PLANNING FOR BENEFICIARIES WITH SPECIAL NEEDS

By

Kristen M. Lewis
Smith, Gambrell & Russell, LLP
Atlanta, Georgia 30309
(404) 815-3640
klewis@sgrlaw.com

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Kristen M. Lewis

Kristen M. Lewis is counsel in the Tax Practice at Smith, Gambrell & Russell, LLP in Atlanta, Georgia. She has extensive experience in estate planning and wealth protection, "special needs trusts," trust and estate planning and administration, guardianships, fiduciary matters, trusts for pets, and charitable giving techniques.

Ms. Lewis is a nationally recognized expert on "Special Needs Trust" planning for persons challenged by disabilities, and is a frequent speaker and author on this topic. She is an active member of the Special Needs Alliance, the Academy of Special Needs Planners, the National Academy of Elder Law Attorneys, the American Bar Association, the New York Bar Association Elder Law Section, the State Bar of Georgia Fiduciary Law Section, and the Georgia Planned Giving Council. She is a Fellow of the American College of Trust and Estate Counsel. She recently completed her tenure as 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 ABA. In her free time, she trains certified service dogs for Canine Assistants.

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 Law School in 1984. She is admitted to practice law in both New York and Georgia.

Ms. Lewis 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."

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I. THE "SPECIAL NEEDS" OF PERSONS WITH DISABILITIES

A. The scope of the population with disabilities

1. There are an estimated **one billion** people with disabilities in the world, according to a 2011 report published by the World Health Organization. *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." The *International Classification of Functioning, Disability and Health* uses the term "disability" as an umbrella for impairments, activity limitations and participation restrictions. A report issued by the United States Census Bureau 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 www.census.gov/hhes/www/disability/sipp/disable10.html (last visited August 10, 2012)). Another 4.1 million institutionalized people (*i.e.* in correctional institutions or nursing homes) have disabilities, but were not included in the Brault report.

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 "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 limitations 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;

[1] http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

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) In March 2012, the Centers for Disease Control and Prevention issued its "Autism and Developmental Disabilities Monitoring Network" report, concluding that the prevalence of autism has risen to 1 in every 88 births in the United States, affecting almost one in 54 boys, and one in 252 girls. *See* Department of Health and Human Services, Centers for Disease Control and Prevention, "Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008," *Morbidity and Mortality Weekly Report* (Mar. 30, 2012).[3]

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.

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[2] www.census.gov/prod/2011pubs/acsbr10-12.pdf.

[3] http://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf.

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.

II. DO NOT DISINHERIT THE BENEFICIARY WITH SPECIAL NEEDS

A. Disinheritance is an outdated and incorrect approach

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).[4]

B. Do not leave the share of the person with special needs to another family member

1. Able-bodied 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, or (iii) 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.

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

(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 proper arrangements in the Will for the ongoing management of the funds for the benefit of the intended beneficiary. Since an estimated 70% of the population dies intestate, this is another very common flaw in a client's plans to provide 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*). The 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 42 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 **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 and 01120.203 (included in the Appendix). The POMS are also available on-line at http://policy.ssa.gov. 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. The trust is established by (*i.e.* through the actions of) a permissible Settlor, including (i) 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; (ii) a parent or grandparent of the beneficiary; or (iii) a court. Thus, the beneficiary cannot establish a first-party Special Needs Trust for himself, even if he is otherwise mentally competent to do so under relevant State law.

(1) Notwithstanding the unambiguous provisions of the federal enabling statute regarding the authority of "a parent or grandparent" to establish a first-party Special Needs Trust, the Social Security Administration 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. *See* POMS SI 01120.203.B.l.g. 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, to which may be added the assets belonging to the beneficiary. *See* POMS SI 01120.203.B.1.f.

