



# Planning Challenges for Beneficiaries With Special Needs

To accommodate adequately the particular circumstances of beneficiaries with special needs, multiple trusts may be required.

KRISTEN M. LEWIS

Disabilities do not discriminate based on a family's socio-economic status. Families of great wealth have children or other beneficiaries with disabilities at the same rate as families of modest means. Estate planning attorneys, and the other allied professionals who serve these families, are no longer able to take the position that "We don't do special needs planning," or worse yet, recommend that the child or other beneficiary with a disability simply be disinherited (which is likely grounds for malpractice). A recent study by the Centers for Disease Control and Prevention concluded that the prevalence of Autism Spectrum Disorder (ASD) has risen to one in every 68 births in the U.S.<sup>1</sup> A more recent study concluded that the estimated prevalence of children in the U.S. with a "parent-reported" diagnosis of ASD is now one in 40.<sup>2</sup> The 2010 U.S. Census reported that almost 20% of the U.S. civilian non-institutionalized population

claimed to have a disability.<sup>3</sup> With statistics like these, estate planners and allied professionals must become, and remain, educated about the tools and techniques available to help clients secure the future of beneficiaries with disabilities within the broader context of estate planning. A critical first step is recognizing, and knowing how to overcome, the most common challenges to effective special needs planning.

## Challenge #1

*Acknowledging the incorrect assumption that families of means can access on a private-pay basis the programs and services that they want for their beneficiaries with disabilities.*

Increasingly, wealthy families who have never heard of Supplemental Security Income (SSI), which

is the gateway to accessing myriad programs and services for persons with disabilities, and who never dreamed that anyone in their households would need to establish eligibility for Medicaid, are discovering two shocking realities:

1. Many of these beneficial programs and services are categorically unavailable on a private-pay basis.
2. Their beneficiaries with disabilities must indeed establish eligibility for SSI and Medicaid in order to participate in these programs and receive these services.

For example, many community-based congregate living arrangements require eligibility for either SSI or one of the many Medicaid "waiver" programs, as do high-quality "life skills" programs that train persons with disabilities how to live in the community, with appropriate supports, to avoid

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institutionalization. A family's private wealth simply cannot secure access to these beneficial programs, necessitating the same basic special needs planning pursued by families of modest means.

## Challenge #2

*Admitting a lack of proficiency in the increasingly complex area of special needs planning.*

Estate planners who still recommend the disinheritance of a person with a disabling condition often do so because they are unfamiliar with special needs planning. Many traditional estate planning professionals are reluctant to develop new expertise in this estate planning niche. Rather than developing a proficiency in this specialized planning arena, or aligning themselves with co-counsel who can provide the necessary expertise, they recommend that the beneficiary with the disability be disinherited and provided for informally by other family members, often the adult siblings of the person with the disability. This approach is typically destined to fail.

Family members may claim that they are willing to manage on an informal basis the funds designated for the beneficiary with a disability. While such persons often maliciously and purposefully withhold the benefits of such informally designated funds from the intended beneficiary, even well-intentioned persons may ultimately fail to manage the targeted funds for the person with the disability. For example, if the donee of the designated funds

commingles those assets with his or her own and thereafter (1) files for bankruptcy, (2) becomes party to a divorce proceeding and a subsequent equitable division of assets, (3) has a judgment lien recorded against him or her, or (4) fails to pay his or her tax liabilities and becomes subject to a tax lien, then the funds designated informally for the beneficiary with special needs could be dissipated entirely.

A similar result could ensue if the donee of the funds set aside informally for the beneficiary predeceases him or her and (1) dies intestate with heirs-at-law that include persons other than (or in addition to) the intended beneficiary, or (2) dies testate but fails to make proper arrangements in a will or revocable living trust for the ongoing management of the funds to be held for the benefit of the intended beneficiary.

## Challenge #3

*Understanding special needs trusts (and using them properly in an estate plan).*

The cornerstone of securing the future of persons with disabilities within the broader context of estate planning is the special needs trust (SNT). The universe of SNTs can be divided into two main categories:

1. "First-party" SNTs (also sometimes referred to as "self-settled"), which are funded with assets belonging to the beneficiary, or to which the beneficiary is legally entitled.
2. "Third-party" SNTs, which are funded solely with assets derived from someone other than the beneficiary.

Custom-drafted first-party SNTs are federally authorized by 42 U.S.C. section 1396p(d)(4)(A), as part of the Omnibus Budget Reconciliation Act of 1993 (OBRA '93),

as recently amended by the 21st Century Cures Act (P.L. No. 114-255), Title V, section 5007 ("Fairness in Medicaid Supplemental Needs Trusts"), sometimes referred to as "The Special Needs Trust Fairness Act." These federal laws set forth the statutory requirements for a first-party SNT. In addition, the Social Security Administration (SSA) maintains a guidance manual known as the "Program Operations Manual System" (POMS) regarding the validity and effectiveness of all SNTs (both first-party and third-party), the vast majority of which are set forth in POMS SI 01120.200, SI 01120.201, SI 01120.202, and SI 01120.203.<sup>4</sup> In addition, each state maintains similar guidance on SNTs in its Medicaid Manual. (For readers needing a refresher on the basic requirements for compliant first-party and third-party SNTs, the section on Challenge #8 provides such guidance.)

Compliant SNTs, whether first-party or third-party, do not "count against" the beneficiary for purposes of means-tested government benefits, including SSI and Medicaid. This is so because the beneficiary cannot compel the trustee to use the SNT assets for his or her "support" or "maintenance." In most jurisdictions, the mere inclusion of "support" or "maintenance" as a distribution standard for a beneficiary who receives means-tested benefits will result in the assets of the trust being deemed "available" or "countable" to the beneficiary, thus jeopardizing his or her continued eligibility for such benefits. (The section on Challenge #7 provides more guidance on this issue.) Thus, the classic "ascertainable standards" for trust distributions found in most credit shelter/bypass trusts (i.e., "health, education, maintenance, and support") generally disqualify the beneficiaries of those trusts for Medicaid and SSI.

