Alternatives to Special Needs Trusts

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I. **Introduction**

Special needs trusts are designed to keep beneficiaries eligible for Medicaid and other means-tested benefits programs, but there are times when the intended trust beneficiary may not be receiving those benefits. If the intended trust beneficiary is receiving public benefits that are not means-tested and the likelihood is small that the beneficiary will ever qualify or need such benefits, a special needs trust may not be the best solution. If the trust beneficiary has no legal status or citizenship necessary to qualify for public benefits, it might be best to forego an SNT completely. There may be times when the trust funding is too small to justify the costs of an SNT. There may be times when a trust is large enough to self-insure and allow a beneficiary to forego means-tested benefits. While Special Needs Trusts are an invaluable tool, they certainly aren't–or shouldn't be–the only tools in the tool belt.

II. **Settlement Protection/Preservation Trusts**

A settlement protection trust is a support trust commonly used for plaintiffs who are not receiving settlement proceeds and are not receiving means-tested public benefits. They are designed to hold settlement or lawsuit proceeds and are used to provide for the health, education, maintenance, and support of the beneficiary.

If a beneficiary is not eligible for means-tested public benefits, or when a SNT is not in the beneficiary's best interest, a settlement protection trust may be the best choice. Using a trust instead of having the plaintiff receive the money outright can be advantageous. A major concern for many personal injury attorneys is that personal injury settlements often pour significant assets into the hands of an individual who is not used to managing such sums. Without proper support, education, and guidelines, even large settlements may only last a few years. Many plaintiffs face pressure from family or friends to use settlement proceeds unwisely. Establishing a settlement protection trust can prevent the assets from being spent under undue influence and can protect the beneficiary. Using a support trust also allows for the money management to be handled by an expert.

Just as SNTs can accept periodic payments from qualified structures, settlement protection trusts can be designed so that the payments from the structured settlement go into the trust. Doing so helps protect the structured settlement from being sold by the beneficiary at a deep discount at a later date.[1]

Under this type of trust, distributions can be flexible. A trustee can assist the beneficiary in establishing a budget and the trustee will provide the beneficiary with cash to cover the individual's monthly expenses. The trustee can arrange for a care manager and can provide the beneficiary with a team of experts to handle tax

[1] Plaintiffs sometimes rely on these factoring transactions to satisfy an emergency when the plaintiff has spent the cash portion of a settlement. These transactions are usually not advantageous to the beneficiary and they can usually be avoided with a trust.

preparation, buying, building, or modifying a home, purchasing a vehicle, job coaching, and any other obstacle that a beneficiary may face. If there is sufficient money, the goal is usually to ensure that the money lasts for the lifetime of the beneficiary.

If the beneficiary is a minor, a court may order the settlement proceeds into a trust that remains under the court's continued jurisdiction until the beneficiary reaches the age of majority.[2] In the case of an incapacitated person, the trust can last for the duration of the lifetime of the beneficiary. These trusts, if established by a court, are established under state law and each state may differ on requirements for court approval of distributions of income or principal.[3]

In many large settlements, a plaintiff may be receiving means-tested benefits, but those benefits can sometimes be replaced by private insurance. In these cases, it is often beneficial to consider giving up the public benefits in exchange for greater autonomy and flexibility for the beneficiary. Under such circumstances, a settlement protection trust may be the appropriate tool.

III. Qualified Disability Trusts

As a general rule, trusts are required to pay income tax on income the trust receives annually. The trust tax rates are compressed compared to the personal tax rates. An irrevocable, non-grantor trust reaches the maximum tax bracket (Marginal tax rate of 37%) at only $13,050.00 of income annually.[4] Historically, if a person wanted to avail herself of the personal tax exemption and avoid the compressed tax rates for trusts, she would create a grantor trust. A grantor trust passes all income of the trust through to the "grantor," who can then apply her personal tax exemption and will pay taxes at her own personal tax rate, rather than the compressed tax rates imposed on trusts.[5] Historically, if a trust could not avail itself of grantor trust status, however, it was subject to the compressed tax rates and minimal exemption amounts.

The Internal Revenue Code allows for certain types of disability trusts to qualify for a special personal exemption. Trusts that meet the requirements of IRC § 642(b)(2)(C) are referred to as qualified disability trusts. A Qualified Disability Trust ("QDT") receives an exemption of $4,150.00 in 2021.[6] Thus, if a trust has QDT status, no income tax will be due on the first $4,150.00 (in 2021) of income the trust generates. The IRC

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[2] Note that some states allow for the continuance of the trust to some date after age of majority. In Texas, trusts can be continued until age 25 under Section 142.005 of the Texas Property Code.

[3] In Texas, if established by the District Court under 142.005 of property code, no express requirement of annual accountings. May be able to check SNA materials for a chart or to add other state examples?

[4] Rev. Proc. 2020-45, available at **https://www.irs.gov/pub/irs-drop/rp-20-45.pdf** .

[5] 26 U.S.C. §671.

[6] 26 U.S.C. 642(b)(2)(C)(iii).

definition of a qualified disability trust is somewhat confusing because it references public benefit rules, rather than giving an out-right definition.[7] As a general rule, the provision will apply to most non-grantor trusts created for the benefit of an individual who receives Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits.

