributed to an ABLE account are potentially subject to a Medicaid payback claim**, which is not required in the context of a third-party Special Needs Trust. *See, supra,* at Section III.C.2.

(1) Thus, a state theoretically has discretion *not* to exact the Medicaid payback from an ABLE account. As of May 23, 2022, thirteen states (Arkansas, California, Delaware, Florida, Illinois, Kansas, Maine, Maryland, Nebraska, Oregon, Pennsylvania, Virginia and West Virginia) have passed the legislation necessary for a state Medicaid plan to forego a payback claim upon the death of the designated beneficiary of an ABLE account. However, if a non-resident establishes an ABLE account in a state that does not exact a payback, the non-resident's state of residence may nevertheless file its own claim against the ABLE account.

3. The state Medicaid plan is considered a creditor of an ABLE account with respect to its payback claim, not a beneficiary. IRC § 529A(f). Treas. Reg. § 1.529A-2(o) provides that "A state law prohibiting the filing of such a claim against either the ABLE account or the designated beneficiary's estate will not prevent that state's program from being a qualified ABLE program."

4. The option to forego a payback claim against an ABLE account is not available if the designated beneficiary is otherwise subject to separate "estate recovery," *e.g.* he received Medicaid at or after 55 years of age, or received long-term services and supports under certain Medicaid waiver programs. Any funds remaining in an ABLE account after the expiration of the applicable statute of limitations for filing Medicaid claims against the designated beneficiary's estate may then be distributed to the estate of the deceased designated beneficiary, or to a successor qualified designated beneficiary. Treas. Reg. § 1.529A-2(o).

H. Additional Administrative Issues

1. If an **eligible individual is unable to establish or manage an ABLE account** for himself (*e.g.* because he is a minor or an incapacitated adult, or simply chooses not to do so) the ABLE account may instead be established and managed by (i) a person selected by the eligible individual, or (ii) the eligible individual's agent acting under a durable power of attorney, or if none, then by his conservator or legal guardian, spouse, parent, sibling or grandparent, or by his Representative Payee, **in that specific order.** Treas. Reg. § 1.529A-2(c)(1)(A), (B) and (C). A person establishing an ABLE account may self-certify, under penalties of perjury, that he is authorized to do so and that there is no other person with higher priority. Treas Reg. § 1.529A-2(c)(1)(ii). Nevertheless, **regardless of who establishes, funds, or manages the account, the SSA and the IRS always consider the designated beneficiary to be the owner of the ABLE account.** Treas. Reg. § 1.529A-1(b)(4) and POMS SI 01130.740.B.6.

a. Whoever establishes the ABLE account will also have "signature authority" over the account. Treas. Reg. § 1.529A-2(c)(2)(i). Any reference in the ABLE Act or the final regulations to actions taken by the designated beneficiary, such as opening or managing the account, are deemed to include the actions of any individual other than the designated beneficiary who is granted, or deemed to have, signature authority over the ABLE account. However, Treas. Reg. § 1.529A-2(c)(2)(i)(A) then provides that "At any time the designated beneficiary may remove and replace any person with signature authority over the designated beneficiary's ABLE account" with a person of his choice. Presumably, the exercise of this important right is contingent on a finding that the designated beneficiary has the requisite intellectual capacity to do so, but no such requirement is referenced in the regulation.

(1) Treas. Reg. § 1.529A-2(c)(3)(iii) sets forth new concepts and powers not previously contemplated by the proposed regulations. Even though an eligible individual is limited to one ABLE account, the person with signature authority over the account "at any time and from time to time may **create one or more sub-accounts**, may transfer funds in the ABLE account to one or more of the sub-accounts, and may close one or more of the sub-accounts, . . ."

(2) That section of the final regulations further provides:

(a) Each sub-account may have a different person with signature authority over that sub-account.

(b) The power of a person with signature authority over a sub-account is limited to making distributions from that sub-account.