(2) Since the beneficiary is not authorized to establish his own first-party Special Needs Trust, the Social Security Administration takes the position that a mere "agent" of the beneficiary similarly may not serve as the Settlor. *See* POMS 01120.203.B.1.g. Thus, for example, a person serving as attorney-in-fact under a Power of Attorney (which is governed by agency principles) may not establish a first-party Special Needs Trust for the benefit of the principal. *Id.*

(3) 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 01120.203.B.1.f.

b. 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. 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 2012, the income threshold evidencing a person's ability to engage in SGA is $1,010/month. For a person who is blind, the SGA threshold is $1,690 in 2012. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).[5] For purposes of a determination of SGA, a person's gross earnings excludes (i) unreimbursed out-of-pocket "impairment related work expenses" (*e.g.* attendant services, modifications to a vehicle used to transport the person to work, *etc.*), and (ii) the value of any work subsidies or support.

c. The trust is irrevocable and for the *sole benefit* of the beneficiary.

(1) While the federal enabling statute does not expressly require a first-party Special Needs Trust to be irrevocable, both the Social Security Administration and State Medicaid programs require irrevocability. *See, e.g.*, POMS SI 01120.201.D.1 and SI 01120.203.D.1, Step 7.

(2) While the federal enabling statute uses only the phrase "for the benefit of" the beneficiary, the States and the Social Security Administration have effectively required that a stricter "sole benefit" standard be utilized when evaluating Special Needs Trusts. *See, e.g.*, POMS SI 01120.203.B.1.e. 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 exempt, 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.1.e and SI 01120.203.D.1, Step 3, assert the position of the Social Security Administration 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.2, and currently constitutes a major battleground for those who draft and administer Special Needs Trusts.

d. The beneficiary is under age 65 when the trust is established and funded with the beneficiary's assets.

(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.1.b.

(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 prior to the beneficiary's 65th birthday. Similarly, annuity payments to a first-party Special Needs Trust pursuant to an irrevocable assignment to the trust prior to the beneficiary's 65th birthday will not constitute "additions" even if the payments continue after age 65. *See* POMS SI 01120.203.B.1.c.

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[5] http://www.socialsecurity.gov/pressoffice/colafacts.htm.

e. Upon the death of the beneficiary (or other termination event), medical assistance providers (*i.e.* **Medicaid,** but not the Social Security Administration) **will be reimbursed** up to the total amount of medical assistance benefits paid on behalf of the beneficiary under a State Medicaid plan during his lifetime.

(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) 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).

(3) Provisions of the Social Security Administration'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 01120.203B.1.h.

(4) 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 prior to the establishment of the trust for medical care necessitated by the wrongful acts that generated the recovery. However, 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).

(5) If a first-party Special Needs Trust will terminate prior to the actual death of the beneficiary, 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 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.

(6) The Medicaid payback amount is calculated based on the actual Medicaid rate 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).

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 first-party Special Needs Trust designed to receive and distribute any income of the beneficiary which is over 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 "cost of share" 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 limited termination events), any funds remaining in the trust must be paid to the State Medicaid program.

C. Third-Party Special Needs Trusts

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 Social Security Administration do specifically address third-party Special Needs Trusts. *See, e.g.*, POMS SI 01120.200.D.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 Subsection B, *supra*. 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 funded first-party Special Needs Trust, which would unnecessarily subject those funds to the Medicaid payback required for first-party Special Needs Trusts.** Anyone can serve as the Settlor of a third-party Special Needs Trust; the beneficiary need not meet any particular definition of "disability;" there is no age limitation on the beneficiary or the timing of funding the trust; and the beneficiary need not be the sole beneficiary of the trust. The POMS do require that the trust be irrevocable. *See* POMS SI 01120.200.D.1.b and POMS SI 01120.201.D.1.

