

**Beyond the Special Needs Trust:
Essential New Developments in Special Needs Planning**

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Much has been written about the types of special needs trusts (SNT) and how to draft them. Many forms for a third-party testamentary and a stand-alone *inter vivos* SNT exist, as well as suggested provisions for a first-party SNT (also known as a d4A or self-settled or payback trust). For a legal advisor special needs planning requires much more knowledge than how to draft the document, however. The special needs planning attorney will need to know about the new laws and regulations affecting the choices of individuals with special needs in maximizing their chances for a secure and productive life. This outline will focus on important new developments and trends in this area.

I. THE ABLE ACT.¹

ABLE accounts are authorized by the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014, enacted on December 19, 2014, as part of the Tax Increase Prevention Act of 2014, Pub. L. No. 113-295, commonly referred to as the "ABLE Act." The Act allows a state or state agency or instrumentality to establish and maintain a tax-advantaged savings program that benefits certain individuals who have a disability. Account beneficiaries can establish and own an ABLE account, and manage it themselves. If the ABLE account beneficiary does not have capacity, others can manage it for them. With a few restrictions, contributions can be made to and distributions can be made from an ABLE account without adverse tax consequences or causing the beneficiary to be disqualified for public benefit programs.²

Many people are surprised that the ABLE Act is not part of the Social Security Act, but is an addition to the Internal Revenue Code. The ABLE Act added Section 529A to the Internal Revenue Code.³ Social Security has issued initial regulations concerning the effect of ABLE accounts on SSI eligibility and expects to issue more by the end of this year, according to Social Security representatives. The IRS is also expected to issue regulations soon.

A. What is An ABLE Account?

1. Much like a 529 college savings plan, an ABLE account (sometimes called a 529A account) is a type of tax-advantaged account that can be used to save funds for qualified disability expenses of the account's owner while allowing that individual to preserve eligibility for public benefits. Subject to a few limitations, the ABLE account allows a beneficiary to have resources in excess of the \$2,000.00 resource limit that applies to individuals who are eligible for means-tested program benefits, such as Supplemental Security Income (SSI) and Medicaid. Other programs such as Social Security Disability Income and Medicare are not means-tested and do not have a resource or unearned income limit. Control and independence for mentally competent persons with disabilities were significant principals in the initiation of this legislation by the disability community, and these values played a role in the ABLE Act's ultimate success after an eight year lobbying period. See <https://www.congress.gov/113/plaws/pub1295/PLAW-113publ295.pdf> for the Act.

2. There is also a section in the POMS covering ABLE Accounts. See POMS SI 01130.740, at <https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740>, which is attached as **Exhibit A**. The POMS provision is dated October 19, 2016. It is expected that revisions and clarifications will appear in the upcoming POMS amendments due to be published before the end of 2017.

¹ The author would like to thank Mary Alice Jackson and Craig Reaves for the unlimited use of their materials on the ABLE Act in preparing part of the outline.

² 26 U.S.C. §529A(a).

³ [http://uscode.house.gov/vicw.xhtml?reg=\(title:26%20section:529A%20edition:prelim\)](http://uscode.house.gov/vicw.xhtml?reg=(title:26%20section:529A%20edition:prelim)).

3. Proposed regulations for §529A were issued by the Treasury Department on June 19, 2015, and published in the Federal Register on June 22, 2015 (80 Fed. 35602). For copy of the regulations as they were originally proposed go to <https://222.gpo.gov/fdsys/pkg/FR-2015-06-22/pdf/2015-15280.pdf>. Technical corrections to the proposed regulations were published on August 7, 2015.⁴ The IRS issued Notice 2015-81 revising three provisions of the proposed regulations. See <https://www.irs.gov/pub/irs-drop/n-15-81.pdf>. An important amendment in 2015 eliminated the requirement that a person could only participate in an ABLE program that was offered by the state where the person was a resident. For a copy of the laws eliminating the residency requirements for ABLE accounts, see Pub. L. 114-113, Consolidated Appropriations Act, 2016 (12-18-2015), Division Q, Title III, Subtitle A, Section 303, go to <https://www.congress.gov/bill/114th-congress/house-bill/2029>.

4. On September 7, 2017, the Center for Medicare and Medicaid Services ("CMS") issued a letter to State Medicaid Directors addressing the implications of the ABLE Act on state Medicaid programs. See SMD# 17-002 RE: Implications of the ABLE Act for State Medicaid Programs. Here is a link to this letter: <https://www.medicaid.gov/federal-policy-guidance/downloads/smd17002.pdf>.

B. Who Can Use an ABLE Account? To be eligible for an ABLE account, the beneficiary must be blind or "sufficiently disabled" from a condition that began prior to age 26. This means an ABLE account can be used for someone with a disability that began at birth or in childhood (such as Down Syndrome or autism), but will not be an option for persons with disabilities that develop later in life (such as Multiple Sclerosis, Parkinson's, or an accident or illness that occurred after age 25).

1. The "sufficiently disabled" requirement is satisfied if:

a. the person is receiving SSI, Social Security Disability Insurance benefits (SSDI, also referred to as "DIB"), Childhood Disability Benefits (CDB), or disabled widow's or widower's benefits (DWB) because of blindness or disability that began before age 26,⁵ or

b. the person provides a "disability certification" prepared by the person or person's parent or guardian, and the disability certification is accompanied by a doctor's written statement that the person was sufficiently disabled prior to age 26.⁶

c. A "disability certification" is a written document that:

"(1) certifies that –

(a) the individual has a medically determinable physical or mental impairment, which result in marked and severe functional limitations and 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, or is blind (within the meaning of section 1615(a)(2) of the Social Security Act), and

(b) such blindness or disability occurred before the date on which the individual attained age 26, and

2. The ABLE Act refers to a person who meets these requirements as an "**eligible individual**."

C. Can A Person Have More Than One ABLE Account? No, an eligible individual can be the designated beneficiary of only one ABLE account. While there are some protections in place so that other well-meaning family members do not open additional accounts, the beneficiary still needs to coordinate with family and friends who are interested in providing for him or her.

TIP: *This differs from traditional special needs planning where any friend or family member can create and fund separate trusts and still exercise control over where any leftover funds would be distributed after the death of the beneficiary.*

D. Who Can Open An ABLE Account and Who Can Contribute to An ABLE Account? An ABLE account can be opened by (a) an individual with a disability, (b) a parent of such individual, (c) a guardian/ conservator of

⁴ See https://www.ftc.gov/system/files/documents/federal_register_notices/2015/08/150807riyocoppafn.pdf

⁵ 26 U.S.C. §529A(e)(1); POMS SI 01120.740.B.1.

⁶ 26 U.S.C. §529A(e)(2); POMS SI 01120.740.B.1

the individual, or (d) an agent designated through the individual's power of attorney. Regardless of who is responsible for managing the account, it may be advisable to consult a special needs attorney about establishing a power of attorney for the beneficiary to avoid interruptions in signature authority during the term of the ABLE account. Any person, including the beneficiary (i.e., the person with a disability), can contribute to an ABLE account.⁷

TIP: *This makes an ABLE account a cost-effective tool for a beneficiary who struggles to keep assets below \$2,000.00 (the current resource limit for SSI and Medicaid for a single person). Excess funds can be saved in an ABLE account for a larger purchase or just to keep the person eligible for benefits.*

E. How Much Can You Contribute To An ABLE Account?

1. The IRS limits the total annual contribution that an ABLE account can receive from all sources to the amount of the gift-tax exclusion in effect for a given calendar year. For 2018, that limit is \$15,000.00. Only cash can be contributed to an ABLE account.⁸ The same as in gift-planning, an account can receive a contribution in December followed by another in January.⁹

2. In addition to the annual contribution limits, there are limits regarding the maximum amount that can be held by an ABLE account. An ABLE account in excess of \$100,000 will cause a "suspension" of SSI benefits. The excess above \$100,000 will be deemed to be an available (countable) resource for SSI. For a person on Medicaid only (not SSI) the maximum amount is tied to the state's limit for 529 college savings accounts (now \$360,000 in Alabama). This problem will not occur for several years based on the annual contribution limit. Nevertheless, once an individual on Medicaid (not SSI) has an account balance that exceeds a state's 529 limit, the account will not lose its exempt status, but it will not be allowed to receive more contributions.

TIP: *The cap on annual contributions is one of the limitations of ABLE accounts, and hinders its usefulness for larger inheritances and settlements. Special Needs Trusts (which do not have asset caps) are more appropriate planning tools in those situations.*

F. When and Where Can I Set Up An ABLE Account?

1. Like 529 College Savings Plans, ABLE Act accounts can be opened in the state of the beneficiary's residence or in any other state that accepts out-of-state beneficiaries. Some states do not yet have an ABLE account program, so residents of those states should look for one in other states that welcome out-of-state participants. Some states have chosen to allow state programs to be run by another state with extensive experience. For example, in Alabama the program is administered by Nebraska's ABLE Account program. ABLE accounts can be rolled from one state's program to another. Every state's ABLE program has strengths and weaknesses (as well as different fees). The original ABLE statute required individuals to open ABLE accounts in their home states. This was amended in 2015 to allow individuals to open ABLE accounts in any state that offers a nationwide ABLE program. To determine if a state is open to out-of-state residents, check the website for the ABLE National Resource Center at <http://www.ABLENRC.org>.

2. As of October 2017, 27 states¹⁰ plus the District of Columbia have ABLE programs open for enrollment.¹¹ The features and services of these ABLE programs (e.g., investment plans, investment managers, debit card services, etc.) vary by state.¹² Nonresident beneficiaries may enroll in an ABLE program offered by any state with open enrollment. However, not all states allow out-of-state residents to enroll. The Arc's website lists the status of each state with

⁷ 26 U.S.C. §529A(b)(1)(B); 26 U.S.C. §529A(c)(4); POMS SI 01130.740.A.

⁸ 26 U.S.C. §529A(b)(2)(A); POMS SI 01130.740.B.2.

⁹ Pub. L. 113-295, div. B, title I, §103(a)(2) and §103(b), December 19, 2014, 128 Stat. 4063; POMS SI 01130.740.C.3; POMS SI 01130.740.D.1; 26 U.S.C. §529A(b)(6).

¹⁰ States with ABLE programs open to out-of-state participants: Ohio, Tennessee, Nebraska, Oregon ABLE for all, Nevada, Kansas, Alaska, Minnesota, Iowa, Illinois, Michigan, Massachusetts, Virginia, North Carolina, Pennsylvania, Alabama, Rhode Island, Colorado, District of Columbia, Indiana, Iowa, Minnesota, and Montana. States whose programs are open only to state residents are: Florida, Georgia, Kentucky, Louisiana, Missouri, New York, Oregon ABLE and Vermont.

¹¹ ABLE National Resource Center: <http://www.ABLENrc.org/>.

¹² *Id.*

respect to ABLE programs. The ABLE National Resource Center is also very helpful and has the ability to compare programs.¹³

3. Contributions to and earnings and distributions from an ABLE account for qualified disability expenses are not taxable. Furthermore, contributions to an ABLE account are a non-taxable present interest gift for gift tax purposes¹⁴ and earnings on the funds in an ABLE account are not treated as taxable income.¹⁵

G. What Can Funds In An ABLE Account Be Spent On?

1. ABLE accounts should be used for “qualified disability expenses” for the designated beneficiary, which include in part the following: education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses,¹⁶ and any other expenses approved under the IRS regulations. Social Security has stated that ABLE distributions can also be used for “basic living expenses” (such as food, rent, utilities) without causing a reduction in SSI.¹⁷ EnABLE Alabama has interpreted “qualified disability expenses” to include expenses that contribute to a better quality of life for the beneficiary (vacations, social outings, sporting events, clothing, furnishings, personal electronics, etc.).

2. If ABLE funds are not used for a qualified distribution expense, the income portion of the distribution will be taxable and subject to a 10% income tax penalty. Because contributions to the account are limited, the income-tax on interest would likely be very small. Although a consideration, the income tax penalty for improper distributions could be relatively negligible for smaller accounts. The 10% withdrawal penalty is levied only on the income or appreciation portion of the account that is distributed. For example, if the ABLE account was a typical savings account with .5% annual interest, the penalty for a complete improper distribution of the \$14,000.00 annual contribution would only be \$77.00 ($\$14,000.00 \times .5\% = \$70.00 + \$70.00 \times 10\% = \77.00).

H. What If There Is Money Left Over After The Beneficiary's Death?

1. It's critical to understand that all ABLE accounts have a payback requirement on the death of the beneficiary that dates back to the date the account was established. ABLE programs do allow funds remaining in the account at the death of the beneficiary to be used first to pay for final expenses and burial of the beneficiary.

2. The amount remaining after final expenses must next be used to pay back the state(s) that provided Medicaid services to the beneficiary after the date the ABLE account was established, if the state makes a claim. This differs from the "payback to Medicaid" requirements of a first-party, self-settled SNT, which requires payback for all Medicaid services, even prior to establishment of the SNT. While this may not be as important when the account holds the money of the individual with a disability, it can have huge implications when a third-party (e.g., parent or grandparent) is funding the account.

3. Money remaining in the ABLE account after payment of any Medicaid claims becomes part of the beneficiary's estate. This will require a probate procedure in the beneficiary's domiciliary estate. It is not yet known if it will be possible to specify the remaining funds to pass in a manner that will avoid probate. Future regulations by the IRS may answer this question.

TIP: When a third-party (parent or grandparent) wants to make a gift, a discretionary special needs trust should always be considered first because there is no payback requirement and there are less limitations on the types of distributions that can be made.

Also, a gift to an ABLE account qualifies for the annual gift tax exclusion up to the annual contribution limit, whereas a gift to a special needs trust does not.

I. How Is An ABLE Account Different Than A Special Needs Or Pooled Trust?

¹³ *Id.*

¹⁴ 26 U.S.C. §529A(c)(2)(A).

¹⁵ 26 U.S.C. §529A(a). An exception is if the income is unrelated business taxable income as described in 26 U.S.C. §511.

¹⁶ 26 U.S.C. §529A(e)(5).

¹⁷ "Basic living expenses" is added to the above list by POMS SI 01130.740.B.5.

1. The cost of establishing an ABLE account will be less than setting up an individual SNT or a pooled income trust, such as the Alabama Family Trust. Plus, if the beneficiary is competent, he or she will have the ability to control the funds, whereas an SNT or pooled trusts must be controlled by someone other than the beneficiary or the beneficiary's spouse.

2. Remember that funds in an ABLE account are all subject to a Medicaid payback, regardless of who contributed the funds to the account. Third-party SNTs and pooled trusts do not require Medicaid payback, allowing remaining funds to pass to other named beneficiaries.

3. Unless the amount of an inheritance, life insurance or retirement funds are under the ABLE account annual contribution limit (\$15,000.00 in 2018), and unless the contribution is cash, ABLE accounts are not suited to receive an inheritance, life insurance or retirement account proceeds. Nevertheless, for many families the ABLE account will be a significant and viable option in managing funds in a manner that does not eliminate means-tested benefits eligibility.

J. When to Use an ABLE Account.

While ABLE accounts will not allow families to replace traditional SNTs and special needs planning in most cases, they can be a useful tool in certain situations. More and more uses of an ABLE account will be discovered. A few of these are listed below.

1. Getting more spending money to an eligible individual: It is not uncommon for a person who has a disability to have sufficient intellectual capacity to be able to handle some or all of his or her assets. However, if the person is receiving SSI or Medicaid, the amount of money the person can accumulate and control is limited to a small amount, usually not more than \$2,000.

In addition, the spending money available to a person who is receiving SSI or Medicaid assistance is usually limited to the person's earnings from work and what the person receives from a benefit program such as SSI or SSD. If the person receives money from any other source (such as a relative, friend or trust), it will cause the person to suffer a reduction or loss of needs-based public assistance benefits. However, if the person has an ABLE account, then additional money can be transferred to the ABLE account without negatively impacting the person's SSI or Medicaid benefits. This allows the person to have more money to spend for items the person wants or needs without having to provide the details of each purchase to a parent, spouse, caregiver, or trustee.

2. Avoiding SSI reductions.

a. One of the most exciting uses of an ABLE account is to function as a conduit for funds the beneficiary may need to spend for food and shelter that are in excess of the amount he is able to pay from his Social Security check each month. When a person on SSI receives help of any type paying for food and shelter from another person, trust or another entity, or when he lives at home and does not pay rent, a reduction is made in the amount of the SSI payment. The value of the contribution made by other sources is counted against and reduces SSI dollar-for-dollar (except for the first \$20.00). The maximum reduction that can be imposed by Social Security, however, is one-third of the maximum monthly benefit rate. In 2018, the maximum amount of the reduction will be \$250.00. This based on the maximum SSI payment of \$750.00 per month. When payments for shelter and food are paid from the ABLE Act account, the reduction does not occur. In the world of disability planning, this is "a big deal." Adults with disabilities seeking to achieve independence generally want to be able to pay their own expenses and pay their own bills. This feature of the ABLE Act will allow that to be possible in many cases. This can be a difficult concept to understand for those not relatively familiar with SSI eligibility rules.

b. Why not reduction in SSI occurs. In order to fully understand why, it is important to focus on this attribute of an ABLE account:

- in addition to contributions **to** an ABLE account not being treated as "income" for SSI eligibility purposes,
- distributions **from** an ABLE account that are used to pay for any "qualified disability expenses," including housing expenses, are also not treated as "income" for SSI

eligibility purposes. Instead, such distributions are treated as a "conversion of a resource from one form to another.¹⁸

This means that money taken from an ABLE account to pay for the ABLE account designated beneficiary's housing expenses will not be deemed to be an in-kind support and maintenance as long as the distribution is used for the housing related expenses within the same month the money is removed from the ABLE account.¹⁹ This means the distributions will not cause a reduction in the recipient's future SSI payments. It remains unclear how often or thoroughly ABLE account expenditures will be monitored, but as with all special needs trust tools, independent and accurate accountings are the best protection against future requests for repayment.

Tip: ABLE accounts allow independence and dignity to beneficiaries. However, some beneficiaries will be subject to exploitation or the influence of a significant other. Having a discussion with the proposed ABLE beneficiary about this possibility, and perhaps building in some safeguards, is worth considering.

3. Gifts from others to an ABLE account. Parents or other relatives or friends may want to help an eligible individual who is receiving SSI pay for housing expenses or other qualified disability expenses. As we know, if they give money to the individual, there will be a dollar-for-dollar offset against the individual's SSI, except for the first \$20 in that month, which is ignored. If they directly pay for the individual's rent or utilities such as electricity, gas, water, sewer, or garbage removal, they will be providing in-kind support and maintenance to the individual. In 2018, receiving in-kind support and maintenance will cause²⁰ the individual's SSI to be reduced for one month by \$250, or the fair market value of the food or shelter expenses that were paid, if less. But if these people contributed to the eligible individual's ABLE account, then the money can be used for these expenses without any reduction in the individual's SSI.

4. Paying a structured settlement directly into an ABLE account. An eligible individual who is receiving money from a lawsuit settlement can direct a portion of the settlement equal to \$15,000 each calendar year be placed into a structured settlement annuity that distributes into the eligible individual's ABLE account. These distributions to the ABLE account are not income and will adversely impact the eligible individual's SSI or Medicaid, and the money in the ABLE account can be used by the eligible individual to pay for his or her qualified disability expenses. Although this is possible, careful consideration should be given before this is done. Questions that need to be addressed are: What happens if Congress repeals the ABLE Act? Or what if the beneficiary dies shortly after the settlement? Can the structured settlement payments that were directed to the ABLE account be paid to a contingent beneficiary? If so, who or what should that be?

5. A small amount, or portion of a larger amount, received can be put into an ABLE account. If an eligible individual is receiving money from a settlement, inheritance, or some other source, up to \$15,000 of this money

¹⁸ See POMS SI 01130.740.C.4, which says, "Do not count ABLE account distributions as income. A distribution from an ABLE account is not income but is a conversion of a resource from one form to another, see SI 01110.600.B.4.

Do not count distributions from an ABLE account as income of the designated beneficiary, regardless of whether the distributions are for non-housing QDEs, housing QDEs, or non-qualified expenses." (emphasis added)

¹⁹ See POMS SI01130.740.D.2, which says "Count a distribution for a housing-related QDE [qualified disability expense] or for an expense that is not a QDE as a resource, if the beneficiary retains the distribution into the month following the month of receipt. If the beneficiary spends the distributions within the month of receipt, there is no effect on eligibility. However, apply normal SSI resource counting rules and exclusions to assets or other items purchased with funds from an ABLE account." (emphasis added)

This POMS section seems to contradict Section 103(a)(1) of the ABLE Act which says that a distribution for housing expenses shall not be disregarded for SSI eligibility purposes. However, the Social Security Administration has satisfied this by treating such distributions as resource transfers. Therefore, as described in the above-referenced POMS section, if there is a distribution for housing expenses within the month it is received by the beneficiary, then the unspent amount is deemed to be a countable resource to the beneficiary in the following month. This may have the effect of causing the beneficiary to be disqualified from SSI because of having too many resources.

²⁰ The Presumed Maximum Rule is applied in most situations when in-kind support and maintenance is provided to an SSI recipient. This rule values the in-kind support and maintenance as the lesser of: (i) Its actual value; or (ii) its "Presumed Maximum Value" of 1/3 of the maximum monthly SSI payment, plus \$20. A person's SSI is reduced by the value of the in-kind support and maintenance as determined by the Presumed Maximum Value rule.

In 2017, the maximum SSI payment is \$750 [$\$750/3 = \$250 + \$20 = \270]. This is the Presumed Maximum Value of the in-kind support and maintenance provided during a month towards an SSI recipient.

can be transferred directly into the eligible individual's ABLE account. As a result, the money no longer is an "available" or "countable resource" and the eligible individual retains eligibility for SSI and Medicaid. The money in the ABLE account can be used to pay for the eligible individual's qualified disability expenses, including housing expenses, without any adverse impact on the eligible individual's SSI or Medicaid benefits.

6. UTMA account transferred to an ABLE account. When a child reaches the age specified in a particular state's UTMA statute, the funds in the UTMA account will be deemed to be an available resource of the child and will count towards the \$2,000 limit imposed by SSI and Medicaid programs.²¹ If the child is an "eligible individual," the custodian of the UTMA account can transfer up to \$15,000 of the UTMA account into the ABLE account for the child. This will remove the money from being deemed to be an available resource for needs-based public assistance eligibility purposes.

7. Excess income transferred to an ABLE account. An eligible individual receiving SSI or SSD benefits, and also earning income if he or she is working, can contribute any excess unspent money that would cause the \$2,000 limit to be exceeded into an ABLE account. The child then has access to funds in the ABLE account, as well as funds in his or her checking account up to \$2,000. This will allow the eligible individual to save money to be able to take a trip or purchase a higher priced item that he or she wants or needs.

8. Another comprehensive outline on ABLE Act accounts is found in an exhibit to Section Two of this three part outline. It was prepared by Kristen Lewis, Esq., a Co-Presenter on this Panel.

K. Summary.

ABLE AT A GLANCE

²¹ POMS SI 01120.205.D.3.b.

WHEN TO USE AN ABLE ACCOUNT

- Competent beneficiary wants to be able to direct more of his/her financial decisions.
- Beneficiary needs to spend-down small amounts of money (i.e., less than \$14,000) to remain below SSI/Medicaid asset limits.
- Beneficiary wants to save for a larger (over \$2,000 purchase).
- As part of a more comprehensive special needs plan or estate plan.
- To avoid the 1/3 ISM reduction in the beneficiary's SSI check.
- As a possible receptacle for child support payments on behalf of a minor or adult child with a disability. A court order directing the monthly amount to the ABLE account is needed. Other contribution limits still apply.

BENEFITS

- Cost effective.
- Small minimum contribution. Significant protections from creditors.
- Allows more financial independence for capable beneficiaries.
- Can commingle contributions from beneficiary's own money (First-Party money) and contributions from others (Third-Party money).
- Contributions grow tax free.
- No court approval required to establish.

WHEN NOT TO USE AN ABLE ACCOUNT

- When receiving an inheritance or settlement of more than \$14,000 (or applicable annual gift-tax exclusion).
- As part of an estate plan for a loved one without first considering a special needs trust.
- As the beneficiary of life insurance or retirement proceeds over \$14,000 (or applicable annual contribution limit).
- Disability did not occur before age 26.
- A vulnerable beneficiary who is susceptible to exploitation.
- As sole means of special needs planning or estate planning.

See a video by Enable at this link: <https://player.vimeo.com/video/146124112>

LIMITATIONS

- Should only be used for "qualified disability expenses" to keep tax-free.
- Limited annual contributions (currently \$14,000 max/year from all sources).
- Individual must be disabled before age 26. Only one account per beneficiary.
- Limited to cash equivalent contributions only. Cannot hold other types of property (ex. a house).
- No federal income tax deduction for contributions.
- State payback requirements—Funds remaining in an account after the beneficiary's death and final expenses will first be paid back to the state for Medicaid expenses.
- An unsophisticated beneficiary may make withdrawals for unauthorized expenses without understanding the consequences of doing so.

II. THE DISABLED MILITARY CHILD PROTECTION ACT.

A. On December 15, 2014, Congress passed an important piece of legislation that allows military annuity pensions to be paid to a special needs trust for a beneficiary with a disability rather than having to be paid to the beneficiary individually. By the pension being paid directly into the SNT, the beneficiary is allowed to retain means-tested government benefits by not exceeding the income and resource limits for SSI. This legislation passed as H.R. 4435-Howard P. "Buck" McKeon National Defense Authorization Act for Fiscal Year 2015, 113TH Congress (2013-2014), 10 U.S.C. 1450(a)(4), which amends Title 10, U.S.C. The Disabled Military Child Protection Act permits a military parent to name a self-settled (also known as a first-party or Medicaid pay-back) special needs trust, which is established for the benefit of the parent's child with disabilities, as the beneficiary of a parent's survivor benefit plan (SBP).

B. The military allows its members who have children with disabilities to participate in the SBP, with up to 55% of the member's pension being paid for a child with a disability. Prior to this Act, the parent who wished to designate a child with disabilities as a beneficiary on the parent's SBP could not do so; the parent had to name the child individually. This was because prior law provided that the SBP could only be paid to a "person," and the Defense Department took the position that a "person" did not include a trust for a child with disabilities. If the child received SBP payments directly, the income from the SBP would likely cause him to lose his eligibility for SSI and Medicaid. Now, as a result of this Act, children of military parents may maintain their eligibility for their means-tested benefits, while also having the SBP payments held in an SNT and available for their benefit.

C. To assign the SBP benefit to a qualified SNT, special forms must be completed, including a certification from the attorney who prepared the trust that the trust meets the requirements to be a beneficiary of the child's share. While

this is best done prior the military parent's death, the military has issued regulations that allow individuals to establish the first-party SNT to receive the benefit where the selection was not made before the military parent's death. For further information about the Disabled Military Child Protection Act see the May 2016 issue of *The Voice* available on the Special Needs Alliance website at www.specialneedsalliance.org. A copy of the Military's announcement concerning this Act is attached to this Section of the outline as **Exhibit B**.

III. SPECIAL NEEDS TRUST FAIRNESS ACT.

A. The Special Needs Trust Fairness Act, which is part of the Twenty-First Century Cures Act,²² was signed into law on December 13, 2016. Section 5007 of the Act is entitled the "Fairness in Medicaid Supplemental Needs Trusts." This Act corrects a legislative error made over 23 years ago in the Budget Reconciliation Act of 1993 (OBRA '93). It modifies 42 U.S.C. §1396p(d)(4)(A) to enable individuals to establish a self-settled stand-alone SNT for their own benefit. Prior to this Act, individuals had to rely on their parents, grandparents, a legal guardian, or the Court to establish such a trust for their benefit. In situations where an individual did not have a parent or a grandparent, and did not have a guardian because he was competent, he had to incur the expense to petition the Court for authority to establish the trust. As a result of this Act, individuals with capacity will now be able to establish their own self-settled SNT more efficiently and at lesser cost than before the Act.

B. While this change in the prior law seems very slight (only 3 words were added to the statute), the Act, which took effect immediately, has major impact for competent individuals with special needs. The statute at 42 U.S.C. §1396p(d)(4)A now reads as follows, with the words in bold being the only addition to the existing statute:

A trust containing the assets of an individual under age 65 who is disabled (as defined in §1382(c)(a)(3) of this Title) and which is established for the benefit of such individual by the individual, a parent, grandparent, legal guardian of the individual or a court....

As of October 2017, the Social Security POMS at Section SI 01120.203(B)(1)(F) has not been updated to reflect the Social Security Administration's recognition of this new law. Revised POMS are expected by the end of 2017 to do that.

C. Now that the individual with a disability may establish an SNT for himself, an Agent under that individual's power of attorney may also be able to establish the trust for the beneficiary using a Power of Attorney granted by the individual. Best practices for attorneys will be to include provisions authorizing the establishment of a self-settled SNT in a power of attorney of the individual with the disability. Very few states have amended their statutory Power of Attorney provisions to include the power to establish a special needs trust for a principal under a Power of Attorney, so specific language is essential.

For a thorough discussion on requirements of a first-party special needs trust and their numerous requirements, see the Appendix at the end of Section Two of this outline.

IV. DECANTING ACTS.

A. Decanting has become a popular tool in special needs planning. The ability to decant an improperly drafted support trust for a beneficiary with a disability into a discretionary third-party special needs trust is very useful. The authors of the outline for this program have regularly encountered trusts drafted years before the Settlors knew of a beneficiary's disability (for which means-tested benefits are needed). While the Uniform Trust Code for the states that have adopted it²³ has been very helpful in rectifying some of these situations, a decanting statute that specifically addresses decanting for special needs trusts is an even better solution.

The Uniform Trust Decanting Act was completed by the Uniform Law Commission in 2015. It is much narrower in scope than the Uniform Trust Code, in that it pertains only to decanting trusts, whereas the Uniform Trust Code pertains to nearly aspect of trust administration. While the Uniform Decanting Act has not been around as long as the Uniform Trust

²² Twenty First Century Cures Act, Sec. 5007 (H.R. 34-114th Congress 2015-2016) amending 42 U.S.C. §1396p(d)(4)(A).

²³ These include Alabama, Arizona, Arkansas, District of Columbia, Florida, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, South Carolina, Tennessee, Utah, Vermont, Virginia, West Virginia, Wisconsin, and Wyoming.

Code (UTC), the less lengthy provisions of the Decanting Act may ultimately have as much impact as the Uniform Trust Code has had on an individual State's legislation.²⁴ A major advantage of the Decanting Act is that decanting generally does not require court involvement.

B. Section 13 (Trust for Beneficiary with Disability) of the Uniform Decanting Act specifically addresses decanting from a typical trust into a special needs trust appropriate for a beneficiary with a disability. The key provisions of this relatively short section read as follows:

"(c) In an exercise of the decanting power under this section, the following rules apply:

(1) Notwithstanding Section 11(c)(2), the interest in the second trust of a beneficiary with a disability may:

(A) be a pooled trust a defined by Medicaid law for the benefit of the beneficiary with a disability under 42 U.S.C. §1396p(d)(4)(C)[,as amended]; or

(B) contain payback provisions complying with reimbursement requirements of Medicaid law under 42 U.S.C. §1396p(d)(4)(A)[,as amended].

(2) Section 11(c)(3) does not apply to the interests of the beneficiary with a disability.

(3) Except as affected by any change to the interests of the beneficiary with a disability, the second trust, or if there are two or more second trusts, the second trusts in the aggregate, must grant each other beneficiary of the first trust beneficial interests in the second trusts which are substantially similar to the beneficiary's beneficial interests in the first trust."

1. A number of states enacted decanting statutes prior to the issuance of the Uniform Act since it did not achieve final form until 2015. In 2017 the Uniform Act was introduced in Illinois and Nevada and enacted in North Carolina, Virginia and Washington. Alabama expects to enact it in 2018.

2. Generally, the Uniform Trust Decanting Act permits an irrevocable trust that gives the fiduciary the power to make principal distributions the power to decant the trust into a new one that addresses the beneficiary's needs. Decanting should be undertaken not to change the Settlor's intent, but instead to modify the trust adapt to the broad purpose of the Settlor's intent had the Settlor anticipated the circumstances at the time the trust was signed. While the power to decant is generally unavailable to a fiduciary who does not have the discretion to distribute principal, a fiduciary without that power may still decant a trust to create a special needs trust if decanting will further the purpose of the trust.²⁵

3. Section 13 of the Uniform Trust Decanting Act provides broader powers to accomplish decanting to special needs trusts for beneficiaries with disabilities. Note that a beneficiary with a disability need not be currently receiving benefits or even necessarily qualify for such benefits. The fiduciary needs only "a reasonable belief that the decanting may permit the beneficiary to qualify for such benefits."²⁶

The comments to Section 13 provides examples to show how these rules work.

In most cases, if the first trust did not anticipate the beneficiary's disability and the settlor's broader purpose was to provide for the beneficiary's support, a decanting that would permit the beneficiary with a disability to qualify for governmental benefits while

²⁴ Amy J. Fanzlaw, Esq. *Modification of Irrevocable Trust*, presented October 20, 2017, at the Stetson University National Conference on Special Needs Planning and Special Needs Trust.

²⁵ *Id.*

²⁶ Unif. Trust Decanting Act §13cmt.(2015).

still being eligible to receive discretionary distributions from the trust would further the purpose of the trust.

For example, assume the first trust was created and funded by A, requires all income to be distributed to the beneficiary after age 21, permits the trustee to distribute principal to the beneficiary pursuant to ascertainable standard for the beneficiary's support, permits the beneficiary to withdraw the trust principal at age 30, grants the beneficiary a testamentary general power of appointment, and upon the beneficiary's death distributes any unappointed property per stirpes to A's descendants then living. If the beneficiary is age 25 and is disabled, the authorized fiduciary may exercise the decanting power to distribute the principal of the first trust to a trust that provides only for distributions to the beneficiary in the trustee's absolute discretion and upon the beneficiary's death distributes the remaining trust assets per stirpes to A's descendants then living. The exercise of the decanting power may eliminate the beneficiary's right to income, the beneficiary's prospective right to withdraw the trust at age 30 and the beneficiary's power of appointment. The second trust may not, however, change the remainder beneficiaries. Section 13(c)(3).

The result is the same if the beneficiary is age 31 and thus as a right to withdraw the trust assets, because Section 13(c)(2) provides that Section 11(c)(3) does not apply to the interest of the beneficiary with a disability.

If in the above example the Trustee had no discretion to distribute principal, but was either required to distribute income or had discretion to distribute income for A's support, the authorized fiduciary could still decant to a special needs trust. The Trustee would be considered the special needs fiduciary under Section 13(a)(3).

The decanting, however, must further the purposes of the first trust. Section 13(b)(2). For example, if a trust was created solely for the purpose of funding college education for the settlor's grandchildren, the authorized fiduciary may not decant to pay for the support of a grandchild who is the beneficiary with a disability. Conceivably, however, a trust for the education at all levels of the settlor's grandchildren might be decanted to a trust that permits distributions to a grandchild who is a beneficiary with a disability for such grandchild's occupational therapy and vocational training.²⁷

V. NEW POMS AFFECTING SPECIAL NEEDS TRUSTS.

A. The POMS (Program Operating Manual Systems) are the guidelines and procedures that a Social Security Representative will follow in determining whether a person with a disability has countable income and resources. They are available at Social Security's website at www.ssa.gov, and lawyers who practice in this area should check the POMS frequently for updates. The specific link to check is <https://secure.SSA.gov/apps10/poms.nsf/home?readform>. Click on "updates." Among the POMS issued in the past year are regulations explaining the way Social Security will treat ABLE Act accounts, including disbursements from the accounts. See, <https://secure.ssa.gov/apps101poms.nsf/lrx/0501130740> and **Exhibit A**.

B. Additional POMS regarding ABLE accounts are expected this year, along with new POMS concerning SNTs. Travel POMS are among them, along with how to amend the trust and within what period, if the present SNT does not comply with the new POMS.

A lawyer doing special needs planning work would also want to click on "SSA program rules" to see if there have been any new rulings relative to special needs trusts.

VI. REQUIRED REPORTING OF SPECIAL NEEDS TRUSTS TO GOVERNMENT AGENCIES.

A. As discussed more thoroughly in Section Two of the written materials for this program by Kristen Lewis, more and more states are implementing programs to evaluate the eligibility of the trusts as an exempt resource for a

²⁷ See Unif. Trust Decanting Act §13 cmt.

beneficiary receiving Medicaid. Also, Social Security regularly reviews all first-party special needs trusts and has implemented a "Special Needs Trust Review Process." It varies from state to state as to whether a third-party special needs trust should be reported to Social Security and Medicaid. While a third-party special needs trust should not include a Medicaid pay-back provision, the authors sometimes see payback clauses in SNTs drafted by lawyers who do not regularly practice in this area.

B. State Medicaid Agencies have very specific and differing requirements they expect to see in a special needs trust. In figuring out if there is a need to report the SNT after it is funded, the lawyer must identify the programs from which the beneficiary receives benefits. Most clients will not know the name of the federal or state program providing their child's benefits, so it is important that the parent bring a copy of a benefit award letter for the attorney to review.

C. One the most important provisions of the POMS concerns the language that a first-party, self-settled SNT must contain in order to be exempt. POMS SI 1120.20B1H provides important guidance for the beneficiary of a self-settled pay-back trust. Some special needs planning practitioners are not aware that a first-party special needs trust with money belonging to the beneficiary must repay Medicaid liens at death. These include the liens from any state the beneficiary has lived in since turning 18. This POMS requires repayment of the lien to the Medicaid agency before even paying for the funeral or burial expenses of the trust decedent. This makes it critical to pre-purchase the funeral plan and services.

VII. NEW TREND TOWARDS SUPPORTED DECISION-MAKING AND LIMITED GUARDIANSHIPS AND CONSERVATORSHIPS.

A. Part of estate planning for a person with a disability will often involve a discussion of guardianship and conservatorships. The trend, as noted by the American Bar Association in a recent resolution entered into by the Commission on Disability Rights, the Section of Civil Rights and Social Justice, the Section of Real Property and Trust and Estate Law and the Commission on Law and Aging indicates states, territories and tribal legislatures are encouraged to amend their guardianship statutes to require that decision-making supports that would meet a person with a disability's needs be identified and fully considered in proceedings for guardianship and termination of guardianship. All methods of decision-making should be considered, not just the plenary guardianship that strips the beneficiary of all decision-making rights.

B. A project of numerous organizations concerned with guardianship issues participated in a project sponsored by the ABA's Commission on Law and Aging that resulted in a tool for lawyers to use in making determinations about the client's ability to handle decision-making with some assistance. Called "PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making," this worksheet and accompanying manual are available for free download at www.ambar.org/practicaltool. A copy of the Practical Tool is attached as **Exhibit C** to this Section One of the program outline.

C. The National Conference of Commissioners on Uniform State Law completed a new uniform act that updates the Uniform law governing protected proceedings. A new feature of this Uniform Guardianship, Conservatorship, and other Protective Arrangements Act is supported decision-making. This will be a new concept for many attorneys, but with the greying of America, it is critical that every person be informed about this new form of guardianship. The Uniform Law Commissions is looking for states where a committee is formed to help the legislation go through state review committees.

Several states have already passed supported decision-making statutes to give a person with a disability support in making a decision rather than having a guardian make all decisions.²⁸

VIII. WAIVER PROGRAMS.

A. The knowledge of home and community based waiver services for individuals with disabilities can be life changing. Waiver programs are one of the most important services that a family can receive for a child with a disability. There are limited slots in most states to get waiver services. While the family's resources may not be a factor in determining eligibility, assets of the person with a disability are. New waiver services are being proposed and implemented in many states. Knowledge of these programs in order to inform a client are critical, and may become even more critical if Medicaid services are restricted by future government actions.

²⁸ These states include Texas and Delaware.

B. Chief among services provided through waiver programs is residential care. Waiver programs provide various models of supported housing, personal care attendance for activities of daily living, day programs, and employment supports, such as job coaches. In some programs, family income and resource limits apply, but in others, such as the Katie Beckett Waiver, the child's income and resources are the only things considered for eligibility (other than the severity of the disability). The Home and Community Based Service (HCBS) programs are often allowed to target specific populations by diagnosis, such as autism or traumatic brain injury, and to cap enrollment. The agencies that administer the waiver programs in the various states may not be easy to find. For example, in Jefferson County, Alabama, the organization handling waiver programs for young children is the Alabama Office for Senior Care. Waiver services programs often have a long waiting list, with eligibility based on triage of the applicants. Various factors in determining need for the services include the status of the child's situation (is beneficiary in need of 24/7 care, are their multiple children with disabilities in the family, or is a parent ill and not able to help).

EXHIBIT A

1. Program Operations Manual System (POMS)

Effective Dates: 10/19/2016 - Present [Previous](#) | [Next](#)

TN 73 (03-16)

2. **SI 01130.740 Achieving a Better Life Experience (ABLE) Accounts**

Citations:

[Public Law 113-295](#) The Stephen Beck, Jr., Achieving a Better Life Experience Act (ABLE Act) – Enacted December 19, 2014

3. A. What is an ABLE Account?

An Achieving a Better Life Experience (ABLE) account is a type of tax-advantaged account that an eligible individual can use to save funds for the disability-related expenses of the account's designated beneficiary, who must be blind or disabled by a condition that began before the individual's 26th birthday.

An ABLE program can be established and maintained by a State or a State agency directly or by contracting with a private company (an instrumentality of the State). An eligible individual can open an ABLE account through the ABLE program in any State.

An eligible individual can be the designated beneficiary of only one ABLE account, which must be administered by a qualified ABLE program.

Upon the death of the designated beneficiary, funds remaining in the ABLE account, after payment of any outstanding, qualified disability expenses, reimburse the State(s) for certain Medical Assistance (Medicaid) benefits that the designated beneficiary received.

4. B. Definition of terms

5.

6. 1. Designated beneficiary

The designated beneficiary is the eligible individual who established and owns the ABLE account.

To be an eligible individual, he or she must be:

- a. eligible for Supplemental Security Income (SSI) based on disability or blindness that began before age 26;
- b. entitled to disability insurance benefits (DIB), childhood disability benefits (CDB), or disabled widow's or widower's benefits (DWB) based on disability or blindness that began before age 26; or
- c. someone who has certified, or whose parent or guardian has certified, that he or she:
 - o has a medically determinable impairment meeting certain statutorily specified criteria; or,
 - o is blind; and,
 - o the disability or blindness occurred before age 26.

NOTE: You may not draw an inference regarding disability under the Social Security Act from a disability certification.

7. 2. Contributions

A contribution is the deposit of funds into an ABLE account. Any person can contribute to an ABLE account. (“Person,” as defined by the Internal Revenue Code, includes an individual, trust, estate, partnership, association, company, or corporation.) However, the Internal Revenue Service (IRS) limits the total annual contributions that any ABLE account can receive from all sources to the amount of the per-donee gift-tax exclusion in effect for a given calendar year. For 2016, that limit is \$14,000.

8. 3. Distributions

A distribution is the withdrawal or issuance of funds from an ABLE account. The designated beneficiary or the person with signature authority determines when he or she makes distributions. Distributions are only to or for the benefit of the designated beneficiary.

9. 4. Person with signature authority

A person with signature authority can establish and control an ABLE account for a designated beneficiary who is a minor child or is otherwise incapable of managing the account. The person with signature authority must be the designated beneficiary's parent, legal guardian, or agent acting under power of attorney. For SSI purposes, we always consider the designated beneficiary to be the owner of an ABLE account, regardless of whether someone else has signature authority over it.

10. 5. Qualified disability expenses

Qualified disability expenses (QDE) are expenses related to the blindness or disability of the designated beneficiary and for the benefit of the designated beneficiary. In general, a QDE includes, but is not limited to, the following types of expenses:

- Education;
- Housing;
- Transportation;
- Employment training and support;
- Assistive technology and related services;
- Health;
- Prevention and wellness;
- Financial management and administrative services;
- Legal fees;
- Expenses for ABLE account oversight and monitoring;
- Funeral and burial; and,
- Basic living expenses.

11. 6. Rollover

A rollover is the distribution of all or some of the funds from one ABLE account to the ABLE account of a member of the original designated beneficiary's family. For the purposes of a rollover, a member of the designated beneficiary's family means siblings, stepsiblings and half-siblings, by blood or by adoption.

12. 7. ABLE Program

An ABLE program is the program established and maintained by a State (or agency or instrumentality thereof) through which eligible individuals can open ABLE accounts.

13. 8. Qualified disability expense (QDE) for housing

Housing expenses for purposes of an ABLE account are the same as they are for in-kind support and maintenance purposes, except for food. QDEs for housing are payments for:

- Mortgage (including property insurance required by the mortgage holder);
- Real property taxes;
- Rent;
- Heating fuel;
- Gas;
- Electricity;
- Water;
- Sewer; or
- Garbage removal.

14. C. When to exclude ABLE account contributions, balances, earnings, and distributions

15. 1. Exclude contributions

Exclude contributions to an ABLE account from the income of the designated beneficiary. Excluded contributions include rollovers from a family member's ABLE account to an SSI recipient's ABLE account.

NOTE: Do not deduct contributions from the countable income of the person who makes the contribution. The fact that a person uses his or her income to contribute to an ABLE account does not mean that his or her income is not countable for SSI purposes. For example, a recipient or deemor can have contributions automatically deducted from his or her paycheck and deposited into an ABLE account. In this case, include the income used to make the ABLE-account contribution in the recipient or deemor's gross wages.

16. 2. Exclude ABLE account earnings

The funds in an ABLE account can accrue interest, earn dividends, and otherwise appreciate in value. Earnings increase the account's balance. Exclude any earnings an ABLE account receives from the income of the designated beneficiary.

17. 3. Exclude up to and including \$100,000 of balance

Exclude up to and including \$100,000 of the balance of funds in an ABLE account from the resources of the designated beneficiary.

18. 4. Do not count ABLE account distributions as income

A distribution from an ABLE account is not income but is a conversion of a resource from one form to another, see [SI 01110.600B.4](#).

Do not count distributions from an ABLE account as income of the designated beneficiary, regardless of whether the distributions are for non-housing QDEs, housing QDEs, or non-qualified expenses.

19. 5. Exclude retained distributions for non-housing related qualified disability expenses (QDE)

a. Distribution for a non-housing related QDE

Exclude from the designated beneficiary's countable resources a distribution for a QDE other than housing if he or she retains it beyond the month received.

This exclusion applies while:

- the designated beneficiary maintains, makes contributions to, or receives distributions from the ABLE account;
- the distribution is unspent;
- the distribution is identifiable. (**NOTE:** Excludable funds commingled with non-excludable funds must be identifiable. See [SI 01130.700A](#).); and

- the individual still intends to use the distribution for a non-housing related QDE.

NOTE: Apply normal SSI resource counting rules and exclusions to assets or other items purchased with funds from an ABLE account.

b. **Previously excluded distribution used for non-qualified expense or housing-related QDE**

If a designated beneficiary uses a distribution previously excluded per [SI 01130.740C.5.a.](#), for a non-qualified purpose or a housing-related QDE, or the individual's intent to use it for a qualified disability expense changes, see [SI 01130.740D.3.](#).

c. **Example of an excluded distribution**

Eric takes a distribution of \$500 from his ABLE account in June 2016 to pay for a health-related QDE. His health-related expense is not due until September, so Eric deposits the distribution into his checking account in June. The distribution is not income in June. Eric maintains his ABLE account at all relevant times, and the distribution is both unspent and identifiable until Eric pays his health-related expense in September. We therefore exclude the \$500 from Eric's countable resources in July, August, and September. For instructions on identifying commingled excluded and non-excluded funds, see [SI 01130.700](#).

d. **Example of an excluded QDE purchase**

Fred takes a distribution of \$1,500 from his ABLE account in September 2016 to buy a QDE - a wheelchair. The wheelchair is an excluded resource in October and continuing, because it is an individual's personal property required for a medical condition. For instructions on household goods, personal effects, and other personal property, see [SI 01130.430](#).

20. D. When to count ABLE account balances and distributions

21. 1. Count ABLE account balance amounts over \$100,000

Count the amount by which an ABLE account balance exceeds \$100,000 as a countable resource of the designated beneficiary.

22. a. Rule for indefinite benefit suspension and continuing eligibility for Medicaid during periods of excess resources attributable to an ABLE account

A special rule applies when the balance of an SSI recipient's ABLE account exceeds \$100,000 by an amount that causes the recipient to exceed the SSI resource limit--whether alone or with other resources. When this situation happens, place the recipient into a special SSI suspension period where:

- we suspend the recipient's SSI benefits without time limit (as long as he or she remains otherwise eligible);
- the recipient retains continued eligibility for Medical Assistance (Medicaid); and
- the individual's eligibility does not terminate after 12 continuous months of suspension.

Reinstate the recipient's regular SSI eligibility for any month in which the individual's ABLE account balance no longer causes the recipient to exceed the resource limit and he or she is otherwise eligible.

NOTE: There will be no SSI recipients in this suspension status for several years (until ABLE account balance exceeds more than \$100,000, due to the limitation on contributions described in [SI 01130.740B.2](#)).

EXAMPLE: Excess resources — recipient is suspended but retains eligibility for Medicaid

Paul is the designated beneficiary of an ABLE account with a balance as of \$101,000 on the first of the month. Paul's only other countable resource is a checking account with a balance of \$1,500. Paul's countable resources are \$2,500 and therefore exceed the SSI resource limit. However, since Paul's ABLE account balance is causing him to exceed the resource limit (i.e., his countable resources other than the ABLE account are less than \$2,000), we suspend Paul's SSI eligibility and stop his cash benefits, but he retains eligibility for Medicaid.

23. b. Ineligibility due to excess resources other than an ABLE account

The special suspension rule does not apply when:

- the balance of an SSI recipient's ABLE account exceeds \$100,000 by an amount that causes the recipient to exceed the SSI resource limit;
- but the resources other than the ABLE account alone would make the individual ineligible for SSI, due to excess resources

When this situation happens, suspend the recipient's SSI benefits using the payment status code N04. While in N04, the recipient loses eligibility for Medical Assistance (Medicaid) and the individual's SSI eligibility terminates 12 months later if the suspension continues during this period. Reinstate the recipient's regular SSI eligibility and Medicaid benefits for any month in which the individual's resources no longer cause the recipient to exceed the resource limit.

EXAMPLE Combination of resources — recipient loses SSI eligibility

Christine is the designated beneficiary of an ABLE account with a balance as of the \$101,000 on the first of the month. Christine's only other countable resource is a checking account with a balance of \$3,000. Christine's countable resources are \$4,000 and therefore exceed the SSI resource limit.