A. Elements

The statutory definition of a QDT is a trust that is "a disability trust described in subsection (c)(2)(B)(iv) of section 1917 of the Social Security Act (42 USC § 1396p),"[8] and all of whose beneficiaries are "determined by the Commissioner of Social Security to have been disabled (within the meaning of §1614(a)(3) of the Social Security Act, 42 USC 1382c(a)(3)) for some portion of such year."[9] The code continues that: "a trust shall not fail to meet the requirements of sub clause (II)--that all of the beneficiaries must be disabled--merely because the corpus of the trust may revert to a person who is not so disabled after the trust ceases to have any beneficiary who is so disabled."

To qualify as a QDT, all of the beneficiaries must receive benefits under SSI or SSDI. This is not true of all trusts qualified as a Special Needs Trust under § 1396p(c)(2)(B)(iv), which can be established without a finding of disability so long as the person could meet the disability standard as prescribed by the Social Security

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[7] "(C) Disability trusts

> (i) In general. A qualified disability trust shall be allowed a deduction equal to the exemption amount under section 151(d), determined—
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> > (I) by treating such trust as an individual described in section 68(b)(1)(C), and
> >
> > (II) by applying section 67(e) (without the reference to section 642(b)) for purposes of determining the adjusted gross income of the trust.
>
> (ii)Qualified disability trust. For purposes of clause (i), the term "qualified disability trust" means any trust if—
>
> > (I) such trust is a disability trust described in subsection (c)(2)(B)(iv) of section 1917 of the Social Security Act (**42 U.S.C. 1396p**), and
> >
> > (II) all of the beneficiaries of the trust as of the close of the taxable year are 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 such year.

A trust shall not fail to meet the requirements of sub clause (II) merely because the corpus of the trust may revert to a person who is not so disabled after the trust ceases to have any beneficiary who is so disabled." *Id*. § 642(b)(2)(C).

[8] *Id*. § 642(b)(2)(c)(ii)(I).

[9] *Id*. § 642(b)(2)(c)(ii)(II).

Administration.[10] Thus, a trust for a disabled federal retiree who is not qualified for SSA benefits could not qualify as a QDT, but the trust might meet the definition of a special needs trust as prescribed by 42 USC §1396p.

A QDT cannot be a grantor trust. The trust entity must be a taxpaying entity; because a grantor trust does not file a separate return, it will not qualify as a QDT. Most self-settled special needs trusts are grantor trusts because the trustee has ability to use all trust income and principal for the benefit of the beneficiary.[11] Grantor trust treatment can sometimes also apply to third-party special needs trusts. If the beneficiary is a person with a disability and not the original funding source, the grantor trust rules may still cause treatment of the trust as a grantor trust to the original trust creator.[12] In such a case, QDT treatment will not be available to the trust because it is not the taxable entity.

The trust must be established for the benefit of individuals with a disability under age 65 at the time of the trust creation. Under section §1396p(c)(2)(B)(iv), a trust must be established for the benefit of only one trust beneficiary. Thus, a grandparent with more than one grandchild with a disability could not establish a single special needs trust for the benefit of the group of grandchildren with disabilities and still receive the benefits of §1396p(c)(2)(B)(iv). The IRC provision, however, requires that "all of the beneficiaries" be determined to be disabled. The sole benefit rule, then, appears to not be applicable to QDTs.

B. Analysis

Using the QDT tax provisions will generally always be a good idea for third-party non-grantor special needs trusts. There may be, however, good uses for the QDT tax provisions even when a special needs trust is not the appropriate tool.

In a typical special needs trust, one individual with a disability is named as the beneficiary for the duration of life. Consider a situation where grandparents have a two-year-old grandchild receiving SSI because she has a total disability, but the disability can be cured with a major surgery. The surgery cannot be performed until the child reaches age ten when her body is more able to recover from such a major surgery. The grandparents have three other grandchildren for whom they would like to provide.

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[10] The Administration makes disability determinations only when a person seeks benefits because he or she is disabled and meets the other program requirements for SSI or SSDI. 20 C.F.R. §404.1520.

[11] IRC § 673 gives grantor trust status to any portion of a trust in which there is a reversionary interest of as much as 5% of the value of the trust. Because the value of the reversionary share is calculated by "assuming the maximum exercise of discretion in favor of the grantor," most self-settled SNTs are grantor trusts. 26 U.S.C. § 673(c).

[12] *Id*. at §§671-678.

A trust that provides for the grandchild with a disability until she is age eighteen, and then provides for all grandchildren could receive QDT status so long as the first beneficiary receives SSI. Unlike the "sole benefit" requirement in the public benefits provision, which requires that the beneficiary with a disability's interest te rminate only at death, the QDT provision permits reversion after the trust ceases to have any disabled beneficiary.

Next consider a family with four adult children; three of the children receive SSDI benefits. The three children receiving SSDI benefits do not need to adhere to the special needs trust rules because they are not receiving means-tested benefits. The child who is not receiving SSDI benefits has agreed to serve as trustee for a trust established for her siblings, but would prefer to manage only one trust for the whole--not three separate trusts. The parents establish a single trust for the benefit of their three children that meets the QDT tax provisions because the IRC provision permits multiple beneficiaries so long as each has a disability determination by the Social Security Administration.

IV. Sole Benefit Trusts

A Sole Benefit Trust (SBT) is a trust that, when properly drafted, does not create a transfer penalty for the Settlor under the Long-Term Medicaid rules. It can be the perfect planning tool for a Medicaid Spend Down when trying to qualify an applicant for long-term Medicaid, in certain circumstances. If correctly drafted, transfers of the applicant's assets to a sole benefit trust could allow Medicaid eligibility (without a transfer penalty) while also maintaining eligibility for means-tested benefits for the trust beneficiary.