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. "Pooled" Special Needs Trusts

1. In addition to the single-beneficiary first-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A), described in Subsection B, *supra*, OBRA '93 also authorized the concept of a "pooled" Special Needs Trust, separate accounts in which may be 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 requirements.

a. A pooled Special Needs Trust must be "established and managed by a non-profit association." POMS SI 01120.203.B.2.c 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. A pooled Special Needs Trust must contain the assets of individuals who are "disabled," as defined by 42 U.S.C. § 1382c(a)(3) (discussed in Section III.B.2.b, *supra*).

c. The pooled Special Needs Trust must maintain a separate account for the **sole benefit** of each beneficiary with a disability, but may pool the assets of the separate accounts for purposes of investment and management. *See* POMS SI 01120.203.B.2.d and POMS SI 01120.203.B.2.e.

d. A separate 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. (In contrast, as noted in Section III.B.2.a., *supra*, the beneficiary of a (d)(4)(A) Special Needs Trust may not serve as the Settlor to establish a first-party Special Needs Trust for himself.)

e. To the extent that the pooled Special Needs Trust does not retain any amounts remaining in a separate account upon the beneficiary's death, such assets must be used to **reimburse Medicaid** (but not the Social Security Administration) up to the total amount of medical assistance benefits paid on behalf of the beneficiary during his lifetime. *See also* POMS SI 01120.203.B.2.g.

(1) POMS SI 01120.199.F.2 sets forth modified requirements for an acceptable "early termination" provision applicable to a beneficiary's account with a pooled Special Needs Trust. The requirements described in Section III.B.2.e.(5), *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 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 an account with a pooled Special Needs Trust, *i.e.* an account may 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.d., *supra*). However, many States choose to impose a penalty for the uncompensated transfer of the beneficiary's assets to the pooled Special Needs Trust 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), and POMS SI 01150.121.A.3.

(1) The United States Court of Appeals for the Third Circuit has recently 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. Separate accounts for a pooled Special Needs Trust may be established as first-party or as third-party, *i.e.* with reference to the source of the assets with which the account will be funded.

h. Pooled Special Needs Trusts are typically governed by a "Master Trust Agreement" that applies to all of the separate accounts. A separate 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 also 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 (d)(4)(A) Special Needs Trust.

i. An account with a pooled Special Needs Trust is often the only option for a beneficiary who (i) has no living parents or grandparents, (ii) may be "disabled" but who is mentally competent and thus cannot qualify for a legal Guardian or Conservator, (iii) cannot convince a court to serve as the Settlor of a (d)(4)(A) Special Needs Trust, and/or (iv) is age 65 or older.

E. "Sole Benefit" Trusts

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*. These are discussion topics for another program.

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

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

a. A properly drafted Special Needs Trust (whether for a first-party or a third-party trust) will specify that the Trustee is not obligated, and cannot be compelled by the beneficiary, to use the assets of the trust to provide for the beneficiary's "support" or "maintenance." **The use of the "support" or "maintenance" distribution standards typically results in the trust assets being deemed "available" or "countable" to the beneficiary for purposes of means-tested benefits.** *See* POMS SI 01120.200.D.2.

(1) Thus, the classic "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.

(2) While some practitioners utilize a fully discretionary distribution standard for Special Needs Trusts, unadorned by any descriptive standard whatsoever, many 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) Payments directly to the providers of services for the sole benefit of the beneficiary, including medical equipment, supplies, or 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; counseling and therapies.

(b) Payments directly to the providers of goods for the sole benefit of the beneficiary (excluding food and shelter), including 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.

(c) "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.

(d) Transportation costs, including an appropriate private vehicle (and the fuel, maintenance and insurance therefor); taxi or private driver; public transportation passes; bicycle, moped or golf cart.

(e) Non-food grocery and household items; personal care and hygiene items; over-the-counter medications.

(f) Direct payment of the beneficiary's credit card bill for items other than shelter or food (*e.g.* no payment for groceries, restaurant dinners, catered meals).

b. A properly drafted Special Needs Trust (whether for a first-party or third-party trust) will not allow the beneficiary to revoke or terminate the trust. *See, e.g.*, POMS SI 01120.200.D.1.b.

(1) 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).

c. A properly drafted Special Needs Trust (whether for a first-party or a third-party trust) 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 "means-tested" government benefits, such as 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 sole 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").