However, because her ABLE account balance is not the cause of her excess resources (i.e., her countable resources other than the ABLE account are more than \$2,000), the special rule does not apply, and Christine is not eligible for SSI because of excess resources. We suspend Christine's SSI benefits using payment status N04, and her Medicaid benefits stop.

24. c. Ineligibility for other reasons

If an individual is ineligible for any reason other than excess resources in an ABLE account, the special suspension status does not apply. Suspend the individual's SSI eligibility using normal procedures.

EXAMPLE: Ineligibility for a reason other than excess resources in an ABLE account

In April, Sam's ABLE account resource balance is \$102,500 on the first of the month. However, Sam also has excess deemed income in April and is N01 despite the excess funds in his ABLE account. Before the end of April, Sam leaves the U.S. and does not return until July 1. Sam is N03 for May, June, and July. If Sam still has excess resources in his ABLE account effective August 1 and is otherwise SSI eligible, we place him in the special ABLE resource suspension status. He is eligible for Medicaid.

25. 2. Count as a resource retained distributions for housing-related QDEs or expenses that are not QDEs

A distribution from an ABLE account is not income, but is a conversion of a resource from one form to another. For more information see [SI 01110.600B.4](#).

Count a distribution for a housing-related QDE or for an expense that is not a QDE as a resource, if the beneficiary retains the distribution into the month following the month of receipt. If the beneficiary spends the distribution within the month of receipt, there is no effect on eligibility. However, apply normal SSI resource counting rules and exclusions to assets or other items purchased with funds from an ABLE account.

EXAMPLE: Retained housing QDE is a resource

Amy takes a distribution of \$500 from her ABLE account in May to pay her rent for June. She deposits the \$500 into her checking account in May, withdraws \$500 in cash on June 3, and pays her landlord. This distribution is a housing-related QDE and part of her checking account balance June 1, which makes it a countable resource for the month of June.

26. 3. Count previously excluded distributions used for a non-qualified purpose or housing-related QDE

If we excluded a retained distribution for a non-housing-related QDE, per [SI 01130.740C.5.a.](#) and the individual uses the excluded distribution for a non-qualified purpose or a housing-related QDE, count the amount of funds used for a non-qualified expense or housing-related QDE as a resource as of the first moment of the month in which the funds were spent. Presume that the individual's intent to use the funds for a QDE changed as of the first of the month he or she spent the funds. If an individual's intent to use the funds for a QDE changes at any other time, but he or she has not spent the funds, count the retained funds as a resource as of the first of the following month.

27. a. Example of a previously excluded distribution used for a non-QDE

Sam takes a distribution of \$25,000 from his ABLE account to modify a specially equipped van in May. He pays a \$10,000 deposit. While waiting for delivery of the van, Sam takes a trip to a local casino in July where he loses \$1,000 of his ABLE distribution gambling. The \$1,000 he lost gambling is a countable resource in July. The other \$14,000 Sam retains is an excluded resource while it meets the requirements of [SI 01130.740C.5.a.](#) in this section.

28. b. Example of a previously excluded distribution used for a housing-related QDE

In June, Jennifer takes a \$7,000 distribution from her ABLE account to pay her college tuition - a QDE. Her tuition payment is due in September. However, she has to make a \$750 advance rent payment to her landlord for her college apartment in August. She uses some of the distribution she took in June to make the rent payment – a housing-related QDE. The \$750 is a countable resource in August. We exclude the remaining \$6,250 of the retained distribution while it continues to meet the requirements of [SI 01130.740C.5.a.](#) in this section.

29. c. Example of a change of intent on the use of a distribution

In June, Jennifer takes a \$7,000 distribution from her ABLE account to pay her college tuition - a QDE. Her tuition payment is due in September. In August, Jennifer gets a job offer and decides not to return to school. Since she no longer intends to use it for tuition, the \$7,000 becomes a countable resource in September unless Jennifer redesignates it for another QDE or returns the funds to her ABLE account prior to September.

30. E. How to verify, document, and record ABLE account balances

31. 1. Obtain evidence of the ABLE account

Whenever a recipient or deemor alleges being the designated beneficiary of an ABLE account, obtain evidence that provides the following information:

- the name of the designated beneficiary;
- the State ABLE program administering the account;
- the name of the person who has signature authority (if different from the designated beneficiary);
- the unique account number assigned by the State to the ABLE account;
- the account opened date;
- the first-of-the-month account balance or information sufficient to derive a first-of-the-month balance.
-

If the available evidence does not provide the necessary information, contact the appropriate ABLE program to obtain it.

32. 2. Document the evidence

Fax the evidence into the electronic folder (EF) or Non-disability Repository for Evidentiary Documents (NDReD). If you contact the ABLE program directly, document the information you received on a Report of Contact (DROC) in MSSICS or on a Report of Contact (SSA-5002) in non-MSSICS claims.

33. 3. Record the account on a MSSICS “Other Resource” page

Record the account information and balance on a MSSICS Other Resource (ROTH) page. There is an ABLE account drop down under “Type.” See MS INTRANETSSI 013.032 for instructions on completing this screen.

NOTE: The designated beneficiary of an ABLE account is always the owner of the account for SSI purposes.

34. F. How to verify, document, and record ABLE account distributions

35. 1. When to develop

Only verify a distribution when a recipient or deemor alleges retaining, or other evidence indicates he or she retained, all or part of a distribution into months following the month of receipt. Since distributions do not count as income, the distribution is only material in determining whether the recipient's countable resources exceed the limit.

36. 2. Verify the distribution

Obtain evidence showing the amount of any distributions, the distribution dates, and who received the distributions (for example, the beneficiary paid the distribution directly to a vendor). Obtain and accept the recipient or deemor's allegation that he or she used or intends to use the distribution for:

- a QDE other than housing;
- a housing QDE; or
- an expense that is not a QDE.

37. 3. Exclude retained distributions for QDEs other than housing

Exclude any retained distribution, or part of a distribution, for a QDE other than housing, from the designated beneficiary's countable resources per [SI 01130.740C.5.](#) in this section.

Example of a retained QDE other than housing

Elizabeth takes a distribution of \$500 from her ABLE account in May to pay for a health-related QDE she expects to pay in September. She deposits the distribution into her checking account in May and withdraws it in September to pay the health-related QDE. We exclude the \$500 from Elizabeth's countable resources from June through September. Starting in June, we document the deposit on the Financial Institution Account (RFIA) page inputting \$500 as the “excluded amount.” Select “Other” as the exclusion reason and input “ABLE QDE distribution” as the “other reason.”

38. 4. Count retained distributions for housing QDEs and expenses that are not QDEs

Count, as a resource, any distribution or part of a distribution for a housing QDE or an expense that is not a QDE if it is retained into the month following the month of receipt.

Example of a retained QDE for housing

Amy takes a distribution of \$500 from her ABLE account in May to pay her rent for June. She deposits the \$500 into her checking account in May, withdraws \$500 in cash on June 3, and pays her landlord. This distribution, which is a housing-related QDE, is part of her checking account balance as of the first of the month in June, which makes it a countable resource for the month of June.

39. 5. Count previously excluded distributions used for a non-qualified purpose or housing-related QDE

If we excluded a retained distribution for a non-housing-related QDE, per [SI 01130.740C.5.a.](#) and the individual uses the excluded distribution for a non-qualified purpose or a housing-related QDE, count the amount of funds used for the non-qualified expense or housing-related QDE as a resource, as of the first moment of the month in which the individual spent the funds. Presume that the individual's intent to use the funds for a QDE changed as of the first of the month he or she spent the funds.

If an individual's intent to use the funds for a QDE changes at any other time, but he or she still retains the funds, count the retained funds as a resource as of the first of the month following the month of change of intent. Document the individual's change of intent on a Report of Contact (DROC) in MSSICS or on a Report of Contact (SSA-5002) in non-MSSICS claims. For examples, see [SI 01130.740D.3](#).

40. 6. Record the amount excluded on the appropriate resource page

ABLE account distributions are the conversion of a resource from one form to another. Accordingly, they continue to be a resource if retained into the month following the month of receipt. Exclude a retained QDE distribution from resources per [SI 01130.740C.5.a](#).

Depending on how and where the individual retains distributions, record the amount in the "amount excluded" field of the appropriate resource page in MSSICS with a reason of "ABLE QDE distribution."

EXHIBIT B



OFFICE OF THE ASSISTANT SECRETARY OF DEFENSE 4000 DEFENSE PENTAGON WASHINGTON, D.C. 20301-4000

DEC 3 1 2015

MEMORANDUM FOR DEPUTY ASSISTANT SECRETARY OF THE ARMY FOR HUMAN
RESOURCES
DEPUTY ASSISTANT SECRETARY OF THE NAVY FOR
MILITARY PERSONNEL POLICY
DEPUTY ASSISTANT SECRETARY OF THE AIR FORCE FOR
FORCE MANAGEMENT AND PERSONNEL
DIRECTOR, DEFENSE FINANCE AND ACCOUNTING SERVICE

SUBJECT: Enabling Payment of Survivor Benefit Plan Annuities to a Special Needs Trust

This memorandum establishes the policy required for implementing section 624 of the Howard P. "Buck" McKeon National Defense Authorization Act for Fiscal Year 2015 (FY 15 NDAA), Public Law 113-291, which amends title 10, United States Code (U.S.C.), sections 1448, 1450, and 1455. The amendments allow a person who has established a Special Needs Trust (SNT) in accordance with either title 42, U.S.C., section 1396p(d)(4)(A) or (C), to direct payment of a dependent child Survivor Benefit Plan (SBP) annuity directly to the SNT as an add-on election to a member or retiree's SBP election for coverage of a dependent child.¹ In general, members entitled to receive retired pay make an irrevocable decision when they elect to provide SBP coverage for a beneficiary.

The FY 15 NDAA gives military members and retirees the option to direct payment of a SBP annuity for a dependent child to a SNT for the benefit of a disabled child when they elect or elected coverage for that dependent child as a SBP beneficiary (the statute does not apply to disabled spouses). Generally speaking, a SNT is a legal instrument specifically designed solely for the benefit of a person with a disability by providing a set of instructions for managing money set aside to help a disabled person. Unlike many other types of trusts, a SNT is governed by State law. In accordance with the SBP statute, a SNT must also be in accordance with Federal statute (i.e., title 42, U.S.C., section 1396p(d)(4)(A) or (C)). In addition, once created, it must be irrevocable.

As a result of the legislation, a member or retiree who elects SBP coverage that includes coverage for a dependent child may now, at any time, irrevocably decide to substitute a SNT created for the benefit of a disabled dependent child as the SBP beneficiary to receive any SBP annuity payments that would otherwise be payable to or on behalf of the disabled dependent child. This irrevocable decision may be made during the life of the member through a written statement that designates future SBP payments to the SNT (designation in Section X- Remarks of the DD Form 2656 Data for Payment of Retired Personnel will also suffice). In situations

¹ Hereinafter the term "dependent child" means a dependent child as defined in 10 U.S.C. § 1447(11). The dependent child must also be "disabled" as defined in 42 U.S.C. § 1382c(a)(3) (e.g., unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months). Thus, a "disabled dependent child" means a child who is a dependent child pursuant to 10 U.S.C. 1447(11) and "disabled" pursuant 42 U.S.C. § 1382c(a)(3).

where SBP payments are made to more than one dependent child, the SNT shall be treated as a dependent child for purposes of determining the shares payable to each of the children.

1. During the life of the member or retiree. A member or retiree who elects or elected SBP coverage that includes coverage for a dependent child may designate a SNT created for the benefit of the disabled dependent child to receive SBP payments that would otherwise have been payable to the disabled dependent child. To irrevocably elect to substitute a SNT for the benefit of a disabled dependent child as a SBP beneficiary in lieu of the dependent child, the member or retiree must submit a statement of the decision to have the annuity paid to the SNT with the name and tax identification number for the SNT. Further, the member or retiree must either submit a separate statement using the attached template from an actively licensed attorney certifying that the trust is a SNT created for the benefit of the disabled dependent child and is in compliance with all applicable Federal and State laws or a certification from the Social Security Administration that the trust qualifies as a SNT pursuant to title 42 of the U.S.C.

2. Upon or after the death of a member or retiree.

a. Upon the death of a retiree. If SBP coverage for the dependent child has been elected, then the disabled dependent child's surviving parent, grandparent, or court appointed legal guardian may irrevocably elect to have SBP annuity payments made to a SNT established for the disabled dependent child by the member, or the disabled dependent child's surviving parent, grandparent, or court appointed legal guardian.

b. Upon the death of a member on Active Duty in the line of duty. If SBP coverage for the dependent child has been elected by the Secretary concerned due to a member's death on Active Duty while in the line of duty, then a disabled dependent child's surviving parent, grandparent, or court appointed legal guardian may irrevocably elect to have SBP annuity payments made to a SNT established for the disabled dependent child by the member, or the disabled dependent child's surviving parent, grandparent, or court appointed legal guardian.

c. Upon the death of a member during inactive duty training. If a member dies during inactive duty training and leaves no surviving spouse and the SBP becomes payable to the surviving dependent children, then the disabled dependent child's surviving parent, grandparent, or court appointed legal guardian may irrevocably elect to have SBP annuity payments made to a SNT established for the disabled dependent child by the member, or the disabled dependent child's surviving parent, grandparent, or court appointed legal guardian.

d. Requirements for a qualifying SNT designation under 2.a.-c. To make this SNT designation under paragraphs 2.a.- c., the surviving parent, grandparent, or court-appointed legal guardian shall submit a statement of the decision to have the annuity paid to the SNT with the name and tax identification number for the SNT, and a separate statement using the attached template from an actively licensed attorney certifying that the trust is a SNT created for the benefit of the disabled dependent child and is in compliance with all applicable Federal and State laws or certification from the Social Security Administration that the trust is a SNT pursuant to title 42 of the U. S.C.

If the SNT is found to be invalid or otherwise fails, then payment of the SBP annuity shall revert back to being made directly to the dependent child. If this occurs, the dependent child's entitlement to other Federal benefits such as Supplemental Security Income and Medicaid may be impacted. Since there are serious consequences if a SNT is found to be invalid, those seeking to have a SNT created need to exercise due diligence to ensure that they consult with an attorney well-versed in this specialized and complex area of law.

This policy and operational guidance will be included in subsequent updates of the Department of Defense Financial Management Regulation Volume 7B and the Survivor Annuity Program Administration, Department of Defense Instruction 1332.42. Further, this policy regarding the use of SNT supplements currently existing SBP policy, which otherwise remains in effect. If you have any questions, my point of contact is Pat Mulcahy at (703) 693-1059.



Stephanie Barna
Principal Deputy Assistant Secretary of Defense (Manpower and Reserve Affairs), Performing the Duties of the Assistant Secretary of Defense (Manpower and Reserve Affairs)

Attachment:
As stated

cc:
Deputy Assistant Secretary Defense for Military Personnel Policy
Deputy Chief of Staff for Personnel, U.S. Army
Deputy Chief of Naval Operations
for Manpower, Personnel, Training and Education, U. S. Navy
Deputy Chief of Staff for Personnel, U.S. Air Force
Deputy Commandant for Manpower and Reserve Affairs, U.S. Marine Corps
Assistant Commandant for Human Resources,
U.S. Coast Guard
Director, Division of Commissioned Personnel,
U.S. Public Health Service
Director, National Oceanic and Atmospheric Administration Corps Operations-NC
Department of Defense Chief Actuary
Deputy General Counsel (Fiscal)

EXHIBIT C

PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

Jointly produced by the
Commission on Law and Aging;
Commission on Disability Rights;
Section on Civil Rights and Social Justice; and
Section on Real Property, Trust and Estate Law

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PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making. Learn more about the PRACTICAL Tool and Resource Guide at www.ambar.org/practicaltool.

PRESUME guardianship is not needed.

- Consider less restrictive options like financial or health care power of attorney, advance directive, trust, or supported decision-making
- Review state statute for requirements about considering such options

Observations and Notes:

REASON. Clearly identify the reasons for concern.

Consider whether the individual can meet some or all of the following needs.*

Money Management:

- Managing accounts, assets, and benefits
- Recognizing exploitation

Health Care:

- Making decisions about medical treatment
- Taking medications as needed
- Maintaining hygiene and diet
- Avoiding high-risk behaviors

Relationships:

- Behaving appropriately with friends, family, and workers
- Making safe decisions about sexual relationships

Community Living:

- Living independently
- Maintaining habitable conditions
- Accessing community resources

Personal Decision-Making:

- Understanding legal documents (contracts, lease, powers of attorney)
- Communicating wishes
- Understanding legal consequences of behavior

Employment:

- Looking for, gaining, and retaining employment

Personal Safety:

- Avoiding common dangers
- Recognizing and avoiding abuse
- Knowing what to do in an emergency

Observations and Notes (List supports needed.):

*Adapted from University of Missouri Kansas City, Institute for Human Development, "MO Guardianship: Understanding Your Options & Alternatives," <http://moguardianship.com>.

PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

ASK if a triggering concern may be caused by temporary or reversible conditions.

Look for steps to reverse the condition or postpone a decision until the condition improves.

Are concerns the result of or related to temporary or reversible conditions such as:

- Medical conditions:** Infections, dehydration, delirium, poor dental care, malnutrition, pain
- Sensory deficits:** hearing or vision loss
- Medication side effects**
- Psychological conditions:** stress, grief, depression, disorientation
- Stereotypes or cultural barriers**

Observations and Notes:

COMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations.

Ask “what would it take?” to enable the person to make the needed decision(s) or address the presenting concern.

Might any of the following supports meet the needs:

Community Supports:

- In-home care, adult day care, personal attendant, congregate and home delivered meals, transportation
- Care management, counseling, mediation
- Professional money management

Accommodations:

- Assistive technology
 - Home modifications
- Residential Setting:**
- Supported housing or group home
 - Senior residential building
 - Assisted living or nursing home

Observations and Notes:

Informal Supports from Family/Friends:

- Assistance with medical and money management
- Communication assistance
- Identifying potential abuse

TEAM. Ask the person whether he or she already has developed a team to help make decisions.

- Does the person have friends, family members, or professionals available to help?
- Has the person appointed a surrogate to help make decisions?

Observations and Notes:

IDENTIFY abilities. Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.

Can the individual:

- Make decisions and explain his/her reasoning
- Maintain consistent decisions and primary values over time
- Understand the consequences of decisions

Observations and Notes:

CHALLENGES. Screen for and address any potential challenges presented by the identified supports and supporters.

Screen for any of the following challenges:

Possible challenges to identified supports:

- Eligibility, cost, timing or location
- Risk to public benefits

Observations and Notes:

Possible concerns about supporters:

- Risk of undue influence
- Risk of abuse, neglect, exploitation (report suspected abuse to adult protective services)
- Lack of understanding of person's medical/mental health needs
- Lack of stability, or cognitive limitations of supporters
- Disputes with family members

APPPOINT legal supporter or surrogate consistent with person's values and preferences.

Could any of these appointments meet the needs:

- | | |
|---|---|
| <input type="checkbox"/> Agent under health care power of attorney or advance directive | <input type="checkbox"/> Social Security representative payee |
| <input type="checkbox"/> Health care surrogate under state law | <input type="checkbox"/> VA fiduciary |
| <input type="checkbox"/> Agent under financial power of attorney | <input type="checkbox"/> Supporter under representation agreement, legally or informally recognized |
| <input type="checkbox"/> Trustee | |

Observations and Notes:

LIMIT any necessary guardianship petition and order.

If a guardian is needed:

- | | |
|--|---|
| <input type="checkbox"/> Limit guardianship to what is absolutely necessary, such as: <ul style="list-style-type: none">• Only specific property/financial decisions• Only property/finances• Only specific personal/health care decisions• Only personal/health care decisions | <input type="checkbox"/> State how guardian will engage and involve person in decision-making |
| <input type="checkbox"/> Develop proposed person-centered plan | <input type="checkbox"/> Reassess periodically for modification or restoration of rights |

Observations and Notes:

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PRACTICAL Resource Guide

The PRACTICAL Tool for lawyers is a joint product of four American Bar Association entities—the Commission on Law and Aging; Commission on Disability Rights; Section on Real Property, Trust and Estate Law; and Section on Civil Rights and Social Justice, with assistance from the National Resource Center for Supported Decision-Making. These four ABA entities recognize the need to raise the awareness of lawyers about decision-making options for persons with disabilities that are less restrictive than guardianship.¹

“PRACTICAL” is an acronym for nine steps for lawyers to identify these options. The lawyer can use the PRACTICAL checklist of steps during the client interview and immediately after to assist in case analysis. The steps blend in naturally with the case interview process. Lawyers serving in different roles may use the steps differently.

- A lawyer **representing a potential petitioner** for guardianship can go through the steps with the client to screen for other options, including creative ways to target concerns and prevent harm that could moot the need for guardianship.
- A lawyer **representing a respondent** in a guardianship proceeding can use the steps to contest the petition if the client wishes to do so. For example, the lawyer could ask for a continuance to address reversible conditions or put in place community supports that might make guardianship unnecessary. The lawyer could use the steps in preparing hearing arguments identifying the person’s abilities and supports.
- A lawyer **serving as guardian ad litem** can use the steps in interviewing the person and preparing a report for the court.
- A lawyer **serving as guardian** can use the steps to enhance the self-determination of the individual and assess for possible modification of the order or restoration of rights.

Background

Lawyers increasingly encounter the need for decision-making by and on behalf of adults with disabilities—as an advisor to clients who are considering a guardianship petition; as counsel for petitioner or respondent or as a guardian ad litem in a guardianship proceeding; as guardian or conservator; when counseling clients on legal and financial planning; and when advising families on the transition of a minor with disabilities to adult status. With the aging of the population² and the increase in individuals with disabilities,³ lawyers practicing in any area of the law increasingly may encounter issues of consent and capacity when clients need to execute contracts, transfer property or give informed consent for treatment.

¹ In this guide, the generic term “guardianship” refers to guardians of the person as well as guardians of the property, frequently called “conservators,” unless otherwise specified.

² Jennifer M. Ortman, Victoria A. Velkoff, and Howard Hogan, *An Aging Nation: The Older Population in the United States* (May 2014), U.S. Department of Commerce, Economics and Statistics Administration, available at <https://www.census.gov/prod/2014pubs/p25-1140.pdf>.

³ *Disability and Health*, World Health Organization Fact Sheet No 352 (December 2015), available at <http://www.who.int/mediacentre/factsheets/fs352/en/>.

PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

Guardianship is one of society's most drastic interventions, protecting individuals yet infringing upon fundamental human rights and opportunities for self-determination. Many state statutes prioritize less restrictive legal options such as: for financial decisions, appropriate use of joint accounts, durable powers of attorney, trusts, and representative payment for public benefits; and for personal and health decisions, advance directives, living wills, and use of state default consent laws.

If a guardian is appointed, it should be as a last resort, and the order limited to only those areas in which the individual needs decision-making assistance. The importance of limited guardianship is a major theme of the Uniform Guardianship and Protective Proceedings Act (UGPPA).⁴ Limited guardianship, participation of the individual in decision-making, and use of the person's values and preferences are key concepts in many state guardianship laws.

A recent shift in the decision-making landscape is the advent of "supported decision-making." The United Nations Convention on the Rights of Persons with Disabilities (CRPD),⁵ adopted in 2006,⁶ recognizes in Article 12 that persons with disabilities have the "legal capacity" and the right to make their own decisions, and that governments have the obligation to support them in doing so. For people with cognitive, intellectual, or psychosocial disabilities, Article 12 is critical to self-determination and equality. It calls for a switch in perception from a focus on disabilities to abilities, and from protection to support. Supported decision-making can be viewed as a key part of the "least restrictive alternative" spectrum; and has been called "a critically important alternative"⁷ to the guardianship model. Also, supported decision-making precepts can guide guardians in maximizing the voice of individuals they serve.

Despite the strong mandates in statute and standards, use of the least restrictive alternative principle in practice appears uneven at best—and "supported decision-making" is still in the early stages of recognition. While statistics are scant, anecdotal evidence and numerous press accounts confirm that guardianship orders are frequently overly broad or perhaps unnecessary; and that guardians regularly are appointed when practical supports and/or a less drastic legal intervention would have sufficed.

The *PRACTICAL Tool* offers concrete steps to implement the least restrictive alternative principle as a routine practice of law. The *PRACTICAL Tool Resource Guide* describes each of the nine steps, offering examples and including hyperlinks to key materials and community resources.

⁴ *Uniform Guardianship and Protective Proceedings Act (1997/1998)*, drafted by the National Conference of Commissioners on Uniform State Laws, available at http://www.uniformlaws.org/shared/docs/guardianship%20and%20protective%20proceedings/UGPPA_2011_Final%20Act_2014sep9.pdf.

⁵ *United Nations Convention on the Rights of Persons with Disabilities*, available at <http://www.un.org/disabilities/convention/conventionfull.shtml>.

⁶ Ratification of the CRPD currently is pending with the U.S. Senate.

⁷ Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, Saint Louis University Journal of Health Law & Policy (Vol. 4, No. 271), available at http://supporteddecisionmaking.org/sites/default/files/guardianship_for_persons_with_mi.pdf.

PRESUME guardianship is not needed. Notably, such a presumption is typically required by state statutes allowing guardianship only where a person's needs cannot be met by less restrictive means.

Guardianship historically has been a protective device, rooted in the ancient concept of *parens patriae*, in which the state must care for people who cannot care for themselves. In guardianship, an individual's powers, rights, and authority are transferred from the person to a surrogate in the name of protection from harm—a process that has been said to “unperson”⁸ an individual.

When a client presents a situation in which someone seems at risk and unable to protect him or herself, a natural and well-meaning impulse, compounded by collective legal practice over many years, may be for the lawyer to begin to draw up a requested guardianship petition to prevent harm and maximize safety.

In the PRACTICAL approach, the lawyer *stops*—and uses as a starting point that there may be other practical and legal options that can address needs and challenges at hand. Best practice requires that the lawyer thoroughly examine these options *before* proceeding with the guardianship petition.

In effect, the PRACTICAL approach confirms and operationalizes the presumption that guardianship is not the answer, yet retains it in the most limited form as a last resort option if needed. Consider the following rationales:

Statutory Mandate

The “least restrictive alternative”⁹ principle was first established by the U.S. Supreme Court in 1960, limiting state intervention in individual rights and liberties to only what is necessary for the health and welfare of individuals. This principle has been statutorily applied to the state’s intervention in the form of guardianship proceedings. The Uniform Guardianship and Protective Proceedings Act requires a court visitor report to specify “whether less restrictive means of intervention are available.” Most state guardianship laws similarly emphasize exploration of less restrictive decisional options before the filing for, and appointment of, a guardian. Finding less restrictive options is not only good practice; it is generally a state statutory mandate. Check requirements for your state.¹⁰

⁸ Fred Bayles and Scott McCarty, *Guardians of the Elderly: An Ailing System Part I: Declared ‘Legally Dead’ by a Troubled System*, Associated Press (Sep. 19, 1987), available at <http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f>.

⁹ *Shelton v. Tucker*, 364 U.S. 479 (1960), available at <https://www.law.cornell.edu/supremecourt/text/364/479>.

¹⁰ Adult Guardianship Statutory Table of Authorities, American Bar Association Commission on Law and Aging, available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_AdultGuardianshipStatutoryTableofAuthorities.authcheckdam.pdf.

Moreover, a compelling argument can be made that unnecessary guardianship without the examination of workable alternatives violates the 1999 Supreme Court decision in the *Olmstead* decision¹¹ requiring community integration, in that it unnecessarily isolates and segregates individuals in efforts to protect them.

Practice Standards

The *National Probate Court Standards*¹² require that a guardianship petition include “representations that less intrusive alternatives to guardianship or conservatorship have been examined” (3.3.1); provide that a court “should encourage the appropriate use of less intrusive alternatives to formal guardianship and conservatorship proceedings” (3.3.2); and specify that a court visitor report should state “whether less intrusive alternatives are available” (3.3.4 commentary).

The 2013 *National Guardianship Association Standards of Practice*¹³ require that guardians provide a person “with every opportunity to exercise those individual rights that the person might be capable of exercising” (Std 9); “carefully evaluate alternatives that are available” (Std 8); and “identify and advocate for the person’s goals, needs, and preferences” (Std 7).

Ethical Standards

ABA Model Rules of Professional Conduct 1.14¹⁴ instructs attorneys to recognize client self-determination, less restrictive alternatives, and the need for supports. If the lawyer suspects a client has “diminished capacity”¹⁵ that may inhibit the client’s ability to make decisions regarding the attorney’s representation, the lawyer must seek to maintain a “normal client-lawyer relationship.” The Comment notes that this is based on the assumption that the client, “when properly advised and assisted, is capable of making decisions about important matters” (emphasis added). If the attorney believes that the client is at risk of substantial harm, the attorney may take “protective action,” including seeking out and consulting with the client’s support network or assisting the client in executing a power of attorney or another form of legal support.

In taking protective action, the lawyer should be guided by the person’s “wishes and values” to the extent known, with the goal of “intruding into the client’s decision-making autonomy to the least extent feasible, maximizing client capacities. . . .” Further, in considering “appointment of a legal representative” the lawyer should “be aware of any law that requires the lawyer to advocate

¹¹ *Olmstead v. L.C.*, 527 U.S. 581 (1999), available at <https://www.law.cornell.edu/supct/html/98-536.ZO.html>.

¹² *National Probate Court Standards*, National Center for State Courts, available at <http://ncsc.contentdm.oclc.org/cdm/ref/collection/spcts/id/240>.

¹³ National Guardianship Association Standards of Practice, National Guardianship Association, available at http://www.guardianship.org/documents/Standards_of_Practice.pdf.

¹⁴ *Rule 1.14: Client with Diminished Capacity, Model Rules of Professional Conduct*, American Bar Association, available at http://www.americanbar.org/groups/professional_responsibility/publications/model_rules_of_professional_conduct/_rule_1_14_client_with_diminished_capacity.html.

¹⁵ The Model Rules of Professional Conduct use the phrase “diminished capacity,” and many state guardianship laws use the phrase “incapacitated person” or similar language based on capacity. Because the Convention on the Rights of Persons with Disabilities provides that individuals with disabilities have legal capacity and must be given decision support, this guide avoids these phrases.

the *least restrictive action* on behalf of the client.” Most state ethics opinions also instruct the attorney to identify any less restrictive alternatives.

Mental Health and Quality of Life

Encouraging individuals to retain as much autonomy as possible and be “causal agents”¹⁶ in their lives is consistent with gerontological findings¹⁷ that maintaining opportunity for choice and control is an important component of mental health; and that loss of ability—or perceived ability—to control events can lead to or exacerbate physical or emotional illness. Complete loss of status as an adult member of society could in effect act as a self-fulfilling prophecy, intensifying any disability an older person may have. Similar findings show that younger adults¹⁸ with higher levels of self-determination have a more positive quality of life.

Expense and Delay

Identifying supportive arrangements that are less restrictive than guardianship can avoid expenses of legal and court fees, and the delays of court action.

R EASON. Clearly identify the reasons for concern. Which of the individual’s needs are not met?

State the specific triggering concern(s) in your own words (e.g., the person is being financially exploited; the person needs medical treatment requiring informed consent). Be as specific as possible. Use the following checklist of domains of functional needs¹⁹ (adapted from Missouri’s tool on alternatives to guardianship²⁰) as a starting point. For each, consider whether the person can meet some or all of the needs:

Money Management

- Managing accounts, assets and benefits—including daily expenditures, paying bills, making change, and using a bank account

¹⁶ Wehmeyer, et al., *Promoting Causal Agency: The Self-Determined Learning Model of Instruction*, Exceptional Children (Vol. 66, No. 4, pp. 439-453), The Council for Exceptional Children, available at <http://supporteddecisionmaking.org/sites/default/files/promoting causal agency self-determined learning model instruction.pdf>.

¹⁷ Mallers, et al., *Perceived Control in the Lives of Older Adults: The Influence of Langer and Rodin’s Work on Gerontological Theory, Policy, and Practice*, The Gerontologist (Vol. 54, No. 1), available at <http://gerontologist.oxfordjournals.org/content/54/1/67.full.pdf+html>.

¹⁸ Heller, et al., *Self-Determination Across the Life Span: Issues and Gaps*, National Gateway to Self Determination (2011), available at <http://ngsd.org/news/self-determination-across-life-span-issues-and-gaps>.

¹⁹ MO Guardianship: Understanding Your Options & Alternatives, at <http://moguardianship.com/#materials>, sponsored, revised and updated by Jane St. John & Rachel Hiles, Missouri Family to Family, UMKC-Institute for Human Development, sponsored by Missouri Planning Council for Developmental Disabilities, developed and produced by UMKC Institute for Human Development, in collaboration with the Missouri Protection and Advocacy Services & the Missouri Department of Mental Health, Appendix 3 (2013).

²⁰ MO Guardianship: Understanding Your Options and Alternatives, Institute for Human Development (Sep. 2013), available at <http://moguardianship.com/MO%20Guardianship%20RESOURCE%20GUIDE%20rev%20Sept%202013.pdf>.

PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making

- Recognizing exploitation

Health Care

- Making decisions about medical treatment
- Taking medications as needed
- Maintaining hygiene, dental care and diet
- Avoiding high-risk behaviors (such as substance abuse, overeating, high-risk sexual activities, wandering)

Relationships

- Behaving appropriately with different kinds of relationship partners: family, friends, co-workers, intimate partners
- Making safe decisions concerning marriage and sexual relationships

Community Living

- Living independently without risk of serious harm or injury
- Maintaining habitable conditions at home (cleanliness, maintenance, security)
- Accessing community resources (transportation, bank, stores, post office, restaurants, home repair, emergency services)

Personal Decision-Making

- Understanding and communicating consent concerning legal documents (contracts, lease, deed, power of attorney)
- Identifying someone to represent interests and support with decision-making
- Communicating wishes, including specific desire to participate in the voting process
- Understanding legal consequences of behavior

Employment

- Looking for, gaining, and retaining employment

Personal Safety

- Avoiding common dangers (traffic, problems in driving, sharp objects, hot stove, poisonous substances)
- Recognizing and avoiding abuse
- Knowing what to do in an emergency

ASK if a triggering concern may be caused by *temporary or reversible conditions*. Look for steps to reverse the condition and postpone a decision until the condition improves.

Use the following list to systematically screen for conditions or environmental factors affecting decision-making ability that could be mitigated or reversed, mooting the need for a guardianship, or at least delaying the decision to seek guardianship.

Acute Temporary Medical Conditions

- Urinary tract infections:²¹ UTIs often can cause confusion in older people.
- Delirium²² (acute temporary disorientation): in older people often triggered by medical illness or post-operative stress.
- Dehydration,²³ malnutrition:²⁴ Inadequate nutrition, hydration, and vitamin deficiencies can lead to reversible cognitive changes.
- Traumatic brain injury:²⁵ may affect cognitive, social, physical, and psychological functioning but has a significant recovery rate.
- Oral health:²⁶ poor oral health has been linked to poor self-esteem, lack of nutrition, and diminished cognitive functioning.

²¹ *Urinary tract infections (UTIs) and dementia*, Alzheimer's Society, available at http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1777.

²² *When Patients Suddenly Become Confused*, Harvard Women's Health Watch (May 2011), available at <http://www.health.harvard.edu/staying-healthy/when-patients-suddenly-become-confused>.

²³ David Benton, *Dehydration Influences Mood and Cognition: A Plausible Hypothesis?*, National Institutes of Health (May 2011), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3257694/>.

²⁴ M. Hickson, *Malnutrition and ageing*, National Institutes of Health (Jan. 2006), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563720/>.

²⁵ *Basic Information about Traumatic Brain Injury and Concussion*, Center for Disease Control and Prevention, available at <http://www.cdc.gov/traumaticbraininjury/basics.html>.

²⁶ Alan Mozes, *Could Poor Dental Health Signal a Faltering Mind?*, HealthDay (Dec. 2013), available at <http://consumer.healthday.com/senior-citizen-information-31/misc-aging-news-10/could-poor-dental-health-signal-a-faltering-mind-682728.html>.

Sensory Deficits

- Hearing loss:²⁷ may be isolating and may be perceived as dementia or diminished understanding.
- Vision loss:²⁸ can be disorienting but is easily correctable.

Medication Effects; Polypharmacy

Prescription and over-the-counter medication, while potentially improving health, may affect mental status²⁹—especially if multiple drugs are taken simultaneously,³⁰ as is common for older persons, producing drug-to-drug interactions. In addition to the fact that older people take many drugs, as the body ages it may be less able to cope with certain drugs and drug interactions.³¹ Careful review³² of medications could identify changes that significantly improve mental functioning.

Pain

Chronic or acute pain can be associated with cognitive impairment.³³ Effective pain reduction or management could enhance mental status.

Emotional Conditions

- Depression:³⁴ Ongoing depression can impair judgment and cause fatigue.
- Stress; grief:³⁵ Grief and stress due to loss of a loved one are particularly common to older persons. Health problems or loss of employment can cause stress.

²⁷ Jeremy Shere, *Can Hearing Loss Predict—or Lead to—Cognitive Decline?*, The Dana Foundation (Aug. 2014), available at http://www.dana.org/News/Can_Hearing_Loss_Predict%20%80%94or_Lead_to%20%80%94Cognitive_Decline_/.

²⁸ Allen L. Pelletier and Jeremy Thomas, *Vision Loss in Older Persons*, American Family Physician (Jun. 2009), available at <http://www.aafp.org/afp/2009/0601/p963.html>.

²⁹ *Prescription Medication in the Elderly*, Net Wellness Consumer Health Information, available at <http://www.netwellness.org/healthtopics/aging/faq16.cfm>.

³⁰ Roni Caryn Rabin, *Cocktail of Popular Drugs May Cloud Brain*, Well Blog (Feb. 2012), The New York Times, available at http://well.blogs.nytimes.com/2012/02/27/cocktail-of-popular-drugs-may-cloud-brain/?_r=0.

³¹ *Medications & Older Adults*, Health in Aging Foundation (Oct. 2015), available at <http://www.healthinaging.org/medications-older-adults/>.

³² *Avoiding Overmedication and Harmful Drug Reactions*, Health in Aging Foundation (Sep. 2015), available at http://www.healthinaging.org/files/documents/tipsheets/Tip.Avoiding_OverMedication.pdf.

³³ John Gever, *Chronic Pain Disrupts Resting Brain Dynamics*, MedPage Today (Feb. 2008), available at <http://www.medpagetoday.com/PainManagement/PainManagement/8225>.

³⁴ *Depression*, Mayo Foundation for Medical Education and Research (July 2015), available at <http://www.mayoclinic.org/diseases-conditions/depression/basics/symptoms/con-20032977>.

³⁵ Cell Press, *How repeated stress impairs memory*, ScienceDaily (Mar. 2012), available at <http://www.sciencedaily.com/releases/2012/03/120307132202.htm>.

- **Transfer trauma:**³⁶ This is stress and confusion caused by a sudden and perhaps forced move, usually by a person with dementia, as from hospital to nursing home and perhaps back, or from home to assisted living or nursing home.

Age and Disability Discrimination

The trigger for a guardianship petition may well lie not in the person's abilities but the attitudes of others. Social workers, protective services, lawyers, and judges are not immune from the deeply entrenched societal belief that individuals with disabilities and older adults cannot live independently or make their own decisions.

- **Age & disability discrimination; stereotyping.**³⁷ Myths and stereotypes about aging³⁸ and disability³⁹ can cause skepticism about decision-making abilities, resulting in unnecessary guardianship. "Ageism" is systematic stereotyping and discriminating against individuals or groups on the basis of their age. It is important for lawyers to examine and confront their own perceptions and biases⁴⁰ to minimize unnecessary intrusive actions.
- **Cultural barriers.**⁴¹ Cultural variations and language differences may be a barrier to understanding a person's behaviors, but can be addressed by awareness and techniques for cultural competency, and sometimes by translation services.

Family Disputes

The trigger for a guardianship petition may lie in family disputes over care and control of finances, with long-standing sibling feuds re-emerging. In aggravated situations, one sibling may prevent visitation by another, isolating and perhaps neglecting the elder, or misusing powers of attorney. There are many reasons why families may fight⁴² over the care or support for the person, often leaving out the voice of the person him or herself. Family conflict may be addressed by mediation—especially by mediators skilled in elder care or guardianship cases.

³⁶ Kate Jackson, *Prevent Elder Transfer Trauma: Tips to Ease Relocation Stress*, Social Work Today (Vol. 15, No. 1), available at <http://www.socialworktoday.com/archive/011915p10.shtml>.

³⁷ *Are you ready? What you need to know about ageing*, World Health Day Toolkit, World Health Organization, available at <http://www.who.int/world-health-day/2012/toolkit/background/en/index3.html>.

³⁸ Melissa Dittmann, *Fighting ageism*, Monitor (May 2003), American Psychological Association, available at <http://www.apa.org/monitor/may03/fighting.aspx>.

³⁹ *About Independent Living*, National Council on Independent Living, available at <http://www.ncil.org/about/aboutil/>.

⁴⁰ *Understanding the Four C's of Elder Law Ethics*, American Bar Association Commission Law and Aging, available at http://www.americanbar.org/groups/law_aging/resources/ethics_and_counseling_older_clients.html.

⁴¹ Serena Patel, *Cultural Competency Training: Preparing Law Students for Practice in Our Multicultural World*, UCLA Law Review Discourse (Vol. 62, 2014), available at <http://www.uclalawreview.org/cultural-competency-training-preparing-law-students-for-practice-in-our-multicultural-world-2/>.

⁴² Jeff Anderson, *10 Reasons Families Fight about Senior Care*, Senior Living Blog (Mar. 2014), A Place for Mom, available at <http://www.aplaceformom.com/blog/reasons-families-fight-about-senior-care-02-27-2012/>.

C OMMUNITY. Determine if concerns can be addressed by connecting the individual to family or community resources, and making accommodations in place.

At the heart of the PRACTICAL approach are practical actions that can be taken, connections that can be made, and creative accommodations that can be made to enhance decision-making ability. The PRACTICAL steps bring these essential non-legal solutions to the heart of the process. Rather than asking whether the person can make the decisions at hand, ask whether the person can make them with support.

Poor and inadequate social services and poor quality residential care can lead to a dire living situation, which may be the crux of the problem. A fix in social services or living arrangements may moot the need for a guardianship petition.

Community Supports

Lawyers can call on multiple networks of supportive community services for individuals with disabilities and older adults.

- **Human Services.** Most local jurisdictions have human services divisions, often with customer care or intake lines to help match the services to the needs. Some communities have an extensive set of supportive services for older persons and individuals with disabilities, while others have only the rudiments. Local resources may serve as an information or access point for state resources such as Medicaid. Find out about mental health resources, subsidized housing and rental assistance, assistive technology, home modification, supportive memory aids, training and education, and recreation/socialization opportunities that could support the person.
- **Legal Services.** Consider calling on the expertise of legal services,⁴³ especially those funded to help older people under the Older Americans Act, to access public benefits for low and moderate income individuals. Protection and Advocacy Programs (P&As)⁴⁴ in every state have the authority to provide legal representation and advocacy for individuals with disabilities. P&As represent individuals with disabilities on a wide variety of matters including employment and housing discrimination, as well as abuse and neglect.
- **Agencies on Aging.** Under the Older Americans Act⁴⁵ there is an established network of state and area agencies on aging either providing or contracting for key community-based aging services such as congregate or home delivered meals, senior centers, adult day health, care management, money management, transportation, in-home care, and assistance

⁴³ *Find Legal Aid*, Legal Services Corporation, available at <http://www.lsc.gov/find-legal-aid>.

⁴⁴ *P&A/CAP Network*, National Disability Rights Network, available at <http://www.ndrn.org/about/paacap-network.html>.

⁴⁵ Administration on Aging (AoA) Older Americans Act, Administration for Community Living, available at http://www.aoa.gov/AoA_programs/OAA/.

with Medicare problems. To find resources in your area quickly, use the national Eldercare Locator.⁴⁶

- **ADRCs.** The U.S. Administration on Community Living, with the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration has developed a “No Wrong Door” system of Aging and Disability Resource Centers (ADRC).⁴⁷ These centers streamline access to long-term services and support options and aim to simplify access.
- **Independent Living Services.** There is also a system of Independent Living Services—programs established under the Rehabilitation Act, currently based at the Administration for Community Living⁴⁸ in the U.S. Department of Health and Human Services. The independent living programs seek to maximize the independence, well-being, and health of people with disabilities across the lifespan.
- **Ombudsman Programs.** Each state and many localities have long-term care ombudsman programs.⁴⁹ Ombudsmen serve as advocates for residents in nursing homes, assisted living, and other residential settings. An ombudsman may be able to craft a resolution to problems in care or residents’ rights that will meet the perceived need for a guardian.
- **Developmental Disability (DD) Councils.** State Developmental Disability Councils⁵⁰ receive federal funding to promote self-determination, inclusion, and integration for individuals with developmental disabilities.
- **Mediation.** There may be mediators in the community specially trained in elder or guardianship mediation. While there is no specific list of such mediators, contact your state mediation association or your area agency on aging. To be sure the mediator has the relevant experience and skills, review the Association for Conflict Resolution’s (ACR) Training Objectives for Eldercare Mediation.⁵¹ In especially high conflict cases, find out if your court is piloting an “eldercaring coordination”⁵² program according to ACR guidelines.

⁴⁶ Eldercare Locator available at <http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>.

⁴⁷ *Aging & Disability Resource Centers Program/No Wrong Door System*, Center for Integrated Programs (CIP), Office of Consumer Access and Self Determination, available at <http://www.acl.gov/Programs/CIP/OCASD/ADRC/index.aspx>.

⁴⁸ Administration for Community Living website available at <http://www.acl.gov/>.

⁴⁹ National Consumer Voice for Quality Long-Term Care website available at <http://ltcombudsman.org/>.

⁵⁰ National Association of Councils on Developmental Disabilities website available at <http://www.nacdd.org/home/>.

⁵¹ *Elder Care and Elder Family Decision-Making Mediation: Training Objectives and Commentary*, ACR Section on Elder Decision-Making and Conflict Resolution Committee on Training Standards, available at http://acreldersection.weebly.com/uploads/3/0/1/0/30102619/eldercareobjectives_7_30_2012.pdf.

⁵² *Guidelines for Eldercaring Coordination*, Association for Conflict Resolution Task Force on Eldercaring Coordination (2014), available at <http://www.eldersandcourts.org/~media/Microsites/Files/cec/ACR%20Guidelines%20for%20Elder%20Caring%20Coordination%202014.ashx>.

Informal Supports

Family caregivers⁵³ provide the bulk of long-term care in the U.S.

- Have all family members who could provide support been identified? Sometimes it takes a comprehensive search, and is worth digging.
- Is there a network of supportive friends able and ready to work with the individual on decisions in line with his or her values and preferences? Check for close friends over many years, neighbors, co-workers, providers who have become familiar with the person, volunteers, and members of faith-based communities.

Accommodations and Communication Techniques

*It is the person's will and preference, plus support plus accommodations that equals legal capacity.*⁵⁴

Finding the right combination of supports and accommodations can boost understanding and decision-making ability, and may alleviate the need for a guardianship. Start with the challenge at hand and ask “*what would it take*” to enable this person to make the needed decisions in a supportive environment.

There may be accommodations as required under the Americans with Disabilities Act (ADA) that can boost the person’s functioning. But beyond the ADA there is a host of creative possibilities. While some involve funding, others are low-cost or no-cost, limited only by imagination. For example, an individual with an intellectual disability wanted to donate a kidney to his brother, but there were legal questions about his capacity to consent. Accommodations to aid understanding for such a person might include the use of drawings, a conversation with someone who has donated a kidney, a visit to the hospital, and communicating in plain language in a comfortable environment.⁵⁵

There are many communication techniques⁵⁶ that can markedly enhance understanding and response:

- Break information down into more manageable segments.
- Pay special attention to developing trust and confidence.
- Use paraphrasing and active listening.
- Don’t make important points in passing, rephrase them.
- Use plain language, short sentences, active voice.
- Speak directly to the person, not “past” the person.
- Use hands and facial expressions to emphasize what you say.

⁵³ *Caregiving*, Family Caregiver Alliance (2009), available at <https://caregiver.org/caregiving>.

⁵⁴ Michael Bach, *A Disability-Inclusive Approach to the Right to Decide*, Developmental Disabilities Lecture Series (2013), available at <http://rwjms.rutgers.edu/boggscenter/documents/Bach5-3-13packet.pdf>.

⁵⁵ Kristin Booth Glen, *Supported Decision-Making and the Human Right of Legal Capacity*, Inclusion (Vol. 3, No. 1, 2015).

⁵⁶ *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, American Bar Association Commission on Law and Aging and American Psychological Association (2005), available at <https://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>.

TEAM. Ask the person whether he or she already has developed a “team” to help make decisions.

Ask if there are any people or entities already assisting the person in making decisions—and if the person wants such help. It is important the person is able to identify any supporters.

Network of Supporters

The person over time may have developed an informal system for making decisions with the help of a network of trusted supporters such as friends, relatives, colleagues, acquaintances from the community, supportive staff, or co-workers.

The person may have created—or may want to create—a structured “circle of support”⁵⁷ that includes trusted supporters who regularly meet as a group for planning, problem-solving, and decision-making. The circle members help the person with managing and budgeting goals, evaluating risks and consequences, and recognizing and making full use of abilities.

Appointed Surrogate

Guardianship may not be necessary if the person already has appointed a trusted surrogate authorized under state law to make decisions on his or her behalf, ideally with his or her participation.

- Is there already an appointed surrogate?
- Does the surrogate have authority to act in the situation at hand?
- Is the surrogate trustworthy?
- Will the surrogate act in accordance with the person’s values and preferences, and with the person’s involvement?

Legally authorized surrogates⁵⁸ could include:

- An agent under a financial power of attorney.
- A trustee under a revocable living trust.
- An agent under a health care power of attorney or advance directive.
- A family member or other person authorized to make health care decisions under a state default surrogate consent law.
- A representative payee for Social Security or other public benefits, or a VA fiduciary.
- While not a “surrogate,” a supporter under a legally or informally recognized representation agreement can help the person make decisions.

⁵⁷ NYS Self-Determination Consolidated Supports & Services Project, Circle of Support (COS) Training, available at http://www3.opwdd.ny.gov/wp/images/cos_master_01_12.pdf.

⁵⁸ See more information about legally authorized surrogates in the later section of this guide under “APPOINT.”

DENTIFY abilities. If the person does not already have an existing team and has difficulty with specific types of decisions, identify areas of strengths and limitations in decision-making.

Determine whether:

- The person is able to make the specific decision(s) with support from a trusted friend, family member or someone else.
- The person is able to name one or more supporters to help in decision-making; or appoint a surrogate to make the decision(s) in question.