<sup>1</sup> See [www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm](http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm).

<sup>2</sup> See Kogan, et al., "The Prevalence of Parent-Reported Autism Spectrum Disorder Among U.S. Children," *Pediatrics*, Vol. 142, No. 6 (December 2018), available at <http://pediatrics.aappublications.org/content/142/6/e20174161>.

<sup>3</sup> See [www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html](http://www.census.gov/newsroom/releases/archives/miscellaneous/cb12-134.html).

<sup>4</sup> The POMS are available at <http://policy.ssa.gov>, and were substantially updated in April 2018.

#### Challenge #4

*Learning, appreciating, and using “person-first” terminology when referencing the beneficiary with a disability and his or her consequent special needs.*

It does not matter how technically proficient an advisor may be if he or she alienates the client by using outdated and disparaging terminology to refer to the person with the disability. 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 being amended to replace all forms of the “R-word” with more respectful terminology.

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Thus, rather than referring to a client’s “autistic child,” the preferred person-first terminology would be “child with autism.” Rather than a “disabled child,” a client has a “child with a disability.” Instead of a beneficiary who is “wheelchair bound,” that person “uses a wheelchair for mobility.” The client’s beneficiary is not “retarded,” but rather has an “intellectual or cognitive disability.” Using person-first terminology will seem cumbersome and unnatural at first. Clients, however, do take notice of those professional advisors who successfully integrate this concept into their normal parlance.

In time, the old terms that emphasized the disability first,

instead of the person first, will become as offensive to the attorneys, and other allied professionals with whom they collaborate, as such pejorative terms have been to these families. Overcoming this challenge will transform the way a client relates to, and communicates with, the professional advisors.<sup>5</sup>

#### Challenge #5

*Assembling a “team of allied professionals” to facilitate and implement the client’s special needs estate plan.*

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 a client assemble the proper team of allied professionals as the special needs plan is being developed and then implemented.

The quarterback of the team is initially an estate planning attorney who is familiar with the myriad issues that must be addressed when advising families that are grappling with the consequences of a beneficiary’s disabling condition. Another option is to collaborate with co-counsel who is experienced in this area. Any member of the Special Needs Alliance, an invitation-only professional organization whose attorney members devote a majority of their legal practices to special needs planning, would be ideally suited for this role.<sup>6</sup>

**Life Care Planner.** A “Life Care Planner” is an indispensable member of the client’s team of allied professionals. Rather than just guessing the amount of funding needed to support the beneficiary with a disability for the rest of his or her life, a Life Care Planner develops an objective, arm’s-length assessment of the likely cost. A Life Care Plan itemizes those medical and non-medical services, products, equipment, housing options, educational

options, and life-enhancing experiences from which the beneficiary with special needs will derive benefit during his or her estimated life expectancy, along with an economic analysis of the likely expense of each item or service, indexed for inflation. A Life Care Planner may have a background as a nurse, physician, rehabilitation specialist, or social worker. This author prefers to collaborate with Nurse Life Care Planners.<sup>7</sup>

A Life Care Planner plays a critical role in answering the client’s question: “How much is enough to fund my beneficiary’s SNT?” which in turn informs a discussion about how to allocate a client’s estate assets between and among beneficiaries with and without disabilities. A Life Care Plan also provides a roadmap for the trustee of an SNT. If the SNT beneficiary or his or her family has not procured a Life Care Plan prior to the establishment and funding of an SNT, the trustee’s first order of business is to procure this critical tool for administering the SNT effectively.

**Government benefits specialist.** Another essential member of the client’s team is a government benefits specialist who can assist the client with applying for the various government benefit programs for which the person with a disability may be eligible. Many benefits applications are derailed due to the client’s unfamiliarity with the forms or the process, including the failure to adequately document the bene-

<sup>5</sup> For a “cheat sheet” on the proper terminology to use when referring to persons with disabilities, review “Guidelines: How to Write and Report about People with Disabilities,” 8th Edition (2013), published by the University of Kansas Research and Training Center on Independent Living (available at [www.rtcil.org/guidelines](http://www.rtcil.org/guidelines)).

<sup>6</sup> For a list of Special Needs Alliance members, go to [www.specialneedsalliance.org/find-an-attorney/](http://www.specialneedsalliance.org/find-an-attorney/).

<sup>7</sup> See American Association of Nurse Life Care Planners at [www.aanlcp.org](http://www.aanlcp.org).

<sup>8</sup> See 20 U.S.C. section 1400 *et seq.*

fiary's disabling condition from a medical or functional limitation standpoint.

This professional serves as a life-long resource for the beneficiary's team. For example, a government benefits specialist can advise the trustee of an SNT as to whether any proposed disbursements will adversely affect the beneficiary's means-tested government benefits. Many professional trustees have such an advisor on retainer if they do not have this expertise in-house.

**Special education advocate.** If the client's beneficiary with a disability is of school age, then a special education advocate or attorney should also be included on the team. This professional helps the client to obtain the "free and appropriate public education" (FAPE) in the "least restrictive environment" (LRE) to which a child with a disability 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 the child for further education, employment, and independent living, as outlined in an "Individualized Education Program" (IEP) tailored to the child's specific and unique needs.<sup>8</sup> An increasing number of students with autism spectrum disorder (ASD)—or other disorders with consequent disruptive or self-injurious behaviors—are victims of physical abuse by educators who have not been properly trained to manage such behaviors, which implicates various civil and criminal laws that would need to be handled by litigation counsel.

**Accountant.** An accountant who is well-versed in preparing income tax returns for the trustees of SNTs, for the beneficiaries of SNTs, and for the parents or legal guardians of

those SNT beneficiaries who are funding the costs of their medical care and other special needs, is another essential member of the client's team of allied professionals. Many accountants are unfamiliar with the income taxation rules that apply to first-party SNTs (which are generally taxed as "grantor trusts" with respect to the beneficiary) or third-party SNTs (which are generally taxed as "complex" trusts, or occasionally as "qualified disability trusts" under Section 642(b)(2)(C)).