(c) All **sub-accounts must be aggregated with the "primary" account for all purposes**, including the limit on the number of changes in investment direction (Treas. Reg. § 1.529A-2(l)); the annual and aggregate contribution limits (Treas. Reg §§ 1.529A-(g)(2) and (3)); the computation of amounts includable in the gross income of the designated beneficiary or other persons; and all reporting obligations and requirements.

(d) Treas. Reg. § 1.529A-2(c)(2)(B)(iii) provides, in part, that the person with signature authority over the primary ABLE account "may appoint and from time to time may remove, replace, or name a successor for any person with signature authority over a sub-account . . . .." Depending on who established the primary ABLE account (in accordance with the new hierarchy of permissible establishers set forth in Treas. Reg. § 1.529A-2(c)(1)), a family's relative level of dysfunction as between and among those persons trying to secure the future of the designated beneficiary may render illusory the flexibility intended by the sub-account concept.

(e) Indeed, Treas. Reg. § 1.529A-2(g)(5) allows "the designated beneficiary, from time to time, to restrict who may make contributions to the designated beneficiary's ABLE account."

b. Practitioners opine that the designated beneficiary being "unable" to create or manage his ABLE account does not necessarily require a judicial determination that the designated beneficiary is incapacitated, or that the incapacity be related to the disability, but could also include spendthrift tendencies, substance abuse and addictions, and similar financial mismanagement or imprudence. Treas. Reg. § 1.529A-1(b)(3) contemplates that a designated beneficiary may simply choose not to exercise signature authority over his ABLE account for any reason, or no reason.

(1) Anticipating that a designated beneficiary with the requisite mental capacity who is initially capable of establishing his own ABLE account may subsequently lose his capacity or simply choose not to manage the account, it is prudent to have him execute a **durable power of attorney granting a third-party signature authority** over his ABLE account in either such event. (The state's ABLE program is likely to have a form of limited power of attorney available for this purpose.) It is also advisable for his parents to include in their durable powers of attorney the express authority to establish, fund and manage an ABLE account for their child with a disability.

c. Any person with signature authority over an ABLE account who is not the designated beneficiary thereof may neither have nor acquire any beneficial interest in the account during the life of the designated beneficiary, and must only administer that account for the benefit of the designated beneficiary during his lifetime. Treas. Reg. § 1.529A-2(c)(4).

2. The designated beneficiary of an ABLE account may have no more than two opportunities in any calendar year to provide **investment direction**, whether directly or indirectly, with respect to the account assets. IRC § 529A(b)(4) and Treas. Reg. § 1.529A-2(l).

3. With regard to an **improvement, or other ameliorating change, in an designated beneficiary's disability**, the regulations permit continuation of an ABLE account (with some changes in the applicable rules) during any period when the designated beneficiary does not meet the requisite definition of disability or blindness, as long as the individual met the eligibility requirements at the time the account was originally established. Treas. Reg. § 1.529A-2(d)(3).

a. Beginning on the first day of the designated beneficiary's taxable year following the taxable year in which the designated beneficiary ceases to meet the requisite definitions of blind or disabled, there can be no additional contributions to, or distributions from, the ABLE account. Treas. Reg. § 1.529A-2(d)(3).

(1) If the designated beneficiary thereafter again satisfies the requisite definitions of blindness or disability, additional contributions may be accepted, and disbursements for QDEs incurred thereafter may be made, subject to the applicable annual and cumulative limits. Treas. Reg. § 1.529A-2(d)(3).

