

# When the Trust is Better than Entitlement Programs

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## I. Introduction

As special needs trust attorneys and trustees, sometimes it is easy to make assumptions about a beneficiary and her circumstances and move too quickly. We are trained to know the technical rules of special needs trusts. We have seen first-hand the value that means-tested public benefits can provide for our clients. It can be easy to assume that every beneficiary who comes to us has found us because she needs a special needs trust. But, as Abraham Maslow once said, if all you have is a hammer, everything looks like a nail.<sup>1</sup>

There may be times when it is in our client's best interests to forego public benefits and craft a trust that is more flexible and can better provide for the beneficiary's life goals. Making a determination between an SNT and some other type of trust should not be as simple as asking: "Does the beneficiary have a disability?" In fact, making the determination to use trust funds for support, rather than relying on means-tested benefits, can be more important than the words in the trust document itself. While *most* of our clients may need to rely on SSI or Medicaid, it is important to evaluate and recognize the opportunities a beneficiary faces so that we can maximize the resources available to fit the beneficiary's life goals. This process requires time and information.

This presentation outlines factors a drafting attorney or trustee should consider prior to determining what type of trust is the most appropriate. Starting early is helpful and is encouraged. This inquiry starts from a baseline with the following factors:<sup>2</sup>

1. Trust distributions are not a science. There is no way to be perfect.
2. **Usually**, any plan is better than no plan.
3. Aim for perfection by creating a plan.
4. Perfection is the enemy of good (*this is a quote whose author is unknown*).
5. Expect others to also aim for perfection but remain focused on reality, which is that every good result in this field is a resounding success.
6. Recognize that trustees will typically receive trusts in situations where the best opportunities have already been lost. Their job can be remarkably difficult.
7. *Recognize desired SNT circumstances*: If there is an opportunity to allocate more of a settlement to devoted care-giving family members (parents or a spouse) so that they can own the house, distributions and the family's living situation could be greatly

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<sup>1</sup> Maslow, Abraham, *The Psychology of Science*, 1966.

<sup>2</sup> Sections II through VI of this paper were written by attorney Renée Lovelace for her presentation at the University of Texas Special Needs Trust Conference in 2007 on Distribution Plans. They have been updated and adapted for this topic and are included here with her permission.

enhanced throughout the future for many beneficiaries. *However, keep your eye on any parents' duty of support and the legal limitations on allocation options.*

8. *Desired circumstances.* If there is an opportunity to make purchases prior to trust funding, better future living situations are sometimes possible.

9. There is a role for attorneys early in the process—long before drafting takes place.

10. There is a role for care managers and trustee advisors in implementing a distribution plan and in determining if the trust is large enough to meet the needs of the beneficiary, for her entire lifetime (or some time certain, say, age sixty-four), without the reliance on public benefits.

11. Without these considerations, many opportunities to improve the trust beneficiary's life will be lost.

12. The more we know, the more we realize that we can never make all the improvements that we would like to make—given the time constraints that exist in reality.

13. The type of trust drafted, and the distribution plan and budget that follow, all focus on the beneficiary's best interests. It is important to keep emphasizing that fact—both in theory and in practice.

## II. Understand the Key Person: Who is the Beneficiary?

Attorneys often speak in terms of a person's designated "position." Thus, we use the terms grantor, parent, ward, guardian, plaintiff, defendant, trustee, beneficiary, etc. We need to know someone's position to give appropriate advice.

This economical use of language creates the risk of missing individual characteristics when dealing with trust beneficiaries. At some point, it is helpful to engineer a more complete assessment of who this person—the *trust beneficiary*—is in order to properly draft a trust that maximizes opportunities and minimizes risks.

First, use **PEOPLE FIRST** language consistently, starting our analysis with extra **respect** for individuals who navigate life with extra challenges.

*For example*, use the term "a person with disabilities" and not "a disabled person." Or use the term "individuals with mental illness" rather than "the mentally ill."

Second, start with a **focus** on the **individual** by asking questions such as:

- ◆ Where does she live?
- ◆ Where does she want to live?
- ◆ What are the activities in her life from day to day?
- ◆ What are her immediate objectives,

goals, and wishes?