As a general rule, an individual must have less than $2,000.00 in countable assets to be eligible for Medicaid. Medicaid imposes a five-year "look back" period wherein the applicant is penalized for transfers made when the applicant received less than fair market value in return. Some transfers are exempt from this penalty: transfers to the applicant's spouse and transfers to a child who is under age 21 and transfers to a child who is blind or has a disability are all exempt. An often lesser used transfer exemption is a transfer to a trust for the sole benefit of any individual who is under age 65 and who does or would meet the Social Security Administration's criteria for total and permanent disability.

This may sound like a hidden loophole that allows two people to qualify for benefits with just one trust. But, there are some pitfalls to avoid for beneficiaries who receive certain types of government benefits. A sole benefit trust for this purpose combines the aspects of both first and third party special needs trusts. It is established with the funds of someone other than the beneficiary (third-party). The beneficiary must be under the age of 65 and the trust must be for the "sole benefit" of the beneficiary (first-party). It is important to note that the term Sole Benefit Trust is merely descriptive: many trusts that

contain the provisions that allow them to qualify as SBTs are considered standard special needs trusts--however--not all special needs trusts are SBTs. The statute[13] exempts from sanctions any transfer "to a trust (including a trust described in subsection (d)(4) of this section) established solely for the benefit of" a disabled person who is either under age 65 or the transferor's child of any age. While the statute clearly articulates the requirements of a D4A trust--including the payback requirement--it is silent as to what requirements apply to the other types of trusts that might qualify as "solely for the benefit of."

A. Elements

The Centers for Medicare and Medicaid Services (CMS) State Medicaid Manual defines Sole Benefit. "A transfer is considered to be for the sole benefit . . . if the transfer is arranged in such a way that no individual or entity except the spouse, blind or disabled child, or disabled individual can benefit from the assets transferred in any way, whether at the time of the transfer or at any time in the future."[14] A sole benefit trust could be established by a Medicaid applicant for the sole benefit of the community spouse without incurring a penalty. An SBT can also be created for a child--of any age--who is blind or who meets the disability criteria as established by the Social Security Administration (SSA). The Administration defines disability as the inability to engage in substantial gainful activity by reason of a "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 at least twelve months.[15] The individual's impairment(s) must be severe enough to prevent her from performing not only her previous job but, considering her age, education and experience, any other job that exists in the national economy. Lastly, a Medicaid applicant can establish an SBT for any individual under age sixty-five (65) who has a disability.

To be considered "for the sole benefit of" an individual, the trust must require distributions to be actuarially sound based on the life expectancy of the beneficiary.[16] To be actuarially sound, the minimum distribution standard must provide for the complete distribution of the trust principal within the beneficiary's anticipated life expectancy.[17] The trustee can deplete the trust more rapidly, but the trust document

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[13] 42 U.S.C. §1396p(c)(2)(B).

[14] CMS State Medicaid Manual, Chapter 3, Section 3257, *available for download at* **https://www.cms.gov/Regulations-and-Guidance/guidance/Manuals/Paper-Based-Manuals-Items/CMS021927.html**.

[15] 42 U.S.C. §1382c(a)(3)(A).

[16] Texas requires the trust to make distributions that are actuarially sound. Medicaid for the Elderly and People with Disabilities Handbook, I-3300, *available at* **http://www.dads.state.tx.us/handbooks/mepd/**.

[17] *Supra*, note 13 at §3258.9B.

must provide for minimum payments that are actuarially sound. One possible distribution standard would be to include minimum required distributions that are based on the beneficiary's life expectancy with trustee discretion to exceed the minimum standard. This would allow the trustee some flexibility in the event the beneficiary would be better served with larger distributions.

Some state Medicaid authorities have placed additional requirements on SBTs. Some states also require a payback provision to be included. Additionally, some states require the beneficiary's estate to be the sole remainder beneficiary.[18] These requirements are absent from the federal statute and the CMS manual. Ostensibly, these requirements ensure that the trust is solely for the benefit of the beneficiary, but appear to be more restrictive than the federal law.

In States without these extra hurdles, a sole benefit trust may be a solution for a penalty-free Medicaid spend down while also benefitting an individual with disabilities.

B. Analysis

An obvious use of the Sole Benefit Trust is when a would-be beneficiary only receives Social Security Disability Insurance (SSDI). SSDI is federal benefit program without income and asset restrictions. If a person with disabilities is receiving SSDI and will never qualify for SSI because the monthly payments she receives exceed the SSI limits, she could easily be the beneficiary of a Sole Benefit Trust because the mandatory actuarially sound distributions will not negatively impact her SSDI benefits. In this circumstance, an applicant for Long-Term Medicaid could transfer assets--penalty free--to a sole benefit trust for the SSDI recipient with no negative impact on the SSDI recipient's benefits. A true win-win.

The scenario is more complicated when the would-be beneficiary is a Supplemental Security Income (SSI) recipient. Cash received from the trust will reduce SSI benefits dollar-for-dollar.[19] Therefore, it will be necessary to structure the minimum distributions so that they will not be income (under the SSI rules) to the beneficiary. A sole benefit trust for an SSI recipient could require the Trustee to satisfy the minimum distribution requirements first with distributions that do not constitute income (for SSI eligibility purposes) to the beneficiary. If the minimum required distribution cannot be satisfied under the first requirement, the Trustee would next be required to make distributions that constitute In-Kind Support and Maintenance (ISM). The receipt, or right to receive, food or shelter is known technically as In-Kind Support and Maintenance. The trust beneficiary's SSI benefits will be reduced if she receives ISM because SSI benefits are specifically intended to pay for a person's food and shelter; if an SSI recipient receives

[18] *See* 18 NYCRR § 360-4.4(C)(2)(iii)(d)(V).