4. The designated beneficiary of each ABLE account must receive a separate **annual accounting**. IRC § 529A(b)(3) and Treas. Reg. § 1.529A-2(i).

a. IRC § 529A(d)(1) requires ABLE programs to provide **reports to the IRS and to designated beneficiaries** with respect to contributions, distributions, and returns of excess distributions, while IRC § 529A(d)(3) requires notice to the IRS of the establishment of an ABLE account. The IRS has issued forms for this purpose: IRS Form 5498-QA ("ABLE Account Contribution Information"), IRS Form 1099-QA ("Distributions from ABLE Accounts"), and the instructions therefor. Treas. Reg. §§ 1.529A-5(a)-(g), 1.529A-6(a)-(f).

b. IRC § 529A(d)(4) requires the state ABLE program to **electronically transmit to the SSA monthly statements** regarding all ABLE account balances and account distributions. *See also* POMS SI 011130.740.E.1., F., and G.

5. The final regulations generally apply to calendar years beginning after January 1, 2021, and to information required to be furnished after December 31, 2020. Treas. Reg. § 1.529A-8(a).

6. Even in the absence of final regulations, many states established ABLE Programs. IRS Notice 2015-18 (I.R.B. 2015-12, March 23, 2015) provides that if state ABLE legislation, or ABLE implementation regulations and documents, passed or issued before final regulations were published do not fully comply with the final regulations, the states will be allowed a sufficient **transition period** to bring them into compliance. Treas. Reg. § 1.529A-8(b)(2) provides that the transition period begins with the date of establishment of the ABLE program and continues through the later of (i) November 21, 2022, or (ii) the day immediately preceding the first day of the ABLE program's first taxable year beginning after the close of the first regular session of the state legislature that began after November 19, 2020.

I. Additional Tax Considerations

1. If the total aggregate amount distributed from an ABLE account to, or for the benefit of, the designated beneficiary during his taxable year does not exceed his total QDEs paid for that year (or within the 60-day period commencing immediately following the end of his preceding tax year), no amount (whether the "earnings" portion or the "investment in the account" portion) so distributed is includable in his gross income for that year. IRC § 529A(c)(1)(B)(i) and Treas. Reg. §§ 1.529A-3(a)(1) and (2). In making this determination, all amounts distributed from an ABLE account to, or for the benefit of, the designated beneficiary during his tax year are effectively treated as one distribution. IRC § 529A(c)(1)(D)(i) and Treas. Reg. § 1.529A-3(a). Thus, for income tax purposes, there is **no requirement to link a specific distribution from an ABLE account to a specific QDE of the designated beneficiary**. (Indeed, a similar distribution verification requirement was eliminated from IRC § 529 Qualified State Tuition Program accounts because of its unworkability from a staffing and programmatic standpoint.)

2. **Additional amounts excluded from the gross income** of the designated beneficiary include (i) a qualified rollover from one ABLE account to another ABLE account (as defined in Treas. Reg. § 1.529A-1(b)(16)); (ii) a program-to-program transfer (as defined in Treas. Reg. § 1.529A-1(b)(13)); (iii) a change of designated beneficiary during the lifetime of the initial designated beneficiary if the successor designated beneficiary meets the relevant blindness or disability requirements, onset age, and is a sibling by blood, marriage or adoption (including a step-sibling or a half-sibling); and (iv) distributions after the death of the designated beneficiary in payment of outstanding obligations due for qualified disability expenses, as well as the funeral and burial expenses of the designated beneficiary, and any Medicaid payback claims. IRC § 529A(c)(1)(C) and Treas. Reg. § 1.529A-3(b)(1), (2), (3) and (4).

3. As noted in Section VII.E.2, *supra*, if any distribution from an ABLE account is includable in the gross income of the designated beneficiary, it is deemed to be a *pro rata* distribution of a portion of the "investment in the account" and the "earnings portion" attributed thereto, with **the earnings portion constituting gains subject to ordinary income taxation and a 10% surtax thereon**. IRC § 529A(c)(3)(A) and Treas. Reg. §§ 1.529A-3(c) and (d)(1). Exceptions to this 10% surtax include (i) post-death distributions to the designated beneficiary's estate, heirs or legatees, or creditors (but the earnings portion of the distribution is still subject to ordinary income tax); and (ii) returns of excess contributions over the federal gift tax annual exclusion limit, returns of excess cumulative, aggregate contributions over the state's § 529 Qualified State Tuition Program limit, or returns of contributions to "excess" ABLE accounts (*i.e.*

if more than one ABLE account is erroneously established for a single designated beneficiary). Treas. Reg. § 1.529A-3(d)(1) and (2).