- ◆ What public benefits is she receiving?
- ◆ Are there other benefits that the individual could be receiving?
- ◆ If the individual is age 22 or younger, is she in public school receiving adequate special education services?
- ◆ What does the individual need or want for the future that she is not receiving?
- ◆ What are the requirements of each of the programs from which the individual

receives benefits? What could cause the individual to lose these benefits?

- ◆ What are the requirements of the programs that could provide the individual with more of the benefits that she needs, but for which she does not yet qualify?
- ◆ What are the other family circumstances, i.e., what are their funds, needs, income, earning capacity, and support networks?
- ◆ How does the key person's type of disability affect distribution planning?

### III. In the Beginning: *Do It Now*

Logically, a trust distribution plan should precede drafting a trust, just as an architect's house design should precede building a house. If an attorney does not know the basics of the distribution plan, we cannot make a determination as to the necessity of reliance on public benefits.

**A. Maximize Value and Avoid the Second Train Wreck.** When there is a litigation settlement, it may be important to create the distribution plan even before funds are allocated between purchases, structures, cash, and trust funds.

The beneficiary's circumstances will impact how much should be allocated (1) to purchase exempt assets before the trust is funded, (2) to purchase an annuity that will pay into the trust, and (3) to fund the trust with cash.

Furthermore, in settlement cases, the ideal time to create the trust distribution plan is before final apportionment of damages between the parties. While the objective is not to change the reality of how damages should be apportioned, a distribution plan may prevent exhausted caregiving parents from urging the attorneys to apportion more to the child, not realizing that such apportionment may create permanent problems for their abilities to provide their child with the best possible care.

Only with a distribution plan in front of all parties can such parties predict some of the future opportunities and costs of various settlement options and hence distribution options.

When advance planning does not take place, there is often a great deal of waste in settlements. Worse, sometimes beneficiaries are put on course for a predictable second train wreck. When good, experienced, and committed planners are brought into a case

early, there is the possibility of having a trust distribution plan that is closer to optimal. Like going over the car rental return one-way spikes, once a settlement has gone too far, the beneficiary may have lost the very best planning options and henceforth trust distribution options are more limited and more costly.<sup>3</sup>

**B. Obstacles to an Early Start.** In litigation settlement SNT planning, often the biggest obstacle to an early start is the lack of decision-maker awareness of the intricate planning considerations involved with disabilities, benefits, and care—until it is too late.

Courts are reluctant to permit attorneys to charge for analysis of a case when they believe that obtaining an SNT for a few thousand dollars will be adequate.

Meanwhile, in many of these cases, taking the needed steps may indeed take only a few hours whereas deciding which steps to take to maximize long-term benefits and minimize long-term risks could require from ten to a hundred hours or more. It is the search for, and analysis of, the options that takes the most time. In fact, the more we know, the longer it may take, because there will be more opportunities that we recognize and work to incorporate into the planning.

**C. Drawbacks of a Late Start.** Courts often take the position that the trustee will prepare the distribution plan after the trust is funded. Here are some of the reasons why trustees may not create an optimal trust distribution plan when there is no advance planning by an outside professional:

(1) Apportionment and allocation opportunities may be past, leaving the trustee with more limited options.

(2) It is very time-intensive and sometimes requires more hyper-technical expertise of public benefits than a trustee will be able to acquire while managing numerous other tasks for many trusts. For example, benefits received by other family members may also be at risk and need to be factored into the plan.

(3) Beneficiaries will not request this service (because this is their first time down this path) and may actually become upset with the trustee doing anything other than writing checks for the items they have requested.

(4) Trustees are generally paid as a percentage of principal—not an overriding concern, but a factor to consider.

(5) Further, if the trustee does not make many distributions, the trustee reduces the risk of making inappropriate distributions and having the wrath of multiple parties fall down on them. Therefore, good trustees are often cautious about making too many

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<sup>3</sup> **NOTE:** Watch out for the restrictions set out in *Roberts v. Williamson* (Tex. 2003) 111 S.W.3d 113, 2003 Tex. LEXIS 110, 46 Tex. Sup. J. 944.

distributions and are arguably more likely to under-distribute, thus arguably missing opportunities to benefit the beneficiary.