In addition to income tax returns, many states require the preparation of annual SNT accountings for the state Medicaid agency which detail the receipts and disbursements of SNTs. Most accountants are not ideally suited for this task, which can be handled more cost-effectively by a paralegal or a bookkeeper.

**Investment advisor.** Another team member for all clients establishing and funding SNTs is an investment advisor who is sensitive to the generally lower risk tolerance of beneficiaries with disabilities, and who understands how a specific disabling condition affects an SNT portfolio allocation. The beneficiary may have a disability, but may also have a normal life expectancy necessitating SNT investments that will not be eroded by inflation. This

investment challenge is exacerbated if a first-party SNT for the beneficiary has been funded in large part with structured settlement annuity contracts.

**Life insurance specialist.** A life insurance professional who can recommend creative strategies for funding the cost of a beneficiary's Life Care Plan is an indispensable member of the client's team of allied professionals. Nearly 100% of clients trying to secure the future of a beneficiary with a disability will need significant amounts of life insurance to do so. The beneficiary's disability is generally permanent, making term insurance alone an incomplete solution for the funding equation.

Furthermore, it is increasingly necessary to obtain life insurance on the beneficiary with the disability, e.g. to provide for his or her surviving lineal descendants, or to provide liquidity to fund a Medicaid payback obligation in a first-party SNT that holds illiquid assets. Oftentimes, a person's disability does not have an adverse impact on his or her insurability.

**SNT trustee.** Identifying an appropriate trustee to manage an SNT is becoming increasingly difficult as professional fiduciaries establish ever-higher minimums (e.g., \$1 million or more), a reflection of how

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labor-intensive SNT administration can be. Many corporate trustees categorically refuse to administer SNTs of any size. To fill this void, former trust officers, attorneys, and accountants are offering private fiduciary services for SNTs that require professional management.

Ideally, the SNT trustee will not be a family member, as even well-intentioned family members risk sabotaging a perfect special needs estate plan if they improperly administer the SNTs for which they are responsible. If those family members are also designated as the remainder beneficiaries of the SNTs, this inherent conflict of interest may result in less-than-generous use of the SNT assets for the beneficiary, thwarting the client's intention.

**Legal guardian.** Although the estate planning attorney may serve as the initial quarterback of the client's team of allied professionals as the special needs estate plan is being designed and implemented, the beneficiary's court-appointed legal guardian will eventually assume this role after the client's death. However, many clients will refuse to secure the appointment of a legal guardian and conservator for their beneficiaries during their lifetimes. Psychologically, these clients are unwilling to endure a process that necessarily emphasizes their beneficiary's vulnerabilities and weaknesses. They have spent their whole lives emphasizing their beneficiary's abilities (however modest) and steadfastly avoid a realistic focus on his or her vulnerabilities.

This "head-in-the-sand" approach is often facilitated by long-standing health care providers who are willing to continue to deal informally with the natural parents of the adult child with a disability (typically violating the Health Insurance Portability and Accountability Act of 1996 (HIPAA) in so doing). How-

ever, if the beneficiary is being treated by a provider who is unfamiliar with the beneficiary and his or her history, or if the beneficiary's parents are no longer managing his or her health care, providers will typically insist on a legal guardian if the beneficiary is not capable of executing an advance directive or health care proxy.

### Challenge #6

*Recognizing that a comprehensive special needs estate plan is not comprised of a single SNT, but rather consists of a "network" of SNTs that are each designed to be funded from different sources at different times.*

Whenever the author receives a call from a prospective client, or from an attorney seeking co-counsel, requesting the preparation of "an" SNT for the client's beneficiary with a disability, it is immediately evident that the caller has barely scratched the surface of what constitutes a comprehensive special needs estate plan. The network of SNTs for the benefit of a beneficiary with a disability will typically include multiple third-party SNTs, discussed below.

**Revocable living trust.** The most obvious third-party SNTs in the network are those created under the will or revocable living trust (RLT) of each parent of a child with a disability. Even in jurisdictions where the probate process is not difficult or expensive, using a funded RLT as a "will substitute" often avoids the complications of the beneficiary's disability in the context of a probate proceeding. For example, depending on the nature and severity of the beneficiary's disability, and whether a legal guardian or conservator has already been appointed for him or her, the probate court may require a "guardian ad litem" to represent the beneficiary's interests in the probate pro-

ceeding, which can present significant delays in securing an order admitting a will to probate.

**Receptacle SNT.** Because a testamentary SNT, or an SNT to be established under an RLT once the settlor has died, is not actually created until the death of the testator or the settlor, these third-party SNTs cannot receive bequests prior to that time from others who may wish to benefit the beneficiary. Thus, another essential third-party SNT in the network is a "receptacle" SNT designed to coordinate and receive bequests and other *post mortem* distributions from others for the beneficiary with special needs.

These generous donors are advised of this convenient option by means of a "Dear Family and Friends" letter that describes in general terms the special needs planning that has been implemented by the client for the beneficiary, and provides the precise verbiage necessary to "incorporate by reference" the provisions of the receptacle SNT that is on "stand-by" ready to receive a pour-over bequest under a will or RLT, or other *post-mortem* transfers from a donor (e.g., pursuant to a beneficiary designation form for a life insurance policy). In this fashion, the well-intentioned generosity of a third party does not destroy the beneficiary's special needs plan, and the donor avoids the expense of implementing a full-fledged SNT under the donor's estate plan.

**Gifting SNT.** Some wealthy families include in their network of SNTs a

<sup>9</sup> 97 TC 74 (1991).

<sup>10</sup> See Section 7701(a)(1).

<sup>11</sup> See Rev. Proc. 2018-57, 2018-49 IRB 827; IR-2018-222, 11/15/18.