4. The designated beneficiary must pay an **additional excise tax of 6% on any excess annual contributions** (*i.e.* over the amount specified in IRC § 2503(b) for the taxable year of the designated beneficiary), unless the excess amount is returned to the contributor. IRC §§ 4973(a)(6) and (h), and Treas. Reg. § 1.529A-3(e).

5. **Each contribution** to an ABLE account by a person (other than the designated beneficiary) is treated as a **completed present interest gift to the designated beneficiary** for gift tax purposes, and not as a future interest. IRC § 529A(c)(2)(A)(i) and Treas. Reg. § 1.529A-4(a)(1), Treas. Reg. § 25.2503-3(a), and POMS SI 01130.740.C.1.b. If a donor's gifts to the designated beneficiary (including the contribution to his ABLE account) do not exceed the annual gift tax exclusion amount set forth under IRC § 2503(b), the contribution is not subject to gift tax and has a zero inclusion ratio for purposes of the generation-skipping transfer tax. Treas. Reg. § 1.529A-4(a)(1) and (2).

6. **Distributions from** an ABLE account to, or for the benefit of, the designated beneficiary **are not treated as a taxable gift** to him. IRC § 529A(c)(2)(B); and Treas. Reg. § 1.529A-4(b).

7. A contribution to an ABLE account by the designated beneficiary that is comprised of his own property does not constitute a gift. Treas. Reg. § 25.2511-2(b) and (c). However, such property (and any earnings attributable thereto) would **constitute a gift by the designated beneficiary to any successor designated beneficiary** who succeeds to his interest in the account (whether by rollover, program-to-program transfer, or change of beneficiary), unless that successor is both an eligible individual and a "member of the family" of the original designated beneficiary, as described in Treas. Reg. § 1.529A-1(b)(12) and Treas. Reg. § 1.529A-4(c). There are no gift tax or generation-skipping transfer tax consequences to a qualified successor designated beneficiary as a consequence of the change of beneficiary. IRC § 529A(c)(2)(C) and Treas. Reg. § 1.529A-4(c).

8. Upon the death of the designated beneficiary, his ABLE account is **fully includable in his gross estate** for estate tax purposes under IRC § 2031 and Treas. Reg. § 1.529A-4(d). However, the payment of any Medicaid payback claims exacted by a state may be deductible for estate tax purposes under IRC § 2053. Treas. Reg. § 1.529A-4(d).

J. Comparison of ABLE Accounts and Special Needs Trusts

1. The benefits of an **ABLE account over a first-party Special Needs Trust** are few, but include the following.

a. **No attorney, accountant or other paid allied professional** need be consulted or involved in opening an ABLE account.

b. There is **tax-deferred growth** on ABLE account balances, and tax-free distributions of the earnings portion from the ABLE account if made for the QDEs of the designated beneficiary.

c. **Post-death QDE distributions** from an ABLE account (including funeral and burial expenses of the designated beneficiary) are permissible prior to any required Medicaid payback, whereas with a first-party Special Needs Trust, there must be an immediate cessation of payments except for the categories specifically allowed by POMS in SI 01120.203.E.

d. An ABLE account affords some **financial autonomy and fiscal education** to persons with disabilities who would otherwise be precluded by the SSI and Medicaid rules from controlling the investment and disbursement of sums in excess of $2,000.

e. It is arguable that an ABLE account could be established and funded with assets belonging to the designated beneficiary **even after he attains 65 years of age** (assuming that all of the other threshold requirements are met, including the onset of his qualified disability prior to age 26). This is not permissible with first-party Special Needs Trusts.