[19] Social Security Administration Programs Operations Manual (POMS) SI 01120.200E1.a, *available at* **https://secure.ssa.gov/apps10/poms.nsf/lnx/0500815001**.

those goods or services from another source, then theoretically, less SSI income is needed.[20] When a Trustee distributes ISM to the beneficiary, SSI benefits will be reduced, but not on a dollar-for-dollar basis as with cash.[21]

If a potential Medicaid applicant owns a brokerage account with a balance of $500,000.00, the applicant could fund an irrevocable trust for the sole benefit of her 52-year-old son who has a disability and receives SSDI benefits. According to the Administration's actuarial tables, a 52-year-old male has a life expectancy of 27.98 years of remaining life (age 79.98).[22] Thus, the SBT must provide for minimum annual payments of $17,869.90 ($500,000.00÷27.66=$17,869.90). The trust is irrevocable and not a countable asset to the applicant. The trust requires minimum annual distributions of $17,869.90, and thus, is actuarially sound. Because SSDI is not a means-tested program, monthly trust disbursements to (or for the benefit of) the applicant's son do not affect his benefits. Because the trust meets the requirements of an SBT, the applicant will not receive a transfer penalty for the trust funding.

Now consider a Medicaid applicant who owns $100,000.00 in real property and a bank account with $100,000.00. She creates an irrevocable trust for her 35-year-old granddaughter who receives SSI benefits. According to the actuarial tables, a 35-year-old female is 47.20 years of remaining life (age 82.20). The trust provides that the Trustee make minimum annual distributions of $4,237.29 ($200,000.00÷47.20=$4,237.29). The trust is irrevocable and does not result in a transfer penalty for the applicant because the minimum distributions are actuarially sound. Any cash received by the granddaughter will reduce her SSI payment dollar-for-dollar. So long as the applicant's granddaughter continues to receive an SSI check of at least $1.00 per month, she remains eligible for Medicaid.

V. **ABLE ACCOUNT**

ABLE accounts are established pursuant to 26 U.S.C. § 529A of the Internal

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[20] There are sometimes rather fine distinctions between allowable in-kind income and countable ISM. For example, you can pay for some travel arrangements but not others: a plane ticket (in-kind income) --but not a hotel room because that is shelter (ISM). You can pay for some entertainment expenses but not others: a movie pass (in-kind income) but not a restaurant meal because that is food (ISM). *See Id*. at SI 00815.001(C) and (D).

[21] Instead, the formula Social Security uses to reduce the SSI benefits for a person who receives ISM depends on two further factors: the household and living arrangement of the SSI recipient. The formula will either be the Presumed Maximum Value or the One-Third Reduction rule. *Id*. at SI 00835.300.

[22] Social Security Administration Actuarial Life Table, 2017, *available at* **https://www.ssa.gov/oact/STATS/table4c6.html**.

Revenue Code for eligible individuals[23] who have a disability.[24] Accounts established in a qualified ABLE plan[25] are exempt from taxation.[26] The statute limits the types of contributions that can be accepted into the account.[27] A beneficiary may only have one ABLE account but a beneficiary is not limited to establishing an account in her home state.[28] The total amount of annual ABLE account contributions for *all* sources is limited to an amount equal to the federal annual gift tax exclusion amount, unless the person with disabilities is working.[29] Even though favorable tax treatment is a plus,[30] the main

[23] 26 U.S.C. §529A(e)(1) defines eligible individual as a person who "is entitled to benefits based on blindness or disability under title II or XVI of the Social Security Act, and such blindness or disability occurred before the date on which the individual attained age 26, or ….a disability certification with respect to such individual is filed with the Secretary for such taxable year."

[24] Note that the definition for eligible individual requires a disability or a disability certification which is defined as

> "a certification to the satisfaction of the Secretary by the individual or the parent or guardian of the individual that … certifies that the individual has a medically determinable physical or mental impairment, which results 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 1614(a)(2) of the Social Security Act), and … such blindness or disability occurred before the date on which the individual attained age 26, and … includes a copy of the individual's diagnosis relating to the individual's relevant impairment or impairments, signed by a physician meeting the criteria of section 1861(r)(1) of the Social Security Act."

26 U.S.C. § 529A(e)(2)(A). Although the individual may have a disability certification for the purpose of the ABLE account, the statute specifically states that "[n]o inference may be drawn from a disability certification for purposes of establishing eligibility for benefits under title II, XVI, or XIX of the Social Security Act." *Id*. at (e)(2)(B).

[25] A qualified ABLE plan is "a program established and maintained by a State, or agency or instrumentality … under which a person may make contributions for a taxable year, for the benefit of an individual who is an eligible individual for such taxable year, to an ABLE account which is established for the purpose of meeting the qualified disability expenses of the designated beneficiary of the account, … which limits a designated beneficiary to 1 ABLE account for purposes of this section." It also has to meet any other requirements specified in *Id*.

[26] *Id*.

[27] *Id*. Contributions are after-tax dollars and grow tax-free. Contributions must be in cash and may be made "in the form of cash or a check, money order, credit card, electronic transfer, Gift of Independence card, or a similar method." POMS SI 01130.740.B.2.