<sup>12</sup> "An Act to Provide for Reconciliation Pursuant to Titles II and V of the Concurrent Resolution on the Budget for Fiscal Year 2018" (P.L. 115-97, 131 Stat. 2504).

third-party SNT that is designed to receive gifts that will qualify for the federal gift tax annual exclusion under Section 2503(b)(1). Inasmuch as a gift to a complex trust generally does not qualify as a “present interest” for purposes of the gift tax annual exclusion, a third-party gifting SNT must be designed so that secondary beneficiaries of the SNT are vested with “rights of withdrawal” under the rationale of *Estate of Cristofani*<sup>9</sup> to convert a future interest gift to the SNT into the requisite present interest. Thus, a common approach is to grant a *Cristofani* right to a secondary beneficiary of the SNT (typically a sibling of the beneficiary with the disability) who (1) may receive discretionary distributions during the life of the primary beneficiary (for a limited purpose such as “emergency health care”), and (2) is a remainder beneficiary of the SNT upon the death of the primary beneficiary.

Many traditional estate planning attorneys do not understand that vesting a *Crummey* right of withdrawal in the beneficiary with a disability who wishes to retain his or her eligibility for means-tested benefits (such as SSI and Medicaid) will cause the assets subject to the withdrawal right to be considered an “available” resource, thus disqualifying the beneficiary for those essential benefits. This planning *faux pas* may often be remedied by a judicial modification proceeding, or by the express declaration of the donor at the time of the gift to the SNT that the *Crummey* right otherwise granted by the SNT agreement to the beneficiary with a disability do not extend to the gift in question.

**IRA designated beneficiary SNT.** Virtually every client will include in the network of SNTs for their beneficiary with a disability a third-party SNT that is designed to qualify

as a “designated beneficiary” of an IRA, 401(k), or other qualified plan, in compliance with the requirements of Reg. 1.401(a)(9)-4. Such an SNT must be drafted as an “accumulation trust” rather than a “conduit trust.” Furthermore, for purposes of the required minimum distribution rules under Section 401(a)(9), this SNT

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must be drafted so that it constitutes a qualified “see-through” trust as contemplated by Regs. 1.401(a)(9)-4 and A-5(b).

**Qualified disability trust.** For clients with charitable intent, the network of SNTs can also include a third-party SNT designated as the income beneficiary of a charitable remainder trust (CRT) with a stated term not exceeding 20 years.<sup>10</sup> At the end of the CRT term, the remainder could pass to a charitable organization which provided meaningful support to the beneficiary’s family, or which is devoted to the specific disabling condition with which the beneficiary is challenged. Designing this third-party SNT as a “qualified disability trust” (QDT) under Section 642(b)(2)(C) can ameliorate the income tax consequences of the annual CRT distribution.

If the SNT is not designed as a QDT, then distributions from the SNT for the benefit of the beneficiary will “carry out” the “distributable net income” (DNI) of the SNT that would otherwise be tax-

able to the SNT at the compressed tax rates applicable to an irrevocable non-grantor trust so that such income is then properly reported on the beneficiary’s personal income tax returns. In 2019, an individual SNT beneficiary reaches the maximum 37% bracket at \$510,300 income, while an irrevocable non-grantor trust reaches the 37% bracket at only \$12,750 of income.<sup>11</sup>

**Life insurance trust.** Many clients trying to secure the future of a beneficiary with a disability will consider establishing a life insurance trust, with embedded third-party SNT provisions, that is designed to own, and be the beneficiary of, one or more significant policies insuring the life of (typically) the parents of the beneficiary with the disability. Although the beneficiary with the disability should not hold a *Crummey* right of withdrawal under a life insurance trust, as discussed above, secondary permissible beneficiaries can hold *Cristofani* rights to facilitate the gift tax-efficient funding of the premiums for any policies owned by the life insurance trust.

In light of the historically high estate tax exemption afforded by legislation commonly known as the Tax Cuts and Jobs Act of 2017,<sup>12</sup> fewer families are now electing an *irrevocable* life insurance trust.

**“Stand-by” first-party SNT.** In addition to the third-party SNTs described above, the client’s network of SNTs for the beneficiary with the disability should also include at least one first-party SNT on “stand-by.” Notwithstanding the best efforts of the estate planning attorney, and the other members of the client’s team of allied professionals, something *always* slips through the network of third-party SNTs, resulting in the beneficiary with the disability becom-

ing legally entitled to receive property that jeopardizes his or her eligibility for means-tested benefits. Common scenarios leading to this unfavorable result include the following.

A well-intentioned third-party (1) leaves an outright bequest to the beneficiary, (2) makes an outright lifetime gift to the beneficiary, (3) dies intestate with the beneficiary sharing in the estate as an heir-at-law, or (4) designates the beneficiary as a direct payee of a non-probate asset, thus wreaking havoc on the beneficiary's eligibility for his or her means-tested government benefits. A qualified disclaimer of such interests under Section 2518 is *not effective* to preserve those benefits.<sup>13</sup> Similarly, if the beneficiary is legally entitled to receive court-ordered child support or alimony, direct receipt of such benefits would adversely affect his or her means-tested benefits.

The *irrevocable* assignment of the property interest to which the beneficiary is legally entitled in the above scenarios to a “stand-by” first-party SNT designed for this express purpose provides a ready solution that will preserve the beneficiary's eligibility for his or her means-tested benefits.<sup>14</sup> If the beneficiary is a minor or an incapacitated adult when becoming legally entitled to such assets, a court order likely will be necessary to authorize the beneficiary's conservator to make an irrevocable transfer of such assets to the first-party SNT. Any assets that remain in a conservatorship are “available” resources to the conservatee for purposes of means-tested benefits.<sup>15</sup>

If a beneficiary with a disability is designated as the direct beneficiary of an IRA, thus jeopardizing his or her means-tested government benefits, Ltr. Rul. 200620025 outlines a step-by-step procedure for obtaining a court order authorizing the

beneficiary's conservator/guardian of the estate to fund a first-party SNT with the beneficiary's share of the inherited IRA by means of a

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trustee-to-trustee transfer (recognizing, of course, that such letter rulings generally cannot be relied upon or cited as precedent by taxpayers other than the one who paid dearly for the ruling in question).