f. While every Special Needs Trust must be reviewed by SSA Regional Trust Review Teams and corresponding state Medicaid reviewers, a qualified ABLE program is viewed as a "safe-harbor," *i.e.* a designated beneficiary or his advisors **need not seek formal approval** of his specific ABLE account.

g. Under the **"disability certification" option** for ABLE accounts, the regulations allow for a person to **use the more lenient SSA child disability standard** of "marked and severe functional limitations," without regard to the person's age or the ability of the person to engage in "substantial gainful activity." Treas. Reg. § 1.529A-2(e)(1) and (2).

h. It is possible to **increase a designated beneficiary's monthly SSI** payment by using distributions from an ABLE account to pay for his food and housing expenses. Since such payments are **not deemed to be ISM**, there is no reduction of his SSI payment amount under the "Value of One-Third Reduction" or "Presumed Maximum Value" rules, as would be the case if a Special Needs Trust were to make distributions to pay for such expenses. *See* Section IV.A.1.(2)(f)(i) and (ii), *supra*. To facilitate this approach, it is possible to arrange for the direct deposit of SSI payments to the designated beneficiary's ABLE account. POMS SI 01130.740.C.1.a. and GN 02402.030.B.1.

(1) In 2022, the maximum federal SSI monthly benefit is $841. If a Special Needs Trust were to pay the beneficiary's housing or food expenses, a maximum reduction of $280 or $300 (depending on the beneficiary's living arrangement) would apply under the VTR or PMV rules applicable to ISM, yielding a monthly SSI benefit of only $561 or $541, as the case may be. If the same housing or food expenses were instead defrayed by distributions from the designated beneficiary's ABLE account, there would be no ISM reduction to his SSI payments, thus increasing his annual SSI payments by $3,360 or $3,600, as the case may be ($280 x 12 months = $3,360; $300 x 12 months = $3,600).

i. The **Medicaid payback claim** against the funds remaining in an ABLE account at the death of the designated beneficiary is **limited to medical assistance paid for his benefit *after the establishment of the ABLE account***. Funds remaining in a first-party Special Needs Trust at the death of the beneficiary are subject to a Medicaid payback claim for all medical assistance provided for the beneficiary during his lifetime (even prior to the establishment of the Special Needs Trust).

2. An ABLE account is decidedly inferior to a third-party Special Needs Trust for the following reasons.

a. All third-party funds contributed to an ABLE account are potentially subject to a Medicaid payback claim upon the death of the designated beneficiary, if the Medicaid plan of the sponsoring state elects to file a claim (which, it may be anticipated, will be the case with most states that elect to offer an ABLE program). **Funds in a third-party Special Needs Trust are not subject to a Medicaid payback**. If families are not working with a Special Needs Planning attorney or an allied professional who knows these rules, they may never realize that **funding a third-party Special Needs Trust instead of an ABLE account would have avoided the Medicaid payback entirely**, allowing them to designate trust remainder beneficiaries of their choice.

b. While an ABLE account may generally be funded each year with a maximum of $16,000 (in 2022) *from all sources combined*, **a third-party Special Needs Trust has no such annual limit on contributions**. Even though the annual contribution limit set forth in IRC § 2503(b) is indexed for inflation, this annual limitation will make it difficult to accumulate a significant fund for the designated beneficiary in an expeditious manner. Thus, assuming that a designated beneficiary established an ABLE account in 2016 (*i.e.* the first year that any state offered an active ABLE program), funded it each year with the maximum permissible amount ($14,000 per year for the first two years, $15,000 per year for the next four years, and $16,000 in 2022), and made no withdrawals from the ABLE account, the $100,000 limit would not be exceeded until 2022 (not counting any tax-free earnings on the account balance over the years).

c. If the value of an ABLE account exceeds $100,000, the eligibility of the designated beneficiary for **SSI payments is suspended**. If the value of an ABLE account exceeds the state's § 529(b)(6) limit for its Qualified State Tuition Program, the eligibility of the designated beneficiary for Medicaid might be lost. **Neither such result ensues in the case of a Special Needs Trust for the beneficiary (whether a first-party or third-party) that exceeds those maximum limits**.