[28] *Id*. While the original law passed in 2014 did stipulate that an individual had to open an account in his or her state of residency, this provision was eliminated by Congress in 2015. Regardless of where an individual might live, and whether or not that individual's state has decided to establish an ABLE program, a qualified person is free to enroll in any state's program provided that the program is accepting out-of-state residents.

[29] *Id*. In 2021, the annual gift tax exclusion is $15,000.00. 26 U.S.C. §2503(b)(2). The contribution limits and other provisions of section 529A were modified by the 2017 Act. Specifically, the 2017 Act amended § 529A(b)(2)(B) to allow a designated beneficiary described in § 529A(b)(7) to contribute, prior to January 1, 2026, an additional amount in excess of the limit in § 529A(b)(2)(B)(i) (the annual gift tax exclusion amount in § 2503(b)). This additional amount is set forth in § 529A(b)(2)(B)(ii) and is equal to the lesser of

feature of an ABLE account that makes it useful for individuals with special needs it's favorable treatment by the Social Security Administration for SSI eligibility. The Social Security Administration exempts as a resource for SSI eligibility, ABLE accounts up to $100,000.00.[31] Contributions to—and distributions from—ABLE accounts are treated similarly by the SSA to those of SNTs and are countable for SSI eligibility.[32] A distribution from an ABLE account for something other than a Qualified Disability Expense will have tax implications for the beneficiary.[33] However, for SSI eligibility, distributions from an ABLE account are excluded from income to the designated beneficiary regardless of whether the distributions are for a Qualified Disability Expense or for a non-qualified expense.[34]

A qualified disability expense is defined as:

> any expenses related to the eligible individual's blindness or disability which are made for the benefit of an eligible individual who is the designated beneficiary, including the following expenses: 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 other expenses, which are approved by the Secretary under regulations and consistent with the purposes of this section.[35]

(I) the designated beneficiary's compensation as defined by § 219(f)(1) for the taxable year, or (II) an amount equal to the poverty line for a one-person household for the calendar year preceding the calendar year in which the taxable year begins.

[30] 26 U.S.C. §529A (c)(1)(B) exempts within limits, any ABLE account distributions from the recipient's gross income as long as the distribution is for a qualified disability expense.

[31] POMS SI 01130.740(C)(3). To the extent an ABLE account contains more than $100,000.00, the excess amount will be counted as resource for SSI. If the excess causes the beneficiary to exceed the SSI resource limit, the SSA will suspend SSI benefits without time limit. The beneficiary will continue to receive, Medicaid benefits during the SSI suspension, however. SI01130.740(D)(1)(c). Once the ABLE account is below $100,000.00, the beneficiary's SSI eligibility will be reinstated. SI01130.740(D)(1)(c).

[32] POMS SI 01130.740(C)(3). SI01130.740(C)(4).

[33] *See* 26 U.S.C. § 529A.

[34] POMS SI01130.740(C)(4).

[35] 26 U.S.C. § 529A(e)(5).

Similar to a first party SNT, the ABLE account has a payback requirement when the beneficiary dies.[36] The payback requirement for ABLE accounts is present whether the account is funded entirely with either first party or third party funds, so it is important to evaluate the funding source and likelihood of a fund balance upon the death of the beneficiary to determine if the SNT or the ABLE account is a better fit for each particular beneficiary.

An ABLE account may be a good planning option, either alone or in conjunction with a SNT. Some ABLE plans are national[37] while others are limited to residents of a specific state. Some salient definitions regarding ABLE accounts:

- **Designated beneficiary**: is the owner of the ABLE account and was either an eligible person when the ABLE account was created or replaced the former designated beneficiary as the designated beneficiary.[38]

- **Eligible person**: if during the taxable year, the person was entitled to SSD benefits and the disability started prior to the person turning 26, or a disability certification was filed with the IRS during that year.[39] As the POMS provides, the person must be eligible for SSI based on a disability that started before age 26 or eligible for DIB, CDB or DWB with the disability starting before 26.[40]

- **Qualified disability expense** is any expense that is connected to the eligible person's disability and is incurred to benefit that person who is the ABLE account designated beneficiary. These expenses can include expenses for housing, education, assistive technology, health care, transportation, financial management and more.[41] The POMS further explains housing expenses, but notes that there is a difference, "[h]ousing expenses for purposes of an ABLE account are similar to household costs for in-kind support and maintenance

[36] 26 U.S.C. § 529A(f) ("[s]object to any outstanding payments due for qualified disability expenses, upon the death of the designated beneficiary, all amounts remaining in the qualified ABLE account not in excess of the amount equal to the total medical assistance paid for the designated beneficiary after the establishment of the account, net of any premiums paid from the account or paid by or on behalf of the beneficiary to a Medicaid Buy-In program under any State Medicaid plan established under title XIX of the Social Security Act, shall be distributed to such State upon filing of a claim for payment by such State. For purposes of this paragraph, the State shall be a creditor of an ABLE account and not a beneficiary.")

[37] *See, e.g.* Ohio's ABLE plan, known as STABLE: **https://www.ablenrc.org/state-review/ohio/**; **https://www.stableaccount.com/files/STABLEpds.pdf**.

[38] SI01130.740(A)(3).

[39] 26 U.S.C. § 529A(e)(2).

[40] SI01130.740(B)(3).