Without a system of decision-making support in place, there is a need to clearly assess the individual's abilities—both strengths and limitations—in the specific areas in which decisions are needed; as well as the ability to name a supporter or appoint a surrogate.

Sometimes this may be an informal assessment by the lawyer and others involved in the case about what the person is able to do and what support is necessary. The American Bar Association and the American Psychological Association have developed a *Handbook for Lawyers*⁵⁹ detailing the elements of such assessments for older clients, with a framework of factors including statutory provisions and ethical rules. Consider whether the person can:

- Articulate reasoning leading to a decision.
- Maintain consistent decisions and primary values over time;
- Appreciate consequences of decisions.

As explained in the *Handbook*, it is generally not appropriate for a lawyer to use formal clinical instruments such as the Mini-Mental Status Examination (MMSE). Lawyers are not trained to administer these tests or interpret the results. The test questions (such as clock drawing or counting backwards) have little direct bearing on understanding of the tasks or decisions at hand. Even for clinical professionals, the MMSE is simply a screening tool to determine whether further evaluation is needed, not an assessment tool itself.

In some cases, a lawyer may find that consultation with a *clinical specialist* would be helpful.

- The lawyer could **consult informally** with a clinician such as a geriatrician, geriatric psychiatrist, psychologist, neurologist or other mental health professional with experience in assessments.
- Or the lawyer could **seek a formal clinical assessment** with the individual's consent. Such an assessment can be a good tool in planning for needed supports, determining whether the person has the ability to either make certain decisions or to appoint a legal representative to

⁵⁹ *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, American Bar Association Commission on Law and Aging and American Psychological Association (2005), available at <http://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>.

assist. If there is a decision to file for limited guardianship, an assessment can help to clarify the specific powers that would be retained, making for a much more tailored court order.

- In seeking a formal assessment, be specific with the clinician about the reason for the referral, and the person's circumstances, history and values. Ask for opinions on supports in any areas of deficit, and approaches less restrictive than guardianship.

CHALLENGES. Screen for and address any potential challenges presented by the identified supports and supporters.

Once a support system or individual supporters are identified, the biggest challenge is making sure the situation remains viable and the supporters are trustworthy.

Challenges with Support Systems

- Are there challenges in accessing community or other support systems? Are there barriers in eligibility, cost, timing or location?
- Is an institutional support system—such as a community-based mental health agency or a homeless outreach organization—underfunded, overburdened with paperwork and bureaucratic delay?
- Does the individual receive public benefits that are at risk if not vigilantly protected?
- Are there certain prerequisites that the individual must establish in order to access the support systems?

Challenges with Supporters

- Do the identified supporters present any risk of substantial physical, emotional, or financial harm?
- Do you have any suspicion that the supporters may engage in abuse, neglect, exploitation or undue influence? Be sure to report any suspected abuse to Adult Protective Services.⁶⁰
- Do the supporters understand the individual's potentially complex medical and/or mental health needs?
- Are the supporters stable? Do they need an incentive to remain so?

Coercion; Undue Influence

It is important to consider whether concerns triggering a possible guardianship petition may be rooted in coercion, fraud, intimidation, or undue influence. Guardianship may be perceived as a key strategy in protecting an individual from the perpetrator. However, making a report to adult protective services and removing the cause of the undue influence—admittedly often not an

⁶⁰ National Adult Protective Services Association website available at <http://www.napsa-now.org/>.

easy task—may reduce the impetus for guardianship. Often the person will not recognize what is happening and will side with the perpetrator.

Undue influence⁶¹ has been defined as instances in which “people use their role and power to exploit the trust, dependency, and fear of others. They use this power to deceptively gain control over the decision-making of the second person” (psychologist Margaret Singer). Legal definitions⁶² vary, but often include factors relating to: (1) the relationship between the alleged influencer and the alleged victim; (2) the alleged victim’s vulnerability to undue influence; (3) the alleged influencer’s opportunity to gain control; and (4) whether the alleged victim’s decisions were the outcome of the undue influence. Other definitions focus on the nature of the transaction(s) at hand, the mental condition of the individual, and the relationship of the parties. Be alert to the possibility that a supporter might potentially unduly influence the person in the guise of support.

Note that being subject to undue influence does not necessarily mean a person has “diminished capacity” as defined under state guardianship laws. Be careful to separate the external coercion from the individual’s abilities.

APOINt. If the person is able and wishes to select a trusted supporter to help make decisions and/or to appoint a legal surrogate, help the person do so in a way that is consistent with the person’s values and preferences.

Consider the following options for clarifying or implementing a supporter relationship in a legally recognizable form that may help ensure the person’s wishes are honored. The National Guardianship Network has a full list of options⁶³ for decision-making that are less restrictive than guardianship.

Health Care Advance Directive

The person may be able to name someone as an agent to make health care decisions in a written advance directive document,⁶⁴ which also could include statements of the person’s wishes concerning medical treatment. The real challenge will be ensuring that the person effectively

⁶¹ Lisa Nerenberg, *Undue Influence: An Insidious Form of Elder Abuse*, NYC Elder Abuse Center website (2013), available at <http://nyceac.com/undue-influence-an-insidious-form-of-elder-abuse/>.

⁶² Lori A. Stiegel, *Legal Issues Related to Elder Abuse: A Pocket Guide for Law Enforcement*, Bureau of Justice Assistance (2014), available at <https://www.bja.gov/Publications/ABA-ElderAbuseGuide.pdf>.

⁶³ *Decision Making Without Guardianship*, National Guardianship Network, available at http://www.naela.org/NGN/About_Guardianship/Decision_Making_Without_Guardianship/NGN/About_GuardianshipMain/Decision_Making.aspx?hkey=eb9c2ced-35aa-4499-acd1-26cd208f02ac.

⁶⁴ *Living Wills, Health Care Proxies, & Advance Health Care Directives*, American Bar Association Section of Real Property, Trust and Estate Law, available at http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html.

communicates his or her values and wishes to the agent. Check your state's laws⁶⁵ for any specific requirements. Some state laws⁶⁶ also direct a guardian to comply with a health care advance directive if possible.

A health care agent may consent to or participate in discussion concerning two other kinds of advance care planning documents—a Do Not Resuscitate (DNR) Order⁶⁷ directing a physician not to perform cardio-pulmonary resuscitation if an individual's breathing or heart stops; and in some states a Physician's Orders for Life-Sustaining Treatment (POLST)⁶⁸ in which a seriously ill patient can indicate and document his or her desired end of life care, which is translated into a physician's order.

Health Care Surrogate Under State Law

In the Uniform Health Care Decisions Act and statutes in 44 states,⁶⁹ if the person is not able to make health care decisions him or herself, the authority to make some or all health care decisions automatically devolves to a surrogate generally designated according to a hierarchy of family members. In over 20 of these states, a "close friend" familiar with the person's history and values can make decisions if there is no family, and in approximately 12 states some combination of physicians and ethics committee can decide if there is no one else. It is important to consider whether these legally authorized health care surrogates actually know or try to find out what the person wants or would have wanted and support the person in those choices. A surrogate could be a member of a support team assisting the person—or may be the only one on which the clinicians rely.

Financial Power of Attorney

The person may be able to execute a financial power of attorney,⁷⁰ a legal document assigning authority to make financial decisions to another party. Unlike the healthcare advance directive, a financial power of attorney can be effective while an individual has capacity. Or, it can become effective only if the individual loses capacity. It is helpful to delegate specific categories of authority, such as managing pensions, control over a checking account, or accountability for a lease.

⁶⁵ *Links to State-Specific Advance Directive Forms*, American Bar Association Commission on Law and Aging, available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/Links_to_State_Advance_Directive_Forms.authcheckdam.pdf.

⁶⁶ *Guardianship Law & Practice Resource Website*, American Bar Association Commission on Law and Aging, available at <http://ambar.org/guardianship>.

⁶⁷ *Do-not-resuscitate order*, MedlinePlus, U.S. National Library of Medicine, available at <http://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000473.htm>.

⁶⁸ The National POLST website is available at <http://www.polst.org/>.

⁶⁹ *Default Surrogate Consent Statutes*, American Bar Association Commission on Law and Aging (July 2014), available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_default_surrogate_consent_statutes.pdf.

⁷⁰ *Power of Attorney*, American Bar Association Section of Real Property, Trust and Estate Law, available at http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/power_of_attorney.html.

Trustee

For complex or substantial assets, the person may be able to execute a document transferring title and authority to manage property to a trustee⁷¹ for the benefit of either the person or others as beneficiaries, under a revocable living trust.

Representative Payee

The Social Security Administration administers a representative payment program⁷² for recipients of Social Security and SSI who it deems “incapable” of managing their own funds. The representative payee receives and manages the payment, using it to pay for current and foreseeable needs such as rent, food and spending money. An individual can apply to Social Security to become a payee for a recipient, or designated organizations can serve as payees for many recipients. The representative payee has authority only over the benefits and cannot make any other decisions on the person’s behalf. It is very difficult for an individual to revoke a payee’s status once appointed.

The Veterans Administration can appoint a VA Fiduciary⁷³ upon a determination that a VA beneficiary is unable to manage his or her VA benefits. Generally, family members or friends serve as fiduciaries for beneficiaries, but when friends and family are not able to serve, VA looks for qualified individuals or organizations to serve. The VA fiduciary has authority only over VA benefits.

Legally Recognized Supporter

Law in selected Canadian and other jurisdictions allows individuals who require some decision-making assistance to enter into a “representation agreement”⁷⁴ with a support person or network, which is legally recognized by third parties. Under a representation agreement, an individual can authorize one or more “supporters” to assist in managing his or her affairs and help the person to make his or her own decisions. The agreement can be effective immediately or at a future date if circumstances change due to disability, age or another reason requiring support. The agreement can be revoked by the individual, and it can be supplanted by a legally appointed guardianship.

Under the Canadian model, an individual does not have to demonstrate “legal capacity” to enter into a representation agreement. The standard is that the individual has “trust” in the supporter/s in his or her network. This cutting edge alternative to guardianship is gaining international acceptance. Currently, the best resource to learn more about representation agreements is a Canadian nonprofit organization called Nidus, the Personal Planning and Resource Center Registry.⁷⁵ Texas has enacted a legally recognized supported decision-making agreement,⁷⁶ and in some areas in the U.S. such agreements are informally recognized.

⁷¹ *Revocable Trusts*, American Bar Association Section of Real Property, Trust and Estate Law, available at http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/revocable_trusts.html.

⁷² *When People Need Help Managing Their Money*, Social Security website, available at <http://www.socialsecurity.gov/payee/>.

⁷³ Fiduciary, U.S. Department of Veterans Affairs website, available at <http://benefits.va.gov/fiduciary/>.

⁷⁴ *Representation Agreement*, Nidus Personal Planning Resource Centre and Registry, available at http://www.nidus.ca/?page_id=46.

⁷⁵ The Nidus Personal Planning Resource Centre and Registry website is available at <http://www.nidus.ca/>.

⁷⁶ Supported Decision-Making: Alternatives to Guardianship, Texas Council for Developmental Disabilities, available at <http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>.

LIMIT any necessary petition and order.

Judges are not like baseball umpires, calling strikes and balls or merely labeling someone competent or incompetent. Rather, the better analogy is that of a craftsman who carves staffs from tree branches. Although the end result—a wood staff—is similar, the process of creation is distinct to each staff. Just as the good wood-carver knows that within each tree branch there is a unique staff that can be “released” by the acts of the carver, so too a good judge understands that, within the facts surrounding each guardianship petition, there is an outcome that will best serve the needs of the incapacitated person, if only the judge and the litigants can find it⁷⁷

If no less restrictive measures can reasonably meet the individual's need, and there is risk of significant harm, seek a limited guardianship order transferring authority to a surrogate only in those areas in which decision-making support is needed. A major theme of the UGPPA, is that “limited guardianship or conservatorship should be used whenever possible.” Many state laws⁷⁸ reflect the emphasis on limited guardianship.

Through completing all of the foregoing PRACTICAL steps, you will gain a solid grasp of the individual's needs, strengths, and deficits—as well as actual or potential substantial harm, and any ways the harm could be addressed without a guardianship. If after this “due diligence” analysis you determine a guardianship is in fact needed as a last resort, aim to limit the scope of the order.

Specify Limits in Petition and Order

There are barriers to petitioning for limited guardianship. Some petition forms don't provide for it. Moreover, conditions change, and going back to court to petition again later for a modification of the order may be at significant cost to—or simply unaffordable for—your client. Some judges may not draft or approve limited orders, reasoning that a plenary order will give more flexibility without coming back to court. But despite these very real barriers, apply the statutory language concerning limited orders if possible.

- Use a good clinical assessment to clarify specific powers that should be retained
- Work with the court and bar to make petition and order forms acknowledge limitations. As a start, using templates for limited orders⁷⁹ in your court may work.

Seek Person's Participation in Decision-Making

Even though the guardian is a surrogate decision-maker, he or she should nonetheless consult with and allow the individual to lead in decisions when possible. Ideally, *the guardian is there as a support*, not as an authoritarian voice restricting self-determination.

⁷⁷ Lawrence A. Frolik, Promoting Judicial Acceptance and Use of Limited Guardianship, *Stetson Law Review* (Vol. 31, 2002), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1348105.

⁷⁸ *Limited Guardianship of the Person*, AARP Public Policy Institute, available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/Limited_Guardianship_of_the_Person_Chart.authcheckdam.pdf.

⁷⁹ The form for the State of Rhode Island Petition for Limited Guardianship or Guardianship is available at <http://sos.ri.gov/documents/probate/PC2.3.pdf>.

- The UGPPA provides that “the guardian or conservator should always consult with [the individual] to the extent feasible, when making decisions.”
- State laws frequently provide that a guardian must seek to maximize the participation of the person in decision-making and be guided by the person’s values and preferences.
- Concepts of decision-making participation are embedded in court and guardian standards of practice (*National Probate Court Standards*⁸⁰ and *National Guardianship Association Standards of Practice*⁸¹).

Develop Plan to Maximize Self Determination

Some state laws require guardians to formulate forward-looking plans both as a practical tool and as a baseline of accountability for the courts. But even if a plan is not required, it is a good practice. The NGA *Standards of Practice* require the guardian to develop “a person-centered plan.” A plan should not only show anticipated actions and services over the upcoming period, but the means by which the guardian will seek out and incorporate the person’s voice.

Reassess for Restoration or Modification

Periodically reassess whether conditions have changed and rights could be restored.⁸² Under the NGA *Standards*, a guardian is to “assist the person under guardianship to develop or regain the capacity to manage his or her personal and financial affairs;” and should “seek termination or limitation of the guardianship: (A) When the person has developed or regained capacity . . . (B) when less restrictive alternatives exist; and (C) when the person expresses the desire to challenge the necessary of all or part of the guardianship” (Std #21).

A lawyer representing an individual in a restoration proceeding should:

- Thoroughly interview the person, seeking evidence of changes in abilities or circumstances that would make guardianship unnecessary. Interview those close to the person as well.
- Review evidence from the initial determination. Perhaps it was insufficient, inaccurate or overlooked at the time of the order.
- Ensure there is a solid clinical evaluation.
- Use evidence and testimony from third parties knowledgeable about the person’s abilities.
- Articulate plans for overcoming deficits with supports.
- Show that supports are in place or ready.
- Thoroughly prepare the individual for the hearing; and secure any needed accommodations.
- If full restoration is not possible, consider a plan to progressively restore rights.

⁸⁰ National Probate Court Standards, National Center for State Courts, available at <http://ncsc.contentdm.oclc.org/cdm/ref/collection/spcts/id/240>.

⁸¹ National Guardianship Association Standards of Practice, National Guardianship Association, available at http://www.guardianship.org/documents/Standards_of_Practice.pdf.

⁸² Jenica Cassidy, *State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship*, Bifocal (Vol. 34, No. 6), American Bar Association Commission on Law and Aging, available at http://www.americanbar.org/publications/bifocal/vol_34/issue_6/august2013/guardianship_restoration_of_rights.html.



The PRACTICAL Tool aims to help lawyers identify and implement decision-making options for persons with disabilities that are less restrictive than guardianship. It is a joint product of four American Bar Association entities – the Commission on Law and Aging, Commission on Disability Rights, Section on Civil Rights and Social Justice, and Section on Real Property, Trust and Estate Law, with assistance from the National Resource Center for Supported Decision-Making.

Learn more about the ABA entities that produced this Tool:

- Commission on Law and Aging: www.americanbar.org/aging
- Commission on Disability Rights: www.americanbar.org/disability
- Section on Civil Rights and Social Justice: www.americanbar.org/crsj
- Section on Real Property, Trust and Estate Law: www.americanbar.org/rpte



**Beyond the Special Needs Trust:
Essential New Developments in Special Needs Planning**

(Part Two of Three)

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The beneficiaries of Special Needs Trusts (“SNTs”) are increasingly on the move. Gone are the days when a person with a disability was born, lived their entire life, and died in the same household or community. The increased mobility of SNT beneficiaries, who often reside in numerous communities and states during their lifetimes, presents significant issues as SNTs are called upon to be more “portable” and to better accommodate the relocations of the beneficiaries. Consequently, special needs planning attorneys are increasingly called upon to help facilitate the transition of mobile beneficiaries, and the SNTs they bring with them, from one jurisdiction to another.

I. NEW TEAM OF “ALLIED PROFESSIONALS”

A. No “One-Stop” Shopping: Identifying the Team Members

1. Facilitating the assembly of a new team of “allied professionals” for a SNT beneficiary who is new in town is a critical first step to a successful transition. As any parent of a child with disabilities already knows, securing their child’s present and future is a team effort. While many clients are frustrated that there is no “one-stop” shopping provider of the various professionals who will collaborate to serve them and their children with disabilities, the knowledgeable special needs planning attorney is ideally suited to assist with assembling this team of allied professionals.

2. One of the most frustrating aspects of special needs planning from the client’s perspective is not knowing who is proficient in this increasingly complicated arena, or even which allied professionals should be part of their child’s team. The ideal team members would include the following.

B. Special Needs Planning Attorney

1. A knowledgeable, experienced attorney who devotes a significant portion of her practice to special needs planning is likely to be the initial quarterback of the team, and to take the lead in helping the SNT beneficiary to assemble the rest of the team members in his new community. Any member of the Special Needs Alliance (www.specialneedsalliance.org) will be well-suited for the task of helping a client to identify a new team of allied professionals in the SNT beneficiary’s new community. (This author is a proud member of the Special Needs Alliance.)

2. In addition to the basic “blocking and tackling” of special needs planning that all families need to secure the future of their child (or other loved one) with disabilities, wealthy families are increasingly implementing special needs planning as part of their overall estate planning. Many of these families require a special needs planning attorney who is also well-versed in addressing estate tax minimization, gift tax advice, and increasingly, even generation-skipping transfer tax planning as their children with disabilities bless the family with grandchildren (who may either be neuro-typical or similarly challenged by special needs).

3. Other sources of special needs planning attorneys may include the Academy of Special Needs Planners (www.specialneedsplanners.com) or the National Academy of Elder Law Attorneys (www.naela.com).

C. Trustee Authorized to Administer SNTs

There are often state law impediments to the initial Trustee of a SNT continuing to administer the SNT in the beneficiary's new state of residence.

1. If the initial Trustee of the SNT is a corporate entity with a *national* charter, it is likely that a Trustee transition from one state to another will be relatively smooth. While there may not be a "bricks and mortar" local office in the new state, the Trustee's authority to continue to administer the SNT in the new state should not be questioned. If the initial Trustee of the SNT is an entity with a *state* charter, the new state may prohibit or restrict the authority of an out-of-state entity to administer a SNT in its jurisdiction. The new state may permit an out-of-state-chartered entity to administer SNTs in its jurisdiction if the laws of the other state have a reciprocity statute. The provisions of the agreement governing the administration of the SNT may also specifically address Trustee succession issues if the beneficiary relocates to a state other than the initial situs of the SNT.

2. A pooled SNT (authorized under 42 USC § 1396p(d)(4)(C)) may accommodate only residents of the state in which it is organized and operated. If the beneficiary of a pooled SNT sub-account relocates to a new state, it may be necessary to transfer the assets in his original sub-account to a new sub-account with a different pooled SNT established in the beneficiary's new state of residence, or, alternatively, to a national pooled SNT that accepts residents of all states. This is expressly permitted by POMS SI 01120.199.F.2.

D. Accountant or CPA Familiar with New State Law

1. When the SNT beneficiary moves to a new state, there may be complex rules which govern the ability of the new state's revenue authorities to tax the SNT and the beneficiary, as well as the authority of the initial situs of the SNT to continue to tax the SNT and the beneficiary after the move.

2. The beneficiary's new state may also have different rules regarding permissible deductions for SNT disbursements, *e.g.*, not all states allow income tax deductions for contributions from an SNT to an ABLE account for the beneficiary under the state's ABLE program.

3. N.B. Many accountants are clueless about how to prepare SNT tax returns. A first-party SNT is generally taxed as a "grantor trust" with respect to beneficiary, with all income and gains generated by the SNT assets properly reported on the beneficiary's personal income tax return (IRS Form 1040). Most third-party SNTs are designed and taxed as "complex trusts," with the income and gains generated by the SNT assets taxed either to the SNT or to the beneficiary depending on whether and how trust distributions have "carried out" the "distributable net income" of the SNT to the beneficiary.

4. While an accountant or CPA can usually prepare state and federal income and transfer tax returns for the beneficiary and for the SNT, less certain is their ability to prepare accountings and reports designed for review by state Medicaid authorities. Numerous states (Alabama, Georgia, Iowa and North Carolina, with several others pending) have implemented a formal SNT accounting program (for both first-party and third-party SNTs). These annual accountings are designed to identify sloppy SNT administration, including violations of the "sole benefit rule" applicable to first-party SNTs, as well as disbursements from both first-party and third-party SNTs that constitute "In-Kind Support and Maintenance" that adversely impact the beneficiary's monthly Supplemental Security Income ("SSI") payment. Most accountants are not ideally suited to prepare this type of annual accounting, which can often be handled more cost-effectively by a paralegal or bookkeeper.

E. Government Benefits Advocate

1. While some of the government benefits for which a SNT beneficiary is eligible may be easily transferable between states, many are not. A local government benefits advocate can work with the SNT beneficiary to verify which federal benefits will be relatively easy to transfer, which state benefits are non-transferable, and whether the beneficiary is eligible for brand new benefits under local or state law that were previously unavailable to the beneficiary in his prior community.

2. Local benefits advocates can also assist the family with the necessary applications for transferable and new government benefits more cost-effectively than can most attorneys. These local fonts of knowledge can also assist a family to fill in the gap with new resources where benefits from a prior state are not available in the new community.

3. While the fees of such benefits advocates are generally less expensive than those of attorneys, they are generally not *gratis*. For a SNT beneficiary who does not have a large SNT to fund the compensation of these advocates, local legal aid clinics may be of assistance in this effort. Many law schools offer legal clinics that may be able to provide advice on a *pro bono* basis.

4. A local benefits advocate may also be willing to advise the Trustee of the beneficiary's SNT as to whether any proposed disbursements will adversely impact the beneficiary's means-tested government benefits. Similarly, the advocate may know that a specific local or state program can provide, or defray the cost of, goods or services that the SNT has been asked to cover, thus leveraging the various sources for funding the beneficiary's needs.

F. Care Manager

1. A local care manager is a treasure trove of wisdom and practical advice for a SNT beneficiary and his family who are new in town. This professional will update the beneficiary's personal care plan using local providers, and assist the SNT beneficiary and his family in identifying and retaining the services of those caregivers. A care manager can oversee the implementation of the personal care plan in the beneficiary's new community and periodically verify the quality of care being rendered.

2. Increasingly, individual care managers with nursing or medical backgrounds are willing to serve as an independent health care agent for a beneficiary with legal capacity to execute a health care directive, living will or other similar document.

G. Life Care Planner

1. An indispensable member of the team is a Life Care Planner who will develop, or update, a Life Care Plan to guide the Trustee of the SNT in administering the SNT assets over the course of the beneficiary's expected lifetime. Life Care Planners frequently have nursing or medical backgrounds, or may be trained as a rehabilitation therapists or social workers. (This author prefers to work with nurse Life Care Planners. See www.aanlcp.org for information about the American Association of Nurse Life Care Planners.) There are several national associations that purport to "certify" Life Care Planners, but it is a generally unregulated emerging specialty without consistent standards.

2. Even if the SNT beneficiary secured an initial Life Care Plan at the inception of the SNT (*e.g.* in connection with the settlement of a personal injury claim, the net proceeds of which funded the SNT), no Life Care Plan is fool-proof or immutable. As the disability of the SNT beneficiary ameliorates or worsens, the Life Care Plan may need to be updated accordingly.

H. Special Education Advocate and Litigator

1. If the SNT beneficiary has not yet attained 22 years of age, education battles are likely still being fought. A special education advocate can help a family new to the local school district to obtain the "free and appropriate public education" ("FAPE") in the "least restrictive environment" 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 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.*

2. There is a small, but growing, cadre of attorneys and paraprofessionals who limit their practice to advising and representing parents and students in IDEA hearings since many public school systems fail or refuse to provide the FAPE guaranteed by IDEA.

3. An increasing number of students with Autism Spectrum Disorder (or other disorders with consequent disruptive or self-injurious behaviors) are the victims of physical abuse at the hands of their teachers, who have not been properly trained in the management of such behaviors. Civil remedies and criminal penalties are often available for redress of such abuse, and a special education litigator should be retained for that purpose.

I. Investment Advisor

1. Increasingly, the investment aspect of SNT administration is wholly delegated by the Trustee to an independent portfolio advisor. Investing the principal of a SNT is not for the faint-of-heart: a loss of principal can be life-

threatening for a beneficiary who will never be fully self-supporting. While the beneficiary may have a lower risk tolerance, his normal (or near normal) life expectancy requires the investment advisor to understand how the SNT beneficiary's specific disability impacts a long-term portfolio allocation.

2. Although many investment advisors purport to have expertise in investing for the future of SNT beneficiaries with special needs, families are advised to proceed with caution in verifying whether such designations actually warrant reliance.

J. Professional Fiduciaries to Serve as Guardian

1. As the aging parents of a SNT beneficiary become incapacitated or die, leaving a vacancy in the office of legal Guardian for their child, it may be necessary or advisable to retain the private fiduciary services of a professional to serve in that role. Increasingly, attorneys, former trust officers, and persons with experience as court-appointed guardians *ad litem* are willing to step into the vacuum created when the parents or other close family members of a SNT beneficiary fail or cease to serve as legal Guardian.

2. In many families, the aging parents simply refuse to take steps during their lifetimes to secure the appointment of a legal Guardian for their adult child with disabilities. Many clients are paralyzed with fear by the prospect that (i) no one will agree to serve as legal Guardian 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 team of allied professionals described above during the parent's lifetime can provide a solution to both of these concerns.

(1) If a person nominated to serve as legal Guardian of the client's child with a disability believes that he must personally undertake all of the responsibilities of the team members discussed above, the client's fear would be justified. However, if the person nominated to serve as the legal Guardian were able to view his role as the "quarterback" of the team of allied professionals, with a division of labor agreed upon in advance once the team is assembled, the proposed service as legal Guardian is not nearly as daunting.

(2) If the members of the team are identified and assembled while the parents are still living, then the parents can take an active role in communicating their expectations so that, working together, the team members may indeed collaborate to do as well (or better than) the parents have done. Each team member can be afforded appropriate opportunities to interact with the SNT 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.

(3) Assembling the members of the special needs team while the parents are still alive can also facilitate a more accurate analysis of the cost of procuring the services of the team members, currently and in the future. If, as is often the case, the likely cost exceeds the client's wildest nightmares, steps can be taken to bridge any funding gap that may be identified.

II. THE “NETWORK” OF THIRD-PARTY SPECIAL NEEDS TRUSTS

A. “I know I need a SNT.”

1. Most prospective clients start a discussion about Special Needs Estate Planning with the following statement: “I know I need a Special Needs Trust to help secure the future of my child [or grandchild, or spouse, or other person] who has a disability.” Many traditional estate planning attorneys who seek to co-counsel with Special Needs Planning attorneys (such as any member of the Special Needs Alliance) will similarly lead with this request: “My client has a child [or grandchild, or spouse, or other person] with a disability, and I’d like you to draft a Special Needs Trust for my client to fund.” These folks may be commended for knowing that the Special Needs Trust (“SNT”) is the cornerstone of securing the future of a person with a disability. What they typically do not know is that comprehensive Special Needs Planning encompasses a *network* of SNTs, each designed to receive funding from different sources at different times.

(1) For families planning on a pro-active strategic basis, that network will be compromised of numerous “third-party” SNTs (referred to hereafter as “TPSNTs”), *i.e.* designed to hold assets that the beneficiary of the TPSNT does not already own and to which the beneficiary is not already legally entitled. In contrast, a “first-party” SNT is designed to hold assets which the beneficiary already owns or to which he is already legally entitled. While at least one first-party SNT should also be part of the network of SNTs that comprise a comprehensive Special Needs Estate Plan, this outline will address only TPSNTs.

(2) While this outline focuses largely on a TPSNT that is custom drafted by an attorney, clients can also establish a TPSNT as a sub-account with a “pooled” SNT, that is governed by a “Master Trust Agreement” that has been approved by state and federal authorities.

2. TPSNTs are not subject to most of the federal statutory requirements mandated for first-party SNTs under 42 USC § 1396p(d)(4)(A). Thus, most importantly, there is no “Medicaid payback” for a TPSNT that is drafted properly from the outset. Anyone can serve as the Settlor of a TPSNT. The beneficiary of a TPSNT need not meet any particular definition of “disabled.” There is no age limitation on the beneficiary of a TPSNT, or on the timing of funding the TPSNT. The beneficiary of the TPSNT need not be the sole beneficiary. However, as is the case with a first-party SNT, the beneficiary cannot hold the right or power to revoke or terminate a TPSNT. *See* POMS SI 01120.200.D.1.b and POMS SI 01120.201.D.1.

B. Testamentary SNT or TPSNT under a Funded Revocable Trust

1. The most basic type of TPSNT is one created under the Last Will and Testament of the donor (typically the parent or grandparent of the beneficiary with a disability). By definition, a testamentary Special Needs Trust does not exist until the donor’s Will “matures,” *i.e.* he dies. A testamentary SNT is a TPSNT designed to hold assets that are subject to disposition under the testator/donor’s Will.

2. If one spouse wishes to establish and fund a TPSNT for the benefit of the other spouse after the death of the first spouse to die, such a TPSNT *must* be established under a Will. *See* 42 USC § 1382b(e). Accordingly, a TPSNT established under a Revocable Living Trust, a technique used by many clients as a “Will substitute” to avoid probate as to any assets held in the Revocable Trust upon the death of the settlor/grantor, would *not* qualify.

3. For clients who utilize a simple “pour-over” Will in tandem with a funded Revocable Living Trust, the provisions of the TPSNT for the client’s child [or grandchild, or another person *other than* a surviving spouse] may have two stages: (i) while the client is still alive, whether with mental capacity or during a period of lifetime incapacity, and (ii) after the client’s death. Only upon the client’s death is a separate and distinct TPSNT created and funded for the beneficiary.

4. Assets passing to a TPSNT established and funded under the client’s Will or Revocable Living Trust, and which were includable in the client’s gross estate for federal estate tax purposes, will receive a “stepped-up” basis under IRC § 1014.

C. *Inter-Vivos TPSNT Funded with Post Mortem Transfers*

1. In most families, there are numerous relatives in multiple generations who wish to help secure the future of the client's beneficiary with a disability as part of a comprehensive Special Needs Estate Plan. However, since a testamentary TPSNT does not materialize until the client's Will "matures," those other relatives cannot leave a gift or bequest as part of their own estate plans if the client is still living and the testamentary TPSNT is thus not yet established or available to receive the intended *post-mortem* benefits.

2. This author uses the term "receptacle" TPSNT to describe an *inter vivos* TPSNT designed for the sole purpose of receiving *post-mortem* transfers from collateral relatives or others. Created during the client's life, and nominally funded to breathe life into it for state trust law purposes, the receptacle TPSNT is ideally suited to coordinate the well-intended generosity of relatives and friends who wish to help secure the future of the beneficiary, but who do not wish to create a TPSNT under their own estate planning documents. These benefactors are typically 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 already 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 TPSNT that is ready and waiting to receive "pour-over" bequests or other *post-mortem* transfers from the beneficiary's relatives or friends. The letter should also include a strong caveat that any potential benefactor should seek the advice of his professional tax advisor prior to implementing any proposed *post-mortem* transfer to the TPSNT.

D. *Inter-Vivos Gifting TPSNT*

1. Many families wish to include the beneficiary of a TPSNT in an annual gifting program designed to move assets to younger generations as part of a family's overall estate plan. When it is contemplated that a TPSNT will be the recipient of lifetime gifts for which the donor wishes to claim the annual gift tax exclusion under IRC § 2503(b)(1), then an *inter vivos* gifting TPSNT for this express purpose should be included as part of the network.

2. A gift to a trust does not generally qualify as a "present interest" for purposes of the annual gift tax exclusion of \$15,000 per donee (in 2018). Thus, the gifting TPSNT must be drafted to include appropriate rights of withdrawal under the rationale of *Crummey v. Commissioner*, 397 F.2d 82 (9th Cir. 1968). Vesting *Crummey* powers in secondary permissible beneficiaries of the TPSNT under the rationale of *Estate of Cristofani v. Commissioner*, 97 T.C. 74 (1991), can effectively convert a future interest gift to the TPSNT into a present interest gift that qualifies for the gift tax annual exclusion.

E. *Inter-Vivos Irrevocable Life Insurance TPSNT*

1. In light of the current historically high estate tax exemption (\$5.6 million, in 2018) under IRC § 2010(c), fewer families are utilizing Irrevocable Life Insurance Trusts ("ILITs") to own large life insurance policies that will be excluded from their gross estates for estate tax purposes. However, because the cost of fully funding the needs of a beneficiary with a disability (who may never be fully self-supporting) can be astronomical, one or more ILITs are typically included in the network of TPSNTs created for the beneficiary. This author prefers to design an ILIT as the owner and beneficiary of single-life or second-to-die policies insuring (typically) the beneficiary's parent(s), with TPSNT provisions embedded within the trust agreement that establishes the ILIT. Many families wish for the child with the disability to be the sole beneficiary of the TPSNT during his life, while some are comfortable allowing their children without disabilities to be secondary permissible beneficiaries while the child with the disability is still living.

(1) Families are often concerned about "over-funding" the anticipated needs of the child with the disability. One option to address this concern is to divide the policy proceeds paid to the ILIT into separate trust shares among the client's lineal descendants, *per stirpes*, but provide that the child with special needs is a secondary permissible beneficiary of his siblings' shares if the proceeds allocated to his own separate share prove insufficient to fully pay for his needs.

(2) As with the *inter vivos* gifting TPSNT discussed, *supra*, contributions to an ILIT to enable the Trustee pay the premiums on life insurance policies owned by the ILIT must be covered by sufficient *Crummey* powers of withdrawal held by the beneficiaries of the ILIT (*other than* the beneficiary with a disability) in order to qualify as "present interest" gifts eligible for the gift tax annual exclusion under IRC § 2503(b)(1).

F. Inter-Vivos TPSNTs in the Context of Divorced Parents

1. It is estimated that ninety percent of the parents of a child with a disability will end up in divorce court. The toll that a child's disability exerts on a marriage is often insurmountable. After the divorce, the relatives of each parent, *e.g.* usually the maternal and paternal grandparents of the child with a disability, may still wish to help secure their grandchild's future, but each "side" of the family wishes to designate different remainder beneficiaries of a TPSNT upon the death of the grandchild. This often necessitates two (or more) separate TPSNTs, contributions to which have vastly different beneficiaries both during the life, and after the death, of the beneficiary with the disability.

2. If the divorce is amicable, it may be realistic to create a TPSNT to which each ex-spouse may freely and gratuitously contribute funds to secure the future of their child with a disability. However, if the divorce settlement agreement, or a court order, mandates either ex-spouse to contribute to a SNT for their child with a disability, then a TPSNT may not be used; rather, a first-party SNT would be required.

G. Inter-Vivos Community Fundraising TPSNT

1. Often times, the circumstances of a person's disability are so heart-wrenching that the greater community-at-large wishes to help secure that person's financial future with organized fundraising efforts. While paying funds raised directly to the parents or other relatives of the person with a disability seems like an easy and uncomplicated option, that approach often results in further heartache for both the well-intentioned community donors and the person with the disability.

(1) The same reasons that obviate against disinheriting a person with a disability and leaving that person's share of an estate to another person to manage informally also make this an imprudent approach in the context of a community raising funds for a person with a heart-wrenching disability story. Even well-intentioned parties may fail to manage designated funds for the benefit of the person with a disability, for myriad reasons. If the donee of the designated funds commingles the assets with his own, and thereafter (i) files for bankruptcy, (ii) becomes party to a divorce proceeding and a subsequent equitable division of property, (iii) has a judgment lien recorded against him by a creditor, (iv) fails to pay his tax liabilities and becomes subject to a tax lien, or (v) dies intestate with heirs-at-law that include persons other than the intended beneficiary, or dies testate but fails to make proper provision in his Will for the ongoing management of the funds for the intended beneficiary, the intention of the community that raised the funds is defeated.

2. A carefully drafted TPSNT may serve as the repository for funds raised by well-intentioned donors in the community. To address the often problematic issue of an appropriate remainder beneficiary upon the death of the beneficiary with the disability, the trust agreement may designate a disability-specific non-profit that focuses on the beneficiary's disabling condition, or a charitable entity that supports persons with multiple disabilities, *e.g.* an organization that trains service dogs (*e.g.* Canine Assistants, www.canineassistants.org).

3. Contributions to such a TPSNT would not qualify as a present interest for purposes of the annual gift tax exclusion under IRC § 2503(b)(1) (unless it is drafted to include appropriate *Crummey* powers of withdrawal), thus requiring the donor to use a portion of his lifetime gift tax exclusion under IRC § 2010(c). Furthermore, contributions to this type of TPSNT do not qualify for the charitable income tax deduction under IRC § 170(c), often to the dismay of the donors.

III. FUNDING CONSIDERATIONS FOR TPSNTs

A. Do Not Commingle Third-Party Funds And First-Party Funds

1. As the term implies, third-party funds derive from a person or entity other than the beneficiary of the SNT. In contrast, a first-party SNT is designed to hold assets that already belong to the SNT beneficiary, or to which the beneficiary is legally entitled. The cardinal rule of SNT funding is "Do not commingle first-party and third-party funds." Clients are routinely tempted to do just that in an effort to minimize the number of SNTs in the network of SNTs described *supra*.

2. Adding third-party funds to a first-party SNT could unnecessarily subject those funds to the "Medicaid payback" obligation that applies only to first-party SNTs pursuant to 42 USC § 1396p(d)(4)(A) and (C), *i.e.* "free money" for Medicaid (and a possible claim for legal malpractice against the practitioner who encouraged or permitted such commingling). The reverse, *i.e.* adding first-party funds to a TPSNT, will result in the beneficiary whose funds were so added to incur a transfer penalty and a period of disqualification for purposes of his ongoing eligibility for means-tested government benefits.

B. “How Much is Enough to Fund a TPSNT?”

1. Clients will often ask the attorney who drafted a TPSNT, “How much is enough to fund this TPSNT?”

Rather than pull a number out of thin air and hope for the best, the practitioner should encourage the client to secure a Life Care Plan for the beneficiary of the TPSNT that represents an arm’s-length assessment of the estimated cost of, and the amount needed to fund, the special needs of the beneficiary. 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 beneficiary of the TPSNT could derive benefit during his estimated life expectancy, along with an economic analysis of the likely expense and cost of same, indexed for inflation.

2. A Life Care Plan also provides an indispensable road-map for the Trustee of the TPSNT. If there is no

Life Care Plan in place at the inception of the TPSNT, the Trustee is advised to procure one as the first order of business. A Life Care Plan is developed by an allied professional known as a “Life Care Planner” who frequently has a medical background as a nurse, physician, or rehabilitation therapist, or as a social worker. (This author prefers to collaborate with a Nurse Life Care Planner. *See American Association of Nurse Life Care Planners at www.aanlcp.org.*)

3. The cost of a formal Life Care Plan can be significant. As an alternative, various financial service providers offer on-line “financial planning calculators” to help families quantify the cost of fully funding the needs of the beneficiary of a TPSNT, and to illuminate the general proposition that “they don’t know what they don’t know.” However, those same financial services providers are primarily interested in selling products to fund the purported needs of the beneficiary, and must be viewed with a healthy dose of skepticism.

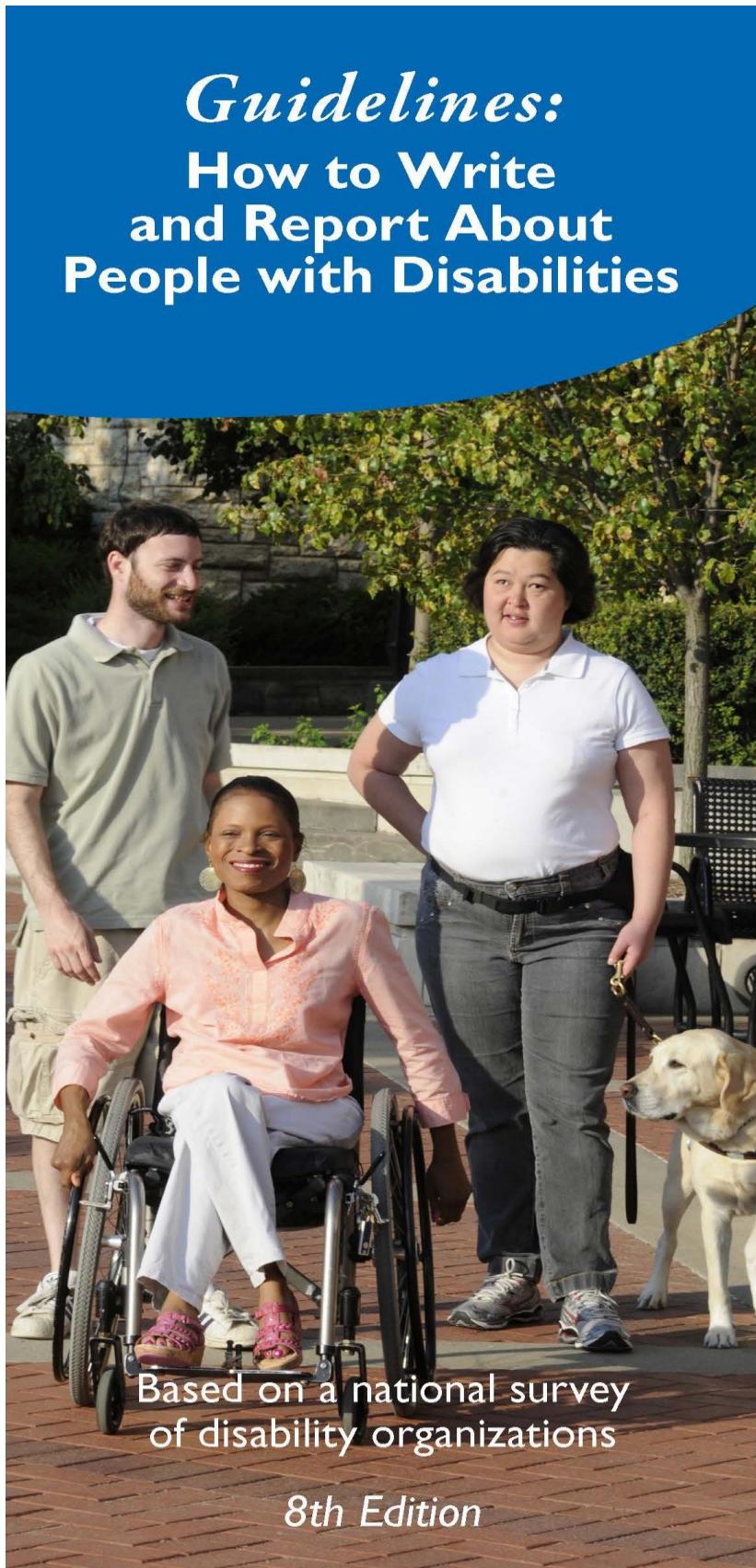
4. Nevertheless, no Life Care Plan is immutable or static. Appropriate updates should be secured as the beneficiary’s disabilities ameliorate or exacerbate over the course of his lifetime to the extent that such changes impact the level of care required to address his needs. Updating an existing Life Care Plan is not nearly as costly as generating the initial Life Care Plan (especially if the same Life Care Planner prepares the update).

5. Furthermore, changes in the federal government benefit programs for which the beneficiary is eligible as a consequence of his disabling condition will also impact the substance of a Life Care Plan. As government benefit programs pay for fewer of the services that the beneficiary needs, the private funding held in his network of TPSNTs will be called upon to pay for more of what the beneficiary needs. Currently, the United States Congress is engaged in a battle on multiple fronts to reduce or eliminate funding for many of the long-standing government programs upon which persons with disabilities have relied (*e.g.* Medicaid and Medicaid Waivers), as well as some of the recently available programs that have become a critical element of funding their health care needs (*e.g.* “Obamacare” coverage under the AFFORDABLE CARE ACT, part of the PATIENT PROTECTION AND AFFORDABLE CARE ACT (Pub. L. 111-148, 124 Stat. 119) and the HEALTH CARE AND EDUCATION RECONCILIATION ACT (Pub. L. 111-152, 124 Stat. 1029)).

6. All states are not created equal when it comes to state-funded programs and benefits for persons with disabilities. As TPSNT beneficiaries are becoming increasingly mobile and living in multiple communities and states over the course of a lifetime, the funding formula and calculations for their needs can be dramatically affected by a difference in state and local benefits and programs for which the TPSNT beneficiary is eligible as a consequence of his disabilities. For many of these programs, there are waiting lists with hundreds or thousands persons whose position on the list ahead of a “new kid in town” makes access to such programs unlikely for the TPSNT beneficiary who moves to a new state.

[Supplemental materials continue on following pages]

- IV. “*Guidelines: How to Write and Report About People with Disabilities*,” 8th Edition (2013), reprinted with permission from the University of Kansas Research and Training Center on Independent Living (available at www rtcil org/guidelines).



The difference between the right word and the almost right word is the difference between lightning and the lightning bug.

- Mark Twain

Your Words, Our Image

Writers, editors, reporters and other communicators strive to use the most accurate terminology about people with disabilities. However, inaccurate, archaic and offensive expressions are still commonly used, perpetuating negative stereotypes and beliefs about people with disabilities.

For example, a person *who uses a wheelchair* – an objective fact – is often described as *wheelchair-bound*, a subjective description that implies victimhood.

As one wheelchair user puts it, “I personally am not ‘bound’ by my wheelchair. It is a very liberating device that allows me to work, play, maintain a household, connect with family and friends, and ‘have a life.’ ”

Who Says?

Since the first edition was published in 1984, we have consulted with hundreds of disability groups and individuals who have disabilities to produce *Guidelines: How to Write and Report About People with Disabilities*. The eighth edition presents the latest terminology preferred by people with disabilities.

The Associated Press Stylebook, the *Publication Manual of the American Psychological Association* (6th edition) and the *American Association for the Advancement of Science* have all adopted some of the recommendations from previous editions of the *Guidelines*.

The first edition of the *Guidelines* was produced with funding from the National Institute on Disability and Rehabilitation Research. Since then, more than one million copies have been distributed, and the electronic version is now used by people around the world.

Please use the *Guidelines* when you write or report about people with disabilities. We also offer a poster that presents a short list of disability writing style dos and don’ts.

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Portrayal Issues

The Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that substantially limits one or more major life activities.

That said, people with disabilities are like every other human being – they have strengths and weaknesses, successes and failures, hopes and dreams. Like other minority groups, they don't want to be stereotyped when their stories are told. By following these guidelines, you can portray people with disabilities in an accurate and objective manner.

Put the person first, not his or her disability. Use *person with a disability, woman with multiple sclerosis or a child who has an intellectual disability*. This “person-first language” puts the focus on individuals, not their functional limitations. Labeling a person (for example, *an autistic*) dehumanizes him and equates a person with a condition. Think people first, too, for indicating disability groups, such as *people who have cerebral palsy*.

Emphasize abilities, not limitations. For example, uses *a wheelchair or uses a communication device* rather than *confined to a wheelchair or unable to speak*. In reality, wheelchairs and other assistive devices represent independence for their users, not a burden. To emphasize capabilities, avoid negative words that portray the person as passive or suggest a lack of something, such as *victim, invalid or defective*. While the term *disability* itself implies a negative, it is the most objective term we have in English.

Do not focus on a disability unless it is essential to a story. Avoid tear-jerking human interest stories about incurable diseases, congenital disabilities or severe injury. Focus instead on issues that affect the quality of life for those same individuals, such as accessible housing and transportation, affordable health care, employment opportunities and discrimination. Focus on personal characteristics that aren't related to disability, such as artist, professional, mother, etc.

Bypass condescending euphemisms. Terms such as *special, handicapped, differently abled and challenged* reinforce the idea that people cannot deal honestly with their disabilities. While *special* is used in the names of some educational programs and organizations, the use of *special needs* is offensive to many adults with disabilities, who want to be treated like everyone else in their community. *Special* also implies a paternalistic need to be taken care of, which is frequently not true. Just say *children with disabilities*.

Do not portray successful people with disabilities as heroic overachievers or long-suffering saints.

Every human faces challenges in life. Even though the public may find such portrayals inspirational, these stereotypes raise false expectations for people with disabilities.

Avoid sensationalizing and negative labeling. Saying *afflicted with, crippled with, victim of or suffers from* portrays individuals with disabilities as helpless objects of pity and charity. State the facts in neutral terms, saying *a person who has AIDS*. Avoid emotional descriptors such as *unfortunate or pitiful*.

Do not equate disability with illness. People with disabilities can be healthy, though they may have chronic diseases such as arthritis, heart disease and diabetes. People who had polio and experienced after-effects have *post-polio syndrome*; they are not currently experiencing the active phase of the virus. Also, do not imply disease if a person's disability resulted from anatomical or physiological damage (for example, *a person with spina bifida*). Finally, do not refer to people with disabilities as *patients* unless their relationship with their doctor is under discussion, or if they are referenced in the context of a clinical setting.

Respect the person. Do not use offensive words such as *retard, freak, lame, subnormal, vegetable and imbecile*. If you maintain the dignity and integrity of each individual, there is no need to panic about being politically correct. When appropriate, you may ask a person how she prefers you to describe her disability. While some common phrases can be hurtful, such as *blind as a bat*, it's fine to use everyday expressions like *See you later*.