(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 Supplemental Security Income (maximum federal benefit for 2012 is $698/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 rent or mortgage payment that is due, or (ii) pays the entire rent or mortgage payment that is due, this will in turn reduce the beneficiary's SSI payment for that month. *See* POMS SI 01120.200.F. As long as the Trustee is cognizant of the impact on the beneficiary's 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) Cash (or items that can be converted to cash, *e.g.* a gift card) 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, such as Supplemental Security Income.

3. As noted in Section III.B.2.c.(2), *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.a and b.

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.

4. Late-breaking development. 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 (iv) 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, *expressio 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.* at 343. This issue is thus ripe for a review by the United States Supreme Court.

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 wish to maintain are **Supplemental Security Income ("SSI")**, a monthly cash benefit intended to cover a person's food and shelter needs (maximum Federal Benefit Rate for 2012 of $698/month, although some States provide "State supplements" to this base amount) and **Medicaid**, 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 "exempt" (*e.g.* a home, one automobile, normal household items and personal effects, certain burial funds and items) or "countable." Countable resources cannot exceed $2,000 for an individual, or $3,000 for a couple.

(1) 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.

(b) 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 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*).

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

(2) "Unearned" income is all income that is not earned, and includes ISM; private pensions and annuities; periodic payments, such as Social Security Disability Income payments, worker's compensation, veterans benefits, unemployment benefits; life insurance proceeds or other death benefits; gifts and inheritances; support and alimony; dividends and interest; and rents and royalties.

(3) "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 come 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 "fair share." If a person is not paying at least this amount towards his fair share (*e.g.* with his monthly SSI benefit), his SSI benefit will be reduced by the lesser of the actual value of his share of these items, or a full one-third of the SSI Federal Benefit Amount (even if the deficit between his fair share and the amount he can contribute is less than the one-third figure). *See* POMS SI 01120.200.E.1.b. and POMS SI 01120.200.F.3.c.

(c) In certain circumstances, the income or resources of other persons may be "deemed" 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.

(3) The applicant is a **U.S. citizen, U.S. national or a "qualified alien,"** as defined in 8 U.S.C. § 1641(b).

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) **"§ 1634 States,"** in which SSI recipients automatically qualify for, and are enrolled in, the State Medicaid program. Thirty-two States and the District of Columbia fall into this category. *See* POMS SI 01715.010.A.3.

(2) **"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.

(3) **"§ 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. Eleven states fall into this category (Connecticut, Hawaii, Illinois, Indiana, Minnesota, Michigan, New Hampshire, North Dakota, Ohio, Oklahoma and West 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).

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, and is 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 Rate (*i.e.* $2,094 in 2012).

(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) 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 2012, the Income Cap States include Alabama, Alaska, Arizona, Arkansas, Colorado, Delaware, Florida, Georgia, Idaho, Iowa, Kentucky, Louisiana, Mississippi, Nevada, New Jersey, New Mexico, Oklahoma, Oregon, South Carolina, South Dakota, Tennessee, Texas and Wyoming.[6]

(4) "Dual eligibles" are persons who qualify for both Medicaid and Medicare. 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. Theoretical Medicaid eligibility is also required for numerous private and community-based programs, *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 theoretically eligible for SSI and Medicaid (regardless of whether Medicaid is actually providing medical assistance), and some will only accept SSI benefits as payment for program services. **A family's private wealth cannot guarantee access to these beneficial programs, contrary to the belief of the many wealthy clients** are who 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 so as to gain access to these programs.

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

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 or that of his or her spouse or parent. 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 Social Security Administration 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, for at least 40 "quarters of coverage." *See* 42 U.S.C. § 414(a)(2). In 2012, the amount of earnings needed to earn one quarter of coverage is $1,130. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).[7]

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 "quarters of coverage" varies depending on the age at which the worker became disabled. 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 monthly benefits to certain unmarried persons over the age of 18 whose disability began prior to the age of 22. *See* 20 C.F.R. § 404.350(a)(5) and POMS DI 10115.001. This category of benefits is currently called **"Childhood Disability Benefits"** ("CDB"), but it was formerly known as "Disabled Adult Child" benefits. 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 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 income exclusion).