[41] 26 U.S.C. § 529A(e)(5).

purposes. However, for ABLE purposes, food is considered a qualified disability expense (basic living expense), but not a housing expense."[42]

The best option may be to use an ABLE account in conjunction with a special needs trust. A trustee may make contributions to an ABLE account for a trust beneficiary without incurring a reduction in SSI for In-Kind Support and Maintenance.[43]

VI. Health Insurance Under the ACA

The Affordable Care Act (ACA) is the comprehensive health care reform signed into law ten years ago.[44] The Act includes a list of health-related provisions intended to extend health insurance coverage to Americans who have historically been without insurance. The Act expands Medicaid eligibility, creates health insurance exchanges, and also prevents insurance companies from denying coverage based on pre-existing conditions. The expansion of coverage is provided through health insurance exchanges where private health insurance companies list their health plans with the exchange and buyers can compare policies to choose the most appropriate plan. There are both public and private insurance exchanges. Private health insurance exchanges typically serve large employers providing job-based health insurance for employees. The public health insurance exchanges are maintained by the U.S. government to allow individuals and families to purchase plans that comply with the requirements of the ACA. By using the public exchange, a person can receive premium subsidies and cost-sharing subsidies that help make the plans more affordable for enrollees.

It is possible to shop for an ACA plan without accessing the exchange by using a broker or purchasing directly through an insurance company, the premium and cost-sharing subsidies are not available, however, if you do not purchase coverage through an exchange. Generally, though, the plans themselves will be similar on or off the exchange because insurance companies cannot sell non-compliant major medical health plans in the individual market even if sold outside of an exchange.

All U.S. citizens and legally present residents who are not in prison are eligible to purchase coverage through the exchange unless the individual is eligible for premium-free Medicare Part A. Undocumented immigrants cannot enroll in coverage through the exchange.

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[42] SI01130.740(B)(9).

[43] POMS SI 01130.740.B.2 states that contributions to an ABLE account "may be made by any person." And a "person" is defined by the Internal Revenue Code to include "an individual, trust, estate, partnership, association, company or corporation."

[44] The ACA is not one single health care bill that became law, but is actually composed of two laws: Patient Protection and Affordable Care Act (ACA) (Pub. L. No. 111-148, 124 STAT. 119) and Health Care and Education Reconciliation Act of 2010 (HCERA) (Pub. L. No. 111-152, 124 Stat. 1029).

The ACA prevents non-lawfully present immigrants from enrolling in coverage through the exchanges.[45] Beneficiaries without legal status are also not eligible for Medicaid under federal guidelines, making the two major cornerstones of coverage expansion under the ACA unavailable to undocumented immigrants. However, if a trust can afford it, a trustee for an undocumented person can purchase an unsubsidized insurance policy through a broker or directly from an insurance provider.

It's important to understand that if a beneficiary is lawfully present, she can enroll in a plan through the exchange even if some members of the beneficiary's family are not lawfully present. Family members who aren't applying for coverage are not asked for details about their immigration status. And HealthCare.gov clarifies that immigration details provided to the exchange during the enrollment and verification process are not shared with any immigration authorities.[46]

A few states have implemented programs to cover undocumented immigrants, particularly children or pregnant women. Oregon, for example, has established the Cover All Kids program that provides coverage to kids in households with income up to 305 percent of the poverty level, regardless of immigration status.[47] California has a similar program for children, and as of 2020, it will also apply to young adults through the age of 25.[48] New York covers kids and pregnant women in its Medicaid program regardless of income, and covers emergency care for other undocumented immigrants in certain circumstances.[49]

All health insurance policies offered must conform to one of five benefit tiers: catastrophic, bronze, silver, gold, or platinum. Both on- and off-exchange, a policy's benefit tier describes the percentage of covered health care expenses the plan will pay, otherwise known as the actuarial value (AV) of the plan.[50]

An ACA compliant policy must cover the following essential health benefits:

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[45] *See Id.* §1312(f)(3) available at **http://housedocs.house.gov/energycommerce/ppacacon.pdf**.

[46] *See* **https://www.healthcare.gov/immigrants/immigration-status/**.

[47] *See* **https://www.oregon.gov/oha/HSD/OHP/Contractor%20Workgroups%20Member%20Engagement%20Outreach%20M/MEOC%20Cover%20All%20Kids%20update%20101817.pdf** .

[48] See **https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/SB-75.aspx** and **https://www.npr.org/sections/health-shots/2019/07/11/739536305/young-undocumented-californians-cheer-promise-of-health-benefits**.

[49] **https://www1.nyc.gov/site/ochia/find-what-fits/immigrants.page**.

[50] **https://www.healthcare.gov/choose-a-plan/plans-categories/**.

- Ambulatory care (outpatient care)
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health care, including treatment for substance use disorders)
- Prescription drugs
- Rehabilitation services and habilitative services, including devices
- Laboratory services
- Preventive care
- Pediatric vision and dental care (coverage for adult dental and vision services is not required. The rules for pediatric dental coverage are a little different from the other essential health benefits).

While all plans are required to cover these essential health benefits, the percentage of coverage will depend on the tier of each particular policy.

VII. Public Benefits NOT Based on Financial Need

Trustees and parents of children with disabilities are usually aware of public benefits available for those children that are based on financial need, for example Supplemental Security Income (SSI) and Medicaid. There are, however, many public benefits available that are not based on financial need. The purpose of this section is to survey non-needs-based public benefits that may be available.