Person-First Language: A Partial Glossary of Disability Terms

We know that language shapes perceptions, so a small word choice can make a big difference in communicating attitudes towards people with disabilities and assumptions about the quality of their lives.

Person-first language literally puts the person first instead of his or her disability. By referring to an individual as *a person with a disability* instead of a *disabled person*, you are providing an objective description instead of a label. While opinions differ on some words, this partial list offers preferred terms for many visible and invisible disabilities, illustrated with person-first language.

AD/HD (Attention Deficit/Hyperactivity Disorder) is the clinical diagnosis for a genetic neurobehavioral condition that is characterized by symptoms in three categories: inattention, excessive activity and impulsive behavior. While the medical community includes **ADD** (Attention Deficit Disorder) as a subset of this condition, disability advocates consider the two conditions as distinctly different. A person who has ADD has difficulty focusing attention and a high level of distractibility, but does not experience hyperactivity or impulsive behavior. Say *person with ADHD* or *student with ADD*. Do not use *hyper* or *lazy*.

Autism spectrum disorders (ASD) refers to a group of complex disorders of brain development that may cause difficulty with social interactions, problems with verbal and nonverbal communication and repetitive behaviors. In terms of symptoms, **Asperger's syndrome** is on the milder end of the spectrum. People with an ASD can have severe limitations in one area with no limitations in others. Use *child with autism* or *Asperger's syndrome* or *person on the spectrum*. Do not say *autistic*. (See also "A Few Exceptions" on page 11.)

Blind describes a condition in which a person has loss of sight for ordinary life purposes. A person is *legally blind* when vision with best correction is no better than 20/200. *Low vision* and *vision loss* are generic terms for

vision loss caused by macular degeneration and other conditions. *Low vision* usually denotes someone who is legally blind, but can still see large print, bright colors, light and shadow, and large shapes, while *vision loss* refers to those who have lost vision after birth. Say *boy who is blind*, *girl who has low vision* or *man who is legally blind*. (You may ask which term best suits the person.) Some blind people consider themselves visual thinkers so they regard *visually impaired* and *visually challenged* as negative terms.

Brain injury or **traumatic brain injury (TBI)** describes a condition where there is temporary or long-term disruption in brain function resulting from injury to the brain. Difficulties with cognitive (thinking, remembering, learning), physical, emotional and/or social functioning may occur. Use *person with a brain injury* or *employee with a traumatic brain injury*. Do not say *brain damaged*.

Chemical and/or electrical sensitivities describe chronic medical conditions characterized by neurological impairment, muscle pain and weakness, respiratory problems and gastrointestinal complaints. Reactions for those with chemical sensitivities are triggered by low-level exposure to everyday substances and products including pesticides, solvents, cleaning agents, new carpeting and adhesives, fragrances and scented products. Electrical sensitivities are triggered by electromagnetic fields from electrical devices and frequencies. These conditions are also called *environmental illness*, *toxicant-induced loss of tolerance* or *sick building syndrome*. Use *person with chemical intolerance* or *people with environmental illness*. People with this condition should not be called *chemophobic* or described with the term *idiopathic environmental intolerance*.

Chronic fatigue syndrome refers to a chronic condition in which individuals experience six or more months of fatigue accompanied by physical and cognitive symptoms. *Chronic fatigue*, *immune dysfunction syndrome* and *myalgic encephalomyelitis* are currently preferred. Do not say *Yuppie Flu*. Also, don't confuse this syndrome with overlapping or similar conditions such as *Epstein-Barr virus syndrome* and *fibromyalgia*.

Cleft palate or lip describes a specific congenital disability involving the lip and gum. Say *person who has a cleft palate*. The term *hare lip* is anatomically incorrect and stigmatizing.

Congenital disability describes a disability that has existed since birth but is not necessarily hereditary. Use *person with a congenital disability* or *disability since birth*. Do not say *birth defect* or *deformity*.

Deaf refers to a profound degree of hearing loss that prevents understanding speech through the ear. *Hearing impaired* or *hearing loss* are generic terms used by some individuals to indicate any degree of hearing loss, from mild to profound, although some dislike the negative term *impaired*. *Hard of hearing* refers to a mild to moderate hearing loss that may or may not be corrected with amplification. A person who has hearing difficulties may have speech difficulties, too, but deafness does not affect mental abilities. Say *woman who is deaf* or *boy who is hard of hearing*. People who have some degree of both hearing and vision loss prefer the term *deaf-blind*. Also acceptable is *person with combined vision and hearing loss* or *dual sensory loss*. Never use *deaf and dumb*. (See also “A Few Exceptions” on page 11.)

Developmental disability is a broad term that describes any physical and/or mental disability that starts before the age of 22. Examples include cerebral palsy, autism spectrum disorders and sensory impairments. People with developmental disabilities have a wide range of functioning levels and disabilities. Although the term *intellectual disability* is often used in conjunction with developmental disability, many people with a developmental disability do not have an intellectual disability. Say *she has cerebral palsy*, *he has autism* or *he has a developmental disability*. Do not say *she is mentally retarded*.

Disability is a general term used for an attribute or a functional limitation that interferes with a person’s ability, for example, to walk, lift or learn. It may refer to a physical, sensory or mental condition such as Lyme disease, depression, irritable bowel syndrome, post-

traumatic stress syndrome, diabetes, multiple sclerosis and other conditions that restrict the activities of daily living. Do not use the term *handicapped* because many people with disabilities consider it offensive.

We recognize the need for succinctness, but when possible, avoid using *the disabled* as a generic label. It describes a condition, not people, and has connotations of “non-functioning” (as in *a disabled car*). It also implies a homogenous group separate from the rest of society. Instead use *people with disabilities* or *the disability community*.

Disfigurement refers to physical changes caused by burns, trauma, disease or congenital conditions. Do not say *burn victim*. Say *burn survivor*.

Down syndrome describes a chromosomal disorder that causes a delay in physical, intellectual and language development. Say *person with Down syndrome*. Do not use *Mongol*, *mongoloid* or *Down person*.

HIV/AIDS is a disease of the immune system. Over time, HIV (human immunodeficiency virus) can weaken the immune system to a point where the body becomes susceptible to certain illnesses that healthy immune systems resist. People with HIV are diagnosed with AIDS (acquired immunodeficiency syndrome) when one or more specific conditions are met. Use *person living with HIV* or *people who have AIDS*. Do not use *AIDS victim*.

Intellectual disability refers to limitations in intellectual functioning and adaptive behaviors that require environmental or personal supports for the individual to live independently. Though *mental retardation* was previously accepted as a clinical term, many consider it an insult, so people who have this condition, their families and related organizations have campaigned to end its use. (See “Rosa’s Law and the Language of Bullying” on page 8.) Say *people with intellectual disabilities*. Do not use *mentally retarded* or *subnormal*.

Learning disability describes a neurologically based condition that may manifest itself as difficulty learning and using skills in reading (called dyslexia), writing (dysgraphia), mathematics (dyscalculia) and other cognitive processes due to differences in how the brain processes information. Individuals with learning disabilities have average or above average intelligence, and the term does not include a learning problem that is primarily the result of another cause, such as intellectual disabilities or lack of educational opportunity. Say *person with a learning disability*. Do not use *slow learner* or *retarded*.

Rosa's Law and the Language of Bullying

Signed into U.S. law in 2010, Rosa's Law replaces the term *mental retardation* with the phrase *intellectual disability* in federal health, education and labor statutes. The law was named for nine-year-old

Rosa Marcellino, whose brother Nick explained the change this way: "What you call people is how you treat them. If we change the words, maybe it will be the start of a new attitude towards people with disabilities."*

Most states have also changed their laws to use more respectful language in statutes and the names of state agencies.

The disability community supports a national campaign called "Spread the word to end the word," which raises the public's awareness about ending use of "the R word." This movement is also part of the battle against bullying, which often begins with demeaning and destructive words.

*From "Remarks by the President at the Signing of the 21st Century Communications and Video Accessibility Act of 2010," <http://www.whitehouse.gov/the-press-office/2010/10/08/remarks-president-signing-21st-century-communications-and-video-accessib>, accessed 12/7/12.



Nondisabled is the preferred term when the context calls for a comparison between people with and without disabilities. Use *nondisabled* or *people without disabilities* instead of *healthy*, *able-bodied*, *normal* or *whole*.

Post-polio syndrome is a condition that affects some persons who have had poliomyelitis (polio) long after recovery from the disease. It is characterized by new muscle weakness, joint and muscle pain and fatigue. Say *person with post-polio syndrome*. Do not use *polio victim*.

Psychiatric disability refers to a variety of psychological conditions. Say *person with a psychiatric disability* or *mental illness*. In a clinical context or for medical or legal accuracy, use *schizophrenic*, *psychotic* and other diagnostic terms. Note, too, that *bipolar disorder* has replaced *manic depression*. Words such as *crazy*, *maniac*, *lunatic*, *schizo* and *psycho* are offensive and should never be applied to people with mental health conditions.

Seizure describes an involuntary muscle contraction, a brief impairment or loss of consciousness resulting from a neurological condition such as epilepsy or from an acquired brain injury. Say *girl with epilepsy* or *teen with a seizure disorder*. The word *convulsion* should be used only for seizures involving contraction of the entire body. Do not use *epileptic*, *fit*, *spastic* or *attacks*.

Service animal or **service dog** describes a dog that has been individually trained to do work or perform tasks for people with disabilities. In addition to guiding people who are blind, they may alert people who are deaf, pull wheelchairs, alert and protect a person who is having a seizure, remind a person with mental illness to take prescribed medications, or calm a person with post-traumatic stress disorder during an anxiety attack. Miniature horses are also considered service animals under the Americans with Disabilities Act (ADA), though monkeys no longer are. Do not use *seeing eye dog*.

Short stature describes a variety of genetic conditions causing people to grow to less than 4'10" tall. Say *person of short stature*, although some groups prefer *little people*. *Dwarfism* is an accepted medical term, but should not be used as general terminology. Do not refer to these individuals as *midgets* because of its circus sideshow connotations.

Speech disability is a condition in which a person has limited or impaired speech patterns. Use *child who has a speech disability*. For a person without verbal speech capability, say *person without speech*. Do not use *mute* or *dumb*.

Spinal cord injury describes a condition in which there has been permanent damage to the spinal cord, resulting in some degree of paralysis. *Quadriplegia* denotes loss of function in all four extremities, while *paraplegia* refers to loss of function in the lower part of the body only; in both cases the individual might have some function in the affected limbs. While people with spinal cord injuries often refer to themselves as a *para* or a *quad*, communicators should use *man with paraplegia*, *woman who is paralyzed* or *person with a spinal cord injury*. Don't say *cripple* or *handicapped*.

Substance dependence refers to patterns of substance use that result in significant impairment in at least three life areas (family, employment, health, etc.) over any 12-month period. Although such terms as *alcoholic* and *addict* are medically acceptable, they may be derogatory to some individuals. Acceptable terms are *people who are substance dependent* or *person who is alcohol dependent*. Individuals who have a history of dependence on alcohol and/or drugs and are no longer using alcohol or drugs may identify themselves as *recovering* or as a *person in recovery*.

Survivor is used by people to affirm their recovery from or conquest of an adverse health condition such as *cancer survivor*, *burn survivor*, *brain injury survivor* or *stroke survivor*. Avoid calling them *victims*.



A Few Exceptions

Language is continually evolving, and no rule is absolute. Here are a few notable exceptions to person-first language.

Deaf/deaf. As a group, this population typically refers to itself as *the Deaf* or *Deaf community* (with a capital D) rather than *people who are deaf*. They identify with a specific community made up of those who share a common language, American Sign Language, and culture.

Disability humor. Some people with physical disabilities who embrace the culture of disability refer to themselves with the same offensive terms that we urge you to avoid. This familiarity is a form of disability humor and should not be adopted by those outside of the group.

Identity language. Some people prefer "identity language" to person-first language as a way to signal their disability pride. Thus, a person who values her autism as an inseparable and important part of who she is might proudly say, "I am autistic," in the same way she describes herself as an American. Similarly, many regard *a blind man* as a neutral descriptor (the same as *a tall man*), and *amputee* is more often used than *a person with an amputation*.

Still, the guiding principle remains: Accord people with disabilities the dignity that all people want. By using person-first language, you will maintain objectivity and convey respect.

Key Concepts in the Disability Community



These terms and concepts may be helpful when writing about people with disabilities.

Accessible describes the nature of accommodations for people who have a disability. Say an *accessible parking space* rather than *handicapped parking* or *disabled restroom*. Accessible

also describes products and services for people with vision or hearing disabilities, such as when a hospital provides patient education materials in large print or a university adds captions to a recruitment video. *Handicapped* has negative connotations because it suggests that obstacles to participation are in the person rather than in the environment.

Advocacy is an active process designed to make institutions and social and political systems more responsive to the civil rights, needs and choices of individuals. Through individual and group advocacy, people with disabilities can assert their rights under various civil rights laws and participate in decision-making that affects them.

Consumer is the term used by many in the disability community to refer to someone with a disability. The civil rights movement in the U.S. inspired the independent living movement of the 1970s, which maintained that people with disabilities are *consumers* of assistive services and have a responsibility to evaluate and control those services. On a similar note, some people prefer to be described by what they use, such as *wheelchair user*, *ventilator user* or *mental health service user*.

Independent living (IL) refers to the philosophy that people with disabilities should be able to make decisions that affect their own lives. IL also refers to a civil rights movement that advocates for equal participation in community life and a service system

made up of centers for independent living. These nonresidential resource centers are run by and for people with disabilities, as well as for the benefit of the entire community. Their core services include advocacy, information and referral, independent living skills training, peer counseling and, most recently, de-institutionalization of people with disabilities.

Inclusion is perhaps best known for its role in public school programs, though the concept has a wider significance. It means that people with disabilities are considered full citizens, with equal opportunity to participate in community life. As the largest minority in the U.S., people with disabilities should also be included in conversations about diversity.

The medical model is an attitude and practice that regards disability as a defect or sickness that must be cured or normalized through medical intervention. People in the disability community prefer the **social or independent living model**, which regards disability as a neutral difference between people – and acknowledges that people with disabilities can be healthy. In the social model, problems related to disability are caused by the interaction between the individual and the environment rather than the individual's disability itself. These problems can be remedied by changing social attitudes, physical environments, public policies and other barriers to full participation.

On the cover: Jeff Gordon, Ranita Wilks, Rachel Magario and Magario's service dog, Nettie, on the University of Kansas campus. Photo by Diane Guthrie.

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Want a quick overview?

Download our poster that lists disability writing style dos and don'ts at [www rtcil.org/guidelines](http://www rtcil org/guidelines).

Thanks to Our Reviewers

We are grateful to many individuals and disability organizations for their input on this edition of the *Guidelines*. A partial list of endorsers includes:

American Association of People with Disabilities
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 Beach Center on Disability, University of Kansas
 Brain Injury Association of America
 Christopher & Dana Reeve Foundation
 Hearing Loss Association of America
 Institute for Disability Studies, University of Southern Mississippi
 Learning Disabilities Association of America
 National Ataxia Foundation
 National Council on Independent Living
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Administering a Special Needs Trust

A Handbook For Trustees
(2017 Edition)



Administering a Special Needs Trust

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Administering a Special Needs Trust: A Handbook for Trustees

Introduction and Definition of Terms

“Special Needs” trusts are complicated and can be hard to understand and administer. They are like other trusts in many respects—the general rules of trust accounting, law and taxation apply—but unlike more familiar trusts in other respects. The very notion of “more familiar” types of trusts will, for many, be amusing—most people have no particular experience dealing with formal trust arrangements, and special needs trusts are often established for the benefit of individuals who would not otherwise expect to have experience with trust concepts.

The essential purpose of a special needs trust is usually to improve the quality of an individual’s life without disqualifying him or her from eligibility for public benefits. Therefore, one of the central duties of the trustee of a special needs trust is to understand what public benefits programs might be available to the beneficiary and how receipt of income, or provision of food or shelter, might affect eligibility. Because there are numerous programs, competing (and sometimes even conflicting) eligibility rules, and at least two different types of special needs trusts to contend with, the entire area is fraught with opportunities to make mistakes. Because the stakes are often so high—the public benefits programs may well be providing all the necessities of life to the beneficiary—a good understanding of the rules and programs is critically important.

Before delving into a detailed discussion of special needs trust principles, it might be useful to define a few terms:

GRANTOR (sometimes “Settlor” or “Trustor”)—the person who establishes the trust and generally the person whose assets fund the trust. There might be more than one grantor for a given trust. The tax agency may define the term differently than the public benefits agency. Special needs trusts can make this term more confusing than other types of trusts, since the true grantor for some purposes may not be the same as the person signing the trust instrument. If, for example, a parent creates a trust for the benefit of a child with a disability, and the parent’s own money funds the trust, the parent is the grantor. In another case, where a parent has established a special needs trust to handle settlement proceeds from a personal injury lawsuit or improperly directed

inheritance, the minor child (through a guardian) or an adult child will be the grantor, even though he or she did not decide to establish the trust or sign any trust documents.

TRUSTEE—the person who manages trust assets and administers the trust provisions. Once again, there may be two (or more) trustees acting at the same time. The grantor(s) may also be the trustee(s) in some cases. The trustee may be a professional trustee (such as a bank trust department or a lawyer), or may be a family member or trusted adviser—though it may be difficult to qualify a non-professional to serve as trustee.

BENEFICIARY—the person for whose benefit the trust is established. The beneficiary of a special needs trust will usually (but not always) be disabled. While a beneficiary may also act as trustee in some types of trusts, a special needs trust beneficiary will almost never be able to act as trustee.

The essential purpose of a special needs trust is usually to improve the quality of an individual’s life without disqualifying him or her from eligibility to receive public benefits.

DISABILITY—for most purposes involving special needs trusts, “disability” refers to the standard used to determine eligibility for Social Security Disability Insurance or Supplemental Security Income benefits: the inability to perform any substantial gainful employment.

INCAPACITY (sometimes *Incompetence*)—although “incapacity” and “incompetence” are not interchangeable, for our purposes they may both refer to the inability of a trustee to manage the trust, usually because of mental limitations. Incapacity is usually important when applied to the trustee (rather than the beneficiary), since the trust will ordinarily provide a mechanism for transition of power to a successor trustee if the original trustee becomes unable to manage the trust. Incapacity of a beneficiary may sometimes be important as well. Not every disability will result in a finding of incapacity; it is possible for a special needs trust beneficiary to be disabled, but not mentally incapacitated. Minors are considered to be incapacitated as a matter of law. The age of majority differs slightly from state to state, though it is 18 in all but a handful of states.

REVOCABLE TRUST—refers to any trust which is, by its own terms, revocable and/or amendable, meaning able to be undone, or changed. Many trusts in common use today are revocable, but special needs trusts are usually irrevocable, meaning permanent or irreversible.

IRREVOCABLE TRUST—means any trust which was established as irrevocable (that is, no one reserved the power to revoke the trust) or which has become irrevocable (for example, because of the death of the original grantor).

SOCIAL SECURITY DISABILITY INSURANCE—sometimes referred to as SSDI or SSD, this benefit program is available to individuals with a disability who either have sufficient work history prior to becoming disabled or are entitled to receive benefits by virtue of being a dependent or survivor of a disabled, retired, or deceased insured worker. There is no “means” test for SSDI eligibility, and so special needs trusts may not be necessary for some beneficiaries—they can qualify for entitlements like SSD and Medicare even though they receive income or have available resources. SSDI beneficiaries may also, however, qualify for SSI (see below) and/or Medicaid benefits, requiring protection of their assets and income to maintain eligibility. Of course, just because a beneficiary’s benefits are not means-tested, it does not follow that the beneficiary will not benefit from the protection of a trust for other reasons.

SUPPLEMENTAL SECURITY INCOME—better known by the initials “SSI,” this benefit program is available to low-income individuals who are disabled, blind or elderly and have limited income and few assets. SSI eligibility rules form the basis for most other government program rules, and so they become the central focus for much special needs trust planning and administration.

MEDICARE—one of the two principal health care programs operated and funded by government—in this case, the federal government. Medicare benefits are available to all those age 65 and over (provided only that they would be entitled to receive Social Security benefits if they chose to retire, whether or not they actually are retired) and those under 65 who have been receiving SSDI for at least two years. Medicare eligibility may forestall the need for or usefulness of a special needs trust. Medicare recipients without substantial assets or income may find that they have a difficult time paying for medications (which historically have not been covered by Medicare but began to be partially covered in 2004) or long-term care (which remains largely outside Medicare’s list of benefits).

MEDICAID—the second major government-run health care program. Medicaid differs from Medicare in three important ways: it is run by state governments (though partially funded by federal payments), it is available to those who meet financial eligibility requirements rather than being based on the age of the recipient, and it covers all necessary medical care (though it is easy to argue that Medicaid’s definition of “necessary” care is too narrow). Because it is a “means-tested” health care

program, its continued availability is often the central focus of special needs trust administration. Because Medicare covers such a small portion of long-term care costs, Medicaid eligibility becomes centrally important for many persons with disabilities.

The Most Important Distinction

Two entirely different types of trusts are usually lumped together as “special needs” trusts. The two trust types will be treated differently for tax purposes, for benefit determinations, and for court involvement. For most of the discussion that follows, it will be necessary to first distinguish between the two types of trusts. The distinction is further complicated by the fact that the grantor (the person establishing the trust, and the easiest way to distinguish between the two trust types) is not always the person who actually signs the trust document.

“Self-Settled” Special Needs Trusts

Some trusts are established by the beneficiary (or by someone acting on his or her behalf) with the beneficiary’s funds for the purpose of retaining or obtaining eligibility for public benefits—such a trust is usually referred to as a “self-settled” special needs trust. The beneficiary might, for example, have received an outright inheritance, or won a lottery. By far the most common source of funds for “self-settled” special needs trusts, however, is proceeds from a lawsuit—often (but not always) a lawsuit over the injury that resulted in the disability. Another common scenario requiring a person with a disability to establish a self-settled trust is when they receive a direct inheritance from a well-intentioned, but ill-advised relative.

A given trust may be treated as having been “established” by the beneficiary even if the beneficiary is completely unable to execute documents, and even if a court, family member, or lawyer representing the beneficiary actually signed the trust documents. The key test in determining whether a trust is self-settled is to determine whether the beneficiary had the right to outright possession of the proceeds prior to the act establishing the trust. If so, public benefits eligibility rules will treat the beneficiary as having set up the trust even though the actual implementation may have been undertaken by someone else acting on their behalf. Virtually all special needs trusts established with funds recovered in litigation or through a direct inheritance will be “self-settled” trusts.

Self-settled special needs trusts are different from third-party trusts in two important ways. First, self-settled trusts must include a provision directing the trustee, if the trust contains any funds upon the death of the beneficiary, to pay back anything the state Medicaid program has paid for the beneficiary. Second, in many states, the rules governing permissible distributions for self-settled special needs trusts are significantly more restrictive than those controlling third-party special needs trusts.

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Because Social Security law specifically describes self-settled special needs trusts, these instruments are sometimes referred to by the statutory section authorizing transfers to such trusts and directing that trust assets will not be treated as available and countable for SSI purposes. That statutory section is 42 U.S.C. §1396p(d)(4)(A), and so self-settled special needs trusts are sometimes called, simply, “d4A” trusts.

“Third-party” Special Needs Trusts

The second type of special needs trust is one established by someone other than the person with disabilities (usually, but not always, a parent) with assets that never belonged to the beneficiary. It is often used, when proper planning is done for a disabled person’s family, to hold an inheritance or gift. Without planning, a well-meaning family member might simply leave an inheritance to an individual with a disability. Even though it may be possible to set up a trust after the fact, the funds will have been legally available to the beneficiary. That means that any trust will probably be a “self-settled” special needs trust, even though the funds came from a third party.

Parents, grandparents and others with the foresight to leave funds in a third party special needs trust will provide significantly better benefits to the beneficiary who has a disability. This type of trust will not need to include a “payback” provision for Medicaid benefits upon the beneficiary’s death. During the beneficiary’s life, the kinds of payments the trust can make will usually be more generous and flexible.

The “Sole Benefit” Trust

Although there are two primary types of special needs trusts, there is actually a third type that might be appropriate under certain unusual circumstances. Because Medicaid rules permit applicants to make unlimited gifts to or “for the sole benefit of” disabled children or spouses, some individuals with assets may choose to establish a special needs trust for a child or grandchild with disabilities in hopes of securing eligibility for Medicaid for both themselves as grantor and for the disabled beneficiary. A number of states are very restrictive in their interpretation of the “sole benefit” requirement, so that such trusts are rarely seen. In many ways they look like a hybrid of the two other trust types; they may be taxed and treated as third-party trusts, but require a payback provision like a self-settled trust (at least in some states).

Some trusts are established by the beneficiary for the purpose of retaining or obtaining eligibility for public benefits with the beneficiary’s funds. By far the most common source of funds for “self-settled” special needs trusts is proceeds from a lawsuit—often (but not always) a lawsuit over the injury that resulted in the disability.

The Second Most Important Distinction

Once the type of trust is determined, the next important issue is discerning the type of government program providing benefits. Some programs (like SSDI and Medicare) do not impose financial eligibility requirements; a beneficiary receiving income and all his or her medical care from those two programs might not need a special needs trust at all, or might benefit from more flexibility given to the trustee. A recipient of SSI and/or Medicaid, however, may need more restrictive language in the trust document and closer attention on the part of the trustee.

SSDI/Medicare Recipients

Neither Social Security Disability Insurance benefits nor Medicare are “means-tested.” Consequently, it may be unnecessary to create a special needs trust for someone who receives benefits only from those two programs. After 24 months of SSDI eligibility, the beneficiary will qualify for Medicare benefits as well, so it may be appropriate to provide special needs provisions to get the SSDI recipient through that two-year period, during which he or she may rely on Medicaid for medical care. Restrictive special needs trust language may actually work against an SSDI beneficiary if it prevents distribution of cash to the beneficiary in all circumstances; an SSDI recipient will almost always benefit from broad language giving more discretion to the trustee.

Some SSDI/Medicare recipients may also receive SSI and/or Medicaid benefits. It may be critically important for those individuals to have strict special needs language controlling use of any assets or income that would otherwise be available. As the Medicare prescription drug benefit evolves over the next few years, this concern may be somewhat lessened—but for the moment, it remains true that availability of the drug coverage provided by Medicaid is critically important to many Medicare recipients.

Even an SSDI/Medicare beneficiary who does not receive any SSI or Medicaid benefits may be a good candidate for special needs trust planning. Future developments in public benefits programs, including housing, are uncertain, but constant budget pressure may well make benefits now taken for granted completely or partially indexed to income and/or assets in the future. Medical conditions also change, of course, and some persons with disabilities living in the community who presently receive adequate support from Medicare may one day become dependent on Medicaid for services not available under Medicare-like long term care.

SSI/Medicaid Recipients

Most special needs trust beneficiaries are eligible for (or seeking eligibility for) Supplemental Security Income payments. In many states, receipt of SSI payments automatically qualifies one for Medicaid eligibility. Many other government programs explicitly rely on SSI eligibility rules as well, so that SSI eligibility rules become the central concern for those charged with administering special needs trusts.

Veterans' Benefits

"Veterans' benefits" is the term used to describe the benefits available to veterans, the surviving spouses, children or parents of a deceased veteran, dependents of disabled veterans, active duty military service members, and members of the Reserves or National Guard. These benefits are administered by the U.S. Department of Veterans Affairs ("VA").

The benefits available to veterans include monetary compensation (based on individual unemployability or at least ten-percent disability from a service-connected condition), pension (if permanently and totally disabled or over the age of 65 and have limited income and net worth), health care, vocational rehabilitation and employment, education and training, home loans and life insurance. Although the pension is available to low-income veterans, it is important to note that some income, such as child's SSI or wages earned by dependent children, is excluded when determining the veteran's annual income. Also keep in mind that a service-connected disability payment will not offset SSDI, but any VA disability payment will offset SSI.

The benefits available to dependents and survivors of the veteran include Dependency and Indemnity Compensation ("DIC") and, in certain circumstances, home loans.

Transferring a VA recipient's assets into a special needs trust may not be fully effective. According to VA interpretation, the assets of such a trust will be counted as part of the claimant's net worth when calculating an improved pension. It is important to remember that the VA may place a "freeze" on new enrollees in order to manage the rapid influx of new veterans or older veterans who did not previously enroll for services. Therefore, it is important to evaluate current and future need for VA services in order to anticipate and plan for a situation where a person is otherwise eligible for VA benefits but, due to a freeze, cannot receive services. Under a new law, attorneys must become accredited with the VA to advise clients in this area.

Parents, grandparents and others with the foresight to leave funds in a third-party special needs trust will provide significantly better benefits to a beneficiary with disabilities.

Subsidized Housing

FEDERAL SUBSIDIZED HOUSING

The U.S. Department of Housing and Urban Development ("HUD") provides opportunities to low-income individuals and families to rent property at a cost that is lower than the open market. This is especially important to those people who are expected to pay for their shelter costs (rent or mortgage, plus utilities) with their insufficient SSI income. There are two issues to consider when evaluating the role of special needs trusts and subsidized housing: the initial eligibility for subsidized housing and the rent determination.

Eligibility for subsidized housing depends on the family's annual income. Annual income includes earned income, SSI, SSDI, pension, unemployment compensation, alimony, and child support, among other items. Annual income also includes unearned income, which is comprised, in part, of interest generated by assets. If the family has net family assets in excess of \$5,000, the annual income includes the greater of the actual income derived from all net family assets or a percentage of the value of such assets based on the current passbook savings rate, as determined by HUD.

Assets that are not included as income upon receipt are lump sums, such as inheritances and insurance settlements for losses (although the income they generate will be countable), reimbursement for medical expenses, PASS set-asides, work training programs funded by HUD and the income of a live-in aide.

In general, to qualify for federal subsidized housing, an individual's countable income may not exceed eighty percent of the median income in the area to be considered "low income", and the individual's income may not exceed fifty percent of the median income to be considered "very low income". The result is a disparity in eligibility depending on where the person resides within the county, state, and region of the country.

There is no asset limit to be eligible for federal subsidized housing, although as described above, if countable assets are greater than \$5,000, the interest income generated will be counted towards eligibility. If a person transfers an asset for less than its fair market value, then HUD will treat the asset as if it were still owned by the individual for two years after the transfer. HUD will assume that the asset generates

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income at the passbook rate and will include that income in calculating the individual's rent. Therefore, it is very likely that HUD will treat transfers to a special needs trust as a transfer for less than fair market value and, for the next two years, will include the interest generated by the special needs trust as income to the individual, either at the passbook rate or the actual earnings, whichever is greater.

Special Needs Trusts are excluded from family assets and the income generated by the trust assets is not included once the two-year penalty period has expired. It is important to note that, similar to other programs such as Medicaid and SSI, "regular" distributions from a special needs trust, even if made to a third-party provider, will be treated as countable income, even if used for non-food and shelter items.

The second issue relating to subsidized housing and a special needs trust is determining the monthly rent. Generally, an individual/family's rent will be thirty percent of their adjusted gross income. Similar to treatment under the threshold eligibility rules, the special needs trust and the income generated by trust assets are excluded, but "regular" distributions made directly to the beneficiary (as opposed to a third-party provider of goods or services) will be considered as income.

SECTION 8

Section 8 is a voucher program that is administered by HUD but managed by local public housing authorities ("PHA") or metropolitan housing authorities ("MHA"). The tenant pays their rent, typically thirty percent of their net adjusted income, to the landlord. The PHA pays the remaining balance due, which is called the voucher, to the landlord. The rent is based on the market value for the area and established by the PHA according to payment standards issued by HUD.

While a family member generally cannot serve as a Section 8 landlord, it is possible for a special needs trust to do so, even if the trustee is a family member. Although there are special rules applicable to a Section 8 landlord, it can be a beneficial relationship. The trust beneficiary would pay rent to the trustee (using the thirty percent of income rule) and the PHA would pay the remainder to the trustee.

It is important to investigate how your local housing authority's rules differ from the general rules listed above.

Temporary Assistance for Needy Families ("TANF")

TANF provides assistance and work opportunities to needy families. TANF is administered locally by the states, but is overseen by The Office of Family Assistance ("OFA"), which is located in the United States Department of Health and Human Services, Administration for Children and Families. TANF is a result of combining two other programs: Aid to Families with Dependent Children ("AFDC") and Job Opportunities and Basic Skills Training ("JOBS"). Because TANF is administered on a local level, the program and eligibility rules vary greatly from state to state. However, it is safe to assume that distributions directly made to the beneficiary of a special needs trust, or to the beneficiary's family if a minor, may be considered income and will impact eligibility for TANF.

In many states, receipt of SSI payments automatically qualifies one for Medicaid eligibility. Many other government programs explicitly rely on SSI eligibility rules as well, so that SSI eligibility rules become the central concern for those charged with administering special needs trusts.

Other Means-Tested Benefits Programs

State supplements to SSI and other government benefit programs, like vocational rehabilitation services, also play important roles in the lives of many individuals with disabilities. Because the welter of eligibility programs is confusing and the reach of most other programs is not as broad as those described in detail here, those other programs are not described in any depth. In analyzing the proper approach to establishment or administration of a special needs trust, however, care should be taken to consider all the available program resources and restrictions on use of trust funds mandated by those programs.

Eligibility Rules for Means- Tested Programs

As previously noted, the primary program with financial eligibility restrictions is SSI, the Supplemental Security Income program. Because the concepts are central to an understanding of other eligibility rules, and because many other programs explicitly utilize SSI standards, the SSI rules become the most important ones to grasp. They are described here in a general way, with a few notations where other programs (particularly long-term care Medicaid) differ from the SSI rules.

Income

SSI eligibility requires limited income and assets. SSI rules have a simple way of distinguishing between income and assets: Money received in a given month is income in that month, and any portion of that income remaining

on the first day of the next month becomes an asset. SSI rules also distinguish between what is “countable” or “excluded,” “regular” or “irregular,” and “unearned” or “earned” income. “Countable” income means that it is used to compute eligibility and benefit amount. “Excluded” means that it is not counted. “Regular” means that it is received on a periodic basis, at least two or more times per quarter or in consecutive months, and “irregular” or “infrequent” means that it is not periodic or predictable. “Unearned” means that it is passively received, such as SSDI benefits or bank account interest. “Earned” means that work is performed in exchange for the income. An SSI recipient is permitted to receive a small amount of any kind of income (\$20 per month) without reducing benefits. That amount is sometimes referred to as the SSI “disregard” amount.

Each classification or grouping has a somewhat different rule, and it is an understatement to call these income rules “confusing.” Any unearned income reduces the SSI benefit by the amount of the income, so investment income or gifted money simply reduces the benefit dollar for dollar, less the disregard. Earned income is treated more favorably, only reducing benefits by about half of the earnings. This is designed to encourage SSI recipients to return to the workforce. Keeping in mind that disability is defined as “unable to perform any substantial gainful activity,” it is easy to see that any significant amount of earned income will eventually imperil SSI eligibility and, since trust administration does not usually involve earned income in any event, we will not attempt to deal with those issues here.

SSI also has a concept of “in-kind support and maintenance” (ISM) that is central to much understanding of special needs trust administration. Any payment from a third party (including a trust) for necessities of life—food or shelter (note that the federal government deleted “clothing” from the list of necessities in March 2005) to a third party provider of goods or services—will be treated as countable income, albeit subject to special rules for calculating its effect.

The effect of receiving ISM on SSI benefits is different from the receipt of cash distributions. Where as cash payments reduce the SSI payment dollar for dollar, ISM reduces the benefit by the lesser of the presumed maximum value of the items provided or an amount calculated by dividing the maximum SSI benefit by three and adding the \$20 disregard amount.

For 2017 the maximum federal SSI benefit for a single person is \$735. One-third of that amount is \$245, and so the maximum reduction in benefits caused by ISM (no matter how high the value) is \$265 per month. The meaning of that confusing collection of information is best illustrated using an example (CAUTION: some states provide SSI supplemental payments that affect this calculation).

Consider John, who is disabled as a result of his serious mental illness. He has no work history, and he does not

qualify for SSDI. He is an adult, living on his own. He qualifies for the maximum federal SSI benefit of \$735; he lives in a state which does not provide an SSI supplement.

If John’s mother gives him \$100 cash per month (for food and cigarettes), he is required to report that as countable unearned income each month. Although SSI may take two or three months to accomplish the adjustment, the program will eventually withhold \$80 (\$100 minus the \$20 disregard) from his benefit for each month in which his mother makes a cash gift to him. The same result will obtain if John’s mother is trustee of a special needs trust for John and the cash comes from that trust.

If, however, John’s mother does not give him the \$100 directly, but instead purchases \$70 worth of food and \$30 worth of cigarettes each month, only the food will affect his SSI payment—reducing it by \$50 (\$70 minus the \$20 disregard). If she purchases \$20 worth of food and \$80 worth of cigarettes, there will be no effect at all—the food purchase is within the \$20 monthly disregard amount. Similarly, if she purchases \$20 worth of cigarettes and \$30 worth of movie tickets, there will be no effect—provided that the movie tickets cannot be turned in for cash (because if the movie tickets can be converted to cash, John could—even if he does not—convert the movie tickets into payment for food or shelter).

In other words, the effect of John’s mother’s payments to him or for his benefit changes with the nature of her payments. Any cash she provides to him (over the \$20 monthly amount ignored by SSI) reduces his SSI payment directly. Direct purchase of items other than food or shelter does not affect his SSI, so long as the purchased items cannot be converted to food or shelter. Finally, any payment she makes for food or shelter reduces his SSI check as well, but not as harshly as cash payments directly to John.

Now suppose that John’s mother decides to give up on trying to work around the strictures of SSI rules, and she simply pays his rent at an adult care facility that provides his meals. Assume that the facility costs her \$1500 per month, which she pays from her own pocket. Because of the ISM rules, John’s SSI benefit will be reduced by only \$265 per month, and so his SSI check will be \$490. Critically important, however, John will still qualify for Medicaid benefits in most states because he receives some amount of SSI. If the adult care home payment comes from a special needs trust for John’s benefit, the same result will occur, assuming that the room and board portion of the payment exceeds \$265. Incidentally, the same result will also obtain if John’s mother simply takes him in and allows him to live and eat with her without charging him rent.

Now assume that John does have a work history before becoming disabled, and that he qualifies to receive \$500 per month from SSDI. Because he has been receiving SSDI for more than two years, he also qualifies for Medicare.

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Because his countable income is less than \$735, he continues to receive \$255 in SSI benefits (\$20 of the SSD is disregarded), and qualifies for Medicaid as well (we will ignore the effect of the QMB and SLMB programs for qualified, special low-income Medicare beneficiaries, and the Medicare Part B premium which would ordinarily be withheld from his SSDI check). Now if John's mother pays his rent at the adult care home, or takes him into her own home, he will lose his SSI altogether—since he is receiving less than \$265 per month from SSI, the effect of the ISM rules will be to knock him off the program. Unless he separately qualifies for Medicaid, he will also lose his coverage under that program. The income strictures are the same or similar for other programs, with one important exception. In some states, but not all, eligibility for community or long-term care Medicaid is also dependent on countable income. The income tests vary. In some, you can "spend down" excess income over the limit to become eligible. In others, if countable income exceeds the benefit "cap" (like SSI), you cannot become eligible at all.

Some states also attempt to limit expenditures from self-settled (and even third-party) special needs trusts, and can require amendments to the language of those trusts in order to allow eligibility. While a good argument can be made that the Medicaid program does not have that ability, as a practical matter, the trustee of the special needs trust will have to either litigate that issue or acquiesce in the Medicaid agency's demands.

Assets

The limitation on assets for SSI eligibility may be somewhat easier to master, or at least to describe. A single person must have no more than \$2,000 in available resources in order to qualify for SSI. Some types of assets are not counted as available (called "non-countable"), including the beneficiary's home, one automobile, household furnishings, prepaid burial amounts plus up to \$1500 set aside for funeral expenses (or life insurance in that amount), tools of the beneficiary's trade, and a handful of other, less important items. Each of these categories of assets is subject to special rules and exceptions, so it is easy to become tangled in the asset eligibility structure.

Deeming

The SSI program considers portions of the income and assets of non-disabled, ineligible parents of minor disabled children and of an ineligible spouse living with the SSI recipient as available, and countable for eligibility purposes. This is called "deeming". A certain portion of the ineligible person's income and assets is considered as necessary for his or her own living expenses, and therefore is excluded.

As soon as a child reaches age 18, parental deeming no longer occurs, even if the child continues to live in the household. If spouses voluntarily separate and live in different households, then deeming from the separate spouse or parent also ends. However, in both instances, if the separate person continues to provide support or maintenance to the SSI eligible individual, it will still count as income as described above unless a Court orders it to be deposited directly into the trust. There is also a limited exception to all parental deeming for a severely disabled minor child returning home from an institution or whose condition would otherwise qualify them for institutionalization, which is called a waiver.

"I Want to Buy a..." or "I Want to Pay for..."

What do these complicated rules mean for expenditures from a special needs trust? In-kind purchases, meaning purchase of goods or services for the benefit of the beneficiary, only potentially affect the SSI benefit amount, and not Medicaid benefits, although the Medicaid agency may restrict expenditures for approved things. There are a number of specific purchases that frequently recur:

Home, Upkeep and Utilities

Keep in mind that SSI's in-kind support and maintenance (ISM) rules deal specifically with payments for "food and shelter." The Social Security Administration includes only these items as food and shelter:

1. Food
2. Mortgage (including property insurance required by the mortgage holder)
3. Real property taxes (less any tax rebate/credit)
4. Rent
5. Heating fuel
6. Gas
7. Electricity
8. Water
9. Sewer
10. Garbage removal

The rules make special note of the fact that condominium assessments may in some cases be at least partial payments for water, sewer, garbage removal and the like.

In other words, a payment for rent will implicate the ISM rules, as will monthly mortgage payments. The outright purchase of a home, whether in the name of the beneficiary or the trust, will not cause loss of SSI (although it may reduce the beneficiary's SSI benefit for the single month in which the home is purchased). This brings up

another consideration. Purchase of a home in the trust's name will subject it to a Medicaid "payback" requirement on the death of the beneficiary, whereas purchase in the name of the beneficiary may allow other planning that will avoid the home becoming part of the payback. This complicated interplay of trust rules, ISM definition, estate-recovery rules, and home ownership makes this area of special needs trust administration particularly fraught with difficulty.

However, the Medicaid state agency's treatment of distributions from special needs trusts may differ from the Social Security interpretation—especially when the beneficiary of a self-settled trust is eligible for Medicaid benefits. For example, contrary to putting the house in the individual's name, a state may require that any purchase of a home by such a trust would result in title being held in the trust's name, thereby ensuring that the state will at least receive the proceeds from the sale of the residence upon the death of the beneficiary.

Clothing

Until March 7, 2005, purchase of clothing by a trust was considered as ISM for SSI, similar to shelter and food. Since then, a clothing purchase for the beneficiary will not affect the benefit amount or eligibility, whether the clothing in question is special garments related to the disability or just ordinary street clothes and shoes. Not all state Medicaid regulations reflect this change.

Phone, Cable, and Internet Services

Other than those utilities listed above, there is no federal limitation on utility payments. In other words, the trust can pay for cable, telephone, high-speed internet connection, newspaper, and other "utilities" not on the list.

Vehicle, Insurance, Maintenance, Gas

Purchase of a vehicle and maintenance (including gas and insurance) is permitted under federal law. Note that there is a mechanical difficulty in providing gasoline without providing cash that could be converted to food or shelter. One technique which has worked well has been to arrange for the beneficiary to have a gas-company credit card. Because eligibility for such cards is easier to meet, and because the cards cannot be used to purchase groceries, administration of the credit account is easier to set up and monitor, and the card can then be billed directly to the trust.

Some state Medicaid agencies put limitations on the value, type, and title ownership of vehicles, such as only allowing a vehicle valued at up to \$5,000, handicapped-equipped, or requiring a lien in favor of the payback trust on the title. The SSI program does not specifically require or monitor such limitations.

As soon as a child reaches age 18, parental deeming no longer occurs even if the child continues to live in the household.

Pre-paid Burial/Funeral Arrangements

Nothing in federal law prohibits or restricts use of special needs trust funds for purchase of burial and funeral arrangements during the beneficiary's lifetime— except to the extent that the beneficiary has access to the funds used to pay for the arrangements, and thereby subject to the asset limitations affecting SSI recipients. State Medicaid agencies may limit the value of the burial contract. It is important to ask for an "irrevocable, pre-paid" funeral plan.

Tuition, Books, Tutoring

No limit under either federal or state law. This is an excellent use of special needs trust funds.

Travel and Entertainment

Once again, no limit except that there may be some concern about payment for hotels. When the beneficiary still maintains a residence at home, the hotel stay and restaurant may be considered "shelter" and "food" expenses. Some states may impose limitations on companion travel not found in federal law. These might include not allowing recipients to have the special needs trust pay for more than one traveling companion, the companion must be necessary to provide care, and the companion may not be a person obligated to support the beneficiary such as a minor beneficiary's parent. Note that foreign travel can have two other adverse effects: (1) airline tickets to foreign destinations, if refundable, will be treated as being convertible into food and shelter, and (2) if an SSI recipient is out of the country for more than a month, he or she may lose eligibility until return. For those reasons, foreign travel, unlike domestic travel, usually must be limited in time.

Household Furnishings and Furniture

The trust can be used to purchase appliances, furniture, fixtures and the like. Before March 2005, there was a theoretical concern in the SSI program that the value of household furnishings might exceed an arbitrary limit and affect the beneficiary's eligibility; that value limit has now been removed.

Television, Computers and Electronics

There is no specific limitation on purchase of household televisions or other electronic devices, although under SSI rules the individual is only allowed to own "ordinary household goods" that are not kept for collectible value and are used on a regular basis. The trust can also provide a computer for the beneficiary, plus software and upgrades.

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Durable Medical Equipment

There is no federal limitation on any medical related equipment, but individual states may limit purchase of some equipment as not being "necessary." Problem areas could be if the equipment could also be considered as recreational, such as a heated swimming pool needed for arthritic or other joint conditions.

Care Management

No federal limitation, but many states attempt to limit payments for care or management if made to a family member or other relative, especially if there is an obligation of support (e.g., parents of minor children).

Therapy, Medications, Alternative Treatments

Same principle as durable medical equipment, above, so long as the state does not regulate the treatment, there is no federal limitation.

Taxes

No federal limitation, but states may attempt to direct trust language on what taxes can be paid for, such as taxes incurred as a result of trust assets or at the death of the beneficiary. Since it is difficult to imagine an SSI or Medicaid beneficiary having significant non-trust income, it is hard to see how this limitation is so much troublesome as it is quarrelsome.

Legal, Guardianship and Trustee Fees

At least some states allow legal, guardianship, and trustee fees to be paid from the trust, although some federal law indicates that payment of guardian's fees or guardian's attorney fees may really benefit the guardian and not the beneficiary. Payments for trust administration expenses, including the trust's attorney's fees, are clearly permissible under both federal and state law, and are rarely limited beyond reasonableness standards.

Loans, Credit, Debit and Gift Cards

Receipt of a "loan" will not count as income for the SSI or Medicaid programs, which means that a trust can make a loan of cash directly to a beneficiary. There are rules that must be followed for loans to be valid and non-countable. There must be an enforceable agreement at the time that the loan is made that the loan will be paid back at some point, which usually means that it should be in writing. The agreement to pay back cannot be based on a future

contingency such as, "I only have to pay it back if I win the lottery..." Finally, the loan must be considered as "feasible," meaning that there is a reasonable expectation that the beneficiary will have the means at some point to pay back the loan.

If a loan is forgiven, then it would count as income at that time. Also, if the beneficiary still has the loaned amount in the following month, it will then count as a resource. However, school loans are not countable as income or as a resource so long as the funds are spent for tuition, room and board, and other education-related expenses within nine months of receipt.

Since goods or services purchased with a credit card are actually a "loan" that must be paid back to the credit card company, they are also not considered as income to the beneficiary at time of purchase. As long as the beneficiary doesn't sell the goods for cash, there is also the added advantage that the trust can pay back the credit card company without the payment counting as income, except for purchases that are considered as food or shelter. Food and shelter related purchases use the same ISM countable income rules (and particularly the countable income limits) described above.

It is generally beneficial for a self-settled special needs trust to be a grantor trust. This is true because the tax rates for non-grantor trusts are tightly compressed, and the highest marginal tax rate on income is reached very quickly for trusts.

Use of a debit card by a beneficiary when purchases are made for payment through a trust-funded bank account is income to the beneficiary for the amount accessed. The total amount in the account available to be accessed could possibly be a countable resource. Is a gift card purchased by a trust and provided to a beneficiary considered to be a distribution of income, a line of credit to a vendor (similar to a credit card), or just access for in-kind purchase of goods or services on behalf of a beneficiary by the

trust? SSI rules are not yet clear on this point, and it is probable that different Social Security and Medicaid offices will treat the use of debit and gift cards differently until precise guidelines are provided by the agencies. The safe approach is to use them in a very limited way; if they are to be used at all, keep receipts for all special needs items, and be prepared for adverse treatment.

Trust Administration and Accounting

Actual administration of a special needs trust is in most respects similar to administration of any other trust. A trustee has a general obligation to account to beneficiaries and other interested parties. Tax returns may need to be filed (though not always), and tax filing requirements will be based on the tax rules, not special needs trust rules. Some special needs trusts, but by no means all, will be subject to court supervision and control.

Trustee's Duties

As with general trust law requirements, the trustee of a special needs trust has an obligation not to self-deal, not to delegate the trustee's duties impermissibly, not to favor either income or remainder beneficiaries over one another, and to invest trust assets prudently. The obligations of a trustee are well-discussed in several centuries of legal precedent, and cannot be taken lightly. Legal counsel (and professional investment, tax and accounting assistance) will be required in administration of almost every special needs trust.

A few cardinal trust rules bear special mention:

NO SELF DEALING

As with other trusts, the trustee of a special needs trust is prohibited from self-dealing. That means no investment of trust assets in the trustee's business or assets, no mingling of trust and personal assets, no borrowing from the trust, no purchase of goods or services (by the trust) from the trustee (other than, of course, trust administration services), and no sale of trust assets to the trustee. The same strictures also apply to the trustee's immediate family members, and the existence of an appraisal, or the favorable terms of a transaction, do not change these rules.