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 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.

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[7] http://www.socialsecurity.gov/pressoffice/colafacts.htm.

(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 Subsection 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.

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 full discussion of the rules that govern trust taxation is beyond the scope of this outline.)

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). Ltr. Rul. 200620025 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 Social Security Administration has attempted to characterize a power to substitute property as tantamount to an impermissible right of the beneficiary to revoke the first-party Special Needs Trust. A power of revocation held by the beneficiary of a first-party Special Needs Trust is grounds for disqualification under POMS SI 01120.201.D.1.

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 for income tax purposes, inasmuch as most 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 2012, a single individual taxpayer reaches the 35% bracket at $388,350 of taxable income, while an irrevocable non-grantor trust reaches the 35% bracket at only $11,650 of income. *See* Rev. Proc. 2011-52, 2011-45 I.R.B. 701.

a. 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.

b. "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).(b), *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" 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 taxable "income" (which, of course, always exceeds the amount of "income" that a Medicaid recipient can have and still retain eligibility). A benefits termination letter to

the beneficiary, 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.

c. 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). 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 encompass the following.

(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 the services 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 costs of maintaining medically necessary special 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 (last visited August 10, 2012)).

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 trust Employer Identification Number ("EIN"), to report the trust's income and gains on the beneficiary's individual Form 1040. However, many Trustees do obtain a separate EIN 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 EIN, 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. However, the gift tax consequences of a transfer of the beneficiary's assets to a first-party Special Needs Trust were tangentially addressed in Ltr. Rul. 9437034. 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* Ltr. Rul. 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.B.3.a 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. (Thus, the Trustee can choose which government entity to please: the IRS or Medicaid, neither of which pleases the remainder beneficiaries of the trust!)

b. To the extent that a first-party Special Needs Trust has been funded by means of guaranteed annuity payments (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 EIN, and be subject to the compressed tax brackets applicable to irrevocable non-grantor trusts. 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 the beneficiary. The trust then issues the

beneficiary a Schedule K-1 showing the taxable income properly reportable on his personal income tax return. (A full discussion of the rules that govern trust taxation is beyond the scope of this outline.)

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. 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 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. Status as a QDT entitles the trust to the full personal exemption under IRC § 151(d) allowed to all individual taxpayers ($3,800 in 2012) as opposed to the $100 exemption under IRC § 642(b)(2)(A) allowed to an irrevocable non-grantor complex trust. 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 disabled beneficiary, but it is permissible to designate remainder beneficiaries upon the death of the disabled beneficiary.)

(3) The disabled beneficiary 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 disabled 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 disabled beneficiary 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).

3. The gift tax consequences 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 2012, $13,000 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 most 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.

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 non-disabled secondary beneficiary who (i) may receive 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. 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 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 power of appointment). A third-party Special Needs Trust that is not designed to implement significant 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. COMMON 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. "Person-first" terminology

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. State and federal statutes are increasingly amended to replace all forms of the "R-word" with more respectful terminology.

a. A 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 a "Downs child;" she's a child who has Down Syndrome. She's not "mentally retarded;" she "has a cognitive disability." Her siblings without disabilities aren't "normal;" they are "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 attorney, 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 quick "cheat sheet" on the proper terminology to use when referring to individuals with disabilities, see the last page of the Appendix. *See also* John Folkins, American Speech-Language-Hearing Association, *The Language Used to Describe Individuals with Disabilities* (Dec. 1992).[8]

B. <u>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 "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 typical siblings to inherit only upon that child's death. This option is usually neither fair nor appropriate.

(1) Delaying the inheritance of the 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 personal level.

b. Although disinheriting the beneficiary with special needs is generally a very inadvisable option, 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.

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[8] http://www.asha.org/publications/journals/submissions/person_first.htm.