#### **Challenge #7**

*Addressing existing trusts with “support” or “maintenance” distribution standards for the beneficiary with a disability that jeopardize his or her eligibility for means-tested government benefits.*

Practitioners are frequently confronted with pre-existing irrevocable trusts that set forth the classic “ascertainable standards” for distributions to the trust beneficiaries (i.e., health, education, maintenance, and support). These are the distribution standards found in most bypass/credit shelter trusts and in many “dynasty” generation-skipping trusts, and threaten to disqualify a beneficiary from ongoing eligibility for means-tested government benefits. Options to address this challenge may include one or more of the following approaches.

If the trust grants the power to amend those provisions, the exercise of that power (by someone

other than the beneficiary with a disability) is an unexpectedly easy solution. Similarly, the exercise of a power of appointment granted under the trust (by someone other than the beneficiary with special needs) in favor of a newly created third-party SNT can often solve the problem. A decanting encroachment by the trustee into a newly created third-party SNT is another frequently used solution.

The most laborious solution is a judicial modification of the trust which replaces the “support” and “maintenance” distribution standards for the beneficiary with a disability with third-party SNT provisions. State law varies widely regarding the logistics for a judicial modification, but it is generally necessary to prove that had the creator of the trust known that its original provisions for the beneficiary with special needs would disqualify him or her from ongoing eligibility for a significant source of funding for care (i.e., means-tested government benefits), the creator would have taken the steps needed to modify those provisions accordingly by replacing them with third-party SNT provisions.

Whichever of the above solutions is pursued, some states take the position that a trust which would have been considered an “available” or “countable” asset as originally drafted must include a Medicaid payback provision in the newly created or judicially modified trust (which, as the reader knows, is generally not required for third-party SNTs). If a Medicaid payback provision is required in the newly created or judicially modified trust, and if there are other current or remainder beneficiaries

<sup>13</sup> See POMS SI 01150.110.E.

<sup>14</sup> See POMS SI 01120.200.G.1.d and SI 01120.201.J.1.d.

<sup>15</sup> See POMS SI 01140.215.B.1.

<sup>16</sup> See POMS SI 01120.203.B.8.



of the trust whose beneficial interests would be adversely affected by the satisfaction of the Medicaid payback from the property remaining in the trust upon the death of the beneficiary with special needs, the client could consider other available sources of liquidity for satisfying the payback obligation (e.g., a life insurance policy covering the beneficiary, if his or her disability does not negatively affect insurability).

Medicaid cares only that its payback right is satisfied, not the source of the funds with which it is satisfied. This solution is particularly helpful if the major asset of the newly created or judicially modified trust is illiquid or otherwise sacred to the beneficiaries, such as the family home place or other sentimental asset which they do not wish to liquidate upon the death of the beneficiary with special needs to satisfy the Medicaid payback.

There is one last “nuclear” option for the trustee of an irrevocable trust that contains problematic distribution standards for a beneficiary who wishes to retain eligibility for means-tested government benefits: a complete encroachment of the entire trust principal

and accumulated income outright to the beneficiary (or to his or her conservator) followed by an immediate funding of a first-party SNT with that property. This approach would necessarily entail subjecting the property to a Medicaid payback; however, if the trust principal 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, it is generally necessary to obtain court approval for this approach.

#### Challenge #8

*Appreciating the distinctions between first-party SNTs and third-party SNTs, knowing and complying with the federal and state requirements for each, and effectively deploying each type of SNT appropriately in a special needs estate plan.*

**First-party SNTs.** The basic federal statutory requirements for a custom drafted first-party SNT are set forth in 42 U.S.C. section 1396p(d)(4)(A). (This statute does *not* apply to third-party SNTs.) The first federal statutory requirement prescribes the per-

missible settlors of a first-party SNT, including:

1. An adult beneficiary who retains sufficient mental capacity notwithstanding his or her disability (but only for first-party SNTs established on or after 12/13/2016).
2. A court-appointed guardian of the estate or conservator of the beneficiary, in the case of a minor or an incapacitated adult who meets the relevant threshold under state law.
3. A parent or grandparent of the beneficiary.
4. A court of competent jurisdiction.

In the case of a first-party SNT established through the actions of a court, the creation of the SNT must be *required* by a court order, not merely approved by the court.<sup>16</sup> Thus, the creation of the SNT cannot have been completed before the court order is issued.

Second, the SNT beneficiary must satisfy the SSA’s definition of “disabled” at the time the first-party SNT is established, i.e., unable to engage in any “substantial gainful activity” (SGA) by rea-



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son 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 12 months.<sup>17</sup> If the beneficiary of the first-party SNT is under the age of 18, “disabled” 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 12 months.<sup>18</sup>

For 2019, the income threshold evidencing a person’s ability to engage in SGA is \$1,220/month (or \$2,040/month for a person who is blind).<sup>19</sup> For purposes of an SGA determination, a person’s gross earnings excludes unreimbursed out-of-pocket “impairment-related work expenses” (IRWEs) and the value of any work subsidies or support.

Third, a first-party SNT must be irrevocable. While the federal enabling statute does not expressly require irrevocability, both the SSA and state Medicaid programs do require irrevocability.<sup>20</sup>

Fourth, a first-party SNT must be for the “sole benefit” of the beneficiary. While the federal enabling statute uses only the phrase “for the benefit of” the beneficiary, the SSA and the state Medicaid programs have effectively required the stricter “sole benefit” standard to be used when evaluating first-party SNTs.<sup>21</sup> Defending alleged violations of the sole-benefit rule is a constant battle for the trustees of first-party SNTs.