IMPARTIALITY

Because the trust has both an "income" beneficiary (the person with disabilities) and a "remainder" beneficiary (the state, in the case of a Medicaid payback trust, or the individuals who will receive assets when the income beneficiary dies), the trustee has a necessarily divided loyalty. It is important to remain impartial as between the trust's beneficiaries. Thus, investment in assets exclusively designed to maximize income at the expense of growth, or vice versa, may violate the trustee's duty to the negatively affected class of beneficiaries. Note that a trust may, by its terms, make clear that the interests of one or the other class of beneficiaries should be paramount—though such language will probably earn the disapproval of the Medicaid agency in any self-settled trust which must be submitted to Medicaid for approval.

DELEGATION

Generally speaking, a trustee may delegate functions but may not avoid liability by doing so. In other words, while the trustee may hire investment advisers, tax preparers and the like, he or she will remain liable for any failures by such professionals.

Some states do limit the trustee's liability. For example, in states which have adopted the Uniform Prudent Investor Act, delegating investment authority pursuant to the Act will limit the trustee's liability so that he or she will only be required to carefully select and monitor the investment adviser.

INVESTMENT

Any trustee should be familiar with the principles of Modern Portfolio Theory, with its emphasis on risk tolerance and asset diversification. A trustee who holds himself, herself, or itself out as having special expertise in investments or asset management will be held to a higher standard, but any trustee will be required to understand and implement prudent investment practices. Some courts will institute an investment policy that requires a percentage of assets to be held in fixed income investments and the remainder in securities (e.g., a 60/40 split is common).

A trustee has a general obligation to account to beneficiaries and other interested parties. Tax returns may need to be filed (though not always), and tax filing requirements will be based on the tax rules, not special needs trust rules.

Bond

A trustee, especially one who administers a special needs trust supervised by a probate court, may need to be bonded. Bond is a type of insurance arrangement whereby the trustee pays a premium in order to guarantee that the trustee manages the trust and carries out his or her fiduciary duties correctly. The bond premium is an acceptable expense of the trust, and need not come out of the trustee's own pocket. If the trustee fails to exercise his or her fiduciary duty and the trust loses money as a result, the insurance company that issued the bond will compensate the trust and take action to collect from the trustee.

The bond premium depends on multiple factors, including the credit history of the trustee and the value of the trust. Most corporate trustees are exempt from posting bond. Individual trustees must "post bond"; that is, provide written documentation to the probate court that the individual is bonded. The bond is typically issued for a set period of time, for example one year, and at the expiration of the time period, the trustee must pay an additional premium or show the bond issuer that bond is no longer required by the probate court.

It is possible in most states, at least when the trust is supervised by a court, to ask the court for permission to deposit the assets in a restricted or "blocked" account with a financial institution rather than posting bond. While this circumvents the issue of being bonded, the financial institution should require a certified copy of the court's order authorizing the expenditure of funds prior to making a distribution from the special needs trust. This can result in frequent in-person trips to the bank by the trustee, although it avoids the sometimes costly bond premium.

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Titling Assets

The trust assets should not be titled in the beneficiary's name except in limited circumstances, such as when it is advantageous to title the home in the individual's name. Typically, the trust assets should be titled in the name of the trustee. For example, if James Jones is the trustee of the Lisa Martin Special Needs Trust, and that trust was signed on March 15, 2007, then the trust assets should be titled as follows: "James Jones, Trustee of the Lisa Martin Special Needs Trust u/a/d March 15, 2007" ("u/a/d" means "under agreement dated").

It is important that most assets not be held in James Jones's or Lisa Martin's name individually. If the assets are not titled properly, then the assets may be counted as a resource, or the interest earned counted as income, by the agencies that administer means-tested government benefits, which will frustrate the purpose of the special needs trust, as well as contribute to confusion during tax preparation. Additionally, as discussed in further detail below, it may also be important to request a separate Tax ID number for the trust as well as properly title the assets.

Accounting Requirements

A trustee is required to provide adequate accounting information to beneficiaries of the trust. That requirement generally means annual accountings. While there is no specific form required for accountings if the trust is not under court supervision, it is important to provide enough information that a reader could determine the nature and amount of any payment or investment. For some trusts, a simple "check register" accounting may be sufficient, showing interest income and the names of payees, with dates and amounts. Any trust with significant assets or diverse investments, however, should provide a thorough accounting.

Regular, complete accountings are critical. A beneficiary is generally foreclosed from later raising objections to investments or expenditures if he or she received adequate disclosure in the annual accounting at the time. In other words, thorough accounting can limit the trustee's later exposure to claims by beneficiaries, and therefore benefits the trustee.

In addition to the accounting requirements to the beneficiary, the trustee may be required to provide an annual or biennial accounting to the probate court. The trustee should use the county-specific forms available

upon request from the court, and may also be required to provide the court with copies of bank statements and cancelled checks or receipts as evidence of trust distributions and deposits. This requires the trustee to be organized or be prepared to pay potentially substantial bank fees for duplicate account statements or cancelled checks.

Reporting to Social Security

The simple term "income" has different meanings in trust accounting, tax preparation, and public benefits eligibility determinations. Trustees sometimes raise concerns that thorough trust accountings (to SSI, especially) may result in suspension of benefits, or that tax return information may be used to terminate SSI or other benefits. While such things undoubtedly do occur, Social Security workers are increasingly likely to be relatively sophisticated about such distinctions, and willing to work through any problems. In a general way, then, it is better to disclose more fully to Social Security rather than withhold any information. Annual accountings of any self-settled trust naming an SSI recipient as beneficiary should be provided to Social Security. Any third-party trust which makes significant distributions for the benefit of an SSI recipient should probably be provided to Social Security, just to prevent later problems that could have been headed off. If distributions disrupt eligibility, the problem is with the distribution, not with the accounting.

If the beneficiary receives only SSDI and not any concurrent SSI, there is no point in providing accounting information to Social Security, because SSDI benefits are not means-tested. If the trust is a third-party trust, the trustee may not have any obligation to provide accounting information, though the beneficiary may (if the beneficiary receives SSI and trust distributions invoke the ISM rules) be required to do so.

Although it no longer occurs as regularly, some Social Security eligibility workers may misunderstand the effect of special needs trust expenditures or terms and reduce or eliminate benefits improperly. When this does occur, it should be possible to remedy the error, but the beneficiary may suffer for months (or years) while the system works out the problem. Far better to head off problems in advance, rather than have to spend substantial resources and time resolving them after the fact. Be aware that fees for a trustee's time spent directly dealing with Social Security on the beneficiary's behalf may be subject to approval by SSA.

Reporting to Medicaid

If the beneficiary resides in a state where the receipt of SSI results in the beneficiary also being automatically enrolled in Medicaid, then no separate accounting requirement need be made to the Medicaid agency. However, if the individual is in a state where SSI and Medicaid are not interrelated, then it may be necessary to account to both agencies. The Medicaid consumer (or their guardian) is required to notify Medicaid of a change in resources or income within a set period of time, usually as short as ten days. This includes situations where the Medicaid consumer receives an inheritance or settlement and immediately transfers the funds to a special needs trust.

The trustee of a third-party special needs trust may not have the same duty to account, but may choose to provide accounting information to Medicaid rather than risk later disqualification of the beneficiary, even though Medicaid's power to consider trust expenditures may be subject to challenge.

Reporting to the Court

Many self-settled special needs trusts will be treated in essentially the same fashion as a conservatorship or guardianship of the estate. This is so because, typically, the court was initially asked to authorize establishment of the trust. Most courts expect any trust established by the court to remain under court supervision, including bonding, seeking authority to expend funds, and filing periodic accountings.

Even if the trust does not require court accounting, some consideration should be given to seeking court involvement. One great advantage of court supervision of the trust is that each year's accounting is then final as to all items described in that accounting (provided, of course, that the appropriate notice has been given to beneficiaries who might otherwise complain about the trust's administration and other court procedural requirements are followed).

The Court may also have a set fee schedule that governs the amount the trustee can be compensated for providing trust administration services.

Modification of Trust

As explained above, a special needs trust must be irrevocable in order for the trust to be considered an exempt resource. However, that does not preclude the trust itself from permitting the trustee to amend or modify the trust in limited ways, particularly as it relates to program eligibility for the beneficiary. This is particularly important since we cannot predict future changes to the laws governing means-tested benefits. The courts may also be willing to modify or terminate a trust whose purpose has been frustrated by law changes or other factors, such as the trust assets being valued at a nominal amount.

Wrapping up the Trust

If the special needs trust is a self-settled trust with a provision requiring repayment of Medicaid expenses, it will obviously be necessary to determine the "payback" amount upon the death of the beneficiary or termination of the trust. Because Medicaid's historical experience with these trusts is still slight, state agencies may have difficulty providing a reliable and final figure. The prudent trustee will request a written statement of the amount due, including evidence showing how it was calculated and a statement of authority to make the final determination. Once any payback issues have been addressed (and remember that most third-party special needs trusts will have no requirement of repayment to the state), then termination of the trust will follow the usual requirements of tax preparation and filing, final accounting and distribution according to the trust instrument. Remember, because Social Security requires that Medicaid reimbursement and certain tax liabilities must be squared away before the trustee may even pay for the beneficiary's funeral, purchase during the beneficiary's lifetime of an irrevocable pre-paid funeral is critical.

Income Taxation of Special Needs Trusts

Special needs trusts, like other types of trusts, can complicate income tax preparation. The first question to be addressed is whether—for income tax purposes—the trust is a "grantor" trust or not. Tax rules defining "grantor" trusts are neither simple nor intuitive, but fortunately there are some easy rules of thumb to apply, and they will work for most special needs trusts.

"Grantor" Trusts

A "grantor" trust is treated for tax purposes as a transparent entity. In other words, the grantor of a "grantor" trust is treated as having received the income directly, even though the accounts are titled to the trust and all income shows up in the name of the trust.

Generally speaking, a self-settled special needs trust will be a grantor trust if a family member is the trustee. If the trust names an independent trustee it may still be a grantor trust if one of several specific provisions exists in the trust. A qualified accountant or lawyer should be able to tell whether a given trust is a grantor trust at a glance. If it is, it remains a grantor trust for its entire life—or at least until the death of the grantor (when the trust may either terminate or convert into a non-grantor trust as to its new beneficiaries). Until the trust has been reviewed by an expert, assume that it is probably a grantor trust.

It is generally beneficial for a self-settled special needs trust to be a grantor trust. This is true because the tax rates for non-grantor trusts are tightly compressed, and the highest marginal tax rate on income is reached very quickly for trusts. The practical difference will be small

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if the trust actually makes distributions for the benefit of the beneficiary in excess of its annual taxable income, but the proper tax reporting approach should still be followed.

TAX ID NUMBERS

A grantor trust may, but need not, obtain an Employer Identification Number (an EIN). Some attorneys and accountants choose to secure an EIN in each case, while others resist doing so—either approach is defensible. Although banks, brokerage houses and other financial institutions may insist that the trust requires its own EIN, they are simply wrong. There is widespread confusion about the necessity for an EIN for irrevocable trusts, but a confident and well-informed trustee, attorney or accountant should be able to convince the financial institution that no separate EIN is required. Instead, the trustee can simply provide the financial institution with the grantor's Social Security number.

FILING TAX RETURNS

A grantor trust ordinarily will not file a separate tax return. If a grantor trust has been assigned an EIN, it may file an “informational” return. The return can include a paragraph indicating that the trust is a grantor trust, that all income is being reported on the beneficiary’s individual return, and that no substantive information will be included in the fiduciary income tax return. Actually, completing the fiduciary income tax return is not an option for a grantor trust, although again there is much confusion on this point, even among some professionals.

Non-Grantor Trusts

Virtually all third-party, and some self-settled, special needs trusts will be non-grantor trusts. Because income will not be treated as having been earned by the beneficiary, a fiduciary income tax return (IRS form 1041) will be required.

TAX ID NUMBERS

A non-grantor trust will need to obtain its own EIN by filing a federal form SS-4. Nearly all third-party special needs trusts will be “complex” trusts—this designation simply means that the trust is not required to distribute all its income to the income beneficiary each year. Although the trust will be listed as “complex” on the SS-4, it may in fact alternate between “complex” and “simple” on each year’s 1041.

FILING TAX RETURNS

The non-grantor trust must file a 1041 each year. All distributions for the benefit of the beneficiary are conclusively presumed to be of income first, so any trust expenditures in excess of deductions will result in a Form

K-1 showing income imputed to the beneficiary. This should not cause particular concern, since Social Security (and even Medicaid) eligibility workers are increasingly likely to understand that “income” for tax purposes is different from “income” for public benefits eligibility purposes. Any tax liability incurred by the individual beneficiary as a result of this imputation can be paid by the trust, though the trustee may not have the authority to prepare and sign the individual’s tax return.

Administrative and other deductible expenses on an individual tax return must reach 2% of the taxpayer’s income before being deducted at all. The same is not true of a trust tax return, leading to a modest benefit to treatment as a non-grantor trust in some cases. This benefit may not offset the compressed income tax rates levied against non-grantor trusts, but each case will be different. The difficulty in determining the proper—and the best—income tax treatment is made worse when one adds the confusing option of treatment as a “Qualified Disability Trust.”

Qualified Disability Trust

Beginning in 2002, Congress allowed some non-grantor special needs trusts to receive a modest income tax benefit. Trusts qualifying under Internal Revenue Code Section 642(b)(2)(C) receive a special benefit—they are permitted to claim a personal exemption on their federal income taxes. In tax year 2017, for example, the personal exemption will be \$4,050, which means that income up to that amount will not generate any tax liability at all. In fact, once the trust uses its exemption and calculates the remaining taxable income, it is usually passed through to the beneficiary—who gets to claim another \$4,050 personal exemption.

Coupled with the greater flexibility available to non-grantor trusts in deducting administrative expenses, Qualified Disability Trust treatment may be advantageous in some cases. Typically, the Qualified Disability Trust election will be attractive when there is a fair amount of income on trust assets, and relatively few medical or other expenses incurred on behalf of the beneficiary. Careful review with a qualified income tax professional is usually necessary to determine whether to pursue Qualified Disability Trust treatment.

Seeking Professional Tax Advice

It should be apparent from this brief discussion of taxation of special needs trusts that professional tax preparation and advice are essential. Although most accountants are qualified to prepare fiduciary (trust) income tax returns, most do not have much experience in the field. A first question to ask a prospective accountant might be “How many 1041s do you typically prepare in a year?” Follow that with “Could you please explain the concept of Qualified Disability Trusts to me?” and you will quickly locate any truly proficient practitioner. You probably will not want to automatically reject an

accountant who cannot tell you about Qualified Disability Trusts immediately, unless you are prepared to deal with an accountant in another city—there are simply not very many accountants or tax preparers who have ever had occasion to claim that status on any fiduciary income tax return. As always, you can get some assistance in complicated special needs trust issues from the attorney who prepared the document, or the attorney who advises you as trustee. Members of the Special Needs Alliance® are usually among the very few who are familiar with these concepts, and your attorney may have worked with an accountant in your area who is familiar with the special tax treatment of these trusts.

For Further Reading

There are a handful of books and articles, and a growing number of websites, available to aid trustees of special needs trusts. Among our favorites:

Special Needs Trust Administration Manual: A Guide for Trustees, by Jackins, Blank, Macy and Shulman—this guide is among the best available. It was written by four Massachusetts lawyers, and is frankly focused on Massachusetts law and practice. Much of what the authors have to say, however, is applicable to special needs trusts in every state.

Special People, Special Planning: Creating a Safe Legal Haven for Families with Special Needs, by Hoyt and Pollock—provides some general advice and direction, but is more conversational than detailed. This volume also tends to focus on the “why” more than the “how”, which is an important message but not as useful to someone who is already administering a special needs trust.

Special Needs Trusts: Protect Your Child’s Financial Future, by Elias—this recent addition to the literature comes from Nolo Press, an organization that many lawyers find annoying at best. We disagree. This is a plain-language, straightforward explanation of special needs trusts from a lawyer who doesn’t even practice in the area (his previous books for Nolo Press include explanations of bankruptcy, trademark and other areas of law).



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VI. SPECIAL NEEDS TRUST REVIEW PROGRAMS (used with express permission)

THE EVOLUTION OF SPECIAL NEEDS TRUST REVIEW

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Not only must today's special needs trusts include the flexibility to address changing situations, but the attorneys preparing them must stay current on the volatile environment in order to be effective. OBRA 93 ushered in a new age in the use of Special Needs Trusts as planning vehicles for persons with disabilities with new requirements for federal and state SNT reviews. The states, however, have little in the way of resources to meet the demand for effective SNT review programs. Creative states are increasingly seeking the assistance of private resources. This session will describe the successful HMS program for SNT reviews, and give the practitioner practical insight into state perspectives on SNTs and SNT accounting reviews, with focus on the HMS Georgia and North Carolina Trust Units.

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I. INTRODUCTION: BRIEF BACKGROUND OF SPECIAL NEEDS TRUSTS AND THE HMS TRUST PROGRAMS

In 1993 Congress enacted the Omnibus Budget Reconciliation Act of 1993 (OBRA 93).²⁹ This legislation had significant impact on the Medicaid program, including in the form of altering the Medicaid law regarding transfers of assets and trusts. For Medicaid eligibility purposes it exempts certain Special Needs Trusts from application of the OBRA 93 Medicaid transfer of asset and trust rules.³⁰ SNTs established in accordance with these provisions are often referred to as "d4" trusts, for the section of Medicaid law enacted by OBRA 93 that recognizes them and specifies the mandatory criteria. Then in 1999 FCIA 99 reinstated SSI transfer penalties and promulgated new rules for treatment of trusts for the SSI program that parallel the OBRA 93 trust provisions. Certain transfers are exempted from the imposition of the reinstated SSI transfer penalties and the SSI treatment of trust rules,³¹ including transfers to certain d4 Special Needs Trusts authorized by OBRA 93.³² The SSI trust provisions became effective January 1, 2000, and apply to all trusts established on or after January 1, 2000.³³

The trust and transfer provisions of OBRA 93 and FCIA 99 have presented the Social Security Administration (SSA), the Centers for Medicare and Medicaid Services (CMS) and the state Medicaid agencies with the challenge of determining how to review SNT documents for compliance, and, ultimately, how to review accountings of trust activities by the trustees of SNTs. At the federal level, national guidance has been given for Medicaid purposes through the CMS State Medicaid Manual,³⁴ but only to a limited extent. The majority of federal guidance has been given for SSI purposes through the SSA's Program Operations Manual System (POMS).³⁵

At the state level there is no uniformity in approach to the challenge of reviewing SNTs and SNT accountings. Some states review SNTs through the state Attorney General's office; some through state agency legal departments; others put the responsibility on Medicaid case workers; most make no review whatsoever. With regard to SNT accountings, virtually none of the states have been making reviews, even when accountings are submitted, unless a dispute arises between the state agency and the trustee of a particular SNT.

This is changing, however. In recent years states have struggled with declining revenues and budget cuts, and have realized that their legal resources are overwhelmed and generally incapable of adding the highly complex and technical area of trusts -- especially Special Needs Trusts -- to legal department responsibilities. As a result, a growing number of states are making the determination that it would be more efficient, costs significantly contained, and recoveries significantly enhanced, if they were to contract with a private vendor rather than incurring the hard and soft costs of creating, establishing, staffing and administering an "in-house" Trust and Accounting Review program. This is the evolution and the future of Special Needs Trust review.

²⁹ Omnibus Budget Reconciliation Act of 1993, Public Law No. 103-66, August 10, 1993.

³⁰ Codified at 42 U.S.C. § 1396p(d)(4).

³¹ FCIA 99 Sec. 206(a)(5), codified at 42 U.S.C. 1382b(c)(1)(C).

³² FCIA 99 Sec. 206(a)(5), codified at 42 U.S.C. 1382b(c)(1)(C)(ii).

³³ FCIA 99 Sec. 205(d).

³⁴ Available on line at www.cms.hhs.gov/Manuals/IOM/list.asp, publication #100-12; see Sections 3257 through 3259 regarding Transfers of Assets and Treatment of Trusts, published in November, 1994 as Transmittal 64 to the State Medicaid Manual (provides the basis for the POMS trust provisions).

³⁵ <https://secure.ssa.gov/apps10/poms.nsf/aboutpoms>

Health Management Systems (HMS) is the contractual partner chosen by a number of states to develop and administer a Trust and Accounting Review program. HMS is a publicly-traded national corporation based in New York that provides health care cost containment services to state and federal agencies. As stated on the corporate website, HMS is the nation's leader in cost containment, program integrity, and coordination of benefits solutions for government-funded and commercial healthcare entities.³⁶ It is the largest and most experienced private provider of Medicaid recovery services in the country, and the only vendor that offers a Trust and Accounting Review program.

HMS established a Trust Services Unit that has developed and implemented programs for the review of SNTs and SNT accountings for state clients. The first state to take this evolutionary step with HMS in 2008 was the State of Georgia; the program was expanded in 2009 to include a trust accounting review component. These programs have been designed and implemented as best practice models and are being utilized by an increasing number of state agencies around the country, including Iowa, Alabama and North Carolina.

II. THE TRUST REVIEW PROGRAM.

Overview of the Trust Review Program. Through HMS Trust Services all types of Special Needs Trusts are reviewed that are sent to a contracting state Medicaid agency from any source, including attorneys, trustees, and local agency offices. The purpose of the review is to make sure that each trust meets the mandatory requirements and criteria set forth in federal and state law and policy so as to qualify as a resource exemption for Medicaid eligibility purposes. As noted above, this includes OBRA 93, FCIA 99, the CMS State Medicaid Manual, and the SSA POMS. The applicable state policy appears in the Medicaid Manual of the appropriate state Medicaid agency.³⁷ In addition, most states have administrative rules that serve to implement state policies. All in all, this is quite an extensive body of law and policy.

The HMS Trust Services Unit first developed and established a formal trust review process and workflow, including a full library of correspondence, notices and checklists. The program is designed to review all types of SNTs, including d4As, d4C pooled trusts, Third Party SNTs, testamentary SNTs, Sole Benefit Trusts (SBTs), and for some clients Qualified Income Trusts (QITs/d4Bs) that contain confusing or questionable provisions.

The Trust Services Unit. The Trust Services Unit is administered by recognized experts, and the staff of JDs and a CPA is trained, knowledgeable, and experienced. The Unit is part of the Subrogation Division of HMS, which provides all types of TPL services to government agencies. The Unit utilizes a case management system developed and maintained by HMS, and has created a specific Trust Unit structure and workflow within that system. When a Special Needs Trust file is opened by the Unit for a state client, an electronic copy is made and attached to the file in the case management system, including the SNT document and supporting documentation and correspondence.

The Review Process. One of the most significant values the HMS Trust and Accounting Review program brings to each state client is a standardized, systematic approach to trust program administration. This is of great benefit both to the state and the Bar, since each knows how the program works and what to expect. In addition, the Review Program provides the opportunity to have a draft trust reviewed. This enables questions and issues to be identified and addressed prior to execution of the trust document, thus avoiding the need to formally amend the document and the possible need to obtain a court order authorizing the change.

For the Trust Unit and our state clients the underlying primary goal of Trust Review is to approve trusts, not deny them. To achieve this goal the review process and procedures have been constructed to allow every opportunity for a SNT to be approved. The workflow for the trust review program generally includes the following steps or stages:

Receipt of New Case and Data Match. A new trust document is logged in immediately upon receipt, a case number assigned, and basic information captured. Case numbers are assigned in numerical order, and case files are in the name of the trust beneficiary. At the same time, a data match is performed in the state MMIS (Medicaid Member Information System) to determine if the trust beneficiary is currently Medicaid eligible.

³⁶ http://www.hms.com/about_us/index.asp

³⁷ For example, see the Medicaid Manual for the State of Georgia, Sections 2337 (Trust Property - OBRA '93), 2338 (Trust Property), 2346 (Special Needs Trust), 2407 (Qualified Income Trust), and 2342 (Transfer of Assets). For North Carolina, the Adult Medicaid Manual of the North Carolina Department of Health and Human Services, Section MA-2230, Section XI, Trust Funds. For Alabama, the Alabama Medicaid Agency Administrative Code, Section 560-X-25-.08 Development of Ownership Interest In Liquid Resources For SSI-Related Individuals and 560-X-25.09 Transfer of Assets Affecting Eligibility.

Case Tracking. An electronic case file is created for each trust case, including all information and documentation required. Document imaging is used to scan and image documents into the electronic case file.

Correspondence: A step-by-step correspondence library of state-approved correspondence items is programmed into the case tracking system. The system automatically retains an image of the correspondence in the online case file.

Pre-Trust Liens: As part of the review process, a determination is made of whether the trust is being funded with proceeds of a lawsuit or settlement. If so, the case is referred to the Subrogation Unit to determine if there is a pre-trust lien, and if so, whether the lien has been resolved. If there is an outstanding pre-trust lien, the review process is suspended until the lien is resolved.

Communication: A dedicated Trust Unit telephone number is staffed to provide information from 8 a.m. to 5 p.m., Monday to Friday. There is also a dedicated fax number, and email addresses for staff are provided. The majority of trust documents and other related documents are filed electronically via email.

Case Closure: Upon receipt of payment of the required payback at termination of the trust, a Release is issued to the trustee of the SNT and the file is closed.

III. THE TRUST ACCOUNTING REVIEW PROGRAM

In parallel with the trust review process, one of the most significant values the HMS Accounting Review program brings to each state client is a standardized, systematic approach to accounting review program administration. This is of great benefit both to the state and the Bar, since each knows how the program works and what to expect. In addition, the accounting review program begins with the process of establishing and implementing trust accounting rules and guidelines based on the requirement of the POMS. For the Trust Unit and our state clients the underlying primary goal of the accounting review is to ensure that each trust is administered for the primary benefit of the trust beneficiary, and to approve trusts, not deny them. To achieve this goal the review process and procedures have been constructed to allow every opportunity for an accounting to be approved. The framework is virtually identical to the trust review process, with dedicated state approved correspondence items. Once the accounting has been fully processed an electronic image is attached to the case file in the cse management system.

IV. THE REVIEW EXPERIENCE:

STATE PERSPECTIVES ON TRUST AND ACCOUNTING REVIEWS

From the perspective of state clients, there are a number of noteworthy issues that have surfaced thus far in SNT reviews:

Doctrine of Worthier Title. In basic terms, under this Doctrine an otherwise irrevocable trust becomes revocable if one individual is both the grantor and the beneficiary of the trust, and the trust does not name a specifically identifiable remainder beneficiary. For example, although the Georgia law on trusts has long overridden this doctrine, a special Atlanta Region Directive issued by the SSA and included in the trust section of the POMS stated that the Doctrine applies in Georgia. Efforts to get the SSA to rescind this Directive as to Georgia were unsuccessful for some time. A new Georgia Trust Code, effective July 1, 2010, specifically overrides the Doctrine of Worthier Title at O.C.G.A. § 53-12-44. Apparently word of these new Trust Code provisions got to SSA; in October, 2010, Georgia was quietly removed from the Atlanta Region Directive on the Doctrine of Worthier Title.³⁸

Foreign Fiduciaries. Another issue that arose early on was that of whether foreign trust entities can operate in a given state, and if so, in what manner. For example, Georgia law provides that any Trustee serving “where permitted so to serve by the laws of this state” does not constitute “transacting business” as would require obtaining a certificate of authority from the Georgia Secretary of State.³⁹ The apparent next question was what provisions of Georgia law “permit” a particular Trustee to serve in Georgia. These controlling provisions appear in Georgia trust law (both the prior 1991 Trust Code and the current 2010 Trust Code) rather than

³⁸ See SI ATL01120.201 Trust Property.

³⁹ O.C.G.A. § 14-2-1501(b)(12).

corporation law, in the sections that specify what foreign corporations may serve as Trustee in Georgia.⁴⁰ Pursuant to these provisions, a nationally chartered financial institution that offers trust services may offer those services in Georgia without needing to obtain a certificate of authority from the Secretary of State. For other types of foreign corporations – *i.e.*, local banks or pooled trusts in the various states – the corporation must be “organized or existing under the laws of any state of the United States which borders upon this state, namely, Florida, Alabama, Tennessee, North Carolina, or South Carolina,”⁴¹ and must make certain filings with the Secretary of State.⁴² Similar issues exist in North Carolina and Alabama.

Trusts Established with Federal Funds. Issues also arose early on with regard to trusts established with federal funds. That is, funds derived from the National Vaccine Injury Compensation Program (VICP) (established October 1, 1988 and administered by the U. S. Department of Treasury), and funds derived through settlements or recoveries under the Federal Tort Claims Act (FTCA) and placed in Medical Reversionary Trusts.⁴³ With regard to the VICP, the funds are handled by and through the Vaccine Injury Compensation Trust Fund. By virtue of specific provisions of the National Childhood Vaccine Injury Act, vaccine injury compensation funds are the primary source of funding for medical expenses related to the claimed vaccine injuries, as opposed to Medicaid, and secondary payor to every other payment source.⁴⁴ Therefore, generally speaking, vaccine injury funds cannot be placed in a Special Needs Trust. By contrast, Medical Reversionary Trusts established in accordance with the FTCA remain the property of the U.S. Government, and the trust is last payor to any state or federal program for payment for medical services (*i.e.*, Medicaid).⁴⁵ Up to the current time the federal government has consistently resisted having funds from settlements under the FTCA placed into a SNT.

Decanting. A more esoteric issue that quickly arose in the review program was that of the viability of decanting provisions. The usual scenario involves a Will that contains a provision expressing the desire of the Testator/Testatrix that a trust be established for a particular disabled beneficiary. The provision is treated by the Executor as a decanting provision, and a separate SNT is established for the beneficiary to receive the inheritance. The question becomes whether the Testator/Testatrix contemplated that the trust would be a Special Needs Trust.

Trust Reformation/Modification. An issue that arises with some frequency involves situations where a trust, either third party or testamentary, has been established for a disabled beneficiary, and the trust does not contain special needs provisions and thus is considered “available” for Medicaid eligibility purposes. The usual remedy is to obtain a court order reforming or modifying the trust to include special needs provisions. For third party trusts, this is sometimes to the extent of being a complete restatement rather than a more limited reformation or modification.

- **Failure to Resolve pre-SNT Medicaid Lien.** An issue that is particularly significant from the state perspective is where a SNT is being funded with proceeds of a tort settlement and the SNT beneficiary has received Medicaid assistance as a result of the injury. The issue is failure to resolve the pre-settlement Medicaid lien before funding the SNT, in spite of state laws that create a right of subrogation in the state for recovery of assistance from any third party liable for sickness, injury, disease, or disability paid for by the Medicaid program. The Unit frequently finds (a) that the trial attorney never checked to see if there was a Medicaid lien, or (b) more troubling, that the trial court or the Probate Court ordered a settlement without any notification being given to the state and without providing for payment of the pre-settlement lien – even in situations where the Court is informed that Medicaid provided assistance.

Experience to date with the Accounting Review program has been as expected but also surprising in many respects. Overall, experience is demonstrating that trustees of SNT’s are greatly in need of knowledgeable and experienced guidance and counsel. Expected was that accountings and inventory updates would be received in all kinds of varying formats, and that accountings by individual trustees as opposed to professional and corporate trustees would tend to lack needed detail. Surprising has been that even professional trustees, including some corporate trustees, often do not seem to understand the

⁴⁰ Former O.C.G.A. §§ 53-12-390 – 394; see new O.C.G.A. §§ 53-12-2(4), and 53-12-320 thru 323.

⁴¹ Former O.C.G.A. § 53-12-390; see new O.C.G.A. § 53-12-2(4)

⁴² Former O.C.G.A. §§ 53-12-393, 394; see new O.C.G.A. § 53-12-323.

⁴³ See [28 USC § 1346](#) and [28 USC §§ 2671-80](#).

⁴⁴ Codified at 42 USC § 300aa-10, *et seq.* (the Vaccine Act).

⁴⁵ *Ibid*, footnote 16.

basic structure of an accounting, providing only copies of monthly statements (often missing one or more months of the year) or annual account statements, often without adequate expenditure descriptions.

Also expected was that the expenditure categories of vehicle expenses, household expenses, and caregiver expenses would be issues of note, at least in the cases involving larger SNT's. Surprising has been the frequency with which these expenditure categories are showing up, even in cases involving modest SNT's. This is problematic from the state perspective, since, without adequate explanation, these expenditures raise the issue of whether they benefit someone other than the beneficiary, unless other family members contribute their pro-rata share of the expenses.

Typical issues that have arisen in these categories include:

Vehicle Ownership. Vehicle has been purchased with trust funds but is titled in the name of a parent or other person with trust retaining no ownership interest or lien.

Vehicle Use. Trust is paying all or half of vehicle expenses including fuel, insurance and repairs, even though there are other family members in the household and the vehicle is used as family transportation in addition to transportation for the beneficiary.

Residential Expenses. Trust is paying the full rental, even though other family members live in the residence, and/or is paying all or half of household utilities and other expenses, even though there are other family members in the household.

Purchase/Modification of Residence. Trust provided down payment for the residence, or contributed significantly to modification and repair costs of a residence owned by someone other than the trust of the beneficiary, but title does not reflect any ownership or lien interest by the trust.

Family Caregivers. Trust is paying a family member, usually a parent, full time or more than full time for providing caregiving services to the beneficiary, without documentation of training and experience, level of care and time commitment. In one trust case the trust was paying the mother full time, a nursing service full time, and 3 other persons part time on a regular basis, plus the grandmother for babysitting.

- **Reimbursements to Parents.** Trust reimburses a parent with inadequate or no explanation of what is being reimbursed.

Some of the more "colorful" situations the Unit has run into include:

"Guns and Ammo." Trust initially funded with about \$83,000 spent down to \$900 in 9 months, primarily purchasing guns and ammunition for the beneficiary. The brother is the trustee.

Debit Card. Trust initially funded with \$21,500 was spent out in less than three months, primarily on fast food, speeding tickets, natural makeup, and a trip to California that included first class airfare and a high end hotel. When the SNT was first set up, the trustee (father) and family met with the drafting attorney and following discussion of "how" the SNT was supposed to be administered, declined further counsel. Apparently on the way from the attorney's office the family stopped by the bank and obtained an ATM card on the trust account for the beneficiary.

Family (Dis)Harmony. Beneficiary threatened to kill the Trustee, his mother, if she did not give him the cash in the trust account. He also told her "not to lie down at night in her house and think she was safe." Beneficiary had also had Trustee purchase vehicles for him, which he pawned for cash.

"Mid-Life Crisis." Beneficiary was diagnosed as bipolar manic. He told trustee, his wife, he thought he was the second coming of Christ. God appeared to him in their basement telling him to help people. He refused to see a psychiatrist and would not take any medication. In his efforts to help people, he accessed trust funds and began giving away money. God had told him not to worry about money as he was going to win the lottery, being the first person to win both Mega Millions and Powerball in the same weekend. He bought a used truck and bass boat. He spent thousands on clothes/shoes/boots for himself, their son, nephew, and son-in-law. Then he came home with a Shelby cobra, a special edition Mustang and a Ford Raptor truck, to the tune of roughly \$200K

"The Wild Side." Trust spent \$14,500 purchasing an ATV for a beneficiary who is paralyzed from the neck down. The brother is the trustee. The trust also purchased a pickup truck for the paralyzed beneficiary.

"Poor Me." Corporate trustee reported making down payment on a house for mother and disabled daughter, mother having told trustee that she was having to physically carry her disabled daughter up two flights of rickety stairs to her apartment. Corporate trustee also reported that mother was being paid \$38,000 a year to care for her disabled daughter, and to help the mother afford to keep a house, they planned to raise her annual salary to about \$50,000 per year. Corporate trustee had never visited the beneficiary. Investigation revealed that mother and disabled daughter – and another child – were living in a Section 8 home in a pleasant middle class neighborhood; no rickety stairs. Mother had never reported trust, nor her salary, to Medicaid. Mother told Medicaid at annual review that she had no income other than “a couple of dollars from a friend.” Mother and daughters were all receiving food stamps, and mother and second daughter were receiving Medicaid by virtue of being linked to the disabled daughter.

“Working Hard.” Corporate trustee filed accounting showing that the mother of the disabled minor beneficiary was being paid over \$50,000 annually to care for her disabled child. Corporate trustee had never visited the beneficiary. When questioned about the basis for the salary being paid to the mother, the trustee asked the mother to send Accounting Review a letter outlining the care she was giving. In the letter the mother described how she “got him up” in the morning, helped him dress, cooked his breakfast, watched him get on the bus to school, cleaned the house and did the laundry, watched him get off the bus after school, fixed his dinner, and made sure he went to bed on time.

IV. CONCLUSION: EVOLUTION OF THE TRUST PROGRAMS -- A WIN-WIN PROPOSITION

States have struggled with declining revenues and budget cuts, and have realized that their legal resources are overwhelmed and generally incapable of adding the highly complex and technical area of trusts to their responsibilities. As a result, the review of Special Needs Trust and SNT accountings is evolving. This evolution is seen in the establishment and expansion of the partnership of public and private enterprise -- state governments and HMS -- for Trust Review and Accounting Review programs. From the perspectives of the state and the Elder/Special Needs bar, this partnership brings forth the most advantageous trust services programs that are compliant and administered efficiently, effectively and in a systematic and predictable fashion -- a true win-win proposition for all, to the ultimate benefit of the trust beneficiaries.

**Beyond the Special Needs Trust:
Essential New Developments in Special Needs Planning
[Supplemental Outline]**

(Part Two of Three)

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PLANNING FOR BENEFICIARIES WITH SPECIAL NEEDS

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This outline will review the various types of Special Needs Trusts that serve as the cornerstone for securing the future of persons challenged by disabilities; the types of government benefits and programs that can be accessed and preserved with proper Special Needs Trust planning; and the most common challenges (and solutions) encountered in Special Needs Trust planning.

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).⁴⁶ 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.

⁴⁶

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

(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; 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).⁴⁷

(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 April 2016, the Centers for Disease Control and Prevention issued a report which included a finding that the prevalence of **Autism Spectrum Disorder (“ASD”)** has risen to 1 in every 68 births in the United States. ASD is 4.5 times more common among boys (1 in 42) than among girls (1 in 189). See Christensen DL, Baio J, Braun KV, et al. “Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012.”⁴⁸

B. The “special needs” of persons with disabilities

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

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

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

⁴⁷ <http://www.census.gov/prod/2011pubs/acsbr10-12.pdf>.

⁴⁸ <http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm>.

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).⁴⁹

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

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, (iii) has a judgment lien recorded against his property, or (iv) fails to pay his tax liabilities and becomes subject to a tax lien, the funds designated informally for the beneficiary with special needs could be dissipated entirely. These are but a few of the most **common creditor traps** that defeat the intention of clients trying to secure the future of beneficiaries with special needs.

(2) A similar result could ensue if the donee of the funds set aside informally for the beneficiary with special needs **predeceases** him and (i) dies intestate with heirs-at-law that include persons other than the intended beneficiary, or (ii) dies testate but fails to make proper arrangements in the Will for the ongoing management of the funds for the benefit of the intended beneficiary. Since an estimated 65% of the population dies intestate, this is another very common flaw in a client's plans to provide informally for beneficiaries with special needs.

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

A. Types of Special Needs Trusts

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

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

⁴⁹ http://www.courts.state.me.us/opinions_orders/opinions/documents/Bar-01-6%20Brown.htm.

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

B. First-Party Special Needs Trusts

1. As part of the Omnibus Budget Reconciliation Act of 1993 ("OBRA '93"), Congress specifically authorized the creation of a single-beneficiary Special Needs Trust to be **funded with assets belonging to the beneficiary**, the statutory requirements for which are set forth in 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. The POMS are 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) an adult beneficiary who retains mental capacity notwithstanding his disability (for trusts established on or after December 13, 2016); (ii) the legal Guardian of the Property or Conservator of the beneficiary, *e.g.* in the case of a minor or an incapacitated adult who meets the relevant threshold under State law for the appointment of a Guardian or Conservator; (iii) a parent or grandparent of the beneficiary; or (iv) a court. (**N.B. "The Special Needs Trust Fairness Act" was signed into law on December 13, 2016 to allow a mentally competent, yet disabled, beneficiary to establish his own first-party Special Needs Trust.**) See Title V, Section 5007 ("Fairness in Medicaid Supplemental Needs Trusts") of the 21ST CENTURY CURES ACT, P.L. No. 114-255. The Social Security Administration's POMS are being updated accordingly to reflect this statutory change to 42 U.S.C. § 1396p(d)(4)(A). See "Emergency Message No. 16053 issued December 15, 2016, at <https://secure.ssa.gov/apps10/reference.nsf/links/12152016025223pm> ("retention date" June 16, 2017).

(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.1.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) Before the beneficiary was authorized to establish his own first-party Special Needs Trust, the Social Security Administration took the position that **a mere "agent" of the beneficiary** could not serve as the Settlor. See POMS 01120.203.B.1.g (which is in the process of being updated). Thus, for example, a person serving as attorney-in-fact under a Power of Attorney (which is governed by agency principles) could not previously establish a first-party Special Needs Trust for the benefit of the principal under the laws in effect prior to December 13, 2016. *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. Furthermore, a recent announcement from the Social Security Administration (dated May 28, 2015) indicates that the creation of the trust cannot have been completed before the court order is issued. "Court approval of an already created

special needs trust is not sufficient . . . The court must specifically either establish the trust or order the establishment of the trust.”

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 2018, the **income threshold** evidencing a person’s ability to engage in SGA is \$1,180/month. For a person who is blind, the SGA threshold is \$1,970 in 2018. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).⁵⁰ 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 first-party 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.

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** from any property remaining in the first-party Special Needs Trust (*if* any remains) up to the total amount of medical assistance benefits paid on behalf of the beneficiary under 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.”**

⁵⁰ <http://www.socialsecurity.gov/news/press/factsheets/colafacts2018.pdf>.

(2) The only disbursements that may be made from a first-party Special Needs Trust after the beneficiary's death and before satisfaction of the Medicaid payback, are (i) taxes due from the trust to the state or federal government as a consequence of the beneficiary's death, and (ii) reasonable fees associated with administering, terminating and "wrapping up" the trust. *See POMS SI 01120.203.B.3.a.*

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

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

(4) Courts were initially split regarding the scope of the "total amount" that must be paid back to Medicaid. *See, e.g., In the Matter of Ruben N.*, 55 A.D.3d 257 (App. Div., 2d Dept. 2008), which initially held that Medicaid should be paid back only for assistance paid after the Special Needs Trust was established. *In the Matter of Abraham XX, Deceased v. State of New York*, 11 N.Y.3d 429 (2008), next held that Medicaid should be reimbursed for assistance paid even before the Special Needs Trust was established. Subsequently, the earlier opinion and order in *Ruben N.* were recalled and vacated, citing *Abraham XX*, allowing the State to recover the **cost of care provided over the course of the plaintiff's entire lifetime**. *In the Matter of Ruben N.*, 71 A.D.3d 897 (App. Div., 2d Dept. 2010).

(5) Provisions of the 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.*

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

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

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

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

(9) If the beneficiary during his life has received Medicaid benefits from more than one State, POMS SI 011210.203B.1.h specifies that the "**trust must provide payback to any State(s) that may have provided medical assistance under the State Medicaid plan(s) and not be limited to any particular State(s) . . .**" Presumably, this requirement dictates a *pro rata* allocation of the property remaining in a first-party Special Needs Trust if the remaining

assets are insufficient to satisfy fully the claims of all of the State Medicaid Plans which have provided medical assistance to the beneficiary during his lifetime.

3. In addition to the first-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A), 42 U.S.C. § 1396p(d)(4)(B) authorizes a limited-use Trust designed to receive and distribute any income of the beneficiary which 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.

f. A Miller Trust/Qualified Income Trust is *not* considered an excluded trust for SSI eligibility purposes. However, some States may exclude these trusts from counting as a resource for Medicaid eligibility purposes. *See* POMS SI 01120.203.B.5.

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 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 “disabled;” 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 as to the Beneficiary**, *i.e.* the Beneficiary cannot hold the right to revoke or terminate the trust. *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 first-party 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 for a first-party account with a pooled Special Needs Trust.**

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. First-party accounts with 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 first-party 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 first-party 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*, only since December 13, 2016 has it been permissible for the beneficiary of a first-party (d)(4)(A) Special Needs Trust to serve as the Settlor of his trust.)

e. To the extent that the pooled Special Needs Trust does not retain any amounts remaining in a separate first-party 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 first-party 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 a first-party account with a pooled Special Needs Trust, *i.e.* a first-party 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 after the age of 65 if the beneficiary wishes to qualify for Medicaid long-term care (*i.e.* nursing home) coverage, or for certain long-term care services rendered in the community. *See* 42 U.S.C. § 1396p(c)(1)(B)(i)-(ii), (c)(1)(G), (e)(1), (f), 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 with a pooled Special Needs Trust may also be established with assets derived from a **third-party**. While the beneficiary of a third-party account with a pooled Special Needs Trust must meet the government’s definition of “disabled,” (i) there is no restriction on who can establish the third-party account; (ii) the beneficiary’s age does not limit the timing of the establishment or funding of the account; and (most importantly) (iii) **there is no Medicaid payback with a third-party account.**

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

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. Special Needs Trusts are not “available” or “countable” for purposes of most “means-tested” government benefits

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

a. 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.” **In most jurisdictions, 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 professional Trustees prefer an **illustrative listing of permissible types** of distributions that can be made from a Special Needs Trust without adversely impacting the beneficiary’s means-tested benefits. The following are a few of the most common types of permissible disbursements.

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

(b) Payments directly to the **providers of goods** for the sole benefit of the beneficiary (excluding food and shelter), including medical equipment and supplies, household appliances, furniture and furnishings; clothing and personal effects; camera and computer equipment; musical instruments; fitness and sporting

equipment; hobby supplies; magazine and newspaper subscriptions; holiday decorations and cards; linens and towels; stationery and stamps; tickets to recreational or entertainment events.

(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; helicopter or private airplane.

(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 most “means-tested” government benefits, including Medicaid and Supplemental Security Income (discussed in Section IV, *infra*).

a. In general, the Trustee of a Special Needs Trust must make disbursements **directly to the provider** of goods and services for the 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 Rate for 2018 is \$750/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 nominally 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 means-tested benefits of such disbursements, any potentially adverse impact on the beneficiary’s overall living situation can generally be managed in the best interest of the beneficiary.

(2) **Cash** (or an **unrestricted debit card**, a credit card with cash advance features, 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. An alternative tool that does not pose as many problems is the True Link debit card, a "reloadable" Visa card that can be customized to allow "approved" purchases only. See www.truelinkfinancial.com.

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. Recent 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. On January 14, 2013, the United States Supreme Court denied a Petition for Writ of Certiorari, thus leaving intact the Third Circuit's decision. *See* 133 S.Ct. 933 (2013). This issue is thus **ripe for a review by the United States Supreme Court.**

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 most 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. In 2018, the maximum Federal Benefit Rate (“FBR”) is \$750/month, although some States provide “State supplements” to this base amount. **Medicaid** is the means-tested program which provides basic health care and medical services. Financial eligibility for means-tested government benefits is determined by reference to the applicant’s “available” or “countable” income and resources. **Properly drafted, established, funded and administered Special Needs Trusts do not count against the beneficiary in determining financial eligibility for these means-tested benefits.**

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

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

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

(a) Resources include the applicant’s cash or other assets that he owns and can convert to cash and **use for his support and maintenance**. Resources are either “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 subject to the Employee Retirement Income Security Act (“ERISA”) (29 U.S.C.A. § 1056(d), as well as periodic payments, such as Social Security Disability Income payments, worker’s compensation, veterans benefits, unemployment benefits (most of which are non-assignable to a Special Needs Trust, *see, e.g.*, POMS SI 01120.200.G.1.c and SI 01120.201.J.1.d); life insurance proceeds or other death benefits; gifts and inheritances; support and alimony; dividends and interest; and rents and royalties.

(A) There is one recent notable exception to the general rule that veterans benefits are non-assignable and thus constitute unearned income to the recipient: the **military “Survivor Benefits Plan” (“SBP”)** retirement annuity option for the benefit of a “disabled dependent child.” For purposes of this program, a “dependent child” is defined in 10 U.S.C. § 1447(11), and “disabled” is defined in 42 U.S.C. § 1382c(a)(3). The “Disabled Military Child Act” (Public Law 113-291, amending Title 10, U.S.C. §§ 1448, 1450 and 1455), signed by President Obama on December 19, 2014, now authorizes a **military parent to elect (during the parent’s lifetime) that the SBP annuity for a disabled dependent child shall be payable to a first-party Special Needs Trust.** (*See* discussion, *supra*, at Section III.B., for the requirements of a first-party Special Needs Trust.) The Department of Defense issued implementation guidance on December 31, 2015 in the form of a “Memorandum” to the Deputy Assistant Secretaries of the Army, Navy and Air Force,

captioned “Enabling Payment of Survivor Benefit Plan Annuities to a Special Needs Trust” (available at http://www.moaa.org/uploadedFiles/Content/Take_Action/Top_Issues/Spouse_and_Family/SNTPolicyFinal31Dec15.pdf). Under current law, the beneficiary with a disability does not have the option of a *post mortem* assignment of the SBP annuity payments if his parent has not made this election during life.

(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 some cases), regardless of the actual value of the food and shelter provided. **“Shelter” includes only the following items: mortgage payments (including any property insurance required by the mortgage holder); real property taxes; rent; heating fuel; gas; electricity; water; sewer; and garbage removal.** See POMS SI 00835.465.D.1. The dollar value of these items is added and divided by the number of people living in the home to determine each person’s *pro rata* share. If a person is not paying at least this amount towards his *pro rata* share (e.g. with his monthly SSI benefit), his SSI benefit will be reduced in one of two ways, depending on his living arrangement. See POMS SI 01120.200.E.1.b and POMS SI 01120.200.F.3.c.

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

i. In 2018, the FBR is \$750/month, so the VTR reduction is \$250/month ($\$750 \div 3$). (For the current FBR and VTR amounts, see POMS SI 00835.901.)

ii. If the VTR applies, the SSI payment is reduced by the full VTR amount, regardless of how “short” the recipient is towards paying his *pro rata* share of the household food and shelter expenses. For example, if his *pro rata* share is \$790/month, and he can only pay \$750/month towards his *pro rata* share, his **SSI payment will be reduced by the full VTR of \$250 rather than just the deficit of \$40.**

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

i. If the PMV Rule applies, the SSI recipient’s SSI payment is reduced by the *lesser of* (A) one-third of the FBR *plus* the \$20 general income exclusion (i.e. \$270 in 2018, calculated as follows: $\$750 \div 3 + \20), or (B) the *actual value* of the food and shelter received by the SSI recipient from the person outside the household.

ii. For example, if the Trustee of a Special Needs Trust pays \$4,000/month towards the beneficiary’s food and shelter expenses, his SSI payment is reduced by no more than \$270/month. If, on the other hand, the Trustee pays only \$100/month towards those expenses (e.g. because the beneficiary’s other income and resources are sufficient to pay for the balance of his *pro rata* share of the household expenses), then his SSI payment is only reduced by \$100, not by \$270. (In contrast, if the VTR were applicable, as explained above, the SSI payment would be reduced by the full \$250/month, not just by \$100/month.)