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. There are several national associations that purport to "certify" Life Care Planners, but it is a generally unregulated emerging area 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 form, which typically is not preserved for posterity in the same fashion as a Will. Using life insurance (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 most clients.

C. Coordinating gifts, bequests and distributions for a beneficiary receiving means-tested benefits

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 several third-party Special Needs Trusts** for the beneficiary with a disability, including the following.

a. A testamentary third-party Special Needs Trust under the Will or Living Trust of each parent.

b. An *inter vivos* third-party Special Needs Trust designed to receive bequests from other family members or friends who want to help secure the financial future of the beneficiary, who 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. 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 secondary permissible 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. An *inter vivos* third-party Special Needs Trust designed as an "accumulation trust" to serve as the "Designated Beneficiary" of an IRA, 401(k) or other qualified plan account, which is in compliance with all of the requirements set forth in Treas. Reg. § 1.401(a)(9)-4.

e. An Irrevocable 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.

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. 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.

b. The beneficiary becomes 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.

(1) If a beneficiary receiving means-tested government benefits is legally entitled to receive any of the property described in a. or b., 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. The beneficiary with special needs wins the lottery or another significant cash prize.

d. The beneficiary becomes legally entitled to child support or alimony payments as a consequence of divorce.

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 disposing of the beneficiary's asset in a manner that will not jeopardize his means-tested government benefits. It is especially important to secure the execution of a first-party Special Needs Trust while at least one of the beneficiary's parents (or grandparents) is still living. As discussed, *supra*, in Section III.B.2.a., the federal enabling statute specifies the permissible Settlors of a first-party Special Needs Trust, including the beneficiary's parents, grandparents, legal Guardian of the Property or Conservator, or a court. If the beneficiary cannot qualify for a Guardian or Conservator under relevant State statutes (*e.g.* he is "disabled" within the meaning of the Social Security Act, but he is also mentally competent), having the beneficiary's parent (or grandparent) establish a first-party Special Needs Trust as a "seed trust" (authorized by POMS SI 01120.203.B.1.f) as part of their estate planning is 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, 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 "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 Ltr. Rul. 200620025 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 (i) to create a

first-party Special Needs Trust, and (ii) to 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 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 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.

D. Pre-existing trusts with "support" or "maintenance" distribution standards

Inasmuch as special needs estate planning is a relatively new sub-specialty, practitioners are frequently confronted with older irrevocable trusts that utilize the classic 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 distribution standards found in most "Bypass/Credit Shelter" Trusts, and many "Dynasty/Generation-Skipping" Trusts, threaten to disqualify the beneficiary with a disability from ongoing eligibility for means-tested government 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 only fourteen 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" 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; 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 program 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) 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 funding of the first-party Special Needs Trust in the same month so that his eligibility for means-tested benefits is adversely impacted for only a single month.

E. Lack of a "Special Needs 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 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[9] and the Academy of Special Needs Planners.[10]

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 failure to adequately document the 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** can help the family obtain the "free appropriate public education" to which he is legally entitled. Under the federal "Individuals with Disabilities Education Act" ("IDEA"), 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 free appropriate public education guaranteed by IDEA.

6. **Accountants** who are well-versed in preparing 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.

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.

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.

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[9] http://www.specialneedsalliance.org.

[10] http://www.specialneedsplanners.com.

9. An **appropriate Trustee**, and successors, for the various Special Needs Trusts which 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 plan if they improperly administer the Special Needs Trust 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 (which shall remain nameless) 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.

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.

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 what they cannot do. Third parties 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.

Conclusion

Vast numbers of estate planning attorneys and allied professionals are finally taking steps to become educated about (and perhaps proficient in addressing) the myriad issues implicated by the special needs of their clients with disabling conditions. 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).[11] Advising clients with special needs is fraught with challenges, but the personal and professional rewards for successful planning are unparalleled.

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[11] http://www.americanbar.org/content/dam/aba/publications/probate_property_magazine/v24/02/2010_aba_rpte_pp_v24_2_mar_apr_barr_davis_lewis.pdf