Fifth, the federal enabling statute requires that the beneficiary of a first-party SNT be under the age of 65 when the SNT is established and funded with the beneficiary’s

assets.<sup>22</sup> If the SNT was established and funded prior to the beneficiary’s 65<sup>th</sup> birthday, it continues to qualify even after he or she attains age 65.<sup>23</sup> While it is impermissible to add property to a first-party SNT after the beneficiary attains age 65, this does not include (1) interest, dividends, or other earnings on trust principal deposited to the SNT prior to the beneficiary’s 65<sup>th</sup> birthday, or (2) annuity payments, support payments, or other periodic payments pursuant to an *irrevocable* assignment to the SNT prior to the beneficiary’s 65<sup>th</sup> birthday.<sup>24</sup>

The final statutory requirement for a first-party SNT is the “Medicaid payback” obligation. Upon the death of the beneficiary (or other earlier termination event), medical assistance providers (i.e., Medicaid, but not SSA) must be reimbursed from any property remaining in the first-party SNT (*if* any remains) up to the total amount of medical assistance benefits paid on behalf, or for the benefit, of the beneficiary under one or more state Medicaid plans during his or her entire lifetime (i.e., not just from and after the establishment of the first-party SNT).<sup>25</sup>

The Medicaid payback amount is calculated based on the actual Medicaid rate for expenditures during the beneficiary’s lifetime (which is significantly lower than private-pay rates for the same services) and does *not* include an “interest” component (thus amounting to an inter-

est-free loan from the government). The trustee of a first-party SNT is well advised to review the details of the alleged Medicaid payback amount with persons who were intimately involved in the beneficiary’s health care, as frequent (and significant) errors abound in Medicaid’s record-keeping. If the beneficiary received Medicaid benefits from more than one state, the SNT must provide for payback to any and all state(s) that may have provided medical assistance under the state Medicaid plan(s), and cannot be limited to any particular state(s).<sup>26</sup> Furthermore, if the first-party SNT does not have sufficient funds upon the death of the beneficiary to reimburse in full each state that provided medical assistance, the trustee of the first-party SNT may reimburse the states on a *pro-rata* or proportional basis.<sup>27</sup>

In the context of a first-party SNT that is funded with proceeds derived from a personal injury claim (whether by settlement or verdict), it is also necessary to satisfy a super-priority *pre*-SNT Medicaid lien for medical assistance paid for the beneficiary prior to the establishment of the SNT for medical care necessitated by the wrongful acts that generated the recovery. Only after satisfaction of this pre-SNT lien can the first-party SNT be funded with any remaining proceeds allocable to the beneficiary. *Arkansas Dep’t of Health &*

<sup>17</sup> See 42 U.S.C. section 1382c(a)(3), 20 C.F.R. section 416.905, and POMS SI 01120.203.B.4.

<sup>18</sup> See 20 C.F.R. section 416.906.

<sup>19</sup> See [www.socialsecurity.gov/news/press/factsheets/colafacts2019.pdf](http://www.socialsecurity.gov/news/press/factsheets/colafacts2019.pdf).

<sup>20</sup> See POMS SI 01120.201.D.2 and SI 01120.200.D.2.

<sup>21</sup> See POMS SI 01120.203.B.6, SI 01120.203.I.1, and SI 01120.201.F.

<sup>22</sup> See also POMS SI 01120.203.B.2.

<sup>23</sup> See POMS SI 01120.203.B.2.

<sup>24</sup> See POMS SI 01120.203.B.3.

<sup>25</sup> See POMS SI 01120.203.B.10.

<sup>26</sup> *Id.*

<sup>27</sup> *Id.*

<sup>28</sup> 547 U.S. 268 (2006).

<sup>29</sup> See POMS SI 01120.201.A.2.

<sup>30</sup> See POMS SI 01120.200.D.1.a, SI 01120.200.D.2, and SI 01120.201.D.1.

<sup>31</sup> *Id.*

<sup>32</sup> See POMS SI 01120.200.B.13, SI 01120.200.D.1.a, and SI 01120.200.D.1.b.2.

<sup>33</sup> 42 U.S.C. section 1396p(d)(4)(C), and related POMS provisions, set forth the following statutory requirements.

<sup>34</sup> POMS SI 01120.203.D.1 and SI 01120.203.D.3.

<sup>35</sup> POMS SI 01120.203.D.1.4 and 5.

<sup>36</sup> POMS SI 01120.203.D.2.

*Human Services v. Ahlborn*<sup>28</sup> held that this pre-SNT lien may be satisfied only from that portion of the beneficiary's recovery that is specifically allocable to past medical expenses and costs. Despite a series of attempts by Congress to legislatively overrule the *Ahlborn* decision, the Bipartisan Budget Act of 2018 (H.R. 1892, 11th Congress, Section 53201, Subsections (b)(1) and (c)(3)), "permanently" and retroactively repealed the anti-*Ahlborn* legislation enacted as part of the Bipartisan Budget Act of 2013 (Joint Resolution, 113th Congress, H.J. Res. 59, P.L. No. 113-67).

Finally, numerous POMS provisions must also be satisfied before a first-party SNT will be considered fully compliant, including POMS SI 01120.203.B (for those established after 12/13/2016), SI 01120.203.C.4, SI 01120.203.B.8, SI 01120.203.B.10, SI 01120.201, SI 01120.200.D.1.a, SI 01120.203.A, SI 01120.203.B.1, SI 01120.203.C.1, SI 01120.200.A.1, and SI 01120.200.B.13. POMS SI 01120.200.D.1.a. and b.2 effectively require the inclusion in the trust agreement governing a first-party SNT a spendthrift clause that is valid under state law, to preclude the beneficiary from selling his or her beneficial interest in the SNT for cash that can be used for his or her food or shelter needs (i.e., the beneficiary's "support" and "maintenance"). POMS SI 01120.200.B.13 sets forth the SSA's understanding of a spendthrift clause. Best practice dictates the inclusion of a spendthrift clause that prohibits both voluntary and involuntary transfers of the beneficiary's interest in the first-party SNT.