(C) Warning: If the SSI recipient’s monthly SSI payment is \$250/\$270 or less (e.g. because of other countable income, including government benefits), then a distribution for his food or housing expenses that results in a VTR or PMV reduction could “zero out” his SSI payment, resulting in the consequent loss of SSI-linked Medicaid.

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

(c) In certain circumstances, the income or resources of other persons may be **“deemed” to be available** to the applicant for purposes of financial eligibility for SSI, including from a parent who is not

eligible for SSI to an unmarried minor child who is applying for SSI, and from a spouse who is not eligible for SSI to a spouse who is applying for SSI. *See POMS SI 01310.001.*

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

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

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

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

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

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

c. There are three main types of Medicaid eligibility:

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

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

(2) **“Optionally categorically needy”** persons with limited resources can qualify for Medicaid if their monthly incomes are not more than 300% of the Federal Benefit Rate (*i.e.* \$2,250 in 2018).

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

(a) In 2017, “**Spend Down**” States include California, Connecticut, Hawaii, Illinois, Kansas, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New York, North Carolina, North Dakota, Ohio, Pennsylvania, Rhode Island, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin.

(b) Some States, known as “**Income Cap**” States, do not allow the “medically needy” to qualify for Medicaid by means of a “spend-down” of excess income. However, any excess income may be transferred to a Qualified Income Trust authorized by 42 U.S.C. § 1396p(d)(4)(B), discussed in Section III.B.3, *supra*. In 2017, the Income Cap States include Alabama, Alaska, Arizona, Arkansas, Colorado, Delaware, Florida, Georgia, Idaho, Indiana, Iowa, Kentucky, Louisiana, Mississippi, Nevada, New Jersey, New Mexico, Oklahoma, Oregon, South Carolina, South Dakota, Tennessee, Texas and Wyoming.⁵¹

(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. **Eligibility for SSI and Medicaid is also required for numerous community-based programs and services**, *e.g.* group home residential arrangements and “life skills” programs. Access to these programs is limited to those persons whose financial affairs have been arranged so that they are eligible for SSI and Medicaid, and some will only accept SSI benefits as payment for program services, *i.e.* private pay is not an option. **A family’s private wealth cannot guarantee access to these beneficial programs, contrary to the belief of 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 in order gain access to these programs.

B. Employment-based government benefits for persons with disabilities

1. Many persons with disabilities are eligible for employment-based government benefits **determined by reference to the employment history of a worker**. The applicant’s income and resources generally do not adversely impact these benefits, *i.e. these benefits are not means-tested*. Under Title II of the Social Security Act, the “Old Age, Survivors and Disability Insurance” program (“OASDI”), the 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, and have earned at least 40 “credits” (a maximum of four credits each year) (formerly referred to as “quarters of coverage”). *See* 42 U.S.C. § 414(a)(2). In 2018, the amount of earnings needed to earn one credit is \$1,320 (or \$5,280 to earn the maximum of four credits for the year). Credits are based on total wages (or self-employment income) during the entire year, no matter when during the year the actual work was performed. *See* U.S. Social Security Administration, Cost-of-Living Adjustment (COLA).⁵²

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

c. The **SSDI** program also pays a monthly cash benefit to a person over the age of 18 (i) whose disability began prior to the age of 22, (ii) who is consistently unable to engage in “Substantial Gainful Activity,” and (iii) who is unmarried, or is married to another similarly situated person. *See* 20 C.F.R. § 404.350(a)(5) and POMS DI 10115.001. This category of benefits is currently called “**Childhood Disability Benefits**” (“CDB”), but it was formerly

⁵¹ <http://payingforseniorcare.com/longtermcare/resources/medicaid.html>.

⁵² <http://www.socialsecurity.gov/news/press/factsheets/colafacts2018.pdf>.

known as “**Disabled Adult Child**” (“**DAC**”) 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 earned “credits” (formerly known as “quarters of coverage”). **Payments under the CDB program count as “unearned income”** to the adult child for purposes of the SSI program, thus reducing the SSI benefit dollar-for-dollar (after a \$20 income exclusion), and often eliminating the SSI benefit entirely, as well as eligibility for SSI-linked Medicaid.

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

d. There are various ways for a person to become eligible for **Medicare**, a federal insurance program with no income or resource limitations. See Title XVIII of the Social Security Act, 42 U.S.C. §§ 1395-1395kkk-1. Workers who have attained age 65, and are eligible for Social Security retirement benefits, are also eligible for Medicare. In addition, once a person has received **SSDI benefits (including CDB benefits) for 24 months**, he can become eligible for Medicare coverage, which includes the following elements.

(1) “Part A” providing hospital insurance.

(2) “Part B” providing medical insurance.

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

(4) “Part D” providing prescription drug coverage.

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

V. SPECIAL NEEDS TRUST TAX CONSIDERATIONS

A. First-Party Special Needs Trusts

1. A first-party Special Needs Trust typically qualifies as a “**grantor trust**” for federal income tax purposes. Regardless of who serves as the Settlor, the sole beneficiary is almost always treated as the “grantor” for income tax purposes. Thus, the income and gains generated by the assets of a first-party Special Needs Trust that is a grantor trust are taxed to the beneficiary of the trust under IRC § 671, whether or not actually distributed to, or for the benefit of, the beneficiary. (A 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 held that a beneficiary’s power to substitute property under IRC § 675(4)(C) is tantamount to an impermissible right to revoke the Special Needs Trust. A power of revocation held by the beneficiary of a 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 with respect to the beneficiary 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 2018, a single individual taxpayer reaches the 39.6% bracket at \$426,700 of taxable income, while an irrevocable non-grantor trust reaches the 39.6% bracket at only \$12,700 of income. *See* Rev. Proc. 2017-58, 2017-45 I.R.B. 707 (10/20/17).

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” as “In-Kind Support and Maintenance” (“ISM”) to the beneficiary for purposes of his means-tested government benefits, but it does not constitute income for income tax purposes. If the Trustee uses trust principal to pay for the beneficiary’s education, the disbursement would not constitute income for purposes of either the income tax or means-tested benefit programs.

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

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 10% 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).

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 Federal Employer Identification Number

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

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

a. 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 consequent to a personal injury claim (often referred to as a “**structured settlement**”), the present value thereof is also fully includable in the beneficiary’s gross estate under **IRC § 2039**. Annuity contracts do not typically provide for the acceleration of future guaranteed payments to pay the annuitant’s estate tax liability unless a “commutation right” has been purchased when the annuity is procured (for a hefty charge of 5% or more of the total premium paid for the annuity).

B. Third-Party Special Needs Trusts

1. An *inter vivos* third-party Special Needs Trust is most typically drafted as a **non-grantor “complex trust”** that is not required to distribute all of its income. Thus, such a trust would file its own income tax returns under **its own FEIN**, and be subject to the compressed tax brackets applicable to irrevocable non-grantor trusts. Nevertheless, if the trust’s **Distributable Net Income (“DNI”)** (as defined under IRC § 643(a)) is “carried out” to the beneficiary in a given tax year, it is taxable to, and reportable by, the beneficiary. The trust then issues the beneficiary a Schedule K-1 showing the taxable income properly reportable on his personal income tax return. (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, *e.g.* the “power of substitution” under IRC § 675(4). In this fashion, the parent would be responsible for paying the income taxes on the trust’s income and gains, leaving the trust property undiminished by the amount of the income tax payments and reducing the parent’s potential taxable estate by a similar amount.

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

a. Status as a QDT entitles the trust to the full personal exemption under IRC § 151(d) allowed to all individual taxpayers (\$4,150 in 2018) 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 beneficiary, but it is permissible to designate remainder beneficiaries upon the death of the beneficiary with the disability.)

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

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

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

3. The gift tax consequences to donors of transfers to a third-party Special Needs Trust depend on whether any of the beneficiaries possess a “**right of withdrawal**” with respect to the contributed funds, commonly referred to as “Crummey powers.” *See Crummey v. Commissioner*, 397 F.2d 82 (9th Cir. 1968). Because a gift to a trust does not generally qualify as a “present interest” for purposes of the annual gift tax exclusion under IRC § 2503(b)(1) (in 2018, \$15,000 per donee), Crummey powers have been used for decades to convert a future interest gift to a trust into a present interest that qualifies the gift for the annual gift tax exclusion. However, **it is inadvisable to give a Crummey power to a beneficiary who receives means-tested government benefits**, such as SSI and Medicaid, inasmuch as the value of the property that is subject to the power could well be considered “income,” or an “available” or “countable” resource, to the beneficiary, thus jeopardizing his continued eligibility for those benefits.

a. Nevertheless, it is certainly possible to **grant a right of withdrawal to a secondary permissible beneficiary** of a third-party Special Needs Trust, under the rationale of *Estate of Cristofani v. Commissioner*, 97 T.C. 74 (1991). Thus, a common approach is to grant a *Cristofani* right to a secondary beneficiary who is not disabled and 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 with a disability. If the holder of the *Cristofani* right fails to exercise it, the property subject to the right remains in trust for the primary benefit of the beneficiary with the disabling condition, thus preserving his ongoing eligibility for his means-tested government benefits.

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

4. The estate tax consequences to the beneficiary of a third-party Special Needs Trust will depend upon whether he is vested under the trust agreement with rights or powers that cause includability for estate tax purposes (*e.g.* a general power of appointment). A third-party Special Needs Trust that is not designed to implement generation-skipping

transfer tax planning will typically be drafted to **avoid estate tax includability** in the gross estate of the beneficiary. This is especially so since the beneficiary may be subject to Medicaid “estate recovery” at the time of his death under the provisions of one or more State Medicaid plans which have provided medical assistance benefits to him after the age of 55. **Furthermore, most third-party Special Needs Trusts are drafted so that contributions thereto qualify as completed gifts by the donor, who typically retains no beneficial interests or powers that would cause estate tax inclusion.**

VI. 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 being amended to replace all forms of the “R-word” with more respectful terminology.

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

b. Using person-first terminology will seem cumbersome and unnatural at first. Clients, however *do take notice* of those who successfully integrate this concept into normal parlance. In time, the old terms that emphasized the disability first, instead of the person first, will become as offensive to the attorneys, and to the other allied professionals with whom they work, as they have been to these families. This may be the easiest challenge to overcome, and will completely transform the way a family relates to, and communicates with, their professional advisors. For a “cheat sheet” on the proper terminology to use when referring to individuals with disabilities, see *“Guidelines: How to Write and Report about People with Disabilities,”* 8th Edition (2013), published by the University of Kansas Research and Training Center on Independent Living (available at www rtcil org/guidelines).

B. Determining an appropriate allocation of assets among beneficiaries with and without disabilities

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

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

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

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

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

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

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

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

C. 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 a network of 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 Revocable Living Trust of each parent may be the foundation of a Special Needs Plan.

b. An *inter vivos* third-party Special Needs Trust **designed to receive bequests** from other family members or friends who wish to help secure the financial future of the beneficiary is an indispensable element of an effective Special Needs Plan. These generous third parties are advised of this option by means of a “Dear Family and Friends Letter.”

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

c. Many families also wish to include an *inter vivos* third-party Special Needs Trust **designed to receive lifetime gifts that will qualify for the gift tax annual exclusion** by vesting *Cristofani* rights of withdrawal in 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. Almost every family will need 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. Many families also require 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.

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

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

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

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

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

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

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

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

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

f. In each of the above situations, having a **first-party Special Needs Trust available on "stand-by," on a pre-need basis**, provides a ready solution for handling the asset to which the beneficiary is legally entitled in a manner that will not jeopardize his means-tested government benefits. As discussed, *supra*, in Section III.B.2.a., the permissible Settlers of a first-party Special Needs Trust include the beneficiary (after December 13, 2016, pursuant to the Special Needs Trust Fairness Act, if the beneficiary, though disabled, is mentally competent), parents, grandparents, legal Guardian of the Property or Conservator, or a court. A beneficiary's parent (or grandparent) may also establish a first-party Special Needs Trust as a "seed trust" (authorized by POMS SI 01120.203.B.1.f) as part of their estate planning as an elegant pre-need solution to an inevitable problem.

(1) If the beneficiary is, in fact, an incapacitated adult (or a minor) when he becomes legally entitled to financial benefits such as those listed above, and which would otherwise be subject to a Conservatorship, it is likely that a **court procedure will be necessary to authorize the transfer** of those assets into a first-party Special Needs Trust established on a pre-need basis. Furthermore, any assets that remain in a **Conservatorship are "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 to **(i) create a first-party Special Needs Trust, and (ii) fund it with the beneficiary's share of the inherited IRA**. The Service held that the first-party Special Needs Trust was a "grantor trust" for federal income tax purposes under IRC § 677(a). Thus, since a grantor trust is disregarded for income tax purposes, the Service held that the funding of the trust with the beneficiary's share of the inherited IRA was not a transfer for purposes of IRC § 691(a)(2). This conclusion remained the same even after the beneficiary's share of the inherited IRA was transferred, by means of a trustee-to-trustee transfer, to a new IRA set up and maintained in the name of the deceased IRA owner to benefit the son through his first-party Special Needs Trust. Finally, the Service held that required minimum distributions from the new IRA to the first-party Special Needs Trust could be calculated using the son's life expectancy.

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

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

therefore, is considered to have received the unitrust amounts directly” from the CRUT for purposes of IRC § 664 (d)(2)(A). “Accordingly, the term of the [CRUT] may be for the life of [the beneficiary of the first-party Special Needs Trust] and is **not limited to a term of years**. The same result would apply if the [CRUT] were a charitable remainder annuity trust.”

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

D. Existing trusts with “support” or “maintenance” standards for distributions to the beneficiary with a disability

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 not all States currently have decanting statutes, well-respected practitioners who have thoroughly considered this topic have concluded that the “common law of every state likely confers decanting authority on trustees.” *See* Jonathan G. Blattmachr, Jerold I. Horn & Diana S.C. Zeydel, *An Analysis of the Tax Effects of Decanting*, 47 Real Prop. Tr. & Est. L.J. 141, 170 (Spring 2012).

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

a. A statement of proper jurisdiction and venue.

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

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

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

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

f. The exact type of government benefits for which the beneficiary is eligible, which would be reduced or eliminated if the original "support" and "maintenance" distribution standards are not replaced with Special Needs Trust provisions. Note: insist on seeing the actual "benefits award letter" 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 plan will require a "payback" provision** to be included in the modified trust, notwithstanding the status of the original trust as a third-party trust (which would normally not be required to include a Medicaid payback provision, as discussed, *supra*, in Section III.C.2). Some States take the position that a trust which would have been considered an "available" or "countable" asset as originally drafted must include a payback provision in the modified version only if the creator made no reference whatsoever to the beneficiary's disabilities. The States are reportedly very inconsistent with regard to requiring the inclusion of a Medicaid payback provision in a modified third-party Special Needs Trust.

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

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

E. Lack of a “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 Alliance⁵³ and the Academy of Special Needs Planners.⁵⁴

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

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

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

5. If the beneficiary with special needs is of school age, a **special education advocate or attorney** can help the family obtain the “free and appropriate public education” (“FAPE”) in the “least restrictive environment” (“LRE”) to which he is legally entitled. Under the Federal “Individuals with Disabilities Education Act” (“IDEA”), 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 and appropriate public education guaranteed by IDEA. An increasing number of students with Autism Spectrum Disorder (or other disorders with consequent disruptive or self-injurious behaviors) are the victims of physical abuse at the hands of their teachers, who have not been properly trained in the management of such behaviors. Civil remedies and criminal penalties are available for redress of such abuse.

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

a. In addition to income tax returns for Special Needs Trusts, numerous States require **annual accountings to the State Medicaid plan** which detail the receipts and disbursements of a Special Needs Trust, both first-party and third-party. For example, the Georgia Medicaid plan has established a first-of-its-kind “Trust Review and Accounting Program” administered by Health Management Systems (a publicly-traded national corporation that provides healthcare cost containment services to both state and federal agencies). This program has already been replicated in Alabama, Iowa and North Carolina (with several others pending). Reviews of these annual trust accountings focus on **potential violations of the “sole benefit rule”** applicable to first-party Special Needs Trusts (*see* Section III.B.2.c.(2), *supra*) as well as disbursements from first-party and third-party Special Needs Trusts that constitute **“In-Kind Support and Maintenance”** that adversely impact the beneficiary’s Supplemental Security Income monthly payment (*see* Section IV.A.(2)(b)(3), *supra*). Most accountants and attorneys are not ideally suited for the preparation of these annual accountings, which can be prepared more cost-effectively by a paralegal or bookkeeper.

⁵³ <http://www.specialneedsalliance.org/>.

⁵⁴ <http://www.specialneedsplanners.com/>.

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.

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

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

10. Last, but not least, the **legal Guardian** of a beneficiary with special needs will eventually serve as the "**quarterback**" of the **Special Needs Team**, after the beneficiary's natural parents are deceased. Many clients are paralyzed with fear by the prospect that (i) no one will agree to serve as Guardian for their children with disabilities because of the monumental task it represents, and (ii) anyone who does agree to serve will not do it as well as they have done. Assembling the Special Needs Team as part of the estate planning process provides a solution to both of these concerns.

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 by themselves. Third parties (especially long-standing health care providers) often enable this "head-in-the-sand" approach as long as one of the natural parents of the adult child with a disability is still living, operating on a "wink-wink" basis (and often violating the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") in the process). Needless to say, this is an imprudent approach which can risk the

health and well-being of the adult child with the disability if, for example, a catastrophic health care emergency were to arise and a doctor unfamiliar with the family insisted on Letters of Guardianship before taking any directions regarding the child's course of care.

VII. ABLE ACCOUNTS

A. Background Information

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

2. On March 23, 2015, the IRS issued Notice 2015-18 setting forth limited guidance for States eager to establish ABLE Programs without the benefit of even Proposed Regulations. A few days later, the **Social Security Administration issued new POMS SI 01130.740 pertaining to ABLE accounts. On June 22, 2015, the Department of the Treasury published Proposed Regulations expanding on the provisions of the ABLE Act.** On November 20, 2015, in response to hundreds of comments on the Proposed Regulations submitted by individuals and organizations, the Internal Revenue Service issued Notice 2015-81, “Interim Guidance Regarding Certain Provisions of Proposed Regulations Relating to Qualified ABLE Programs.” Finally, on September 7, 2017, the Department of Health and Human Services, Centers for Medicare and Medicaid Services, issued further guidance, SMD#17-002, “Implications of the ABLE Act for State Medicaid Programs.”

B. Secondary Policy Rationales

1. In addition to providing an innovative savings mechanism for persons with disabilities, there were two secondary reasons for adding the ABLE account to the arsenal of planning techniques designed to secure the future of such persons: affording individuals with disabilities a sense of independence over a portion of their finances, and providing **an alternative to the complexity and expense of establishing a Special Needs Trust.** For many clients with disabilities, an ABLE account alone will not be a sufficient planning solution, but may serve as an additional tool to accomplish comprehensive special needs planning. *See, e.g., Robert F. Brogan and Bernard A. Krooks “ABLE Act Passes,” Exceptional Parent Magazine* (Feb. 2015).

C. General Requirements for a Qualified State ABLE Program

In order to qualify for tax-exempt status pursuant to IRC § 529A(a) and Proposed Regulation § 1.529A-1(a), a State ABLE program described in IRC § 529A, the Proposed Regulations, and POMS SI 01130.740, must comply with the following requirements.

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

2. The program permits the establishment of an ABLE account only for a “designated beneficiary” who is a resident of that State, or a resident of a State contracting with that State for purposes of affording its residents access to an ABLE program.

3. The program permits the establishment of only one ABLE account, wherever located, for an “eligible individual” who is the designated beneficiary, by (i) the designated beneficiary himself, or, in the case of the beneficiary lacking capacity, (ii) his agent under a power of attorney, or, if none, (iii) his parent, or (iv) his legal guardian (or, presumably, conservator).

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

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

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

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

8. The program must limit the designated beneficiary to no more than two opportunities each calendar year to provide investment direction regarding the assets in his ABLE account.

9. The program must prohibit the pledging or assignment of an interest in the ABLE account.

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

D. State Action to Establish an ABLE Program

1. The ABLE Act authorizes (but does not require) the States to establish ABLE programs. Any State which elects to establish an ABLE program must do so through legislation or regulations.

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

(1) The ABLE National Resource Center reports that as of August 25, 2017, twenty-seven States and the District of Columbia have launched operational ABLE programs, including Alabama, Alaska, Colorado, District of Columbia, Florida, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New York, North Carolina, Ohio, Oregon, Pennsylvania, Rhode Island, Tennessee, Vermont, and Virginia. See <http://www.ablenrc.org> and <http://www.thearc.org/what-we-do/public-policy/issues/able-program-0implementation> (last visited August 10, 2017), for **an update of the status of ABLE program legislation and implementation in all 50 states**.

(2) The Proposed Regulations permit a designated beneficiary to continue to maintain his ABLE account that was created in one State even after he is no longer a resident of that State. Prop. Reg. § 1.529A-2(o). Alternatively, the balance in an existing ABLE account may be rolled over to a new ABLE account in the designated beneficiary's new State of residence, but only once every 12 months. Prop. Reg. § 1.529A-1(b)(17).

E. Eligibility Requirements for a "Designated Beneficiary"

1. The "designated beneficiary" of an ABLE account, who is also **considered to be the owner** of the account, must be an "eligible individual." IRC § 529A(e)(1) and (3); Prop. Reg. § 1.529A-1(b)(1) and (4).

2. An "eligible individual" must qualify as blind or disabled, as defined for Social Security purposes, and **the onset of the blindness or disability must have occurred prior to the individual's 26th birthday**. A qualified ABLE program must require that the designated beneficiary be: (i) eligible for Supplemental Security Income (SSI) based on disability or blindness that began before age 26; (ii) entitled to Disability Insurance Benefits (DIB), Childhood Disability Benefits (CDB), or Disabled Widow's or Widower's Benefits (DWB) based on disability or blindness that began before age 26; (iii) a person who has certified, or whose parent or guardian has certified, that he: (A) has a medically determinable

physical or mental impairment that results in “marked and severe functional limitations” (*i.e.* the standard for children claiming SSI benefits) that can be expected to result in death, or has lasted (or can be expected to last) for at least 12 months, or (B) is blind, and the disability or blindness occurred before age 26; or (iv) satisfies one of the conditions listed in the “Compassionate Allowances List” (*see* <https://www.ssa.gov/compassionateallowances/conditions.htm>). While an individual may file a disability certification meeting specific requirements in order to prove eligibility for an ABLE account, no inference regarding disability for purposes of eligibility for other government benefits may be drawn from such a certification. IRC § 529A(e)(1) and (2); Prop. Reg. §§ 1.529A-1(b)(9)(i) and (ii), and 1.529A-2(e)(1), (2), (3) and (5); POMS SI 01130.740.B.1

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

b. IRS Notice 2015-18 indicates that the final Regulations will eliminate one particularly problematic element of the disability certification requirements set forth in IRC § 529A(e)(2)(A)(ii) and Prop. Reg. § 1.529A-2(e)(1)(B)(iii), *i.e.* that a disability certification include a copy of the individual’s diagnosis related to his impairment, signed by a physician. The final Regulations will reportedly require that the individual will retain the signed physician’s diagnosis and make it available to the State’s ABLE Program “upon request.”

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

F. Contributions to and Disbursements from an ABLE Account

1. Any person (as defined by IRC § 7701(a)(1)), including the designated beneficiary, may contribute to an ABLE account, *i.e.* an individual, trust, estate, partnership, association, company, or corporation. *See also* POMS SI 01130.740.B.2. However, the **annual cap on total contributions** to an ABLE account from all sources is limited by reference to the Federal annual gift tax exclusion amount under **IRC § 2503(b)** (which is \$15,000 in 2018). IRC § 529A(b)(2)(B) and Prop. Reg. §§ 1.529A-2(g)(2) and 1.529A-1(b)(10); POMS SI 01130.740.B.2. A qualified ABLE program may accept contributions only in the form of cash, check, money order, credit card payment, or other similar method of payment. IRC § 529A(b)(2)(A) and Prop. Reg. § 1.529A-2(g).

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

b. **Qualified contributions** also include certain rollover distributions from one ABLE account to a different ABLE account for the same designated beneficiary, or to an ABLE account for a designated beneficiary’s family member. IRC § 529A(c)(1)(C); Prop. Reg. § 1.529-1(b)(17). For rollover purposes, a qualified member of the designated beneficiary’s family is limited to a sibling only, including step-siblings and half-siblings, whether by blood or adoption. § 529A(e)(4); Prop. Reg. § 1.529A-1(b)(13).

c. **A rollover from a traditional Qualified State Tuition Program account (“529 Plan”) to an ABLE account is not yet permissible.**

d. While there is no federal income tax deduction for contributions to an ABLE account, some State ABLE programs do allow a modest deduction for purposes of that State’s income tax (*e.g.* Ohio allows a maximum \$2,000 deduction against the donor’s Ohio income tax liability).

2. If distributions made from an ABLE account for the designated beneficiary’s “qualified disability expenses” do not exceed the total qualified disability expenses of the designated beneficiary for his tax year, then **no amount so distributed shall be included** in the designated beneficiary’s gross income. IRC § 529A(c)(1)(B)(i) and Prop. Reg. § 1.529A-3(a). However, the earnings attributable to distributions that are deemed not to be for qualified disability expenses will be includable as ordinary income in the designated beneficiary’s taxable income. In other words, “the earnings portion of the distributions from the ABLE account as determined in the manner provided under IRC § 72, reduced by the product of such earnings portion and the ratio of the amount of the distributions for qualified disability expenses to total distributions, is

includable in the gross income of the designated beneficiary to the extent not otherwise excluded from gross income.” See IRS Guidance under § 529A: Qualified ABLE Programs (RIN 1545-BM68) June 22, 2015, at 20.

a. A well-respected Special Needs Planning tax attorney known to the author opines as follows. “The income taxation of non-qualified ABLE distributions under IRC § 529A(c)(1)(A), by its reference to IRC § 72 (regarding annuity taxation), attempts to tax only the *gain* related to the non-qualified distributions, not the entirety of the distribution. IRC § 529A(c)(3) then requires the tax imposed by IRC § 529A(c)(1)(A) to be increased by 10%, and includable in the gross income of the designated beneficiary. It’s framed in the nature of a *surcharge on the tax*, not a separate penalty.” Perhaps the Final Regulations will include some helpful illustrations of these taxation provisions. Or not.

3. The term “**qualified disability expenses**” means those incurred while the designated beneficiary is an eligible individual, which are related to the designated beneficiary’s blindness or disability, and which are made “**for the benefit of**” the designated beneficiary to maintain or improve his health, independence, or quality of life. ABLE Act § 101(1); IRC § 529A(e)(5); Prop. Reg. §§ 1.529A-1(b)(16) and 1.529A-2(h)(1); POMS SI 01130.740.B.3. “Qualified disability expenses” should be broadly construed to include basic living expenses, and should not be limited to expenses for items for which there is a medical necessity or which provide no benefits to others in addition to benefiting the eligible individual. Prop. Reg. § 1.529A-2(h)(1).

a. IRC § 529A(e)(5) and Prop. Reg. § 1.529A-2(h)(1) provide an initial list of **types of qualified disability expenses**, which the IRS can augment through regulation: education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and basic living expenses (including food and special dietary items). *See also* POMS SI 01130.740.B.5.

(1) Both the ABLE Act and Proposed Regulation § 1.529A-2(h)(1) initially required a qualified ABLE program to establish “safeguards” to distinguish between distributions used to pay qualified disability expenses and other non-qualified distributions, and to facilitate the identification of **amounts distributed for the designated beneficiary’s “housing expenses”** including mortgage payments (as well as insurance required by the mortgage holder); real property taxes; rent; heating fuel; gas; electricity; water; sewer; and garbage removal. POMS SI 01130.740.B.8. These are also included as elements of “In-Kind Support and Maintenance” attributed to an SSI recipient in the context of calculating the amount of his monthly cash benefit. *See discussion supra* at IV.A.1.a.(2)(b)(3). The Proposed Regulations provided no guidance or suggested methodology to accomplish such required classification or tracking.

(i) In response to hundreds of negative comments regarding this aspect of the Proposed Regulations, the Treasury Department and the IRS agreed in Notice 2015-81 that “**the final regulations will not require a qualified ABLE program to identify or record whether distributions were made for housing expenses.**” Furthermore, that Notice also confirms that “the final regulations will not require, for any federal income tax purpose, a qualified ABLE program to establish safeguards to distinguish between distributions used for the payment of qualified disability expenses and other distributions.”

(1) However, the designated beneficiary must be prepared to **categorize distributions** from his ABLE account in order to properly determine his federal income tax obligations, and **for purposes of the “resource” analysis** required of SSI recipients under POMS SI 01130.740.C.5 and 01130.740.D.2. and 3.

G. ABLE Accounts and Means-Tested Government Benefits

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

a. The new SSA POMS state that distributions made from an ABLE account are not considered income to the designated beneficiary. *See* POMS SI 01130.740.C.4. Instead, distributions from an ABLE account are deemed to be conversions of resources from one form to another. *See* POMS SI 01130.740.C.4. **Distributions from an ABLE account are not counted as income (including “In-Kind Support and Maintenance,” discussed *supra* at IV.A.1.a.(2)(b)(3)) to the designated beneficiary regardless of whether they are for non-housing qualified disability expenses, housing qualified disability expenses, or non-qualified expenses.** POMS SI 01130.740.C.4.

b. While the POMS which govern ABLE accounts acknowledge that distributions from an ABLE account do not count against the designated beneficiary as income (including income that constitutes “In-Kind Support and Maintenance”), there are numerous provisions that address **an ABLE account, and distributions therefrom, as an available resource** to the designated beneficiary.

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

(2) In contrast, a distribution from an ABLE account for a *housing-related* qualified disability expense, or for an expense that is not a qualified disability expense, that is retained by the designated beneficiary in a month following the month of receipt is includable in the designated beneficiary’s countable resources. POMS SI 01130.740.D.2.

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

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

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

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

d. The **total cumulative value of an ABLE account is capped** at the State’s limitation for § 529 Qualified State Tuition Program accounts (a/k/a “529 Plans”), ranging from \$235,000 to \$445,000. In Georgia, the **IRC § 529(b)(6) limit** is \$235,000. See O.C.G.A. § 20-3-634(b)(1). However, since the State of Georgia does not have its own ABLE program, and has instead partnered with Ohio’s STABLE program, Georgia designated beneficiaries are afforded the benefit of Ohio’s much higher § 529(b)(6) limit of \$445,000. The Proposed Regulations mandate the return to contributors of excess cumulative contributions (and the net income attributable to those contributions) which cause an ABLE account balance to exceed the State’s maximum limitation for § 529 Plans. IRC § 529A(b)(6), and Prop. Reg. §§ 1.529A-1(b)(11) and 1.529A-2(g)(3) and (4). Although the Code and Proposed Regulations are not entirely clear, it is presumed that a designated beneficiary would also lose Medicaid eligibility if the value of his ABLE account exceeds the IRC § 529(b)(6) limit.

e. It is also not entirely clear whether a transfer to an ABLE account by a designated beneficiary of his own assets when he is 65 or older would constitute a penalty transfer for purposes of means-tested government benefits eligibility, as discussed *supra* at III.B.2.d. and III.D.1.f. However, some well-respected practitioners insist that the designated beneficiary may continue to fund his ABLE account even after he attains 65 years of age, since the definition of “designated beneficiary” does not include any upper age limitation. POMS SI 10030.740.B.1. In contrast, no contributions to a first-party Special Needs Trust may be added after the beneficiary’s sixty-fifth birthday, as discussed *supra* at III.B.2.d.

H. ABLE Accounts Are Subject to a Medicaid Payback Claim

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

“A qualified ABLE program must provide that a portion or all of the balance remaining in the ABLE account of a deceased designated beneficiary **must be distributed to a State that files a claim** against the designated beneficiary or the ABLE account itself with respect to benefits provided to the designated beneficiary under that State’s Medicaid plan . . . The payment of such claim (if any) shall be . . . limited to the amount of the total medical assistance paid for the designated beneficiary after the establishment of the ABLE account . . .” *See also* POMS SI 01130.740.A.

a. Thus, even third-party funds contributed to an ABLE account are subject to a Medicaid payback claim, which is not required in the context of a third-party Special Needs Trust. *See supra* at III.C.2. (Oddly enough, this exceedingly disadvantageous provision of the ABLE Act and Proposed Regulations is not widely recognized or reported.)

(1) Apparently, a State theoretically has discretion *not* to exact the Medicaid payback from an ABLE account. Query: how likely is it that any State would decline to exact the payback?

2. The State Medicaid program is considered a creditor of an ABLE account, not a beneficiary. IRC § 529A(f).

3. Any funds remaining in an ABLE account after the Medicaid payback will be distributed to the estate of the deceased designated beneficiary, or to another post-death beneficiary designated for the account. Prop. Reg. § 1.529A-3(d)(2)(i).

I. Additional Issues

1. If an individual cannot himself **establish or manage an ABLE account** (e.g. because he is a minor or “is otherwise incapable of managing” his ABLE account as a consequence of his disability (or otherwise), **the individual’s agent under a power of attorney or, if none, his parent or “legal guardian,” may establish an account for that individual and oversee its management as “a person with signature authority.”** Prop. Reg. §§ 1.529A-1(b)(4) and 1.529A-2(c)(1); *see also* POMS SI 01130.740.B.4. (Notably absent in the list of persons with authority to establish an ABLE account for a designated beneficiary are grandparents or other relatives, and non-related friends or other third parties.) Any reference in the ABLE Act or Proposed Regulations to actions of the designated beneficiary, such as opening or managing the account, are deemed to include the actions of any individual other than the designated beneficiary who is granted signature authority over the ABLE account. Nevertheless, for SSI purposes, the SSA always considers the designated beneficiary to be the owner of the ABLE account, irrespective of who has signature authority over it. Prop. Reg. § 1.529A-1(b)(4) and POMS SI 01130.740.B.4.

a. Practitioners opine that “**incapable of managing**” his ABLE account does not necessarily require a judicial determination that the designated beneficiary is incapacitated, or that the incapacity be related to the disability, but could also include spendthrift tendencies, substance abuse and addictions, and similar financial mismanagement or imprudence. Proposed Regulation § 1.529A-1(b)(4) contemplates that a designated beneficiary may choose not to exercise significant authority over his ABLE account for any reason, or no reason.

(1) Despite the Proposed Regulations and the new POMS expressly allowing a parent or “legal guardian” of a designated beneficiary to establish and maintain an ABLE account on his behalf, State ABLE Programs reportedly vary widely regarding their willingness to allow this practice, some requiring a court-appointed conservator.

(2) Anticipating that a designated beneficiary with mental capacity who is initially capable of establishing his ABLE account but who may subsequently lose his capacity or simply choose not to manage the account, it is prudent to have him execute a **durable power of attorney granting a third-party signature authority** over his ABLE

account in either such event. (The ABLE Program may have a form of limited power of attorney available for this purpose.) It is also advisable for his parents to include in their durable powers of attorney the express authority to establish, fund and manage an ABLE account for their child with a disability.

b. Any person with signature authority over an ABLE account who is not the designated beneficiary thereof may neither have nor acquire any beneficial interest in the account, and must only administer that account for the benefit of the designated beneficiary. Prop. Reg. § 1.529A-2(c)(3).

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

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

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

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

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

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

b. IRC § 529A(d)(4) requires the State ABLE program to **electronically transmit to the Social Security Administration monthly statements** regarding all ABLE account balances and account distributions. Proposed Regulation § 1.529A-2(h)(1) initially provided that such reports must include details regarding distributions for the housing expenses of the designated beneficiary, or distributions used for non-qualified expenses. As discussed at VII.F.3.a.(1)(i), *supra*, the Final Regulations will eliminate these requirements.

5. The Proposed Regulations, when adopted as Final Regulations, will apply to taxable years beginning after December 31, 2014. Prop. Reg. § 1.529A-1(c).

6. Notwithstanding the absence of Final Regulations, numerous States have moved forward with the establishment of State ABLE Programs. IRS Notice 2015-18 (I.R.B. 2015-12, March 23, 2015) provides that if State ABLE legislation, or ABLE implementation regulations and documents, passed or issued before Final Regulations are published do not fully comply with the Final Regulations, the States will be allowed sufficient transition periods to bring them into compliance.

J. Additional Tax Considerations for ABLE Accounts

1. If the total aggregate amount distributed from an ABLE account to, or for the benefit of, the designated beneficiary during his taxable year does not exceed his total qualified disability expenses for that year, no amount (income or principal) so distributed is includable in his gross income for that year. IRC § 529A(c)(1)(B)(i) and Prop. Reg. § 1.529A-3(a). In making this determination, all amounts distributed from an ABLE account to, or for the benefit of, the designated beneficiary during his tax year are treated as one distribution. IRC § 529A(c)(1)(D)(i) and Prop. Reg. § 1.529A-3(a). Thus, for income tax purposes, there is **no requirement to link a specific distribution from an ABLE account to a specific**

expense of the designated beneficiary. (Indeed, a similar distribution verification requirement was eliminated from IRC § 529 Qualified State Tuition Program accounts because of its unworkability from a staffing and programmatic standpoint.)

2. Additional amounts excluded from the gross income of the designated beneficiary include (i) a qualified rollover from one ABLE account to another ABLE account (as defined in Prop. Reg. § 1.529A-1(b)(17)); *see also* POMS SI 01130.740.B.6; (ii) a program-to-program transfer (as defined in Prop. Reg. § 1.529A-1(b)(14); (iii) a change of designated beneficiary during the lifetime of the initial designated beneficiary if the successor designated beneficiary meets the relevant blindness or disability requirements, onset age, and is a sibling by blood or adoption (including a step-sibling or a half-sibling); and (iv) distributions after the death of the designated beneficiary in payment of outstanding obligations due for qualified disability expenses and any Medicaid payback claims. IRC § 529A(c)(1)(C) and Prop. Reg. § 1.529A-3(b)(1), (2), (3) and (4).

3. As noted in VII.F.2, *supra*, if any distribution from an ABLE account is includable in a person's gross income, it is deemed to be a *pro rata* distribution of principal and gains, with the **portion constituting gains subject to ordinary income taxation and a 10% penalty**. IRC § 529A(c)(3)(A) and Prop. Reg. § 1.529A-3(d). Exceptions to this 10% penalty tax include (i) post-death distributions to the designated beneficiary's estate, heirs or legatees, or creditors (but the earnings portion of the distribution is still subject to ordinary income tax); (ii) returns of excess contributions over the Federal gift tax annual exclusion limit, returns of excess cumulative contributions over the State's § 529 Qualified State Tuition Program limit, or returns of contributions to "excess" ABLE accounts (*i.e.* if more than one ABLE account is erroneously established for a single designated beneficiary). Prop. Reg. § 1.529A-3(d)(1) and (2).

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

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

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

7. A contribution to an ABLE account by the designated beneficiary that is comprised of his own property does not constitute a gift. Treas. Reg. § 25.2511-2(b) and (c). However, such property (and any earnings attributable thereto) would **constitute a gift by the designated beneficiary to any qualified successor designated beneficiary** who succeeds to his interest in the account, as contemplated by Prop. Reg. § 1.529A-3(b)(3). Prop. Reg. § 1.529A-4(a)(3). There are no gift tax or generation-skipping transfer tax consequences to a qualified successor designated beneficiary as a consequence of the change of beneficiary. IRC § 529A(c)(2)(C) and Prop. Reg. § 1.529A-4(c).

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

K. Comparison of ABLE Accounts and Special Needs Trusts

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

a. Assuming that a State offers an ABLE program to its residents, or contracts with another State to offer an ABLE program to its residents, **no attorney, accountant or other paid allied professional need be consulted** or involved in opening an ABLE account.

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

c. **Post-death qualified disability expense distributions** from an ABLE account (including funeral and burial expenses of the designated beneficiary) are permissible prior to any required Medicaid payback, whereas with a first-party Special Needs Trust, there must be an immediate cessation of payments except for the categories specifically allowed by POMS in SI 01120.203.B.3.

d. An ABLE account affords some **financial autonomy** to persons with disabilities who would otherwise be precluded by the rules of the means-tested government benefit programs for which they are eligible from controlling the investment and disbursement of sums in excess of \$2,000.

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

f. A mentally competent **designated beneficiary can establish** his own ABLE account. Only recently, *i.e.* as of December 13, 2016, has it been possible for a mentally competent beneficiary to serve as the Settlor of his own first-party Special Needs Trust.

g. While every Special Needs Trust must be reviewed by SSA Regional Trust Review Teams and corresponding State Medicaid reviewers, a qualified ABLE program is viewed as a “safe-harbor,” *i.e.* an individual designated beneficiary **need not seek formal approval** of his specific ABLE account.

h. Under the “disability certification” option for ABLE accounts, the Proposed Regulations allow for a designated beneficiary to **use the more lenient SSA child disability standard** of “marked and severe functional limitations” even for adult beneficiaries. Prop. Reg. § 1.529A-2(e)(1) and (2).

i. It is possible to **increase a designated beneficiary’s monthly SSI payment** by using distributions from an ABLE account to pay for his food and housing expenses. Since such payments are **not deemed to be ISM**, there is no reduction of his SSI payment amount under the “Value of One-Third Reduction” or “Presumed Maximum Value” rules, as would be the case if a Special Needs Trust were to make distributions to pay for such expenses. *See discussion supra at VII.G.1.a.*

(1) In 2018, the maximum federal SSI monthly benefit is \$750. If a Special Needs Trust were to pay the beneficiary’s housing or food expenses, a maximum reduction of \$250 or \$270 (depending on the beneficiary’s living arrangement) would apply under the VTR or PMV rules applicable to ISM, yielding a monthly SSI benefit of only \$480 or \$500, as the case may be. If the same housing or food expenses were defrayed by distributions from the designated beneficiary’s ABLE account, there would be no ISM reduction to his SSI payments, thus increasing his annual SSI payments by \$3,000 or \$3,240, as the case may be ($\$250 \times 12 \text{ months} = \$3,000$; $\$270 \times 12 \text{ months} = \$3,240$).

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

k. Distributions from an ABLE account may be made **to or “for the benefit of” the designated beneficiary**. IRC § 529A(e)(5); Prop. Reg. §§ 1.529A-1(b)(16), 1.529A-2(h)(1); POMS SI 01130.740.B.3. Disbursements from a first-party Special Needs Trust are subject to the stricter “sole benefit” standard. *See discussion supra at III.B.2.c.(2).*

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

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

b. While an ABLE account may be funded each year with a maximum of \$15,000 (in 2018) from all sources combined, **a third-party Special Needs Trust has no such annual limit on contributions.** Even though the annual contribution limit set forth in IRC § 2503(b) is indexed for inflation, this annual limitation will make it difficult to accumulate a significant fund for the designated beneficiary in an expeditious manner. Thus, assuming that a designated beneficiary established an ABLE account in 2016 (*i.e.* the first year that any State offered an ABLE program), funded it each year with the maximum permissible amount (\$14,000/year for the first two years, \$15,000/year for the next five years, assuming no increase in the annual limit), and makes no withdrawals from the ABLE account, the \$100,000 limit would not be exceeded until 2022 (not counting any tax-free earnings on the account balance over the years).

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

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

e. While the designated beneficiary of an ABLE account must satisfy the definition of blind or disabled prescribed by the Social Security Administration, the **beneficiary of a third-party Special Needs Trust need not meet any particular definition of disability.** (As discussed *supra* at III.B.2.b., the beneficiary of a first-party Special Needs Trust must also satisfy the definition of disabled promulgated by the Social Security Administration.)

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

g. While an ABLE account may only be established by the designated beneficiary, or by his parent, legal guardian or attorney-in-fact, **anyone can establish a third-party Special Needs Trust.** Grandparents, other family members or any other interested parties are inexplicably precluded from establishing an ABLE account for a designated beneficiary.

h. While each designated beneficiary may have only one ABLE account, there is **no limit on the number of Special Needs Trusts (first-party or third-party) which may be established** for a beneficiary. This is particularly important if the funders of third-party Special Needs Trusts wish to designate different remainder beneficiaries after the death of the beneficiary with the disability.

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

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

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

a. If the designated beneficiary does not regularly spend all of his SSI or SSDI monthly payments, or his earned income below the "Substantial Gainful Activity" level, and repeatedly runs the risk of exceeding the \$2,000 resource limit for means-tested government benefits eligibility, such **excess first-party funds could be contributed to his ABLE account.**

b. If the designated beneficiary is legally entitled to receive an inheritance, gift, prize, settlement, lottery winnings, or other funds of less \$15,000, **or other periodic payments of less than \$1,250/month**, and does not wish

to “spend down” the funds quickly, *e.g.* by purchasing exempt assets with the otherwise disqualifying resources, such first-party funds could be contributed to an ABLE account.

c. An ABLE account might be beneficial for a mentally competent designated beneficiary who wishes to **use the account as a fiscal education tool**, including twice-a-year opportunities to direct the investment of the account funds.

L. Recent Legislative Developments

On April 5, 2017, members of Congress introduced a package of bills to further enhance the benefits provided through the ABLE Act. This package of bills includes the “ABLE AGE ADJUSTMENT ACT” (S. 817/HR 1874), the “ABLE FINANCIAL PLANNING ACT” (S. 816/HR 1897), and the “ABLE TO WORK ACT” (S. 818/HR 1896). *See* ABLE National Resource Center, <http://www.ablenrc.org/news/members-congress-re-introduce-able-improvement-bills> (last visited May 24, 2017).

a. The ABLE AGE ADJUSTMENT ACT would raise the disability onset age limit from age 26 to age 46.

b. The ABLE FINANCIAL PLANNING ACT would permit families to roll over savings in a 529 Qualified State Tuition Program account into an ABLE account without penalty; however, such a rollover would still be subject to the annual contribution limit applicable to ABLE accounts (currently \$15,000).

c. THE ABLE TO WORK ACT would allow the designated beneficiary of an ABLE account who earns income from a job to contribute from his compensation up to the Federal Poverty Level (in 2018, \$12,060), in addition to the annual contribution limit, which would potentially increase allowable annual contributions to \$27,060.

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).⁵⁵ Advising clients who have beneficiaries with special needs is fraught with challenges, but the personal and professional rewards for successful planning are unparalleled.

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http://www.americanbar.org/content/dam/aba/publications/probate_property_magazine/v24/02/2010_aba_rppe_pp_v24_2_mar_apr_barr_davis_lewis.authcheckdam.pdf.

**Beyond the Special Needs Trust:
Essential New Developments in Special Needs Planning**

(Part Three of Three)

By

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Quality of Life!!! It's the reason most of our clients retain us to prepare special needs trusts for them. They want to secure and ensure that their family member with a disability has the highest quality of life possible after the client, usually parents or siblings, is no longer available to be the primary caregiver and cheerleader. However, it is not just about quality of life after the primary caregiver is deceased that my clients care about; it's also about their son's or daughter's quality of life ***today*** and preparing for a life which brings joy, inclusion and a sense of purpose to the individual with special needs this year, next year and for every year thereafter.

Better than half the time during my first meeting with a client, the first question is about resources. Where can the family find supports locally? Where can the parents find information on the internet? Families inevitably want to learn more about their son's or daughter's disability and what the family might expect over the years. What can the family do now to help their child deal with the behavioral, cognitive and/or physical challenges he/she faces today and will continue to face later in life.

Clients want to know about helping their child with special needs acquire basic education skills; reading, writing, arithmetic, and life care skills -- what should they expect from the school system and how can they best advocate for their child within that system. If reading presents an extra-special challenge, where can they go for help with reading? Where can they find help building social skills?

Whether the topic is employment, transition to adulthood, independent living arrangements, government benefits, guardianship/conservatorship, school advocacy or healthcare, if you working in the special needs arena, you should have a basic understanding of these areas of law and where your clients can obtain assistance with respect to these issues.

I. Finding Resources. In my experience, while local, hands-on and family networking resources are the best referrals you can provide to your special needs clients, it takes time and effort to learn what organizations in your city or your region of the state specialize in the areas needed by your clients. Invest that time and effort; learn the area(s) of specialization of local organizations, the opinions they hold on which therapies are most helpful, and the group's opinion on what the term "quality of life" means. In other words, each organization will have its own personality. Your clients want and value your opinions on resources as much as they do the law.

Often, though, you will find that some of the most important information you need when working with clients is generic information about the disability impacting the client's loved one. They will want to be able to discuss where to find generally accepted therapies, including whether there is scientific consensus about a therapy's benefits. Likewise, questions about quality of life issues will invariably arise.

Therefore, you will find below, grouped as I believe most helpful, some of the more important organizations which provide the types of information, whether general, specific, practical or scientific, which lawyers, financial advisors and clients are often seeking about a specific disability, therapy and/or quality of life issue.

A. Academic Organizations

1. **Introduction.** As you might expect, some of the best information regarding different disabilities, current trends in treatment, available therapies and family supports are found through colleges and universities across the nation. In fact, you may find that one of the best resources for families seeking specific advice with regard to quality of life will come from organizations which are a part of or affiliated with a local college or university.

2. **The Association of University Centers on Disabilities (AUCD)**. AUCD is a membership organization supporting and promoting national networks of university-based interdisciplinary programs focused on bringing those with disabilities, the community and the universities together to provide resources and advocacy. www.aucd.org.

3. **University Centers for Excellence in Developmental Disabilities (UCEEDs)**. Authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, this national network receives its core funding from the Administration on Intellectual Disabilities (AIDD). These centers focus on working with individuals with disabilities, their families, state and local government agencies, and community providers on projects which focus on building the capacity of the community to sustain all of its citizens. As of September, there were 67 UCEED's with at least one in every U.S. state and territory.

a. **Directory**. A full directory of the UCEEDs, sometimes including their area of specialty, can be found on the AUCD website noted above.

b. **Tennessee's UCEEDs**. The Boling Center for Developmental Disabilities at the University of Tennessee Health Center in Memphis and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities in Nashville.

c. **Georgia's UCEEDs**. The Institute on Human Development and Disability at the University of Georgia and the Center for Leadership in Disability at Georgia State University.

d. **Leadership Education in Neurodevelopment and Related Disabilities ("LENDs")**. Focusing on interdisciplinary services and care, LEND programs seek to improve the health of infants, children and adolescents with disabilities.

(1) **In Tennessee**. Tennessee's LEND programs are found at the Boling Center for Developmental Disabilities and at the Vanderbilt University Medical Center.