A proposed trust distribution plan gives trustees an intensive overview of the beneficiary's circumstances, guidance on the public benefits impact from various distributions, and key considerations at certain milestones for the beneficiary.

#### **IV. Profile the Public Benefits**

**A. Public Benefits Basics.** There are many different types of public benefits programs. Social Security Disability Insurance (SSDI) brings Medicare. Supplemental Security Income (SSI) often brings Medicaid. SSD, SSI, Medicare, and Medicaid are often referred to as “The Big Four.”

There are many more programs as well, such as those available through Medicaid waiver programs, county services, state mental health and intellectual disability programs, university medical centers, and the VA. To create the most useful public benefits profile for a person with disabilities—to make the most of an opportunity to maximize benefits for an individual who has no margin for error—a profile of possible benefits may be created by a planner who has extensive knowledge of public benefits programs. The planner should be intimately familiar with federal programs and rules, state programs and rules, and local and regional programs and rules. The planner should have enough in-depth experience to know where program rules are applied consistently and where they are applied less consistently, so that randomness in eligibility determinations can be used to a client's benefit.

In general, most means-tested programs have requirements in the following categories, with the numbers and tests varying among the various programs:

1. Income
2. Resources
3. Transfers
4. Medical Necessity or Disability<sup>4</sup>
5. Status

Further requirements may include, for example, availability of a Medicaid bed or waiver “slot.”

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<sup>4</sup> **NOTE:** There is often confusion between the countable income test and the Social Security Administration (SSA) disability test. The SSA disability test for non-minors is based on a quantitative test – the ability to engage in “Substantial Gainful Activity” (SGA). In 2020, the standard SGA amount is \$1,260 for individuals who are not blind, and \$2,110 for individuals who are blind.

As an illustration, this is a chart of some commonly used public benefits programs. The planner needs a thorough knowledge of key public benefits programs in her State to maximize opportunities and minimize risks for the trust beneficiary.

<b>BENEFIT</b>	<b>ELIGIBILITY</b>	<b>CASH PAYMENTS</b>	<b>MEDICAL SERVICES</b>
SSI	Low Income + Low Resources + Disability	Yes	No—but SSI is gateway to Medicaid in many states
SSDI	Earned based on work history+ Disability	Yes	No—but SSD is gateway to Medicare (usually 29 months after onset of disability)
Medicaid	SSI-linked Medicaid: In many states, Medicaid eligibility for individuals with disabilities who live in the community is linked to SSI eligibility	No	Yes—Medicaid covers medical services + medications
	Long-Term Care Medicaid: Low income + Low resources + Medical necessity	No	Yes—Long-term care Medicaid covers nursing home costs + Medical services + Medications
	Waiver Medicaid: programs differ	No	Yes—Covers many services
Medicare	Eligibility linked to SSD	No	Yes—Medicare covers medical services
County Services	Eligibility criteria varies; usually means-tested	Not Usually	Yes—scope and range varies
State Mental Health and Intellectual Disability Services	Eligibility is often based on medical need with financial liability assessed separately and later	No	Yes—care and some medical services
VA	Various service-related criteria	Yes	Yes—can be a very broad range of coverage

**B. Age-Based Factors.** The trustee may be able to reduce future trust distributions by avoiding costly mistakes with public benefits and by helping the trust beneficiary access more available resources, considering some of special age-based factors.

**(1) Individual Meets SSA Definition of “Disabled” and Is Under Age 22.** When a beneficiary is under 22, focus on the family’s needs and resources, special education services, and upcoming transitions in the individual’s life. Key considerations include:

(a) Parent Has Private Health Insurance. If a parent has work-related health insurance, a significant planning factor may be to make distributions that will help the parent maintain private health insurance by keeping his or her job.

(b) SSI, Medicaid, and Deeming. Consider whether a child can qualify for SSI and/or Medicaid despite living at home with working parents. Some waiver programs do not apply a means test for parents, and often there is less of a parent’s income countable to the child under the deeming rules than one might expect.

(c) Early Intervention Services. Trust distributions directed toward finding specialized services for infants with disabilities as early as possible may reduce future costs.

(d) Special Education. For children under age 22, special education services will generally be critical. Such services are sometimes referred to as the *only guaranteed public benefits* for all children with disabilities because these services are not means tested. Special education programs will sometimes cover the costs of residential care if that is the only setting where a child can learn. **NOTE:** Trust distributions to hire individuals who serve as advocates or guides to assist families in navigating through the special education programs may reduce other care and therapy costs.