d. While distributions from an ABLE account must be used solely for the QDEs of the designated beneficiary, **no such restrictions** exist in the context of a third-party Special Needs Trust.

e. While the designated beneficiary of an ABLE account must satisfy the definition of blind or disabled prescribed by the SSA, the **beneficiary of a third-party Special Needs Trust need not meet any particular definition of disability**. (As discussed, *supra*, at

Section III.B.2.b., the beneficiary of a first-party Special Needs Trust must also satisfy the definition of blind or disabled promulgated by the SSA.)

f. While the designated beneficiary of an ABLE account must prove that the onset of his disability occurred prior to his 26th birthday, **no such age limitation exists in the context of a third-party Special Needs Trust**. (As noted, *supra*, at Section III.B.2.e., a first-party Special Needs Trust must be established and funded prior to the beneficiary's 65th birthday, but the initial age of onset of his disability is irrelevant.)

g. While an ABLE account may only be established by the eligible individual, by a person selected by the eligible individual, or by the eligible individual's agent under a power of attorney, conservator, legal guardian, spouse, parent, sibling, grandparent, or Representative Payee, *in that order*, **anyone can establish a third-party Special Needs Trust.**

h. While each designated beneficiary may have only one ABLE account, there is **no limit on the number of Special Needs Trusts (first-party or third-party) which may be established** for a beneficiary. This is particularly important if the funders of third-party Special Needs Trusts wish to designate different remainder beneficiaries after the death of the beneficiary with the disability. The concept of "sub-accounts" established under the umbrella of the designated beneficiary's sole ABLE account, added in the final regulations, somewhat ameliorates this otherwise serious planning limitation. *See* Treas. Reg. § 1.529A-2(c)(3)(iii).

i. While all property in an ABLE account is fully **includable in the gross estate** of the designated beneficiary under IRC § 2031 (as is also the case with a first-party Special Needs Trust), none of the property in a properly drafted non-generation-skipping third-party Special Needs Trust is includable in the beneficiary's gross estate.

j. While **all funds deposited to an ABLE account must be cash** or its equivalent, no such limitations are imposed on contributions to a Special Needs Trust (both first-party and third-party).

3. Notwithstanding the significant deficiencies of an ABLE account, it often makes sense **to augment traditional third-party Special Needs Trust planning with an ABLE account funded solely with first-party assets** in the following circumstances if the designated beneficiary does not wish to incur the expense of establishing a first-party Special Needs Trust.

a. If the designated beneficiary does not regularly spend all of his SSI payments or his other earned and unearned income, and repeatedly runs the risk of exceeding the $2,000 resource limit for SSI and Medicaid eligibility, such **excess first-party funds could be direct-deposited, contributed, or irrevocably assigned, to his ABLE account**. [N.B. Such funds may nevertheless be initially categorized as "income" to the designated beneficiary for purposes of his government benefits eligibility notwithstanding its subsequent deposit to the ABLE account. *See* POMS SI 01130.740.C.1.a.]

b. If the designated beneficiary is legally entitled to receive an inheritance, gift, prize, settlement, lottery winnings, or other funds of less than $16,000 in a given year, **or**

other periodic payments of less than $1,333 per month, and does not wish to "spend down" the funds quickly, *e.g.* by purchasing exempt assets with the otherwise disqualifying resources, such first-party funds could be contributed, or irrevocably assigned, to an ABLE account.