(2) **In Georgia**. Georgia's LEND programs are housed at Georgia State University and its Center for Leadership in Disability.

e. **Intellectual and Developmental Disabilities Research Centers ("IDDRCs")**. IDDRCs were created in 1963 as "centers of excellence" for research in intellectual and developmental disabilities focusing on prevention and treatment through biomedical and behavioral research. There are only 14 IDDRCs across the nation.

(1) Most of these organizations are found as part of a university's medical center and include the UC Davis MIND Institute, as well as Centers at the University of Kansas, the Kennedy Krieger Institute (affiliated with Johns Hopkins University), the University of North Carolina, the University of Washington and the University of Wisconsin.

(2) The AUCD website contains links for the 14 IDDRCs and information about which of these Centers focus on specific disabilities and/or therapies, as well as which provide technical assistance on quality of life issues such as diversity and inclusion, assistive support for autism and other developmental disabilities.

f. **Other Organizations At Colleges and Universities**. In addition to the formal research and outreach programs listed as part of the AUCD, many colleges and universities have separate "Centers" on disability(ies) which focus on providing research and support relating to quality of life for individuals with disabilities and their families. For example, the University of Kansas hosts the Beach Center on Disability. www.beachcenter.org.

g. **Specific Autism Research**. The University of North Carolina has the TEACH Autism Program specifically designed to create and cultivate the development of community-based interventions across the lifespan of individuals with autism spectrum disorder and their families. www.teacch.com. Within the Vanderbilt Kennedy Center is the Treatment and Research Institute for Autism Spectrum Disorders. www.vkc.mc/vanderbilt.edu. And, Emory University has its Emory Autism Center. www.psychiatry.emory.edu. Likewise, the University of Washington in Seattle has an autism specific center.

4. **Disability Organizations.**

a. The Arc U.S.. A national organization for individuals with a disability and their families, the Arc supports disability education, advocacy and planning in general. Besides being a national organization, the Arc has individual chapters in each of the 50 states as well as the District of Columbia. www.thearc.org.

b. [Your State] Council on Developmental Disabilities. As a Federal program, each state has a Council on Developmental Disabilities. Georgia's is found at www.gcdd.org. The Georgia Council on Developmental Disabilities is one of 55 Developmental Disability Councils established across the United States and its territories under the Developmental Disabilities Assistance and Bill of Rights Act of 1971.

c. American Association on Intellectual and Developmental Disabilities ("AAIDD"). AAIDD is an organization which promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities. www.aaidd.org.

d. Easter Seals. An organization which serves children and adults with disabilities and their families by providing services and support. www.Easter-seals.org.

e. Bazelon Center for Mental Health Law. An organization designed to protect and advance the rights of adults and children with mental disabilities, it is an excellent resource for mental health issues. www.bazelon.org.

f. The Brain Injury Association of America ("BIAA"). The country's oldest and largest nationwide brain injury advocacy education and research organization. www.biausa.org.

g. The Kaiser Family Foundation. The Kaiser Family Foundation provides in-depth information on national health policy questions and issues. www.kff.org.

5. **National Disability Specific Organizations.**

- a. Alzheimer's Association. www.mda.org.
- b. Autism Speaks. www.autismspeaks.com.
- c. Autism Society of America. www.autism-society.org.
- d. Cerebral Palsy Alliance. ([www.cerebralgisy.org](http://www.cerebralgalsy.org)).
- e. Epilepsy Foundation. (www.epilepsy.com).
- f. Muscular Dystrophy Association. www.mda.org.
- g. National Association for Visually Handicapped ("NAHV"). (www.navh.com).
- h. National Association of the Deaf ("NAD"). (www.nad.org).
- i. National Association on Mental Illness ("NAMI"). (www.nami.org).
- j. National Down Syndrome Society. (www.ndss.org).
- k. National Federation of the Blind ("NFB"). (www.nfb.org).
- l. National Multiple Sclerosis Society ("NMSS"). (www.nationalmssociety.org).

6. **State and Local Organizations.**

a. State and Local Chapters of National Organizations. Most of the organizations listed above (for example, The Arc and the Autism Society of America) have, in addition to the national organization, state and/or local chapters which serve as wonderful opportunities for families to network with other local families in similar situations and exchange information with respect to resources such as doctors, dentists and other professionals necessary in the lives of their children.

b. Truly Local Organizations. Many families in cities throughout the United States have recognized the need for support organizations in the community, coming together and forming, through their own efforts, very successful disability support organizations. In Atlanta, one such organization is All About Developmental Disabilities ("AADD") which can be found at www.aadd.org.

7. **National Disability Organizations Focused on Specific Services.**
 - a. Special Olympics. www.specialolympics.org.
 - b. Best Buddies. www.bestbuddies.org.
8. **Government Organizations.**
 - a. Disability.gov. A one stop cross-agency portal for information on Federal programs, services and resources for people with disabilities, their families and employers etc. www.disability.gov.
 - b. The National Council on Disability. A small independent Federal agency charged with advising the government and its agencies regarding policies, program practices and procedures which affect people with disabilities. www.ndc.gov.
 - c. The National Institute on Disability and Rehabilitation Research. This organization administers the principal Federal disability research programs and ADA technical assistance centers for the government. It is part of the U.S. Department of Education. www.ed.gov.
 - d. National Institutes of Health. www.nih.gov.
 - e. Centers for Disease Control and Prevention ("CDC"). www.cdc.gov.
 - f. Centers for Medicare and Medicaid Services ("CMS"). www.cms.gov.
 - g. Social Security Administration ("SSA"). www.ssa.gov.
 - h. Council of Parent Attorneys and Advocates ("COPAA"). A national nonprofit membership organization focusing on the availability and quality of legal representation of parents and children with disabilities in respect to education issues. www.copaa.org.

II. Independent Living/Housing.

A. Introduction. Every family which includes an individual with special needs eventually takes this journey together; the journey to learn whether their loved one can live independently and, if not, what are the alternatives?

B. Acronyms and Definitions (based on Federal and Georgia law and regulations).

- a. ABLE Account.....** The Federal Achieving a Better Life Experience Act which allows families, including the AC, to set aside \$14,000 per year in a 529 type of account (in 2018, the contribution limit increases to \$15,000).
- b. ASSISTED LIVING COMMUNITY** A Personal Care Home serving 25 or more residents providing assistance with medications (by a certified medication aid), assisted self-preservation and other personal services (i.e., assistance with or supervision of the essentials of daily living -- which includes eating, bathing, grooming, dressing and toileting).
- c. CLA** Community Living Arrangements (CLA) are PCHs where the residents are financially supported by DBHDD (or other Georgia government entities).

- d. CMS** Centers for Medicare and Medicaid Services, a part of the U.S. Department of Health and Human Services.
- e. DBHDD** Georgia's Department of Behavioral Health and Developmental Disabilities.
- f. DCH** Georgia's Department of Community Health (in charge of Georgia Medicaid and healthcare facility regulation).
- g. GROUP HOMES** In Georgia, there are two types -- Community Living Arrangements (CLAs) and Personal Care Homes (PCHs), and neither can be an "institutional setting."
- h. HCBS** Home and community-based services (most often used with reference to Medicaid waivers).
- i. HOME and COMMUNITY BASED SETTINGS** See CMS Regulation Section 441.530. **Exhibit III-1**.
- j. HOST HOME** An unrelated family which provides 24/7 care and oversight to no more than two (2) individuals with developmental disabilities (must be licensed by DCH)(O.C.G.A. §37-1-20(18)).
- k. HUD** U.S. Department of Housing and Urban Development.
- l. ICF** Intermediate Care Facilities, most often for individuals with intellectual or developmental disabilities which severely impact the essentials of their daily living.
- m. INSTITUTION or INSTITUTIONAL SETTING** Under CMS regulations, HCBS waivers are not to be provided in *institutional settings*, rather they are to be used to support an individual's ability to live in a home and community-based settings (and expressly excluded are nursing facilities, institutions for mental diseases or ICFs).
- n. PCH(s)** Personal Care Home (PCH) dwellings which provide room, food service and personal services (as described in Assisted Living Communities) for 2 or more adults not related to owner or administrator by blood or marriage and must be licensed by DCH.
- o. POOLED TRUST** A multi-beneficiary type of SNT (often included here with SNTs).
- p. SECTION 8** Federal low-income housing support program sponsored by HUD.

q. SLA Shared living arrangement; a person "lives" with an individual with a disability and provides general support in life in return for rent subsidy or other compensation.

r. SNT..... Special Needs Trust.

C. A Brief Overview on the Policy Debate.

1. For background, the following is an introduction to the political environment and the policy disagreements which impact housing choices for individuals with developmental or intellectual disabilities.

a. As many parents are already aware, the trend from an advocacy and policy standpoint which has now been formally adopted by CMS in regulations is to move away from larger housing in institutional settings and toward smaller housing (in size) choices which are assumed to be integrated with the general community. That push comes not only because of the results of Federal litigation when adequate community-based living options have not been made available, see e.g., Olmstead v. United States, 277 U.S. 438, 48 S. Ct. 564; 67 L. Ed. 785 (1928), but also because national organizations, spurred by academic research, have been advocating for more choice on the part of individuals with a disability in his/her living arrangements and the person-centered delivery of services necessary for the individual to live independently.

b. For those in Georgia, another of the important factors is the state's relatively recent settlement of litigation with the Federal government focused on allegations that Georgia relied too heavily on institutional housing and had failed to meet the Federal government's goals on caring for the housing needs of homeless individuals with disabilities. A settlement which has had a tremendous on Georgia's HCBS Transition Plan.

2. From a policy standpoint, CMS, which sets much of the Federal government's disability policies through its Medicaid regulations, has rejected and abandoned the old model of institutional housing.

a. In final regulations issued in 2014 (42 CFR §441.301), Medicaid embraced the call to integrate those with intellectual and developmental disabilities "in the greater community," by narrowly defining "home and community-based settings" for purposes of when Medicaid waiver supports can be made available to recipients.

b. Another regulatory change adopted in 2014 added that waiver programs must hereafter focus on person-centered planning (e.g., heavily weight the ultimate result to the choice by the individual as to type of living arrangement, type(s) of services to be provided and who will provide those services).

c. A copy of the 2014 HCBS rule is attached as **Exhibit III-2.**

3. According to CMS itself, its intent in issuing the 2014 regulations was to define home and community-based services more by "what [HCBS] is not," and to place more focus on the nature of and quality of life of the individual's experience by requiring that the opinion of the individual with a disability must be taken into account on what adds to his/her quality of life.

4. According to Georgia's interpretation of the HCBS regulations, any setting "with the effect of isolating an individual from the broader community" of those who do not receive waiver services is problematic, and includes any housing set on the grounds of or adjacent to what Georgia believes to be a public institution. In fact, Georgia, at least informally, takes the position that any home or living arrangement associated with an institution of any type cannot, by definition, be an integrated setting.

5. This policy change from the 1960's -- when we were "taking care" of those with disabilities -- to the current push to provide choice and actively require integration means that families must be more creative and much more flexible as they try to solve the challenges of creating opportunities for independent living for family members with special needs, especially where waiver supports are financially necessary for the individual to be independent.

6. Families must understand that finding the best solution for independent housing will require them to be active in designing possible alternatives, not to mention commit time, expertise and financial resources to public and private arrangements in order for those arrangements to have any long-term success.

7. In order to determine the type of setting which best suits any specific adult with a disability, the following factors must be fully examined:

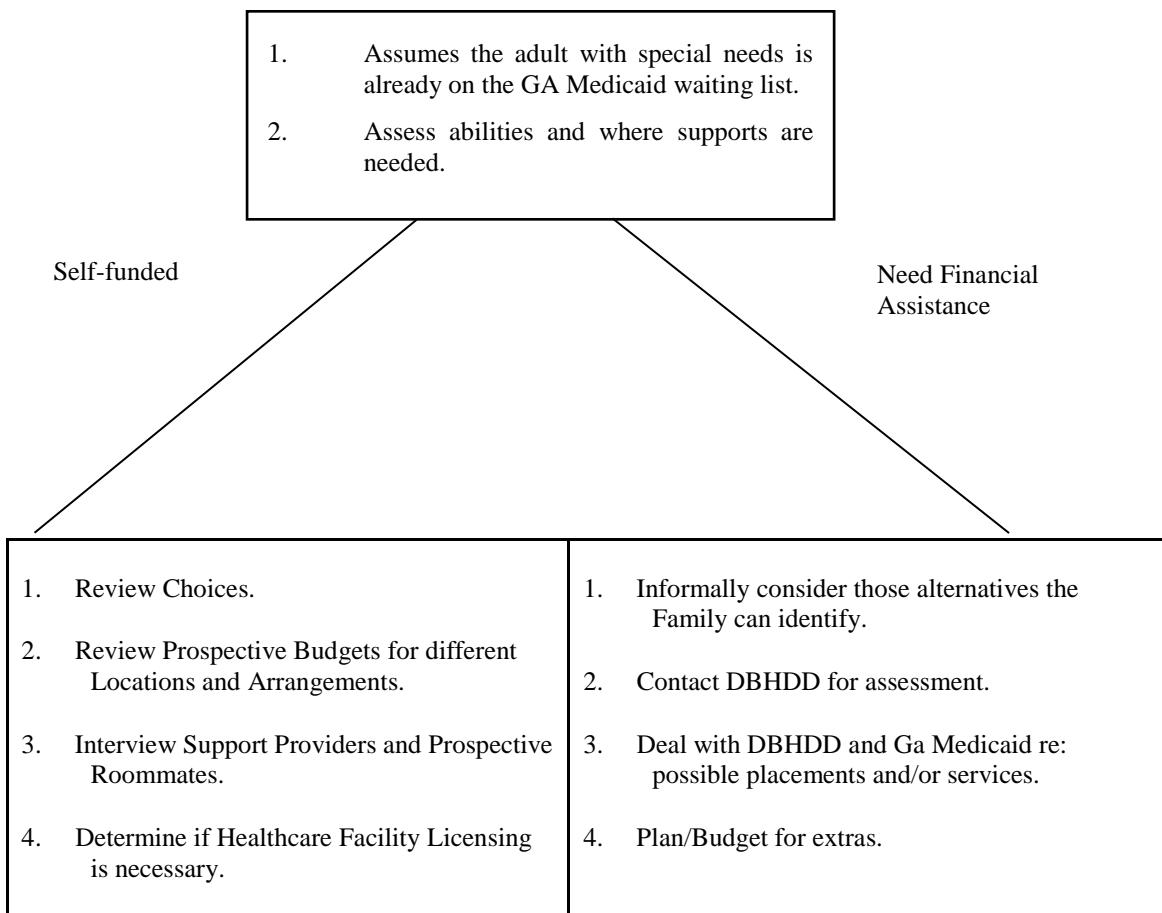
- a. What kind of physical structure is desired/needed?
- b. Who will own the property and/or have primary financial responsibility for the living space?
- c. Who will pay for the property, utilities, property taxes and property maintenance?
- d. How much day-to-day support does the family member with special needs require in order to be independent?
- e. Who will provide those support services (family members, roommates, agencies/organizations, others)?
- f. How will an adult with special needs be able to afford living independently in the community? How will support services be financed?

D. Possible Living Arrangements Matrix.

Description of Physical Housing	Are DCH Services Available?	Where Does Financial Support Come From?
Home of Parent or other family member	HCBS Waiver Process (which analyzes needs, desires, abilities, choices)	Parent, family, SSI, maybe Medicaid (support services) and/or SNT or ABLE
The person with a disability owns or rents his/her condo, house or apartment	SLA and/or HCBS Waiver Process	SSI, work, maybe Medicaid and/or SNT, ABLE, Parent/Family or Section 8 voucher
PCH (If more than 2 unrelated individuals, DCH requires licensing)	SLA and/or HCBS Waiver Process	SSI, work, maybe Medicaid and/or SNT, ABLE, Parent/Family or Section 8 voucher
CLA	Through DBHDD assessment process	SSI, work, Medicaid. Extras from SNT, ABLE or parents/family
Host Home	Through DBHDD assessment process	SSI, work, Medicaid. Extras from SNT, ABLE or parents/family
Private Group Settings	Not Available (after 2022 depending upon the State's Medicaid and Waiver Plans)	SSI, family resources, work, SNT and/or ABLE

E. A Proposed Decision Tree.

The individual with special needs and his/her family



III. Private Pay Options.

A. Introduction. Even before the changes to the Medicaid HCBS rules, a number of facilities accepted residents with disabilities and created their own "communities" for such adolescents and adults.

1. In addition to room and board, these facilities offered organized group activities, nursing and medication assistance and often separate living quarters.

2. It is worth noting that until the change in the Medicaid rules, some states supported segregated living arrangements in farm and rural settings and/or large disability only apartments by paying an agreed amount per resident under the HCBS waiver to the residential provider. Amy Lutz, *Who Decides Where Autistic Adults Live?*, The Atlantic, May 26, 2015.

B. What Do They Look Like? These facilities are mostly segregated and the living arrangements provided more often resemble dorms than individual apartments, but most parents and many residents prefer the comfort and safety of the campus-like settings. Mostly, however, the residents enjoy the ability to make and keep friends and the sense of community.

C. A Few Examples. Some of these types of facilities are listed below.

1. [Annandale Village](http://www.annandale.org) in Suwanne, GA (just north of Atlanta). www.annandale.org.
2. [Stephens Place](http://www.stephensplace.org), Vancouver, WA (nearest Portland, OR). www.stephensplace.org.
3. [The Stewart Home & School](http://www.stewarthome.com), Frankfort, KY (near Lexington). www.stewarthome.com.
4. [Hanna and Friends](http://www.hannahandfriends.org), South Bend, IN. www.hannahandfriends.org.
5. [Marbridge Foundation](http://www.marbridge.org), Manchaca, Texas (outside of Austin). www.marbridge.org.
6. [The Baddour Center](http://www.baddour.org), Senatobia, MS (outside of Memphis). www.baddour.org.

D. A Listing. A partial list of residential options by state can be found at www.joniandfriends.org.

E. Independent Living Centers. Another resource is your local Independent Living Center, a list of which can be found at www.virtualcil.net/cils.

F. Legal Disclaimer. *The resources identified in these materials do not constitute an endorsement of the organization and the authors assume no liability in the identification of these potential resources.*

IV. Guardianship Alternatives.

A. Why We Have Guardianships. As a general proposition, the law presumes that those of us who are over the age of 18 have "sufficient capacity" to make or communicate significant responsible decisions concerning our health and safety and "sufficient capacity" to make or communicate significant responsible decisions concerning the management of our property.

1. If it is clear that an individual lacks "sufficient capacity" to make or communicate such decisions, the family is usually forced to seek a guardianship and/or conservatorship for the individual; often that action is forced by a medical provider or an educational institution.

2. Lately, many states have focused on specifically enumerating which powers are to be given to a guardian and/or conservator (and taken from the Ward). A copy of the list of those powers published by the Probate Court in Davidson County, Nashville, Tennessee, is attached as Exhibit III-3 to these materials.

3. However, what about families who, for one reason or another, believe their child/young adult with special needs does have "sufficient capacity" to make some or all of these decisions? What, then, are their alternatives?

More important, as an attorney working with the family, what do you need to be concerned about in considering these alternatives?

B. The Alternatives.

1. Just like the rest of the U.S., individuals with special needs can specifically designate who he/she wants to help them make financial and other non-health care decisions by executing a power of attorney naming an appropriate family member or friend to make (based upon how the document has been drafted), financial decisions with them or for them.

2. By executing a health care directive or health care power of attorney, an individual with special needs can designate an individual to help make health care decisions.

3. When working with high functioning individuals with special needs, it is important to remember that the traditional health care directive and the general power of attorney may not be sufficient.

4. While most children graduate from high school at age 18 (or thereabouts), the age of majority may not be the end of schooling for an individual with a disability. The state still has the obligation to further assist the individual until the age of 22 under IDEA. It is clear that if a parent has obtained guardianship or conservatorship over an adolescent, that the parent must participate in all education planning (to create the IEP, the transition plan and/or the 504 plan) to make it effective if the adolescent cannot make such decisions. Unfortunately, some school districts still fight the need to provide a meaningful free education to individuals with special needs and have been known to use the lack of a guardianship/conservatorship as a way to limit the parents' involvement in the education decisions for their child after age 18. Accordingly, especially in certain rural areas of Georgia and Tennessee, I advise the family to have their child with special needs execute an *education power of attorney* in addition to the health care directive and a general power of attorney.

C. Capacity to Contract. Because a power of attorney, a health care power of attorney and an education power of attorney are essentially contracts under state law, lawyers working with individuals with special needs must get comfortable that the adolescent being asked to provide his/her parents with a power of attorney has the required capacity to enter into a contract.

1. As estate and trust lawyers, we are all well aware that testamentary capacity is something less than the capacity to contract. Recognizing that powers of attorney are different than wills is not always an issue with respect to which we concern ourselves. Unfortunately, in the special-needs planning world, it is very important to do so.

2. In Georgia, for example, in order to have "testamentary capacity," an individual must "be capable of framing a decided and rational desire as to the disposition of his/her property." O.C.G.A. §53-4-11.

3. With respect to the "capacity to contract," each state has its own standard.

a. Some states have chosen to provide that a person has the capacity to contract if he/she understands and appreciates the nature and effect of the contract; a sliding scale analysis.

b. In Georgia and other states, the law does not define exactly what constitutes "capacity to contract," but rather sets forth circumstances under which contract is voidable; which includes the situation where one party to the contract was "entirely without understanding" at the time the contract is executed. Nelson v. State Farm Life Ins. Co., 178 Ga. App. 670 (1986). Further, the party challenging the validity of the contract is the party which has the burden of demonstrating a party lacked capacity at the time the contract was entered. *Id.*

4. On the other hand, once an individual has been established by a court of competent jurisdiction in Georgia that he/she is incapable of managing his/her own affairs and the affairs of such person have been vested in a guardian, the person has no power to contract.

5. Comparatively, in Tennessee, all that is required to contract is to reasonably know and understand the nature, extent, character and effect of the transaction. Rawlings v. John Hancock Mut. Life Insurance Co., 78 S.W. 3d 291 (Tenn. Ct. App. 2001) (citing Restatement (Second) of Contracts §15(1) (1981)).

6. For an excellent, but somewhat dated analysis of legal capacity issues, see Paul A. Strugil, Advanced Elder Law Review Program: Legal Capacity Issues, National Academy of Elder Law Attorneys (2012). See also, Froehlich and Radford, Sufficient Capacity: The Contrasting Capacity Requirements for Different Documents, NAEJA Journal, Volume 2, page 303 (206).

D. Professional Conduct. Attorneys should therefore carefully determine and then document whether, in their professional judgment, the individual executing a health care directive/health care power of attorney, education power of attorney and/or general power of attorney has the requisite legal capacity to do so. See, e.g., Ga. R. Prof. Conduct 1.14 (Representation of a Client with Diminished Capacity).

E. Issue of Revocation. Georgia and Tennessee provide a wonderful opportunity to compare the different positions of the states with regard to how or whether a healthcare agent can be removed.

2. In Tennessee, an individual having capacity may revoke the designation of an agent only by a signed writing or by personally informing the supervising healthcare provider. T.C.A. §68-11-1804(a).

3. In Georgia, however, the advanced directive may be revoked at any time by the declarant "without regard to the declarant's mental state or competency," by completing a new advance directive with new provisions, by destroying the original health care directive, by subsequent marriage and/or divorce and by orally revoking the instrument in the presence of a witness who later commits the revocation to writing. O.C.G.A. §31-32-6.

4. As a result, it is quite possible in Georgia for an individual who is not in "his/her right mind" to revoke a healthcare power of attorney and not be able to replace it (not then being of "sound mind").

F. Georgia's New Power of Attorney Provisions. Georgia attorneys must note that this summer, Georgia's new Uniform Power of Attorney Act (the "Act") became effective. Under the Act, a power of attorney is automatically durable and only terminates when "the principal revokes the power of attorney, provided that the principal provides the agent with notice of such revocation by certified mail and provided that such notice is filed with the Clerk of Superior Court in the county of domicile of the principal." O.C.G.A. §106B-10. This is a much different standard for revocation than applies to a health care directive.

G. The Family Decision. For many families who have a "high functioning" family member with special needs, the thought of taking that person in front of a judge and having the judge explain to the family member that he/she no longer has any control over the decisions in their life is not acceptable. For that reason we will continue to deal with families who elect, for their own reasons, to use powers of attorney rather than the more restrictive guardianships and conservatorships.

H. A Detailed But Very Worthwhile Resource. In 2008, the American Bar Association ("ABA"), in conjunction with the American Psychological Association ("APA"), published a Handbook for Psychologists dealing with the legal issues of capacity and the assessment of older adults with respect to diminished capacity. That resource also has very practical application when working with individuals with mental illness, autism, mild intellectual disability, Downs Syndrome and other developmental disabilities. I highly recommend it as a learning resource with respect to the medical aspects of capacity. Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists. The ABA/APA Assessment of Capacity Project Working Group (2008).

V. Ensuring Quality of Life Issues.

S	Social and Spiritual
P	Physical/Medical
E	Emotional, Economic, Encouragement
C	Community, Creativity, Contentment
I	Independence, Inclusion
A	Achievement, Academics, Accountable
L	Leadership, Legal

VI. Transition Planning. Whether an adolescent with a disability graduates from high school with a full diploma or a different diploma, the process of planning what that individual's life should look like after leaving school should have already begun. As part of the IEP program, schools are supposed to include independent living life skills and employment options as part of the IEP program. Since almost all disabilities involve a spectrum of functional skill levels, the transition program included as part of the educational process should be individualized as much as possible for your client's child. That will include focusing the educational process on independent living skills; for example cooking, shopping, money management, and potential job skills. For those adolescents who are less able to function in the community, some of that life skills and employment training will seem very rudimentary. For those whose intellectual capabilities are stronger, the focus may focus on behavioral challenges that interfere with the individual's employability. These days, more and more young adults with special needs plan on and do attend college. All of these options are part of the transition process.

A. Is SSI Appropriate and Available? As this panel has discussed, at age 18, the age of majority in every state, individuals are deemed to be competent and have the capacity to make decisions on their own. If, however, an individual is prevented from participating in any "substantial gainful activity" by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months, he or he/she will qualify for supplemental security income ("SSI"). 42 USC §1382(c)(a)(3)(A) and 20 CFR §416.905 (the ability to perform "substantial gainful activity" includes an analysis of the person's age, education, the severity of behavioral challenges and functional capabilities).

1. As well covered in Kristen Lewis' materials, SSI is a means-based program which means that, at 18, if the individual holds less than \$2,000 of countable resources and his/her income, defined as required for Social Security (and *not* for taxes), is below \$1,170 per month, see, 20 CFR §416.1112(b) and (c) (this calculation presumes that all income received by the individual is earned income), the benefit should be available.

2. Therefore, depending upon the severity of the individual's impairment and their likely impact on employability, I tend to advise families that upon the child's eighteenth birthday, they should go ahead and apply for SSI for the young adult.

B. SSI = Medicaid. The second reason for seeking SSI benefits at age 18 is that in most of the states in the South, including the states in which all of your panelists practice, receiving at least one dollar of SSI means that the individual is eligible for and can receive Medicaid, and it is the Medicaid waiver programs which often make the greatest difference in the life of the young adult. Among the important benefits are access to group homes, job coaching, vocational assistance and, if necessary, non-skilled caregivers allowing the individual to live independently and respite care if they are not able to live independently.

C. SSI Does Not Foreclose Other Options. If the family's young adult matures into a better personal situation which allows him/her to work, there are programs which exist within the Social Security system which will support the effort to transition to full-time employment without losing Medicaid or all of his/her SSI.

1. As of 2017, the SSI benefit before considering any state supplements or any deductions for in-kind main support and maintenance, earned income and/or unearned income is \$735.00.

2. SSA Work Programs.
 - a. Ticket to Work.
 - b. Plan for Achieving Self-support (PASS).
 - c. Impairment Work-Related Expenses.
 - d. Trial Work Periods.
 - e. See, the SSA Redbook. www.ssa.gov/redbook.
 - f. Another SSA publication is "Working While Disabled - How We Can Help." www.ssa.gov/pubs.

D. Other Aspects of Transition.

1. What makes you happy? Fulfilled? Purpose? A sense of belonging? Independence?
 - a. It is not living alone in your parent's basement with only the TV and internet as companions.
 - b. The same is true for any person with a disability.
2. Planning for how to keep your family member connected with others once school is no longer an option should be part of the transition plan developed during school.
3. There are many aspects of our social lives and we should not presume that a person with a disability wants or needs less.
 - a. As noted in the Quality of Life matrix, one of the most important parts of a transition is employment.
 - (1) Employment, whether paid or volunteer, adds another "family" for social interaction, a sense of purpose and the opportunity to continue to learn.
 - b. What about local sports and recreational leagues for individuals with a disability?
 - (1) Special Olympics.
 - (2) Local YMCA Full Circle programs.
 - (3) Soccer, softball, football, bowling and other sports are also often available through the local Recreational Department of your city or county.
 - c. Church, Temple or whatever your religious affiliation often provide a special welcoming place in the life of an individual with a disability.
 - (1) So many religious organizations are recognizing their importance in lives of members with disabilities that the **Vanderbilt Kennedy Center** offers an annual program for church officials to learn how to make their services and the entire experience a more friendly and accepting place for those with disabilities.
 - d. Day programs are becoming harder to locate and even harder to get into, but learning what is available locally is something parents should focus on during the transition period of school.
 - e. Creating an independent social group is not difficult and it can meet as often as the parents agree is appropriate. Social groups can be as small as 3 to 5 individuals or as large as the families agree.

(1) A national organization which attempts to match a non-disabled person with a person with disabilities for regular social interaction is **Best Buddies**.

(2) Your local chapter of the national disability organization will also periodically sponsor social gatherings for families and members.

4. These are merely some of the aspects of life that need to be planned out during the transition period of school because once the family member hits age 22, he/she no longer qualifies for school supports and it's like walking off the edge of the proverbial cliff; the family goes from access to many supports and activities to none.

E. College and Post-High School Education

1. Over the last couple of decades, college, whether junior college, trade school or a full 4 year program, has become a more realistic option for many individuals with disabilities.

2. One of the reasons for this has been the recognition by colleges and universities of their obligation to make post-secondary education more accessible to those with disabilities. Those colleges and universities truly committed to the effort have opened Disability Resource Centers or an equivalent to help potential students and those who enroll get the best structure to help them succeed.

3. College Resources for Families with Special Needs.

- a. Think College. www.thinkcollege.com.
- b. Best Colleges. [www.bestcolleges.com/student with disabilities](http://www.bestcolleges.com/student-with-disabilities)).
- c. Online Colleges (a legal rights website). www.onlinecolleges.net/resources.
- d. National Center for College Students with Disabilities (NCCSD). www.nccsdonline.org.
- e. Winning: A College Guide for Students with Disabilities. www.edsmart.org.
- f. Colleges for Students with Disabilities. www.accreditedschoolsonline.org.

4. In addition to college, the number of post-secondary programs focused on life skills for students with disabilities has increased over the past decade and, at least I believe, is likely to continue to increase. The following is a list of some of those programs:

- a. The Horizon School, Birmingham, Alabama.
- b. Next Steps at Vanderbilt University, Nashville, Tennessee.
- c. The Roosevelt Rehabilitation Institute (part of the Georgia Vocational Rehabilitation Agency), Warm Springs, Georgia
- d. KU Transition to Postsecondary Education, Lawrence, Kansas (through the Beach Center).
- e. Minnesota Life College. www.minnesotalifecollege.com.

VII. Employment

A. ID/DD Statistics. According to the most current statistics compiled by the Arc US and various Federal government organizations and agencies, something on the order of 15% of adults with intellectual disabilities and/or developmental disabilities age 22 and older who want to work and would be able to work are working (whether part-time or full-time).

B. How important is employment to individuals with disabilities? Just consider how lost and depressed you would be without meaningful employment. Employment for many of us is how we measure our self-worth. Many individuals with disabilities were raised in homes just like ours where work is highly valued and admired. Our children are our children, disability or not, and they want to be like the rest of the family. Not working has a negative impact on how they feel about themselves; how they view themselves.

C. Things To Know About Employment

1. Like everyone else, it is important to focus the secondary education of a student with a disability on the foundational skills necessary for the type of employment the student shows an interest in and which are a realistic option (otherwise known as "career assessment"). The individual's high school years begin the preparation for employment and parents should insist on such skills being explored through the student's IEP.

2. The next step is often the state's vocational rehabilitation("Voc Rehab") program.

a. In Tennessee, Voc Rehab services are available to a person who has a "physical, mental or sensory impairment that results in a substantial impediment to employment;" where Voc Rehab services are needed "to prepare for, secure, retain or regain employment" and the person can benefit from such services.

b. Individuals receiving SSI or SSDI based upon their own disability are presumed eligible.

c. Georgia's eligibility requirements are not much different from Tennessee's.

d. Voc Rehab services are not as person-centered as the more intensive supports available through Medicaid waiver programs.

3. The next level of employment supports come from Medicaid waiver programs.

a. Remember, not everyone qualifies for Medicaid and waiver services; Medicaid is a means-based benefit.

b. Each state's Medicaid waiver programs are somewhat unique, but certain services are consistently offered from state-to-state and one of those services is ***job coaching***. Certain non-profit organizations also provide job coaching.

c. Job coaching involves hands on training and day-to-day support on the job, all of which is phased out as the individual masters the skills needed for the task. If problems later arise, the job coach can and probably will be brought back in.

4. Employment First Programs.

a. Over the past decade, the concept that employment in integrated settings within the community should be the priority service option has become the norm.

b. According to the State Employment Leadership Network ("SELN"), as of July 2015, 14 states had passed Employment First legislation expressly stating that integrated employment is the first option to be explored. Those states are: Alaska, California, Delaware, Illinois, Kansas, Maine, Mississippi, Ohio, Oklahoma, Oregon, Texas, Utah, Washington and Wyoming.

c. Another 16 states had adopted Employment First Policies by Executive Orders or policy directives issued by the Governor: Arkansas, Colorado, Connecticut, the District of Columbia, Florida, Louisiana, Maryland, Massachusetts, Minnesota, Missouri, New Jersey, Pennsylvania, Rhode Island, South Carolina, Tennessee and Virginia.

d. The remaining 20 states have some type of Employment First-type informal efforts and initiatives on-going.

e. While a laudable goal, these policies have not actually resulted in demonstrable gains in positive employment outcomes for those with disabilities.

- f. More information regarding Employment First initiatives can be found at the following:
- (1) Association of People Supporting Employment First ("APSE"). www.aspe.org/employment first.
- (2) SELN's "Q&A on State Employment First Policies." www.selnmembers.org (a 2008 content upload).
- (3) NTAR Leadership Center Blog by Wendy Parent, University of Kansas.

g. However, until these policies are embraced by private employers, employment for those with disabilities will continue to be a significant challenge.

h. See also, No Greatness without Goodness: How a Father's Love Change a Company and Sparked a Movement (Tyndale House Publishers, 2014).

VIII. Funding Strategies for Special Needs Trusts.

A. How Many Angels Can Dance on the Head of a Pin?

1. Working with families with a child with special needs means helping the clients articulate their financial priorities and look at how their priorities will change over the years.

a. For example, are there other children for whom provision(s) for college must be made if the primary earner passed away before they began college?

b. What if the primary caretaker passes away while the children, including the child with special needs, are young? Can the other parent afford the cost of a full-time caregiver?

c. Once the brothers and sisters are out of college, how are the parents going to retire and still provide for their adult child with special needs?

d. I personally like to meet with my special needs clients every 5 years or so to take stock of what has changed in their family's life and/or in their financial lives.

e. I also insist that they begin working with a Financial Advisor familiar with special needs planning (part of Kristen's required Team).

2. Because of the added financial uncertainties in their lives, I find that life insurance is one of the best tools to use in designing the funding scheme for a special needs trust.

a. Further, there is no reason to use just one type of life insurance; IMHO the best plans include several types of insurance on the life(s) of the parents, siblings and sometimes the individual with special needs.

b. So, get your insurance specialist Team Member to put together quotes based upon the family's specific needs at that time and anticipating those changes which are likely to occur just through the passage of time.

c. You will often find that the insurance for the plan will include some whole life, universal life, term and second-to-die policies.

B. The Other Big Asset of the Family: 401(k)/IRA Accounts.

1. Because of the complexities of having 401(k) or IRA accounts paid to a special needs trust and because most of my special needs parents refuse to leave the other children nothing at the death of the surviving parent (the spouse which is the second-to-die), I often encourage clients to leave these assets to their other children.

2. Unfortunately, that strategy does not always work. Therefore, we must talk about Conduit and Accumulation Trusts. The 401(a)(9) required minimum distribution ("RMD") rules also have to be discussed.

3. Cutting straight to the issue, Conduit Trusts which require the distribution of the RMDs to the beneficiary can disqualify the beneficiary from government benefits and should therefore usually be avoided.

4. Accumulation Trusts work, but only if all of the beneficiaries are individuals. If a charity is an ultimate beneficiary, the trust will not qualify as a designated beneficiary for purposes of the RMD rules and the account must be paid out under the 5 year rule.

a. Remember that "separate account treatment" and spousal roll-over options are unavailable if the designated beneficiary is a trust.

C. Another Funding Option.

1. Ask about the potential of an inheritance from other family members. Perhaps those should go directly to the SNT.

2. Flexibility is available if the grandparent's child (the parent of the adult with special needs) is the named beneficiary, but the SNT is named to take if the parent is deceased or decides to disclaim.

IX. Miscellaneous Other Issues.

A. Trust Protectors. I always include them with the power to ensure the trust meets the requirements for treatment as an SNT, among other powers.

B. Health Care Coverage. Likely to change in some fashion under the Trump administration.

C. Income Tax Planning. Likely to change in some fashion under the Trump administration.

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- (3) Determining how frequently financial management entity performance will be assessed.
 - (c) A financial management entity must provide functions including, but not limited to, the following:
 - (1) Collect and process timesheets of the participant's workers.
 - (2) Process payroll, withholding, filing and payment of applicable Federal, State and local employment-related taxes and insurance.
 - (3) Maintain a separate account for each participant's budget.
 - (4) Track and report disbursements and balances of participant funds.
 - (5) Process and pay invoices for goods and services approved in the service plan.
 - (6) Provide to participants periodic reports of expenditures and the status of the approved service budget.
 - (d) States not utilizing a financial management entity must perform the functions listed in paragraph (c) of this section on behalf of participants self-directing PAS, with the exception of those participants utilizing the cash option who directly perform those functions.
 - (e) States will be reimbursed for the cost of financial management services, either provided directly or through a financial management entity, at the administrative rate of 50 percent.

[73 FR 57881, Oct. 3, 2008, as amended at 81 FR 3012, Jan. 20, 2016]

Subpart K—Home and Community-Based Attendant Services and Supports State Plan Option (Community First Choice)

SOURCE: 77 FR 26898, May 7, 2012, unless otherwise noted.

§ 441.500 Basis and scope.

- (a) *Basis.* This subpart implements section 1915(k) of the Act, referred to as the Community First Choice option (hereafter Community First Choice), to provide home and community-based attendant services and supports through a State plan.

(b) *Scope.* Community First Choice is designed to make available home and community-based attendant services

and supports to eligible individuals, as needed, to assist in accomplishing activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands-on assistance, supervision or cueing.

§ 441.505 Definitions.

As used in this subpart:

Activities of daily living (ADLs) means basic personal everyday activities including, but not limited to, tasks such as eating, toileting, grooming, dressing, bathing, and transferring.

Agency-provider model means a method of providing Community First Choice services and supports under which entities contract for or provide through their own employees, the provision of such services and supports, or act as the employer of record for attendant care providers selected by the individual enrolled in Community First Choice.

Backup systems and supports means electronic devices used to ensure continuity of services and supports. These items may include an array of available technology, personal emergency response systems, and other mobile communication devices. Persons identified by an individual can also be included as backup supports.

Health-related tasks means specific tasks related to the needs of an individual, which can be delegated or assigned by licensed health-care professionals under State law to be performed by an attendant.

Individual means the eligible individual and, if applicable, the individual's representative.

Individual's representative means a parent, family member, guardian, advocate, or other person authorized by the individual to serve as a representative in connection with the provision of CFC services and supports. This authorization should be in writing, when feasible, or by another method that clearly indicates the individual's free choice. An individual's representative may not also be a paid caregiver of an individual receiving services and supports under this subpart.

Instrumental activities of daily living (IADLs) means activities related to living independently in the community,

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including but not limited to, meal planning and preparation, managing finances, shopping for food, clothing, and other essential items, performing essential household chores, communicating by phone or other media, and traveling around and participating in the community.

Other models means methods, other than an agency-provider model or the self-directed model with service budget, for the provision of self-directed services and supports, as approved by CMS.

Self-directed means a consumer controlled method of selecting and providing services and supports that allows the individual maximum control of the home and community-based attendant services and supports, with the individual acting as the employer of record with necessary supports to perform that function, or the individual having a significant and meaningful role in the management of a provider of service when the agency-provider model is utilized. Individuals exercise as much control as desired to select, train, supervise, schedule, determine duties, and dismiss the attendant care provider.

Self-directed model with service budget means methods of providing self-directed services and supports using an individualized service budget. These methods may include the provision of vouchers, direct cash payments, and/or use of a fiscal agent to assist in obtaining services.

§441.510 Eligibility.

To receive Community First Choice services and supports under this section, an individual must meet the following requirements:

- (a) Be eligible for medical assistance under the State plan;
- (b) As determined annually—
 - (1) Be in an eligibility group under the State plan that includes nursing facility services; or
 - (2) If in an eligibility group under the State plan that does not include such nursing facility services, have an income that is at or below 150 percent of the Federal poverty level (FPL). In determining whether the 150 percent of the FPL requirement is met, States must apply the same methodologies as

would apply under their Medicaid State plan, including the same income disregards in accordance with section 1902(r)(2) of the Act; and,

(c) Receive a determination, at least annually, that in the absence of the home and community-based attendant services and supports provided under this subpart, the individual would otherwise require the level of care furnished in a hospital, a nursing facility, an intermediate care facility for individuals with intellectual disabilities, an institution providing psychiatric services for individuals under age 21, or an institution for mental diseases for individuals age 65 or over, if the cost could be reimbursed under the State plan. The State administering agency may permanently waive the annual re-certification requirement for an individual if:

(1) It is determined that there is no reasonable expectation of improvement or significant change in the individual's condition because of the severity of a chronic condition or the degree of impairment of functional capacity; and

(2) The State administering agency, or designee, retains documentation of the reason for waiving the annual re-certification requirement.

(d) For purposes of meeting the criterion under paragraph (b) of this section, individuals who qualify for medical assistance under the special home and community-based waiver eligibility group defined at section 1902(a)(10)(A)(ii)(VI) of the Act must meet all section 1915(c) requirements and receive at least one home and community-based waiver service per month.

(e) Individuals receiving services through Community First Choice will not be precluded from receiving other home and community-based long-term care services and supports through other Medicaid State plan, waiver, grant or demonstration authorities.

§441.515 Statewideness.

States must provide Community First Choice to individuals:

- (a) On a statewide basis.
- (b) In a manner that provides such services and supports in the most integrated setting appropriate to the individual's needs, and without regard to

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the individual's age, type or nature of disability, severity of disability, or the form of home and community-based attendant services and supports that the individual requires to lead an independent life.

§ 441.520 Included services.

(a) If a State elects to provide Community First Choice, the State must provide all of the following services:

(1) Assistance with ADLs, IADLs, and health-related tasks through hands-on assistance, supervision, and/or cueing.

(2) Acquisition, maintenance, and enhancement of skills necessary for the individual to accomplish ADLs, IADLs, and health-related tasks.

(3) Backup systems or mechanisms to ensure continuity of services and supports, as defined in § 441.505 of this subpart.

(4) Voluntary training on how to select, manage and dismiss attendants.

(b) At the State's option, the State may provide permissible services and supports that are linked to an assessed need or goal in the individual's person-centered service plan. Permissible services and supports may include, but are not limited to, the following:

(1) Expenditures for transition costs such as rent and utility deposits, first month's rent and utilities, bedding, basic kitchen supplies, and other necessities linked to an assessed need for an individual to transition from a nursing facility, institution for mental diseases, or intermediate care facility for Individuals with Intellectual Disabilities to a home and community-based setting where the individual resides;

(2) Expenditures relating to a need identified in an individual's person-centered service plan that increases an individual's independence or substitutes for human assistance, to the extent that expenditures would otherwise be made for the human assistance.

§ 441.525 Excluded services.

Community First Choice may not include the following:

(a) Room and board costs for the individual, except for allowable transition services described in § 441.520(b)(1) of this subpart.

(b) Special education and related services provided under the Individuals

with Disabilities Education Act that are related to education only, and vocational rehabilitation services provided under the Rehabilitation Act of 1973.

(c) Assistive devices and assistive technology services, other than those defined in § 441.520(a)(3) of this subpart, or those that meet the requirements at § 441.520(b)(2) of this subpart.

(d) Medical supplies and medical equipment, other than those that meet the requirements at § 441.520(b)(2) of this subpart.

(e) Home modifications, other than those that meet the requirements at § 441.520(b) of this subpart.

§ 441.530 Home and Community-Based Setting.

(a) States must make available attendant services and supports in a home and community-based setting consistent with both paragraphs (a)(1) and (a)(2) of this section.

(1) Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes but does not regiment individual initiative, autonomy, and

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independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the above qualities at paragraphs (a)(1)(i) through (v) of this section, the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors as needed.

(2) Individuals sharing units have a choice of roommates in that setting.

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

(D) Individuals are able to have visitors of their choosing at any time.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under paragraphs (a)(1)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following re-

quirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.

(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(3) Document less intrusive methods of meeting the need that have been tried but did not work.

(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(5) Include regulation collection and review of data to measure the ongoing effectiveness of the modification.

(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

(2) Home and community-based settings do not include the following:

(i) A nursing facility;

(ii) An institution for mental diseases;

(iii) An intermediate care facility for individuals with intellectual disabilities;

(iv) A hospital providing long-term care services; or

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

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(b) [Reserved]

[79 FR 3032, Jan. 16, 2014]

§ 441.535 Assessment of functional need.

States must conduct a face-to-face assessment of the individual's needs, strengths, preferences, and goals for the services and supports provided under Community First Choice in accordance with the following:

(a) States may use one or more processes and techniques to obtain information, including telemedicine, or other information technology medium, in lieu of a face-to-face assessment if the following conditions apply:

(1) The health care professional(s) performing the assessment meet the provider qualifications defined by the State, including any additional qualifications or training requirements for the operation of required information technology;

(2) The individual receives appropriate support during the assessment, including the use of any necessary on-site support-staff; and

(3) The individual is provided the opportunity for an in-person assessment in lieu of one performed via telemedicine.

(b) Assessment information supports the determination that an individual requires Community First Choice and also supports the development of the person-centered service plan and, if applicable, service budget.

(c) The assessment of functional need must be conducted at least every 12 months, as needed when the individual's support needs or circumstances change significantly necessitating revisions to the person-centered service plan, and at the request of the individual.

(d) Other requirements as determined by the Secretary.

§ 441.540 Person-centered service plan.

(a) *Person-centered planning process.* The person-centered planning process is driven by the individual. The process—

(1) Includes people chosen by the individual.

(2) Provides necessary information and support to ensure that the individual directs the process to the max-

imum extent possible, and is enabled to make informed choices and decisions.

(3) Is timely and occurs at times and locations of convenience to the individual.

(4) Reflects cultural considerations of the individual.

(5) Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.

(6) Offers choices to the individual regarding the services and supports they receive and from whom.

(7) Includes a method for the individual to request updates to the plan.

(8) Records the alternative home and community-based settings that were considered by the individual.

(b) *The person-centered service plan.* The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under Community First Choice, the plan must:

(1) Reflect that the setting in which the individual resides is chosen by the individual.

(2) Reflect the individual's strengths and preferences.

(3) Reflect clinical and support needs as identified through an assessment of functional need.

(4) Include individually identified goals and desired outcomes.

(5) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports cannot supplant needed paid services unless the natural supports are unpaid supports that are provided voluntarily to the individual in lieu of an attendant.

(6) Reflect risk factors and measures in place to minimize them, including individualized backup plans.

(7) Be understandable to the individual receiving services and supports,

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and the individuals important in supporting him or her.

(8) Identify the individual and/or entity responsible for monitoring the plan.

(9) Be finalized and agreed to in writing by the individual and signed by all individuals and providers responsible for its implementation.

(10) Be distributed to the individual and other people involved in the plan.

(11) Incorporate the service plan requirements for the self-directed model with service budget at § 441.550, when applicable.

(12) Prevent the provision of unnecessary or inappropriate care.

(13) Other requirements as determined by the Secretary.

(c) *Reviewing the person-centered service plan.* The person-centered service plan must be reviewed, and revised upon reassessment of functional need, at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of the individual.

§ 441.545 Service models.

A State may choose one or more of the following as the service delivery model to provide self-directed home and community-based attendant services and supports:

(a) *Agency-provider model.* (1) The agency-provider model is a delivery method in which the services and supports are provided by entities, under a contract or provider agreement with the State Medicaid agency or delegated entity to provide services. Under this model, the entity either provides the services directly through their employees or arranges for the provision of services under the direction of the individual receiving services.

(2) Under the agency-provider model for Community First Choice, individuals maintain the ability to have a significant role in the selection and dismissal of the providers of their choice, for the delivery of their specific care, and for the services and supports identified in their person-centered service plan.

(b) *Self-directed model with service budget.* A self-directed model with a service budget is one in which the individual has both a person-centered serv-

ice plan and a service budget based on the assessment of functional need.

(i) *Financial management entity.* States must make available financial management activities to all individuals with a service budget. The financial management entity performs functions including, but not limited to, the following activities:

(i) Collect and process timesheets of the individual's attendant care providers.

(ii) Process payroll, withholding, filing, and payment of applicable Federal, State, and local employment related taxes and insurance.

(iii) Separately track budget funds and expenditures for each individual.

(iv) Track and report disbursements and balances of each individual's funds.

(v) Process and pay invoices for services in the person-centered service plan.

(vi) Provide individual periodic reports of expenditures and the status of the approved service budget to the individual and to the State.

(vii) States may perform the functions of a financial management entity internally or use a vendor organization that has the capabilities to perform the required tasks in accordance with all applicable requirements of the Internal Revenue Service.

(2) *Direct cash.* States may disburse cash prospectively to individuals self-directing their Community First Choice services and supports, and must meet the following requirements:

(i) Ensure compliance with all applicable requirements of the Internal Revenue Service, and State employment and taxation authorities, including but not limited to, retaining required forms and payment of FICA, FUTA and State unemployment taxes.