A. Social Security Disability Insurance (SSDI)

A disabled individual is entitled to SSDI benefits if she:

- is under full retirement age,
- has at least 20 credits in the 40 quarter period ending with the quarter in which the individual became disabled (20/40 rule), and is fully insured,[51] is disabled,[52] files an application for benefits, and establishes a waiting period of five consecutive months beginning with a month in which the worker was both

[51] Social Security Handbook, https://www.ssa.gov/OP_Home/handbook/handbook.02/handbook-0207.html §207. See §203 for the definition of fully insured (generally one quarter for each year after attaining the age of 21 up to a maximum of 40 quarters) and §208 for a special exception to the 20/40 rule for workers disabled before age 31.

[52] To be disabled within the meaning of the Social Security Act, the individual must have a severe, medically determinable physical or mental impairment which has or is expected to last for one year or to result in death. In addition, the impairment must make the individual unable to engage in "substantial gainful activity." 20 CFR §404.1505 for SSDI and 20 CFR §416.905 for SSI.

insured and disabled.

Benefits may also be available based on the record of a living (Social Security Dependent's Benefits) or deceased (Social Security Survivors' Benefits) parent. Children who became disabled before age twenty-two and have remained continuously disabled may draw benefits on the record of a parent who is deceased, retired, or who has a disability as long as the child is disabled and unmarried. A child may be biological, adopted, illegitimate and acknowledged, or a stepchild. This program is referred to as Childhood Disability Benefits.[52] A CDB beneficiary who marries another SSDI recipient generally will not lose benefits. The CDB beneficiary should contact the local Social Security Office before marrying to determine the effect of the marriage on her benefits and should not engage in "substantial gainful activity."

SSDI monthly benefits are based on the worker's primary insurance amount (PIA) which is based on the worker's indexed monthly earnings. The worker's benefit is based on a 100% of the PIA. A CDB of a worker is entitled to 50% of PIA and, if the worker is deceased, this increases to 75%. If the child is entitled to benefits based on more than one worker's record, the benefits will be based on the largest PIA.

There are no resource or income limits for SSDI eligibility. However, if the disabled individual's earned income in 2021 exceeds $1,310 a month ($2,190 for Blind) (after deducting the cost of impairment-related work expenses), the person will likely not be considered disabled and therefore may not be eligible for benefits.

B. Medicare

Medicare is a federal health insurance program. The Department of Health and Human Services (DHHS) is the executive department that implements the Social Security Act, to which Medicare is tied. The DHHS has established the Social Security Administration (SSA) and the Centers for Medicaid and Medicare Services (CMS) as the administrative agencies that administer Medicare. Local SSA district offices handle Medicare enrollment, give out basic information, and receive appeals. CMS has direct responsibility for the administration of benefits. SSDI beneficiaries are entitled to Part A Medicare benefits after 24 months (one month for a person disabled with ALS effective 7/1/2001) of qualified disability and no waiting period for people on kidney dialysis. Part

[52] Formerly called Disabled Adult Child ("DAC") benefits.

A covers inpatient hospital services, post hospital extended care services, home health, and hospice benefits. Psychiatric hospital stays are limited to 190 days in the beneficiary's lifetime. Skilled nursing facility stays are limited to 100 days and are 100% covered for only the first 20 days.

Custodial care is not covered. This is care that could be given safely and reasonably by a person who is not medically skilled and that is given mainly to help the patient with daily living such as walking, bathing and dressing. There is no coverage for custodial care even if performed in a skilled nursing facility or home health care environment. SSDI beneficiaries who are eligible for Part A benefits may enroll for Part B benefits but must pay a premium of $148.50 per month in 2021. Part B benefits cover physicians' charges, diagnostic tests, medical equipment, ambulances, and outpatient physical and speech therapy. Medicare generally does not pay the entire cost of hospital stays and physicians' services. In addition, there are deductibles and copays.

There are no resource or income limits for Medicare eligibility.

C. Civil Service and Military Survivor Benefits for Disabled Adult Children

Civil Service Survivor Benefits are available for an unmarried child over age 18 who is incapable of self support because of a mental or physical disability that began before age 18. Guidelines for determination of the disability are less clear than under Social Security guidelines. The applicant must provide a physician's report of the disability, including the date it started, degree of impairment, probable length of the disability, and an educational and employment history. The child is eligible to receive 55% of the parents' annuity after the parents' death as long as the disabling condition continues and the child does not become capable of self support. Payments to a child with disabilities stop at the end of the month before the one in which the child marries, dies, recovers from the disability, or becomes capable of self-support. The child may receive the benefit even if a widow(er) is also receiving a survivor benefit. Children receiving a civil service survivor annuity are also eligible for federal employee group health benefits if the federal employee had family coverage at the date of her death.[53]

Military Survivor Benefits may be available if the military member selected spouse & children coverage, or children-only coverage (not automatic as the Federal Civil Service

[53] **www.opm.gov/retire** (U. S. Office of Personnel Management - Federal Retirees) and **https://www.opm.gov/healthcare-insurance/healthcare/reference-materials/fehb-handbook/** (Federal Employees Health Benefits Handbook, Family Members).

benefits are). If the member elects spouse & children coverage, the child will not receive payments until the surviving spouse becomes ineligible due to remarriage before age 55 or death. These benefits provide 55% of the base amount at the time of the retiree's death, divided by all eligible children. The payments end if the disabled child marries or is no longer disabled. If the child is mentally incompetent, payments must be made to a court-appointed guardian, fiduciary, or representative payee (as determined by the Defense Finance and Accounting Service) of the child.[54]