POST SCRIPT: NOT-SO-BREAKING DEVELOPMENTS

On June 25, 2019, the Social Security Administration ("SSA") published new POMS GN 03920.007., "Legal and Specialized Services Not Subject to Fee Authorization," interpreting 42 U.S.C. §§ 406(a) and (b), which outline the sole permissible methods by which an attorney or other representative may receive fees from a Social Security claimant for services performed "in connection with any claim before the SSA," an administrative law judge or the Appeals Council. *See* Soc. Sec. Admin, *Administering Representatives Fees Provisions*, Transmittal 26 (June 25, 2019). POMS GN 03920.001.A. states: "A claimant may appoint an individual, attorney or non-attorney, to represent him/her in matters before the SSA. A "representative" who wants to collect a fee for services provided in any proceeding before SSA under the Social Security Act must first obtain SSA's authorization . . . ." POMS GN 03920.005.B. then provides that this fee authorization is required "irrespective of whether (among other things) the attorney / non-attorney was ever recognized by SSA as a claimant's representative, or the individual did not deal directly with or actually contact SSA . . ." The consequences for failing to abide by the SSA's fee authorization rules are set forth in 42 U.S.C. § 406(a)(5), as follows:

> "Any person who shall . . . knowingly charge or collect directly or indirectly any fee in excess of the maximum fee, or make any agreement directly or indirectly to charge or collect any fee in excess of the maximum fee, . . . shall be deemed guilty of a misdemeanor and, upon conviction thereof, shall for each offense be punished by a fine not exceeding $500 or by imprisonment not exceeding one year, or both."

POMS GN 03920.005.C. sets forth a non-exclusive list of proceedings before the SSA which require a fee authorization, including (among others) (i) an application for SSI payments; and (ii) a request to modify the amount of benefits. Notably absent from this list is drafting Special Needs Trusts or advising on the proper administration of Special Needs Trusts. New POMS GN 03920.007.C. reiterates (i) and (ii), above (among others), and similarly does not include drafting a Special Needs Trust or advising on the proper administration of a Special Needs Trust in this non-exclusive list.

However, the first three examples set forth under a new POMS GN 03920.007.D., and the accompanying explanations for each, pertain to various aspects of drafting, establishing, amending and administering Special Needs Trusts. Regrettably, the examples included in that new POMS were subject to multiple interpretations and failed to provide clear guidelines for many of the services that comprise Special Needs Planning but do not directly or primarily concern the SSI eligibility of the Special Needs Trust beneficiary. Many Special Needs Planning attorneys (including this author) routinely attempt to delegate to an outside attorney, or other third party, who routinely practices before the SSA those "obvious" SSI eligibility-related issues that may arise in the course of an engagement, *e.g.* applying for SSI benefits and submitting Special Needs

Trusts to the SSA for review and approval. However, the initial version of that new POMS interjected significant uncertainty into the long-standing practices of many attorneys who advise families trying to secure the future of persons with disabilities, as well as the practices of the allied professionals who work to implement comprehensive Special Needs Plans.

For a thorough analysis of POMS GN 03920.007, and the ensuing chaos wrought in the Special Needs Planning arena, *see* Kevin Urbatsch, *New POMS on Attorneys Fees,* NAELA News Online, August 2019 (available at https://www.urblaw.com/wp-content/uploads/2019/08/urbatsch-new-poms-atty-fees.pdf).

NAELA, the Special Needs Alliance, the Academy of Special Needs Planners, and similar organizations strategized and engaged in ongoing discussions with representatives of the SSA to request that POMS GN 03920.007 be suspended until clarifying guidance is issued. On September 25, 2019, without explanation, the SSA "archived" (*i.e.*, de-published) POMS GN 03920.007. Reportedly, the SSA is continuing to seek input from practitioners before it revises and clarifies one or more aspects of the de-published POMS section, which is likely to be re-published by the SSA at an undetermined future date. This battle is far from over.