(e) Transition at Age 18: Guardianship and/or SSI Eligibility. If a guardianship will be necessary, plan in advance for this step at age 18. If an individual was ineligible for SSI prior to age 18 due to deeming of a parent’s income and/or resources, then, at age 18, she may become eligible for SSI and/or Medicaid as her own economic unit. Trust distributions can be valuable when directed toward creating a plan to avoid (when possible) the 1/3 reduction to the SSI payment which often occurs unnecessarily when an SSI recipient lives in the household of another.

A successful plan to obtain the full SSI monthly check to which the individual may be entitled (which may add several hundred dollars per month to the budget for decades to come) could include loans, a guardianship of the estate (sometimes only briefly), and rental or pro rata share expense sharing agreements.<sup>5</sup> If a parent has credible health

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<sup>5</sup> As stated earlier, the client will benefit from using a planner who has extensive knowledge of public benefits to undertake this type of planning. Because there are many steps to analyze, it is easy to make mistakes, and missteps are costly.

insurance coverage, a beneficiary could be better served by maintaining the coverage under a parent's health plan and delaying or forgoing SSI and Medicaid.

**NOTE: A vastly superior alternative for avoiding SSI reductions now exists as well—ABLE Accounts.** By planning to establish and fund an ABLE account, and using ABLE account distributions for food and shelter expenses, SSI beneficiaries may avoid any reduction in SSI benefits, as the ABLE distributions can be made for food and shelter without creating countable income for the SSI income tests.

(f) Transition at Age 22: Special Education Ends; Chaos Can Begin. Families are often surprised by the difficult transition at age 22. For some, the end of special education services has been described as much like falling into a complete void or total chaos. Special education transition programs are rarely adequate for bridging the gap between public special education services and private employment. Private services can be very cost-effective in planning for a job *that begins immediately* at age 22.

(g) Critical Years for Employment and/or Independence Options: Ages 22 – 25. These critical years are often wasted when individuals with disabilities and their advocates rely upon publicly funded transition or rehabilitation services. By the time the individual and advocates realize that publicly funded services are inadequate and that their expectations for such services have been unrealistic, they are exhausted and demoralized. *Critical years for establishing a work pattern will have been wasted.* Alternatively, trust distributions could be used to pay for private job coaches, which may help a beneficiary establish a work pattern that will reduce future costs and, more importantly, promote the trust beneficiary's well-being. It is likely wise to budget for distributions directed toward *doing whatever it takes* to help the beneficiary establish a work pattern during these critical years.

**(2) Individual Meets the SSA Definition of “Disabled” and Is Over Age 22.** Trust distributions made to map out likely changes to benefits resulting from predictable life events could help the beneficiary or trustee steer around costly surprises and continue to search for more resources when the resources are needed.

(a) Individual Meets “Disabled” Definition While Under Age 22. When the individual is age 22 or over, it is important to know whether the person met the definition of “disabled” before or after turning 22. If the individual met the definition of “disabled” when under 22, then there is a possibility of receiving Social Security benefits at the retirement, disability, or death of a parent. These benefits are referred to as CDB, Childhood Disability Benefits, formerly referred to as Disabled Adult Child (DAC) benefits.

However, the right to receive SSD benefits based on the work record of a parent can be **lost** if the person with disabilities marries or works for an extended period of time. (These are among the *No Good Deed Goes Unpunished* rules; **note also, however**, that there may be exceptions to the loss of benefits upon marriage when one individual receiving CDB marries another individual receiving CDB, and CDB status that has been lost due to one's work history may possibly be reinstated if earnings decline below the SGA level.)

There is also the possibility of receiving SSD benefits on the history of certain other persons (grandparents, spouses).

A common problem occurs when an individual receives SSI after turning 18, and the individual and advocates stabilize the individual's life around SSI and Medicaid benefits, but then are suddenly shocked to lose SSI and Medicaid due to a CDB/DAC triggering event (death, disability, or retirement of a qualifying person). It is important to track whether (and when) SSI and Medicaid benefits may be lost by the sudden receipt of CDB or other benefits—and whether the loss of such benefits can be avoided or regained.