D. TRICARE

TRICARE is a health benefit program for all seven uniformed services. TRICARE eligible persons include active duty and retired service members and their spouses and unmarried children. Unmarried children of active duty or retired service members who have died are also TRICARE eligible. Children over 21 are eligible if the child has a severe disability if the condition existed prior to the child's 21st birthday, or if the condition occurred between the ages of 21 and 23 while the child was a full-time student.[55] TRICARE also has the Program for Persons with Disabilities (PFPWD) that provides financial assistance to reduce the effects of mental retardation or serious physical disability. It is not a stand alone program; it may be used concurrently with other TRICARE medical programs.[56]

E. Publicly Financed Education

The federal law known as the Individuals with Disabilities Education Act (IDEA)[57] and related state regulations provide that a free appropriate public education will be provided to all children with disabilities, age 3 to 21[58] (services may be provided from

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[54] **https://download.militaryonesource.mil/12038/MOS/ResourceGuides/A-Survivors-Guide-To-Benefits.pdf** (Survivor Benefits Guide), **https://militarypay.defense.gov/Benefits/Survivor-Benefit-Program/Overview/** (Survivor Benefits Program Overview).

[55] **www.tricare.mil** (TRICARE Website).

[56] **https://manuals.health.mil/pages/DisplayManualPdfFile/P98/3/AsOf/P98/C7S3_2.PDF** (TRICARE Policy Manual, Programs for Persons With Disabilities).

[57] 20 U.S.C. §1400 et seq.

[58] For example, Virginia has elected to begin Special Education at age 2 and Michigan provided special education to students until the age of 26.

age 0 to 3 by other state agencies[59]). The special education laws have four features.[60] First, schools must have continuing child find programs to ensure that all efforts are made to bring children with disabilities into the schools. The second feature is the mandatory requirement for all local education agencies (LEAs) to provide free, appropriate public education and services to children with disabilities. The LEAs also need to document precisely the students' school records to receive state and federal funding for special education programs. The third feature is the mandatory requirement that LEAs involve parents of children with disabilities in the process that creates Individualized Education Programs (IEPs) for their children. The fourth feature is the mandatory requirement that LEAs adhere to safeguards to protect the rights of parents and children when exceptional services and programs are initiated, altered or terminated, including the rights to notice and due process.

The first step of compliance with IDEA consists of six components, beginning with finding children with disabilities and ending with their placement. The first component is "Child Find," in which the school system has the responsibility to ensure that children with disabilities needing special education and related services are identified, located and evaluated. The second component is "Identification," in which anyone in the school system who notices differences in a student that could negatively impact the student's academic achievement considers referring the student for evaluation. This preliminary identification process is well in advance of actually identifying a student's specific disability. The third component is the "Eligibility/Evaluation/Independent Educational Evaluation" or IEE. The eligibility requirements for programs and services need to be known so everyone in the system knows the boundaries within which they must identify students needing evaluation. Once the categories of eligibility are identified, the LEA is tasked to evaluate the student. After the evaluation, with proper notice and due process protections for the parents and the child, the student is then classified according to the student's primary disability, and the appropriate education plan is developed. An IEE is available to parents in two circumstances: first, if the parents request and receive the evaluation by the child's school system; second, if the parents object to the LEAs conclusions and recommendations based on the evaluation. The IEP is the fourth component. To determine what is appropriate for the student, the LEA must devise an IEP for every student with a disability. The parents are integral partners

[59] In Virginia, these services are provided by the local Community Services Boards.

[60] A. Frank Johns, "The Top 10 Things that SNT Attorneys and Trustees Must Know About in the Individualized Education Plan (IEP), 504 Plan or Individualized Program Plan" (2010), **https://www.stetson.edu/law/conferences/homepages/media/snt-friday/document/the-top-10-things-a-frank-johns.pdf**.

with the LEAs in the development of the IEP, with the goal being the design of creative and practical ways to provide children with disabilities with free appropriate education and related services. IEPs must also include transition services for eligible students no later than age 16. If the parents disagree with the IEP, they may request mediation or a due process hearing. If satisfaction is not obtained through mediation or at the hearing, the parents may bring suit in state or federal court.

When the student reaches age 18, the parent's rights to participate in the development of and implementation of the IEP or in challenging the IEP "transfer" to the student will terminate, unless one of the following actions is taken:

- The adult student is declared legally incompetent by a court and a representative has been appointed by the court to make decisions for the student.
- The adult student designates, in writing, by a power of attorney, another adult to be the student's agent to participate and make decisions concerning the student's educational program.
- The adult student is certified as unable to provide informed consent and the LEA appoints an educational representative.

The fifth component is "Related Services," in which LEAs are responsible for providing related services, such as social workers, specialized equipment, transportation, and behavior management. "Placement" is the final component. The child must be provided with free appropriate public education; the environment for receiving that education can range from a regular classroom program to hospital or home-based services. The LEA must make the placement determination with prior notice to the parents, who have the opportunity to object and be advised of their rights. The principles of least restrictive environment, mainstreaming, and full inclusion apply to the placement determination.

Section 504 of the Rehabilitation Act of 1973 also pertains to children with disabilities and is a civil rights statute as opposed to a programmatic statute such as IDEA. Schools that receive federal financial assistance cannot discriminate against students with disabilities. The criteria for eligibility under IDEA and Section 504 are somewhat different, and they will not be detailed here. Educators and parents should be familiar with the criteria provided in both statutes.

Trustees with the help of parents and grandparents should consider developing and implementing a multidisciplinary plan for beneficiaries with special needs as part of the estate plans of these family members. These plans would ensure that parents and

grandparents take into consideration such issues as post-secondary education, transition to independent living, self-determination and employment, when developing estate plans and allocating assets to implement these plans.