**Third-party SNTs.** In contrast, third-party SNTs are not governed by a federal enabling statute, and are *not* subject to most of the fed-

eral statutory requirements mandated for first-party SNTs, as described above.<sup>29</sup> Thus, most importantly, *there is no Medicaid payback for a third-party SNT that is drafted properly from the outset.* Consequently, as a general matter, third-party funds should never be added to a first-party SNT, which could unnecessarily subject those funds to the Medicaid payback required of first-party SNTs, and first-party funds should never be added to a third-party SNT, which will lack the required Medicaid payback provisions.

**Third-party SNTs are not governed by a federal enabling statute, and are not subject to most of the federal statutory requirements mandated for first-party SNTs.**

Furthermore, (1) anyone can serve as the settlor of a third-party SNT; (2) the beneficiary need not meet any particular definition of "disabled;" (3) there is no age limitation on the beneficiary, or on the timing or funding of a third-party SNT; and (4) the beneficiary need not be the sole beneficiary of a third-party SNT. The POMS do require that a third-party SNT be irrevocable as to the beneficiary (i.e., the beneficiary cannot hold the right to revoke or terminate the SNT or to use the SNT assets for his or her "support" or "maintenance" under the terms of the SNT).<sup>30</sup> "If an individual does not have the legal authority to revoke or terminate the trust or to direct the use of the trust assets for his or her own support or maintenance,

the trust principal is not the individual's resource for SSI purposes."<sup>31</sup> Drafters are well advised to include a valid spendthrift clause in a third-party SNT that precludes all voluntary and involuntary avenues for accessing the SNT assets for the beneficiary's support and maintenance.<sup>32</sup>

**"Pooled" SNTs.** In addition to the single-beneficiary first-party SNTs authorized by 42 U.S.C. section 1396p(d)(4)(A), described above, OBRA '93 also expressly authorized the concept of a "pooled" SNT, with a separate first-party sub-account established for the sole benefit of a beneficiary with a disability and funded with his or her assets.<sup>33</sup>

A first-party sub-account with a pooled SNT must be established and managed by a non-profit association (which need not be tax-exempt).<sup>34</sup> The pooled SNT must maintain a separate first-party sub-account for the "sole benefit" of each beneficiary, but may pool the assets of all of the separate sub-accounts for purposes of investment and management.<sup>35</sup> The beneficiaries must all satisfy the SSA's definition of "disabled," discussed above.<sup>36</sup> Each separate first-party sub-account with a pooled SNT must be established by (1) the beneficiary's court-appointed guardian of the estate or conservator; (2) the beneficiary's parent or grandparent; (3) a court of competent jurisdiction; or (4) the beneficiary him or herself, if he or she retains the requisite mental capacity notwithstanding his or her disability.<sup>37</sup> (As noted above, only since 12/13/2016 has it been permissible for a mentally competent beneficiary of a first-party "(d)(4)(A)" SNT to serve as the settlor.)

Finally, to the extent that a pooled SNT does not retain the amount remaining in a beneficiary's

first-party sub-account at the beneficiary's death (not all pooled SNTs provide for this), such remaining assets must be used to reimburse Medicaid (but not the SSA) up to the total medical assistance benefits paid on behalf of the beneficiary during his or her lifetime under one or more state Medicaid plans (i.e., not just after the first-party sub-account is established). If the first-party sub-account with a pooled SNT does not have sufficient funds upon the death of the beneficiary to reimburse fully each state that provided medical assistance, the trustee of the beneficiary's first-party sub-account may reimburse the states on a *pro-rata* or proportional basis.<sup>38</sup>

Although there is no express statutory limitation on the age of a beneficiary of a first-party sub-account with a pooled SNT (as there is with respect to a first-party SNT established under 42 U.S.C. section 1396p(d)(4)(A)), many states choose to impose a transfer penalty for the "uncompensated transfer" of the beneficiary's assets after age 65 if the beneficiary wishes to qualify for Medicaid-paid nursing home long-term care, and for certain long-term care services rendered in the community.<sup>39</sup> Finally, a first-party sub-account with a pooled SNT must also pass muster under POMS SI 01120.200.D.1 and SI 01120.203.D.1 to determine if it is a countable resource.

A separate third-party sub-account with a pooled SNT may also be established to hold assets derived solely from third-parties. While the beneficiary of a third-party sub-account with a pooled SNT must still meet the SSA's definition of "disabled" (which is not required for the beneficiary of a third-party SNT), (1) there is no restriction on who can establish the third-party sub-account; (2) the beneficiary's age does not limit the

timing of the establishment or funding of a third-party sub-account; and (3) (most importantly) *there is no Medicaid payback required for a third-party sub-account with a pooled SNT.*

A sub-account with a pooled SNT is governed by a "Master Trust Agreement" that applies to

**Although promoted as an effective savings mechanism for individuals with disabilities, annual contributions to an ABLÉ account from all sources combined are limited to the federal gift tax annual exclusion amount.**

all sub-accounts, each of which is established by completing a "Joinder Agreement," which generally does not require the involvement of an attorney (one of the most popular aspects of the pooled SNT option). If a first-party sub-account will be funded with the assets of a minor or an incapacitated adult, court approval (and the involvement of an attorney) is typically required. If there are funds remaining in a first-party sub-account (after satisfaction of any Medicaid payback) or in a third-party sub-account after the beneficiary's death, the Joinder Agreement can be customized to specify the remainder beneficiaries.