(b) Individual Meets the “Disabled” Definition after Turning Age 22. It is likely that the individual will not lose SSI benefits due to receipt of CDB/DAC benefits, as described in the prior paragraph, but other risks to benefits still apply, as described below.

(c) Potential Risks to Benefits Throughout the Individual's Lifetime. Due to the income and resources tests, combined with deeming rules, certain changes in one's life may have a significant impact on benefits. Life events that may impact benefits include: (i) employment, which will cause changes in *current income* as well as in work credits that may result in changes in *future income* and which, further, can result in a determination that the individual does not meet the definition of “disabled,” (ii) gifts and inheritances, which can result in excess income and/or excess resources, (iii) marriage, due to deemed income, deemed resources, and possible loss of the definition of “disabled,” (iv) divorce, due to changes to income and resources, (v) having children, due to changes in income calculations and additions to the family's public benefits programs, along with new layers of complex program rules, (vi) changes in household, due to changes in income and expense calculations along with changes in living arrangements, and (vii) changes in the lives of key individuals, such as parents, where payments result from a key individual's death, disability, or retirement.

Trust distributions made to map out the impact of possible changes in circumstances and/or benefits may help avoid some unnecessary costs or losses in benefits. Such mapping is a time-consuming process but can often produce substantial benefits for the individual with disabilities throughout the future by increasing resources and decreasing expenses.

**C. Employment Impact.** For many individuals with disabilities, employment is the best possible therapy. But for many who are seeking employment, there are not appropriate jobs available. One could argue that some of the employment programs that do exist are out of touch with reality, expecting far too much of **employers**, which may result in failed work attempts. Distributions for private job coaches—even when there are public programs providing parallel services—can be very cost-effective.

Employment can also produce unfair and negative impacts (such as the loss of SSI and even SSD) and thus it is important to monitor work credits (or to pay a care coordinator or other professional to do this).

When promoting employment, watch especially for (1) earned income that creates sufficient countable income to result in the loss of SSI and/or Medicaid, (2) increases in Social Security work credits which will result in higher SSD checks and hence can cause the loss of SSI and Medicaid, (3) earnings that do not cause the loss of SSI and Medicaid due to the *countable income* test, but that cause the loss of benefits because the individual is re-classified as “not disabled” due to having income above the SGA level (see Section IV.A., above), and (4) work credits and benefits including impairment-related work expenses, the PASS plan, and trial work periods; the SSA.gov website is a remarkable source of assistance.

**D. Deeming and Other Family Connections.** In cases where the individual who needs public benefits is a minor and where parents have resources and income, there is a significant chance that the individual will not qualify for means-tested benefits— but eligibility should be reviewed carefully.<sup>6</sup>

Litigation Settlements. In personal injury settlement cases, it will often be helpful to carefully consider the apportionment of the award or settlement before the final order. Many times, a larger apportionment to the parents—*where this is possible and appropriate*—can be used to enhance future care for the individual with disabilities. This is only true, however, where careful planning for the parents takes place immediately *and where the parents are devoted caregiver parents who can be depended on throughout a long, difficult future.*

In many cases, by the time a settlement arrives, the good caregiver parents are exhausted and have high debts from coordinating care for 168 hours a week, working, and taking care of other family members. If there is no up-front apportionment of the settlement to the parents, then all too often the parents will need to work harder or longer in order to pay off debts and pay current expenses. This takes time away from the child with disabilities and often causes serious health problems for the parents.

To understand the problem when parents have limited resources and high bills, consider that income paid to the parent(s) as caregiver(s) will be taxable to them as well as being deemed to the child. The better approach, where this is possible, is to project family expenses in advance and to try to reduce ongoing expenses through (1) upfront allocations (i.e., long-term auto warranty rather than ongoing repair bills, paying off debts vs. making monthly payments forever), and (2) direct payments by the trustee throughout the future (i.e., having the trust pay health insurance for the parents as caregivers directly so that they do not pay those costs with after-tax dollars).