CONCLUSION

Each year hundreds of articles, treatises and conferences are made available to help practitioners keep abreast of developments in this ever-changing area of the law. *See, e.g.,* Katherine N. Barr, Richard E. Davis & Kristen M. Lewis, *Top 15 Tips for Estate Planners When Planning for Special Needs*, 24 Prob. & Prop. 38 (Mar. / Apr. 2010), and Kristen M. Lewis, *Planning Challenges for Beneficiaries With Special Needs*, Estate Planning, Vol. 46, No. 3 (March 2019). Advising clients who have beneficiaries with special needs is fraught with challenges, but the personal and professional rewards for successful planning are unparalleled.

(Last Updated on July 25, 2022)

Top 30 Best Practice Tips When Advising Families with Special Needs Beneficiaries

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1. Do not disinherit the person with a disability ("PWD").

2. Understand and procure a Life Care Plan for the PWD.

3. Have a go-to life care planner to prepare a Life Care Plan for the PWD.

4. Insist on seeing the PWD's SSA benefits award letter.

5. Understand that SSI eligibility for the PWD is the gateway to accessing beneficial programs and services that are not available to the PWD on a private pay basis.

6. Have a go-to government benefits consultant to apply for and maximize the current funding of the PWD's government benefits.

7. Understand the difference between "first-party" and "third-party" Special Needs Trusts ("SNTs") for the PWD.

8. Understand the "network" of SNTs for the benefit of the PWD.

9. Review existing funded trusts for the benefit of the PWD; focus on problematic "support" and "maintenance" distribution standards for the benefit of the PWD.

10. Include a limited power to amend in all SNTs (vested in the Trustee).

11. Have a go-to medical coding professional to facilitate the proper administration of SNTs for the PWD.

12. Verify every state in which the PWD has ever lived.

13. Never include a Medicaid "payback" obligation in a properly drafted third-party SNT for a PWD.

14. Verify the source of assets which were used to fund a trust (of any kind) for the PWD.

15. Know the "pooled" SNTs that operate in the state where the PWD resides.

16. Use a funded Revocable Living Trust-based estate plan (instead of a Will-based plan) for clients that have an heir or other beneficiary who is a PWD.

17. Create an *inter vivos* third-party SNT for the PWD as a convenient receptacle for lifetime gifts or *post mortem* bequests.

18. Create an *inter vivos* third-party SNT for the PWD to receive annual exclusion gifts.

19. Create an *inter vivos* third-party SNT for the PWD to receive required minimum distributions from retirement accounts.

20. Create an *inter vivos* first-party SNT for the PWD to hold assets that slip through the network of third-party SNTs.

21. Know how to fix trusts for the benefit of the PWD that are incompatible with Special Needs Planning.

22. Know how to use an ABLE account for the PWD to supplement the network of SNTs for the PWD.

23. Update financial Powers of Attorney to authorize the establishment and funding of SNTs for the PWD, the principal and others.

24. Use professional Trustees to administer SNTs for the PWD.

25. Have a go-to accounting professional who understands the taxation of SNTs.

26. Have a go-to investment advisor who understands how to invest the assets of SNTs.

27. Understand the PWD's legal Guardian as the "quarterback" of the team of allied professionals.

28. Do not place too much responsibility on the relatives or friends of the PWD.

29. Consider the PWD's estate and disability planning, including life insurance coverage on the PWD.

30. Learn, appreciate and use person-first language (instead of disability-first language), e.g. "person with a disability" rather than "disabled person."

As of 7/25/2022

PLANNING FOR PERSONS WITH DISABILITIES:
RECENT DEVELOPMENTS AND CONTINUED CHALLENGES

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APPENDIX

- Kristen M. Lewis, *Planning Challenges for Beneficiaries with Special Needs,* Estate Planning, March 2019, Vol. 46, No. 3 (used with express permission)

- *Administering a Special Needs Trust: A Handbook for Trustees,* published by, and used with express permission of, the Special Needs Alliance (all rights reserved) [also available at https://specialneedsalliance.org/special-needs-101/free-trustee-handbook/

- *Preparing Annual Trust Accountings for Filing with the Georgia Department of Community Health: A General Guide for Trustees of Approved Special Needs Trusts* (used with express permission)