The pooled SNT is a very cost-effective option for a beneficiary who has too many assets to maintain his or her eligibility for means-tested government benefits, but not enough to warrant the expense of hiring an attorney to prepare a custom-drafted first-party or third-

party SNT. Prior to 12/13/2016, a first-party sub-account with a pooled SNT was often the *only* option for a beneficiary who (1) had no living parents or grandparents, (2) had a disability but did not qualify under state law for a court-appointed guardian of the estate or conservator, (3) could not convince a court to serve as the settlor of a (d)(4)(A) SNT, and/or (4) was already age 65 or older. Practitioners should familiarize themselves with the pooled SNT options available in their communities.<sup>40</sup>

### Challenge #9

*Keeping up with new tools and techniques that will supplement, not replace, SNTs, such as the "ABLE" account.*

Individuals whose disability or blindness commenced prior to their 26<sup>th</sup> birthday are eligible to have an ABLÉ savings account, modeled on the more traditional Section 529 Qualified State Tuition Program Account ("529 Plan"). The Stephen Beck, Jr. Achieving a Better Life Experience Act of 2014" (ABLE Act)<sup>41</sup> was signed on 12/19/2014 by President Obama (as part of the Tax Increase Prevention Act of 2014). The ABLÉ Act adds new Section 529A, as well as numerous amendments to related IRC provisions (e.g., Sections 2501, 2503, 2511, 2642, and 2652). In March 2018, the SSA issued the revised current version of POMS SI 01130.740 governing ABLÉ accounts.<sup>42</sup>

Although promoted as an effective savings mechanism for individuals with disabilities, annual contributions to an ABLÉ account from all sources combined are limited to the federal gift tax annual exclusion amount under Section 2503(b), which in 2019 is \$15,000. An individual who has earned income from a job may contribute an additional amount to his or her

ABLE account from compensation up to the federal poverty level (which is \$12,060 in 2019). The total cumulative value of an ABLE account is capped at the state's limitation for Section 529 Plans (currently ranging from \$235,000 to \$445,000 across all 50 states). Contributions to an ABLE account are not considered as income to the individual, and distributions from an ABLE account for the individual's "qualified disability expenses" (QDEs) are similarly not includable in his or her income. The individual's QDEs are those incurred while the individual meets the SSA's blindness or disability thresholds and which are "related to" his or her blindness or disability and are for the benefit of the individual to maintain or improve his or her health, independence, or quality of life.

Section 529A(f) allows the states to file a Medicaid payback claim against an individual's ABLE account balance remaining at his or her death up to an amount equal to the total medical assistance paid for the individual from and after the date the ABLE account was established.<sup>43</sup> This Medicaid payback claim, if filed by a state, extends even to third-party funds contributed to the ABLE account.

Each contribution to an ABLE account by a third party is treated as a nontaxable completed present interest gift to the individual for gift tax purposes, and not as a future interest.<sup>44</sup> If a donor's gifts to the individual (including the contribution to his or her ABLE account) do not exceed the federal gift tax annual exclusion amount

under Section 2503(b), the contribution is not subject to gift tax and has a zero inclusion ratio for purposes of the generation-skipping transfer tax.<sup>45</sup>

The benefits of an ABLE account over a first-party SNT are limited, but include the following:

1. No attorney, accountant or other paid allied professional need be involved in opening an ABLE account, which is accomplished entirely on-line.
2. There is tax-deferred growth on ABLE account balances, and tax-free distributions from the account if used for the QDEs of the individual.
3. An ABLE account affords some financial autonomy and a fiscal education opportunity for individuals who would otherwise be precluded by the SSI and Medicaid rules from controlling more than \$2,000.
4. There is no upper age limitation on contributions of first-party funds to an ABLE account.
5. There is no formal approval from SSA or Medicaid required for an ABLE account.
6. Payments from an ABLE account for the individual's food or housing expenses do not reduce his or her SSI payment amount (as would be the case if an SNT—first-party or third-party—paid the same expenses).
7. The Medicaid payback claim is limited to medical assistance paid for the individual *after* the ABLE account is established.

An ABLE account is decidedly inferior to a third-party SNT for the following reasons:

1. All third-party funds contributed to an ABLE account are potentially subject to a Medicaid payback claim.
2. Annual contributions to an ABLE account are limited to the Section 2503(b) gift tax annual exclusion amount.
3. Once the value of an ABLE account exceeds \$100,000, the individual's monthly SSI payments are suspended.
4. The individual must satisfy the government's definitions of blind or disabled.
5. The onset of the individual's blindness or disability must have occurred prior to age 26.
6. The only persons who can establish an ABLE account are the individual, or his or her parent, legal guardian, or attorney-in-fact.
7. An individual may have only one ABLE account.
8. All funds deposited to an ABLE account must be cash or its equivalent.

None of the foregoing restrictions or limitations apply to a third-party SNT. Clients who are not working with a knowledgeable team of allied professionals may erroneously believe that an ABLE account is all they need, and may not realize that it is not a substitute for the network of SNTs described in the section on Challenge #6.

### Challenge #10

*Persevering in a very challenging area. Do not give up!*

Advising clients who have beneficiaries with disabilities is fraught with challenges, but the personal and professional rewards for overcoming those challenges with successful special needs planning are unparalleled. ■

<sup>37</sup> POMS SI 01120.203.D.1 and SI 01120.203.D.6.

<sup>38</sup> POMS SI 01120.203.D.8.

<sup>39</sup> POMS SI 01120.203.D.1 and SI 01150.121.

<sup>40</sup> The Academy of Special Needs Planners maintains a database of pooled SNTs in each state, as well as several "national" pooled SNTs. See <https://specialneedsanswers.com/pooled-trust>.

<sup>41</sup> P.L. 113-295.

<sup>42</sup> For a current list of states that offer ABLE programs, visit [www.ablencr.org/state-review](http://www.ablencr.org/state-review).

<sup>43</sup> See also Prop. Reg. 1.529A-2(p), and POMS SI 01130.740.A.

<sup>44</sup> See Section 529A(c)(2)(A)(i), Prop. Reg. 1.529A-4(a)(1), Reg. 25.2503-3(a), and POMS SI 01130.740.C.1.b.

<sup>45</sup> Prop. Regs. 1.529A-4(a)(1) and (2).