If the trustee makes as many distributions as possible to benefit the primary beneficiary, even when others in the family may benefit as well, it may be possible for the parents to

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<sup>6</sup> For deeming rules and calculations see (i) the Social Security Program Operations Manual System, SI 01320.500, Deeming of Income from Ineligible Parent(s), located at <https://secure.ssa.gov/apps10/poms.nsf/lnx/0501320500>, (ii) the Social Security Act, Section 1614(f)(2)(A), and (iii) federal regulations at 20 C.F.R. 416.1165.

earn less, still pay necessary bills, meet their legal duty of support, and have more valuable time with the child who is the trust beneficiary.

Deeming rules may also apply between spouses and in certain other situations. For some public benefits programs, household income and resources may be subject to means testing.

Note that there are no “standard rules” here other than to take an attorney’s vast knowledge of the public benefits and trust rules and apply that knowledge to the individual circumstances, often on a line-by-line analysis of the trust beneficiary’s costs, opportunities, and resources.

More collaborative relationships with trustees and public benefits/trust attorneys will often create better outcomes for individuals with disabilities who are trust beneficiaries.

## **V. Understand the Key Person’s Disability**

Trust distributions may be needed for medical care, support, and/or quality of life. Basic support includes food and shelter. Quality of life includes choices in food, housing, personal assistance, transportation, care, employment, and social interaction. The type of disability may impact the distributions that will be needed and/or desired.

A trust beneficiary with a rare chromosome difference will have much different needs, abilities, goals, and life choices than an individual with Alzheimer’s disease. It is important to evaluate factors such as special education, job training and placement, personal assistance needs, and residential care programs to determine the best care plan based on each beneficiary’s particular needs and choices.

This inquiry will require the participation of—or leadership of—the beneficiary herself, a close family member, or a care manager. The goal is to evaluate the beneficiary’s current needs, desires, and circumstances as well as to consider her probable future abilities, needs, hopes, goals, and preferences.

## **VI. Inventory the Resources and/or the Challenges: *People, Paper, and Money***

Creating a sustainable trust distribution plan depends on three key components: People, Paper, and Money. Each of these elements is like a leg on a three- legged stool. Where any one component is weak, the other two must bear more weight and possibly cannot sustain desirable long-term care without great pressure on trust distributions.

**A. The People.** A common flaw in planning is having unrealistic expectations of what family members, advocates, caregivers, and the other people will be able to do. *Effective trust distribution planning* will place a more realistic reliance on the people involved since people who serve as advocates and assistants are often an irreplaceable resource. Consider the following:

(1) **The Individual with Disabilities.** What is the individual's temperament and approach? What are her goals and objectives? How much does the individual want to do for herself? Is the individual willing and able to take personal responsibility for matters that are possibly under her own control?<sup>7</sup> A collaborative relationship between the beneficiary and trustee will save the trust money, whereas relationships in which one or more parties are difficult may require more distributions in order to stabilize services.

(2) **Family.** Is the individual married? Divorced? Does she have children? If the trust beneficiary is a child, is the family intact, stable, and helpful or is the family fragmented and unstable? Does the family have resources to promote future security for the child or do they expect the trust to support them? Strong families add to the resources pool, while difficult families drain resources.

(3) **Advocates.** Does the individual have strong advocates who will work to ensure that the individual's rights and benefits are protected? Are these advocates who will actually assist with the logistics (obtaining information from agencies, waiting in line, running errands, making copies, and whatever else is needed)? Hard-working and collaborative advocates will reduce pressure on trust funds, since more work could possibly be accomplished with fewer trust distributions.

(4) **Care and Medical Providers.** Who is on the treatment team? Does the individual have a cohesive team? Is more care needed? Are different providers needed? Who coordinates and monitors the services of these providers? An experienced and effective care coordinator will almost always protect or enhance the resources available to the individual, reducing pressure on other trust distributions.

(5) **Vendors.** Does the individual have vendors who will meet some or many of the individual's needs in a manner that is cost-effective, timely, and convenient for the individual? Are the basics of living (buying food, paying bills, getting to doctor's appointments) covered or in constant crisis? If vendors consistently provide cost-effective goods and services, fewer distributions may be required.

(6) **Benefactors.** Does the individual have benefactors who will provide additional funding for services? Use trust distributions to make certain these resources are not wasted; a third-party trust or third-party pooled trust sub-account could be established to discourage wasted funds (such as direct inheritances).