(ii) Permit individuals using the cash option to choose to use the financial management entity for some or all of the functions described in paragraph (b)(1)(ii) of this section.

(iii) Make available a financial management entity to an individual who has demonstrated, after additional counseling, information, training, or assistance that the individual cannot effectively manage the cash option described in this section.

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(iv) The State may require an individual to use a financial management entity, but must provide the individual with the conditions under which this option would be enforced.

(3) *Vouchers.* States have the option to issue vouchers to individuals who self-direct their Community First Choice services and supports as long as the requirements in paragraphs (b)(2)(i) through (iv) of this paragraph are met.

(c) *Other service delivery models.* States have the option of proposing other service delivery models. Such models are defined by the State and approved by CMS.

§ 441.550 Service plan requirements for self-directed model with service budget.

The person-centered service plan under the self-directed model with service budget conveys authority to the individual to perform, at a minimum, the following tasks:

(a) Recruit and hire or select attendant care providers to provide self-directed Community First Choice services and supports, including specifying attendant care provider qualifications.

(b) Dismiss specific attendant care providers of Community First Choice services and supports.

(c) Supervise attendant care providers in the provision of Community First Choice services and supports.

(d) Manage attendant care providers in the provision of Community First Choice services and supports, which includes the following functions:

(1) Determining attendant care provider duties.

(2) Scheduling attendant care providers.

(3) Training attendant care providers in assigned tasks.

(4) Evaluating attendant care providers' performance.

(e) Determining the amount paid for a service, support, or item, in accordance with State and Federal compensation requirements.

(f) Reviewing and approving provider payment requests.

§ 441.555 Support system.

For each service delivery model available, States must provide, or arrange for the provision of, a support

system that meets all of the following conditions:

(a) Appropriately assesses and counsels an individual before enrollment.

(b) Provides appropriate information, counseling, training, and assistance to ensure that an individual is able to manage the services and budgets if applicable.

(1) This information must be communicated to the individual in a manner and language understandable by the individual. To ensure that the information is communicated in an accessible manner, information should be communicated in plain language and needed auxiliary aids and services should be provided.

(2) The support activities must include at least the following:

(i) Person-centered planning and how it is applied.

(ii) Range and scope of individual choices and options.

(iii) Process for changing the person-centered service plan and, if applicable, service budget.

(iv) Grievance process.

(v) Information on the risks and responsibilities of self-direction.

(vi) The ability to freely choose from available home and community-based attendant providers, available service delivery models and if applicable, financial management entities.

(vii) Individual rights, including appeal rights.

(viii) Reassessment and review schedules.

(ix) Defining goals, needs, and preferences of Community First Choice services and supports.

(x) Identifying and accessing services, supports, and resources.

(xi) Development of risk management agreements.

(A) The State must specify in the State Plan amendment any tools or instruments used to mitigate identified risks.

(B) States utilizing criminal or background checks as part of their risk management agreement will bear the costs of such activities.

(xii) Development of a personalized backup plan.

(xiii) Recognizing and reporting critical events.

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- (xiv) Information about an advocate or advocacy systems available in the State and how an individual can access the advocate or advocacy systems.
- (c) Establishes conflict of interest standards for the assessments of functional need and the person-centered service plan development process that apply to all individuals and entities, public or private. At a minimum, these standards must ensure that the individuals or entities conducting the assessment of functional need and person-centered service plan development process are not:
- (1) Related by blood or marriage to the individual, or to any paid caregiver of the individual.
 - (2) Financially responsible for the individual.
 - (3) Empowered to make financial or health-related decisions on behalf of the individual.
 - (4) Individuals who would benefit financially from the provision of assessed needs and services.
- (5) Providers of State plan HCBS for the individual, or those who have an interest in or are employed by a provider of State plan HCBS for the individual, except when the State demonstrates that the only willing and qualified entity/entities to perform assessments of functional need and develop person-centered service plans in a geographic area also provides HCBS, and the State devises conflict of interest protections including separation of assessment/planning and HCBS provider functions within provider entities, which are described in the State plan, and individuals are provided with a clear and accessible alternative dispute resolution process.
- (d) Ensures the responsibilities for assessment of functional need and person-centered service plan development are identified.
- § 441.560 Service budget requirements.**
- (a) For the self-directed model with a service budget, a service budget must be developed and approved by the State based on the assessment of functional need and person-centered service plan and must include all of the following requirements:
- (1) The specific dollar amount an individual may use for Community First Choice services and supports.
 - (2) The procedures for informing an individual of the amount of the service budget before the person-centered service plan is finalized.
 - (3) The procedures for how an individual may adjust the budget including the following:
 - (i) The procedures for an individual to freely adjust amounts allocated to specific services and supports within the approved service budget.
 - (ii) The circumstances, if any, that may require prior approval by the State before a budget adjustment is made.
 - (3) The circumstances, if any, that may require a change in the person-centered service plan.
 - (5) The procedures that govern the determination of transition costs and other permissible services and supports as defined at § 441.520(b).
 - (6) The procedures for an individual to request a fair hearing under Subpart E of this title if an individual's request for a budget adjustment is denied or the amount of the budget is reduced.
 - (b) The budget methodology set forth by the State to determine an individual's service budget amount must:
 - (1) Be objective and evidence-based utilizing valid, reliable cost data.
 - (2) Be applied consistently to individuals.
 - (3) Be included in the State plan.
 - (4) Include a calculation of the expected cost of Community First Choice services and supports, if those services and supports are not self-directed.
 - (5) Have a process in place that describes the following:
 - (i) Any limits the State places on Community First Choice services and supports, and the basis for the limits.
 - (ii) Any adjustments that are allowed and the basis for the adjustments.
 - (c) The State must have procedures in place that will provide safeguards to individuals when the budgeted service amount is insufficient to meet the individual's needs.
 - (d) The State must have a method of notifying individuals of the amount of any limit that applies to an individual's Community First Choice services

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and supports. Notice must be communicated in an accessible format, communicated in plain language, and needed auxiliary aids and services should be provided.

(e) The budget may not restrict access to other medically necessary care and services furnished under the State plan and approved by the State but which are not included in the budget.

(f) The State must have a procedure to adjust a budget when a reassessment indicates a change in an individual's medical condition, functional status, or living situation.

§ 441.565 Provider qualifications.

(a) For all service delivery models:

(1) An individual retains the right to train attendant care providers in the specific areas of attendant care needed by the individual, and to have the attendant care provider perform the needed assistance in a manner that comports with the individual's personal, cultural, and/or religious preferences.

(2) An individual retains the right to establish additional staff qualifications based on the individual's needs and preferences.

(3) Individuals also have the right to access other training provided by or through the State so that their attendant care provider(s) can meet any additional qualifications required or desired by individuals.

(b) For the agency-provider model, the State must define in writing adequate qualifications for providers in the agency model of Community First Choice services and supports.

(c) For the self-directed model with service budget, an individual has the option to permit family members, or any other individuals, to provide Community First Choice services and supports identified in the person-centered service plan, provided they meet the qualifications to provide the services and supports established by the individual, including additional training.

(d) For other models, the applicability of requirements at paragraphs (b) or (c) of this section will be determined based on the description and approval of the model.

§ 441.570 State assurances.

A State must assure the following requirements are met:

(a) Necessary safeguards have been taken to protect the health and welfare of enrollees in Community First Choice, including adherence to section 1903(i) of the Act that Medicaid payment shall not be made for items or services furnished by individuals or entities excluded from participating in the Medicaid Program.

(b) For the first full 12 month period in which the State plan amendment is implemented, the State must maintain or exceed the level of State expenditures for home and community-based attendant services and supports provided under sections 1115, 1905(a), 1915, or otherwise under the Act, to individuals with disabilities or elderly individuals attributable to the preceding 12 month period.

(c) All applicable provisions of the Fair Labor Standards Act of 1938.

(d) All applicable provisions of Federal and State laws regarding the following:

(1) Withholding and payment of Federal and State income and payroll taxes.

(2) The provision of unemployment and workers compensation insurance.

(3) Maintenance of general liability insurance.

(4) Occupational health and safety.

(5) Any other employment or tax related requirements.

§ 441.575 Development and Implementation Council.

(a) States must establish a Development and Implementation Council, the majority of which is comprised of individuals with disabilities, elderly individuals, and their representatives.

(b) States must consult and collaborate with the Council when developing and implementing a State plan amendment to provide Community First Choice services and supports.

§ 441.580 Data collection.

A State must provide the following information regarding the provision of home and community-based attendant

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services and supports under Community First Choice for each Federal fiscal year for which the services and supports are provided:

(a) The number of individuals who are estimated to receive Community First Choice services and supports under this State plan option during the Federal fiscal year.

(b) The number of individuals who received the services and supports during the preceding Federal fiscal year.

(c) The number of individuals served broken down by type of disability, age, gender, education level, and employment status.

(d) The specific number of individuals who have been previously served under sections 1115, 1915(c) and (i) of the Act, or the personal care State plan option.

(e) Data regarding how the State provides Community First Choice and other home and community-based services.

(f) The cost of providing Community First Choice and other home and community-based services and supports.

(g) Data regarding how the State provides individuals with disabilities who otherwise qualify for institutional care under the State plan or under a waiver the choice to receive home and community-based services in lieu of institutional care.

(h) Data regarding the impact of Community First Choice services and supports on the physical and emotional health of individuals.

(i) Other data as determined by the Secretary.

§441.585 Quality assurance system.

(a) States must establish and maintain a comprehensive, continuous quality assurance system, described in the State plan amendment, which includes the following:

- (1) A quality improvement strategy.
- (2) Methods to continuously monitor the health and welfare of each individual who receives home and community-based attendant services and supports, including a process for the mandatory reporting, investigation, and resolution of allegations of neglect, abuse, or exploitation in connection with the provision of such services and supports.

(3) Measures individual outcomes associated with the receipt of home and community-based attendant services and supports as set forth in the person centered service plan, particularly for the health and welfare of individuals receiving such services and supports. These measures must be reported to CMS upon request.

(4) Standards for all service delivery models for training, appeals for denials and reconsideration procedures for an individual's person-centered service plan.

(5) Other requirements as determined by the Secretary.

(b) The State must ensure the quality assurance system will employ methods that maximizes individual independence and control, and provides information about the provisions of quality improvement and assurance to each individual receiving such services and supports.

(c) The State must elicit and incorporate feedback from individuals and their representatives, disability organizations, providers, families of disabled or elderly individuals, members of the community and others to improve the quality of the community-based attendant services and supports benefit.

§441.590 Increased Federal financial participation.

Beginning October 1, 2011, the FMAP applicable to the State will be increased by 6 percentage points, for the provision of Community First Choice services and supports, under an approved State plan amendment.

Subpart L—Vaccines for Children Program

SOURCE: 77 FR 66700, Nov. 6, 2012, unless otherwise noted.

§441.600 Basis and purpose.

This subpart implements sections 1902(a)(62) and 1928 of the Act by requiring states to provide for a program for the purchase and distribution of pediatric vaccines to program-registered providers for the immunization of vaccine-eligible children.

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I counseled the individual to be sterilized that alternative methods of birth control are available which are temporary. I explained that sterilization is different because it is permanent.

I informed the individual to be sterilized that his/her consent can be withdrawn at any time and that he/she will not lose any health services or benefits provided by Federal funds.

To the best of my knowledge and belief the individual to be sterilized is at least 21 years old and appears mentally competent. He/She knowingly and voluntarily requested to be sterilized and appeared to understand the nature and consequences of the procedure.

(Instructions for use of alternative final paragraphs: Use the first paragraph below except in the case of premature delivery or emergency abdominal surgery where the sterilization is performed less than 30 days after the date of the individual's signature on the consent form. In those cases, the second paragraph below must be used. Cross out the paragraph which is not used.)

(1) At least 30 days have passed between the date of the individual's signature on this consent form and the date the sterilization was performed.

(2) This sterilization was performed less than 30 days but more than 72 hours after the date of the individual's signature on this consent form because of the following circumstances (check applicable box and fill in information requested): Premature delivery.

Individual's expected date of delivery:

Emergency abdominal surgery: (describe circumstances): _____ (Physician) (Date).

Subpart G—Home and Community-Based Services: Waiver Requirements

SOURCE: 46 FR 48541, Oct. 1, 1981, unless otherwise noted.

§ 441.300 Basis and purpose.

Section 1915(c) of the Act permits States to offer, under a waiver of statutory requirements, an array of home and community-based services that an individual needs to avoid institutionalization. Those services are defined in § 440.180 of this subchapter. This subpart describes what the Medicaid agency must do to obtain a waiver.

§ 441.301 Contents of request for a waiver.

(a) A request for a waiver under this section must consist of the following:

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(1) The assurances required by § 441.302 and the supporting documentation required by § 441.303.

(2) When applicable, requests for waivers of the requirements of section 1902(a)(1), section 1902(a)(10)(B), or section 1902(a)(10)(C)(i)(III) of the Act, which concern respectively, statewide application of Medicaid, comparability of services, and income and resource rules applicable to medically needy individuals living in the community.

(3) A statement explaining whether the agency will refuse to offer home or community-based services to any beneficiary if the agency can reasonably expect that the cost of the services would exceed the cost of an equivalent level of care provided in—

(i) A hospital (as defined in § 440.10 of this chapter);

(ii) A NF (as defined in section 1919(a) of the Act); or

(iii) An ICF/IID (as defined in § 440.150 of this chapter), if applicable.

(b) If the agency furnishes home and community-based services, as defined in § 440.180 of this subchapter, under a waiver granted under this subpart, the waiver request must—

(1) Provide that the services are furnished—

(i) Under a written person-centered service plan (also called plan of care) that is based on a person-centered approach and is subject to approval by the Medicaid agency.

(ii) Only to beneficiaries who are not inpatients of a hospital, NF, or ICF/IID; and

(iii) Only to beneficiaries who the agency determines would, in the absence of these services, require the Medicaid covered level of care provided in—

(A) A hospital (as defined in § 440.10 of this chapter);

(B) A NF (as defined in section 1919(a) of the Act); or

(C) An ICF/IID (as defined in § 440.150 of this chapter);

(2) Describe the qualifications of the individual or individuals who will be responsible for developing the individual plan of care;

(3) Describe the group or groups of individuals to whom the services will be offered;

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(4) Describe the services to be furnished so that each service is separately defined. Multiple services that are generally considered to be separate services may not be consolidated under a single definition. Commonly accepted terms must be used to describe the service and definitions may not be open ended in scope. CMS will, however, allow combined service definitions (bundling) when this will permit more efficient delivery of services and not compromise either a beneficiary's access to or free choice of providers.

(5) Provide that the documentation requirements regarding individual evaluation, specified in §441.303(c), will be met; and

(6) Be limited to one or more of the following target groups or any subgroup thereof that the State may define:

(i) Aged or disabled, or both.
(ii) Individuals with Intellectual or Developmental Disabilities, or both.

(iii) Mentally ill.

(c) A waiver request under this subpart must include the following—

(1) *Person-centered planning process.* The individual will lead the person-centered planning process where possible. The individual's representative should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and supports, the person-centered planning process:

(i) Includes people chosen by the individual.

(ii) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.

(iii) Is timely and occurs at times and locations of convenience to the individual.

(iv) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English

proficient, consistent with § 435.905(b) of this chapter.

(v) Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.

(vi) Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS. In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.

(vii) Offers informed choices to the individual regarding the services and supports they receive and from whom.

(viii) Includes a method for the individual to request updates to the plan as needed.

(ix) Records the alternative home and community-based settings that were considered by the individual.

(2) *The Person-Centered Service Plan.* The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:

(i) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and

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work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.

(ii) Reflect the individual's strengths and preferences.

(iii) Reflect clinical and support needs as identified through an assessment of functional need.

(iv) Include individually identified goals and desired outcomes.

(v) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.

(vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.

(vii) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.

(viii) Identify the individual and/or entity responsible for monitoring the plan.

(ix) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.

(x) Be distributed to the individual and other people involved in the plan.

(xi) Include those services, the purpose or control of which the individual elects to self-direct.

(xii) Prevent the provision of unnecessary or inappropriate services and supports.

(xiii) Document that any modification of the additional conditions, under paragraph (c)(4)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The

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following requirements must be documented in the person-centered service plan:

(A) Identify a specific and individualized assessed need.

(B) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(C) Document less intrusive methods of meeting the need that have been tried but did not work.

(D) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(E) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.

(F) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(G) Include informed consent of the individual.

(H) Include an assurance that interventions and supports will cause no harm to the individual.

(3) *Review of the Person-Centered Service Plan.* The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.

(4) *Home and Community-Based Settings.* Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit

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in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the qualities at § 441.301(c)(4)(i) through (v), the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors.

(2) Individuals sharing units have a choice of roommates in that setting.

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

(D) Individuals are able to have visitors of their choosing at any time.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under § 441.301(c)(4)(vi)(A) through (D), must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

(1) Identify a specific and individualized assessed need.

(2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.

(3) Document less intrusive methods of meeting the need that have been tried but did not work.

(4) Include a clear description of the condition that is directly proportionate to the specific assessed need.

(5) Include regular collection and review of data to measure the ongoing effectiveness of the modification.

(6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.

(7) Include the informed consent of the individual.

(8) Include an assurance that interventions and supports will cause no harm to the individual.

(5) *Settings that are not Home and Community-Based.* Home and community-based settings do not include the following:

(i) A nursing facility;

(ii) An institution for mental disabilities;

(iii) An intermediate care facility for individuals with intellectual disabilities;

(iv) A hospital; or

(v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of

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individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

(6) *Home and Community-Based Settings: Compliance and Transition:*

(i) States submitting new and initial waiver requests must provide assurances of compliance with the requirements of this section for home and community-based settings as of the effective date of the waiver.

(ii) CMS will require transition plans for existing section 1915(c) waivers and approved state plans providing home and community-based services under section 1915(i) to achieve compliance with this section, as follows:

(A) For each approved section 1915(c) HCBS waiver subject to renewal or submitted for amendment within one year after the effective date of this regulation, the State must submit a transition plan at the time of the waiver renewal or amendment request that sets forth the actions the State will take to bring the specific waiver into compliance with this section. The waiver approval will be contingent on the inclusion of the transition plan approved by CMS. The transition plan must include all elements required by the Secretary; and within one hundred and twenty days of the submission of the first waiver renewal or amendment request the State must submit a transition plan detailing how the State will operate all section 1915(c) HCBS waivers and any section 1915(i) State plan benefit in accordance with this section. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(B) For States that do not have a section 1915(c) HCBS waiver or a section 1915(i) State plan benefit due for renewal or proposed for amendments within one year of the effective date of this regulation, the State must submit a transition plan detailing how the State will operate all section 1915(c)

HCBS waivers and any section 1915(i) State plan benefit in accordance with this section. This plan must be submitted no later than one year after the effective date of this regulation. The transition plan must include all elements including timelines and deliverables as approved by the Secretary.

(iii) A State must provide at least a 30-day public notice and comment period regarding the transition plan(s) that the State intends to submit to CMS for review and consideration, as follows:

(A) The State must at a minimum provide two (2) statements of public notice and public input procedures.

(B) The State must ensure the full transition plan(s) is available to the public for public comment.

(C) The State must consider and modify the transition plan, as the State deems appropriate, to account for public comment.

(iv) A State must submit to CMS, with the proposed transition plan:

(A) Evidence of the public notice required.

(B) A summary of the comments received during the public notice period, reasons why comments were not adopted, and any modifications to the transition plan based upon those comments.

(v) Upon approval by CMS, the State will begin implementation of the transition plans. The State's failure to submit an approvable transition plan as required by this section and/or to comply with the terms of the approved transition plan may result in compliance actions, including but not limited to deferral/disallowance of Federal Financial Participation.

[46 FR 48541, Oct. 1, 1981, as amended at 50 FR 10026, Mar. 13, 1985; 59 FR 37717, July 25, 1994; 65 FR 60107, Oct. 10, 2000; 79 FR 3029, Jan. 16, 2014]

§ 441.302 State assurances.

Unless the Medicaid agency provides the following satisfactory assurances to CMS, CMS will not grant a waiver under this subpart and may terminate a waiver already granted:

(a) *Health and Welfare—Assurance* that necessary safeguards have been taken to protect the health and welfare

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of the beneficiaries of the services. Those safeguards must include—

(1) Adequate standards for all types of providers that provide services under the waiver;

(2) Assurance that the standards of any State licensure or certification requirements are met for services or for individuals furnishing services that are provided under the waiver; and

(3) Assurance that all facilities covered by section 1616(e) of the Act, in which home and community-based services will be provided, are in compliance with applicable State standards that meet the requirements of 45 CFR part 1397 for board and care facilities.

(4) Assurance that the State is able to meet the unique service needs of the individuals when the State elects to serve more than one target group under a single waiver, as specified in § 441.301(b)(6).

(i) On an annual basis the State will include in the quality section of the CMS-372 form (or any successor form designated by CMS) data that indicates the State continues to serve multiple target groups in the single waiver and that a single target group is not being prioritized to the detriment of other groups.

(ii) [Reserved]

(5) Assurance that services are provided in home and community based settings, as specified in § 441.301(c)(4).

(b) *Financial accountability*— The agency will assure financial accountability for funds expended for home and community-based services, provide for an independent audit of its waiver program (except as CMS may otherwise specify for particular waivers), and it will maintain and make available to HHS, the Comptroller General, or other designees, appropriate financial records documenting the cost of services provided under the waiver, including reports of any independent audits conducted.

(c) *Evaluation of need*. Assurance that the agency will provide for the following:

(1) *Initial evaluation*. An evaluation of the need for the level of care provided in a hospital, a NF, or an ICF/IID when there is a reasonable indication that a beneficiary might need the services in the near future (that is, a month or

less) unless he or she receives home or community-based services. For purposes of this section, “evaluation” means a review of an individual beneficiary’s condition to determine—

(i) If the beneficiary requires the level of care provided in a hospital as defined in § 440.10 of this subchapter, a NF as defined in section 1919(a) of the Act, or an ICF/IID as defined by § 440.150 of this subchapter; and

(ii) That the beneficiary, but for the provision of waiver services, would otherwise be institutionalized in such a facility.

(2) *Periodic reevaluations*. Reevaluations, at least annually, of each beneficiary receiving home or community-based services to determine if the beneficiary continues to need the level of care provided and would, but for the provision of waiver services, otherwise be institutionalized in one of the following institutions:

- (i) A hospital;
- (ii) A NF; or
- (iii) An ICF/IID.

(d) *Alternatives*—Assurance that when a beneficiary is determined to be likely to require the level of care provided in a hospital, NF, or ICF/IID, the beneficiary or his or her legal representative will be—

(1) Informed of any feasible alternatives available under the waiver; and

(2) Given the choice of either institutional or home and community-based services.

(e) *Average per capita expenditures*. Assurance that the average per capita fiscal year expenditures under the waiver will not exceed 100 percent of the average per capita expenditures that would have been made in the fiscal year for the level of care provided in a hospital, NF, or ICF/IID under the State plan had the waiver not been granted.

(1) These expenditures must be reasonably estimated and documented by the agency.

(2) The estimate must be on an annual basis and must cover each year of the waiver period.

(f) *Actual total expenditures*. Assurance that the agency’s actual total expenditures for home and community-based and other Medicaid services under the waiver and its claim for FFP

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in expenditures for the services provided to beneficiaries under the waiver will not, in any year of the waiver period, exceed 100 percent of the amount that would be incurred by the State's Medicaid program for these individuals, absent the waiver, in—

- (1) A hospital;
- (2) A NF; or
- (3) An ICF/IID.

(g) *Institutionalization absent waiver.* Assurance that, absent the waiver, beneficiaries in the waiver would receive the appropriate type of Medicaid-funded institutional care (hospital, NF, or ICF/IID) that they require.

(h) *Reporting.* Assurance that annually, the agency will provide CMS with information on the waiver's impact. The information must be consistent with a data collection plan designed by CMS and must address the waiver's impact on—

- (1) The type, amount, and cost of services provided under the State plan; and
- (2) The health and welfare of beneficiaries.

(i) *Habilitation services.* Assurance that prevocational, educational, or supported employment services, or a combination of these services, if provided as habilitation services under the waiver, are—

- (1) Not otherwise available to the individual through a local educational agency under section 602 (16) and (17) of the Education of the Handicapped Act (20 U.S.C. 1401 (16 and 17)) or as services under section 110 of the Rehabilitation Act of 1973 (29 U.S.C. 730); and

(2) Furnished as part of expanded habilitation services, if the State has requested and received CMS's approval under a waiver or an amendment to a waiver.

(j) *Day treatment or partial hospitalization, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness.* Assurance that FFP will not be claimed in expenditures for waiver services including, but not limited to, day treatment or partial hospitalization, psychosocial rehabilitation services, and clinic services provided as home and community-based services to individuals with chronic mental illnesses if these indi-

viduals, in the absence of a waiver, would be placed in an IMD and are—

- (1) Age 21 to 64;
- (2) Age 65 and older and the State has not included the optional Medicaid benefit cited in § 440.140; or
- (3) Age 21 and under and the State has not included the optional Medicaid benefit cited in § 440.160.

[50 FR 10026, Mar. 13, 1985, as amended at 59 FR 37717, July 25, 1994; 65 FR 60107, Oct. 10, 2000; 79 FR 3031, Jan. 16, 2014]

§ 441.303 Supporting documentation required.

The agency must furnish CMS with sufficient information to support the assurances required by § 441.302. Except as CMS may otherwise specify for particular waivers, the information must consist of the following:

(a) A description of the safeguards necessary to protect the health and welfare of beneficiaries. This information must include a copy of the standards established by the State for facilities that are covered by section 1616(e) of the Act.

(b) A description of the records and information that will be maintained to support financial accountability.

(c) A description of the agency's plan for the evaluation and reevaluation of beneficiaries, including—

(1) A description of who will make these evaluations and how they will be made;

(2) A copy of the evaluation form to be used; and if it differs from the form used in placing beneficiaries in hospitals, NFs, or ICFs/IID, a description of how and why it differs and an assurance that the outcome of the new evaluation form is reliable, valid, and fully comparable to the form used for hospital, NF, or ICF/IID placement;

(3) The agency's procedure to ensure the maintenance of written documentation on all evaluations and reevaluations; and

(4) The agency's procedure to ensure reevaluations of need at regular intervals.

(d) A description of the agency's plan for informing eligible beneficiaries of the feasible alternatives available under the waiver and allowing beneficiaries to choose either institutional

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services or home and community-based services.

(e) An explanation of how the agency will apply the applicable provisions regarding the post-eligibility treatment of income and resources of those individuals receiving home and community-based services who are eligible under a special income level (included in § 435.217 of this chapter).

(f) An explanation with supporting documentation satisfactory to CMS of how the agency estimated the average per capita expenditures for services.

(1) The annual average per capita expenditure estimate of the cost of home and community-based and other Medicaid services under the waiver must not exceed the estimated annual average per capita expenditures of the cost of services in the absence of a waiver. The estimates are to be based on the following equation:

$$D + D' \leq G + G'$$

The symbol “≤” means that the result of the left side of the equation must be less than or *equal* to the result of the right side of the equation.

D = the estimated annual average per capita Medicaid cost for home and community-based services for individuals in the waiver program.

D' = the estimated annual average per capita Medicaid cost for all other services provided to individuals in the waiver program.

G = the estimated annual average per capita Medicaid cost for hospital, NF, or ICF/IID care that would be incurred for individuals served in the waiver, were the waiver not granted.

G' = the estimated annual average per capita Medicaid costs for all services other than those included in factor G for individuals served in the waiver, were the waiver not granted.

(2) For purposes of the equation, the prime factors include the average per capita cost for all State plan services and expanded EPSDT services provided that are not accounted for in other formula values.

(3) In making estimates of average per capita expenditures for a waiver that applies only to individuals with a particular illness (for example, acquired immune deficiency syndrome) or condition (for example, chronic mental illness) who are inpatients in or who would require the level of care pro-

vided in hospitals as defined by § 440.10, NFs as defined in section 1919(a) of the Act, or ICFs/IID, the agency may determine the average per capita expenditures for these individuals absent the waiver without including expenditures for other individuals in the affected hospitals, NFs, or ICFs/IID.

(4) In making estimates of average per capita expenditures for a separate waiver program that applies only to individuals identified through the preadmission screening annual resident review (PASARR) process who are developmentally disabled, inpatients of a NF, and require the level of care provided in an ICF/IID as determined by the State on the basis of an evaluation under § 441.303(c), the agency may determine the average per capita expenditures that would have been made in a fiscal year for those individuals based on the average per capita expenditures for inpatients in an ICF/IID. When submitting estimates of institutional costs without the waiver, the agency may use the average per capita costs of ICF/IID care even though the deinstitutionalized developmentally disabled were inpatients of NFs.

(5) For persons diverted rather than deinstitutionalized, the State's evaluation process required by § 441.303(c) must provide for a more detailed description of their evaluation and screening procedures for beneficiaries to ensure that waiver services will be limited to persons who would otherwise receive the level of care provided in a hospital, NF, or ICF/IID, as applicable.

(6) The State must indicate the number of unduplicated beneficiaries to which it intends to provide waiver services in each year of its program. This number will constitute a limit on the size of the waiver program unless the State requests and the Secretary approves a greater number of waiver participants in a waiver amendment.

(7) In determining the average per capita expenditures that would have been made in a waiver year, for waiver estimates that apply to persons with Intellectual Disability or related conditions, the agency may include costs of Medicaid residents in ICFs/IID that have been terminated on or after November 5, 1990.

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(8) In submitting estimates for waivers that include personal caregivers as a waiver service, the agency may include a portion of the rent and food attributed to the unrelated personal caregiver who resides in the home or residence of the beneficiary covered under the waiver. The agency must submit to CMS for review and approval the method it uses to apportion the costs of rent and food. The method must be explained fully to CMS. A personal caregiver provides a waiver service to meet the beneficiary's physical, social, or emotional needs (as opposed to services not directly related to the care of the beneficiary; that is, housekeeping or chore services). FFP for live-in caregivers is not available if the beneficiary lives in the caregiver's home or in a residence that is owned or leased by the caregiver.

(9) In submitting estimates for waivers that apply to individuals with Intellectual Disability or a related condition, the agency may adjust its estimate of average per capita expenditures to include increases in expenditures for ICF/IID care resulting from implementation of a PASARR program for making determinations for individuals with Intellectual Disability or related conditions on or after January 1, 1989.

(10) For a State that has CMS approval to bundle waiver services, the State must continue to compute separately the costs and utilization of the component services that make up the bundled service to support the final cost and utilization of the bundled service that will be used in the cost-neutrality formula.

(g) The State, at its option, may provide for an independent assessment of its waiver that evaluates the quality of care provided, access to care, and cost-neutrality. The results of the assessment should be submitted to CMS at least 90 days prior to the expiration date of the approved waiver-period and cover the first 24 or 48 months of the waiver. If a State chooses to provide for an independent assessment, FFP is available for the costs attributable to the independent assessment.

(h) For States offering habilitation services that include prevocational, educational, or supported employment

services, or a combination of these services, consistent with the provisions of § 440.180(c) of this chapter, an explanation of why these services are not available as special education and related services under sections 602 (16) and (17) of the Education of the Handicapped Act (20 U.S.C. 1401 (16 and 17)) or as services under section 110 of the Rehabilitation Act of 1973 (29 U.S.C. section 730);

(i) For States offering home and community-based services for individuals diagnosed as chronically mentally ill, an explanation of why these individuals would not be placed in an institution for mental diseases (IMD) absent the waiver, and the age group of these individuals.

[46 FR 48532, Oct. 1, 1981, as amended at 50 FR 10027, Mar. 13, 1985; 50 FR 25080, June 17, 1985; 59 FR 37718, July 25, 1994]

§ 441.304 Duration, extension, and amendment of a waiver.

(a) The effective date for a new waiver of Medicaid requirements to provide home and community-based services approved under this subpart is established by CMS prospectively on or after the date of approval and after consultation with the State agency. The initial approved waiver continues for a 3-year period from the effective date. If the agency requests it, the waiver may be extended for additional periods unless—

(1) CMS's review of the prior waiver period shows that the assurances required by § 441.302 were not met; and

(2) CMS is not satisfied with the assurances and documentation provided by the State in regard to the extension period.

(b) CMS will determine whether a request for extension of an existing waiver is actually an extension request or a request for a new waiver. If a State submits an extension request that would add a new group to the existing group of beneficiaries covered under the waiver (as defined under § 441.301(b)(6)), CMS will consider it to be two requests: One as an extension request for the existing group, and the other as a new waiver request for the new group. Waivers may be extended for additional 5-year periods.

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(c) CMS *may* grant a State an extension of its existing waiver for up to 90 days to permit the State to document more fully the satisfaction of statutory and regulatory requirements needed to approve a new waiver request. CMS will consider this option when it requests additional information on a new waiver request submitted by a State to extend its existing waiver or when CMS disapproves a State's request for extension.

(d) The agency may request that waiver modifications be made effective retroactive to the first day of a waiver year, or another date after the first day of a waiver year, in which the amendment is submitted, unless the amendment involves substantive changes as determined by CMS.

(1) Substantive changes include, but are not limited to, revisions to services available under the waiver including elimination or reduction of services, or reduction in the scope, amount, and duration of any service, a change in the qualifications of service providers, changes in rate methodology or a restriction in the eligible population.

(2) A request for an amendment that involves a substantive change as determined by CMS, may only take effect on or after the date when the amendment is approved by CMS, and must be accompanied by information on how the State has assured smooth transitions and minimal effect on individuals adversely impacted by the change.

(e) The agency must provide public notice of any significant proposed change in its methods and standards for setting payment rates for services in accordance with § 447.205 of this chapter.

(f) The agency must establish and use a public input process, for any changes in the services or operations of the waiver.

(1) This process must be described fully in the State's waiver application and be sufficient in light of the scope of the changes proposed, to ensure meaningful opportunities for input for individuals served, or eligible to be served, in the waiver.

(2) This process must be completed at a minimum of 30 days prior to implementation of the proposed change or

submission of the proposed change to CMS, whichever comes first.

(3) This process must be used for both existing waivers that have substantive changes proposed, either through the renewal or the amendment process, and new waivers.

(4) This process must include consultation with Federally-recognized Tribes, and in accordance with section 5006(e) of the American Recovery and Reinvestment Act of 2009 (Pub. L. 111-5), Indian health programs and Urban Indian Organizations.

(g)(1) If CMS finds that the Medicaid agency is not meeting one or more of the requirements for a waiver contained in this subpart, the agency is given a notice of CMS' findings and an opportunity for a hearing to rebut the findings.

(2) If CMS determines that the agency is substantively out of compliance with this subpart after the notice and any hearing, CMS may employ strategies to ensure compliance as described in paragraph (g)(3) of this section or terminate the waiver.

(3)(i) Strategies to ensure compliance may include the imposition of a moratorium on waiver enrollments, other corrective strategies as appropriate to ensure the health and welfare of waiver participants, or the withholding of a portion of Federal payment for waiver services until such time that compliance is achieved, or other actions as determined by the Secretary as necessary to address non-compliance with 1915(c) of the Act, or termination. When a waiver is terminated, the State must comport with § 441.307.

(ii) CMS will provide states with a written notice of the impending strategies to ensure compliance for a waiver program. The notice of CMS' intent to utilize strategies to ensure compliance would include the nature of the non-compliance, the strategy to be employed, the effective date of the compliance strategy, the criteria for removing the compliance strategy and the opportunity for a hearing.

[50 FR 10028, Mar. 13, 1985; 50 FR 25080, June 17, 1985, as amended at 59 FR 37719, July 25, 1994; 79 FR 3032, Jan. 16, 2014]

§ 441.305**42 CFR Ch. IV (10-1-16 Edition)****§ 441.305 Replacement of beneficiaries in approved waiver programs.**

(a) *Regular waivers.* A State's estimate of the number of individuals who may receive home and community-based services must include those who will replace beneficiaries who leave the program for any reason. A State may replace beneficiaries who leave the program due to death or loss of eligibility under the State plan without regard to any federally-imposed limit on utilization, but must maintain a record of beneficiaries replaced on this basis.

(b) *Model waivers.* (1) The number of individuals who may receive home and community-based services under a model waiver may not exceed 200 beneficiaries at any one time.

(2) The agency may replace any individuals who die or become ineligible for State plan services to maintain a count up to the number specified by the State and approved by CMS within the 200-maximum limit.

[59 FR 37719, July 25, 1994]

§ 441.306 Cooperative arrangements with the Maternal and Child Health program.

Whenever appropriate, the State agency administering the plan under Medicaid may enter into cooperative arrangements with the State agency responsible for administering a program for children with special health care needs under the Maternal and Child Health program (Title V of the Act) in order to ensure improved access to coordinated services to meet the children's needs.

[59 FR 37720, July 25, 1994]

§ 441.307 Notification of a waiver termination.

(a) If a State chooses to terminate its waiver before the initial 3-year period or 5-year renewal period expires, it must notify CMS in writing 30 days before terminating services to beneficiaries.

(b) If CMS or the State terminates the waiver, the State must notify beneficiaries of services under the waiver in accordance with § 431.210 of this sub-

chapter and notify them 30 days before terminating services.

[46 FR 48541, Oct. 1, 1981. Redesignated at 59 FR 37719, July 25, 1994, as amended at 65 FR 60107, Oct. 10, 2000]

§ 441.308 Hearings procedures for waiver terminations.

The procedures specified in subpart D of part 430 of this chapter are applicable to State requests for hearings on terminations.

[59 FR 10028, Mar. 13, 1994. Redesignated at 59 FR 37720, July 25, 1994]

§ 441.310 Limits on Federal financial participation (FFP).

(a) FFP for home and community-based services listed in § 440.180 of this chapter is not available in expenditures for the following:

(i) Services provided in a facility subject to the health and welfare requirements described in § 441.302(a) during any period in which the facility is found not to be in compliance with the applicable State standards described in that section.

(2) The cost of room and board except when provided as—

(i) Part of respite care services in a facility approved by the State that is not a private residence; or

(ii) For waivers that allow personal caregivers as providers of approved waiver services, a portion of the rent and food that may be reasonably attributed to the unrelated caregiver who resides in the same household with the waiver beneficiary. FFP for a live-in caregiver is not available if the beneficiary lives in the caregiver's home or in a residence that is owned or leased by the provider of Medicaid services (the caregiver). For purposes of this provision, "board" means 3 meals a day or any other full nutritional regimen and does not include meals provided as part of a program of adult day health services as long as the meals provided do not constitute a "full" nutritional regimen.

(3) Prevocational, educational, or supported employment services, or any combination of these services, as part of habilitation services that are—

(i) Provided in approved waivers that include a definition of "habilitation services" but which have not included

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prevocational, educational, and supported employment services in that definition; or

(ii) Otherwise available to the beneficiary under either special education and related services as defined in section 602(16) and (17) of the Education of the Handicapped Act (20 U.S.C. 1401(16) and (17)) or vocational rehabilitation services available to the individual through a program funded under section 110 of the Rehabilitation Act of 1973 (29 U.S.C. 730).

(4) For waiver applications and renewals approved on or after October 21, 1986, home and community-based services provided to individuals aged 22 through 64 diagnosed as chronically mentally ill who would be placed in an institution for mental diseases. FFP is also not available for such services provided to individuals aged 65 and over and 21 and under as an alternative to institutionalization in an IMD if the State does not include the appropriate optional Medicaid benefits specified at §§ 440.140 and 440.160 of this chapter in its State plan.

(b) FFP is available for expenditures for expanded habilitation services, as described in § 440.180 of this chapter, if the services are included under a waiver or waiver amendment approved by CMS.

[59 FR 37720, July 25, 1994, as amended at 65 FR 60107, Oct. 10, 2000]

Subpart H—Home and Community-Based Services Waivers for Individuals Age 65 or Older: Waiver Requirements

SOURCE: 57 FR 29156, June 30, 1992, unless otherwise noted.

§ 441.350 Basis and purpose.

Section 1915(d) of the Act permits States to offer, under a waiver of statutory requirements, home and community-based services not otherwise available under Medicaid to individuals age 65 or older, in exchange for accepting an aggregate limit on the amount of expenditures for which they claim FFP for certain services furnished to these individuals. The home and community-based services that may be furnished are listed in § 440.181 of this subchapter.

This subpart describes the procedures the Medicaid agency must follow to request a waiver.

§ 441.351 Contents of a request for a waiver.

A request for a waiver under this section must meet the following requirements:

(a) *Required signatures.* The request must be signed by the Governor, the Director of the Medicaid agency or the Director of the larger State agency of which the Medicaid agency is a component or any official of the Medicaid agency to whom this authority has been delegated. A request from any other agency of State government will not be accepted.

(b) *Assurances and supporting documentation.* The request must provide the assurances required by § 441.352 of this part and the supporting documentation required by § 441.353.

(c) *Statement for sections of the Act.* The request must provide a statement as to whether waiver of section 1902(a)(1), 1902(a)(10)(B), or 1902(a)(10)(C)(i)(III) of the Act is requested. If the State requests a waiver of section 1902(a)(1) of the Act, the waiver must clearly specify the geographic areas or political subdivisions in which the services will be offered. The State must indicate whether it is requesting a waiver of one or all of these sections. The State may request a waiver of any one of the sections cited above.

(d) *Identification of services.* The request must identify all services available under the approved State plan, which are also included in the APEL and which are identified under § 440.181, and any limitations that the State has imposed on the provision of any service. The request must also identify and describe each service specified in § 440.181 of this subchapter to be furnished under the waiver, and any additional services to be furnished under the authority of § 440.181(b)(7). Descriptions of additional services must explain how each additional service included under § 440.181(b)(7) will contribute to the health and well-being of the beneficiaries and to their ability to reside in a community-based setting.

EXHIBIT III-2

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-26-12
Baltimore, Maryland 21244-1850



January 10, 2014

**Fact Sheet: Summary of Key Provisions of the Final Rule for 1915(i)
Home and Community-Based Services (HCBS) State Plan Option
(CMS 2249-F/2296-F)**

Background

Section 6086 of the Deficit Reduction Act of 2005 (DRA) added section 1915(i) to the Social Security Act (the Act) providing states the option to offer home and community-based services, previously available only through a 1915(c) HCBS waiver, through the state's Medicaid state plan. As originally enacted, states could only serve individuals eligible under the State plan with incomes at or below 150 percent of the Federal poverty level (FPL) or below and could offer some, but not all, HCBS services and supports available through 1915(c) HCBS waivers. In addition, states were not able to target 1915(i) state plan HCBS to particular populations within the state.

The Affordable Care Act expanded coverable services under 1915(i) to include any of the HCBS permitted under section 1915(c) HCBS waivers, certain services for individuals with mental health and substance use disorders and other services requested by a state and approved by the Secretary of Health and Human Services. In addition, the changes support ensuring the quality of HCBS, require states to offer the benefit statewide and enable states to target 1915(i) State Plan HCBS to particular groups of participants but not limit the number of participants who may receive the benefit. CMS published a proposed rule on May 4, 2012 for these 1915(i) provisions. This final rule responds to the public comments received on those proposed rules.

In addition to the above provisions, the final rule also establishes a set of requirements for home and community-based settings under the 1915(i), 1915(c) and 1915(k) Medicaid authorities, and a set of person-centered planning requirements for Medicaid HCBS participants under 1915(c) and 1915(i).

Home and Community-Based Settings

CMS' definition of home and community-based settings has evolved over the past five years, based on experience throughout the country and extensive public feedback about the best way to differentiate between institutional and home and community-based settings. Based on the comments received on the 1915(c) advance notice of proposed rulemaking (ANPRM), the proposed 1915(c) rule, and the comments received on the 1915(i) and 1915(k) proposed rules, CMS is moving away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of participants' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics. The changes related to clarification of home and community-based settings will effectuate the law's intention for Medicaid HCBS to provide alternatives to services provided in institutions and maximize the opportunities for waiver participants to have access to the benefits of

community living, including receiving services in the most integrated setting. For more detail, please refer to the HCBS Settings Fact Sheet available at <http://www.medicaid.gov/HCBS>.

The final rule includes a transition period for states to ensure that their waivers and state plans meet the HCBS settings requirements. New 1915(c) waivers or 1915(i) state plans must meet the new requirements to be approved. For currently approved 1915(c) waivers and 1915(i) state plans, states will need to evaluate the settings currently in their 1915(c) waivers and 1915(i) state plan programs and, if there are settings that do not fully meet the final regulation's home and community-based settings requirements, work with CMS to develop a plan to bring their program into compliance. The public will have an opportunity to provide input on states' transition plans. CMS expects states to transition to the new settings requirements in as brief a period as possible and to demonstrate substantial progress during any transition period. CMS will afford states a maximum of a one year period to submit a transition plan for compliance with the home and community-based settings requirements of the final rule, and CMS may approve transition plans for a period of up to five years, as supported by individual state's circumstances, to effectuate full compliance.

States submitting a 1915(c) waiver renewal or waiver amendment within the first year of the effective date of the rule may need to develop a transition plan to ensure that the specific waiver or state plan meets the settings requirements. Within 120 days of the submission of that 1915(c) waiver renewal or waiver amendment, the state needs to submit a plan that lays out timeframes and benchmarks for developing a transition plan for all the state's approved 1915(c) waiver and 1915(i) HCBS state plan programs. CMS will work closely with states as they consider how to best implement these provisions and will be issuing sub-regulatory guidance to provide the details regarding requirements for transition plans.

Person-Centered Planning

In this final rule, CMS specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. The rules require that the person-centered planning process is directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen and others chosen by the individual to contribute to the process. The rule describes the minimum requirements for person-centered plans developed through this process, including that the process results in a person-centered plan with individually identified goals and preferences, including those related to community participation, employment, income and savings, health care and wellness, education and others. The plan should reflect the services and supports (paid and unpaid), who provides them and whether an individual chooses to self-direct services. This planning process, and the resulting person-centered service plan, will assist the individual in achieving personally defined outcomes in the most integrated community setting, ensure delivery of services in a manner that reflects personal preferences and choices, and contribute to the assurance of health and welfare. CMS will provide future guidance regarding the process for operationalizing person-centered planning in order for states to bring their programs into compliance.

EXHIBIT III-3

IN THE SEVENTH CIRCUIT COURT FOR DAVIDSON COUNTY, TENNESSEE

**LIST OF ENUMERATED POWERS
FOR
CONSERVATOR OVER PERSON AND PROPERTY**

IN RE:

)
)
)

DOCKET NO: _____

IT IS ORDERED that all the following powers and authority described below are removed from and divested out of the heretofore named respondent, and shall be and are vested in the heretofore named Conservator pursuant to T.C.A. §34-3-107(2) as follows:

1. The right to give, withhold, or withdraw consent and make other informed decisions relative to medical and mental examinations and treatment;
2. The right to make end of life decisions:
 - a. To consent, withhold, or withdraw consent for the entry of a "Do Not Resuscitate" Order or the application of any heroic measures or medical procedures intended solely to sustain life and other medications;
 - b. To consent or withhold consent concerning the withholding or withdrawal of artificially provided food, water, or other nourishment or fluids;
3. The right to consent to admission to hospitalization, and to be discharged or transferred to a residential setting, group home, or other facility for additional care and treatment;
4. The right to consent to participate in activities and therapies which are reasonable and necessary for the habitation of the respondent;
5. The right to consent or withhold consent to any residential or custodial placement;
6. The power to give, receive, release, or authorize disclosures of confidential information;
7. The right to apply for benefits, public and private, for which the person with a disability may be eligible;
8. The right to dispose of personal and real property subject to statutory and judicial constraints;
9. The right to determine whether or not the respondent may utilize a Tennessee driver license for the purpose of driving;
10. The right to make purchases;
11. The right to enter into contractual relationships;
12. The right to execute instruments of legal significance;
13. The right to pay the respondent's bills and protect and invest the respondent's income and assets;
14. The right to prosecute and defend lawsuits; and
15. The right to execute, on behalf of respondent, any and all document to carry out the authority vested above.
16. The right to communication, visitation, or interaction with other persons, including the right to receive visitors, telephone calls, or personal mail.

JUDGE RANDY KENNEDY

(Revised May, 2016)

IN THE SEVENTH CIRCUIT COURT FOR DAVIDSON COUNTY, TENNESSEE

LIST OF ENUMERATED POWERS
FOR
CONSERVATOR OVER PERSON

RE: _____

DOCKET NO: _____

IT IS ORDERED that all the following powers and authority described below are removed from and divested out of the heretofore named respondent, and shall be and are vested in the heretofore named Conservator pursuant to T.C.A. §34-3-107(2) as follows:

1. The right to give, withhold, or withdraw consent and make other informed decisions relative to medical and mental examinations and treatment;
2. The right to make end of life decisions:
 - a. To consent, withhold, or withdraw consent for the entry of a "Do Not Resuscitate" Order or the application of any heroic measures or medical procedures intended solely to sustain life and other medications;
 - b. To consent or withhold consent concerning the withholding or withdrawal of artificially provided food, water, or other nourishment or fluids;
3. The right to consent to admission to hospitalization, and to be discharged or transferred to a residential setting, group home, or other facility for additional care and treatment;
4. The right to consent to participate in activities and therapies which are reasonable and necessary for the habitation of the respondent;
5. The right to consent or withhold consent to any residential or custodial placement;
6. The power to give, receive, release, or authorize disclosures of confidential information;
7. The right to execute, on behalf of respondent, any and all document(s) to carry out the authority vested above.
8. The right to communication, visitation, or interaction with other persons, including the right to receive visitors, telephone calls, or personal mail.

JUDGE RANDY KENNEDY

(Revised May, 2016)

IN THE CIRCUIT COURT FOR DAVIDSON COUNTY, TENNESSEE

**LIST OF ENUMERATED POWERS
FOR
CONSERVATOR OVER PROPERTY**

IT IS ORDERED that all the following powers and authority described below are removed from and divested out of the heretofore named respondent, and shall be and are vested in the heretofore named Conservator pursuant to **T.C.A. §34-3-107(2)** as follows:

1. The power to give, receive, release, or authorize disclosures of confidential information;
2. The right to apply for benefits, public and private, for which the person with a disability may be eligible;
3. The right to dispose of personal and real property subject to statutory and judicial constraints;
4. The right to determine whether or not the respondent may utilize a Tennessee driver license for the purpose of driving;
5. The right to make purchases;
6. The right to enter into contractual relationships;
7. The right to execute instruments of legal significance;
8. The right to pay the respondent's bills and protect and invest the respondent's income and assets;
9. The right to prosecute and defend lawsuits; and
10. The right to execute, on behalf of respondent, any and all document to carry out the authority vested above.

JUDGE