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<sup>7</sup> Addressing personal responsibility is difficult and it often feels as if we are being disrespectful of the individual with disabilities. But, according to Austin-based care coordinator Leah Cohen, LMSW-ACP, ACSW, programs of care will be more valuable when the subject of personal responsibility is addressed. Ms. Cohen states that in order to develop a care program that is likely to be successful over time, it is imperative that she understand the individual's choices and goals, and whether such choices and goals are either congruent or incongruent with the actual resources available. As difficult as that assessment may be, Ms. Cohen points out that in many cases a care plan will not be successful for long without an assessment and a plan that incorporates personal responsibility.

(7) **Landlords.** Is the individual in a desirable living situation? Is the individual concerned about the security (or lack of security)? A stable housing situation may save money, while a situation with problems may result in increased costs.

(8) **Employers.** If employed, is the individual in a safe and comfortable employment situation? Is the employer a positive or neutral factor? Is the employer approachable to discuss improvements in the individual's work situation? Where there are ample funds, consider helping someone start a business—make employment for the individual a key priority. In many situations, it will be cost-effective to budget distributions for job coaches anywhere from one to 40 hours per week to help the individual maintain the job.

**B. The Paper: Planning.** A primary goal in planning—when creating those all-important paper documents—is to create plans and draft documents that help both the financial resources and the people resources last longer and accomplish more. While the attorney must have strong technical proficiency in this field, especially with respect to SNT drafting and public benefits eligibility, in order to promote a client's goals, the attorney must also be adept at locating persons, goods, and services in the individual's local area.

**C. The Money.** It is important to determine and access all sources of funds. It is, again, imperative to have a great deal of technical expertise and experience in this field in order to recognize and to tap into as many financial resources as possible. The individual with disabilities and her advisors will want to increase as many income sources as possible, and decrease as many expenses as possible, as much as possible. Even with technical expertise and experience in this field, the attorney needs time to determine options analyze options if the attorney is to help clients maximize opportunities.

The most effective deployment of resources can only be achieved if one has a distribution plan that has examined current income sources, possible income sources, and expenses—in a line-by-line analysis. Consider settlement funds, allocation opportunities, and special purchases along with the individual's own funds, family resources, retirement funds, real property, gifts from other benefactors, and all other funding sources that apply (or that could apply) to the individual.

## **VII. Case Studies**

The biggest factor in deciding to forego public benefits is almost always MONEY. If the beneficiary does not have enough money to pay for the most basic of life's necessities, she usually will not have much of a choice but to rely on means-tested public benefits. There was a time, not too long ago, that our firm drafted SNTs for any beneficiary who came to us who had a disability—even when those beneficiaries were not yet receiving public benefits. However, since the enactment of the Affordable Care Act, it is possible for a person with an underlying disability to qualify for private health insurance. If a trust can be funded with enough money to pay for quality health insurance, a beneficiary may be better off foregoing means-tested benefits so that she can also avoid the many restrictions that come along with those benefits. A beneficiary with private health insurance has much more flexibility in how she receives trust distributions and may very

well prefer to spend an amount for monthly premiums to avoid the SSA's sole benefit trust rule.

The legislature, in recent years, has also enacted state statutes that allow beneficiaries or trustees to amend trusts when circumstances change. In Texas, a court can modify, amend, and restate trusts quite simply and for a low cost. When a beneficiary with a disability comes to us today, we use the steps outlined above to determine if it might be the beneficiary's best interest to let the trust pay and forgo public benefits either permanently or temporarily, until certain circumstances change.

By foregoing public benefits, a Trustee may be able to assist with housing and food costs that would ordinarily cause a reduction in public benefits. For a beneficiary capable of managing money, a Trustee could grant the beneficiary more autonomy by providing monthly cash distributions that would cause a reduction in SSI benefits if the beneficiary were receiving such benefits. Depending on the nature of the beneficiary's disability, having this type of flexibility can make the difference between surviving and thriving. When the amount of funds in a trust will more than provide for the beneficiary for her entire life expectancy without relying on public benefits, we often see beneficiaries and trustees make the decision to obtain private health insurance and to let the trust pay, rather than relying on public benefits.

In some cases, now that ABLE accounts are available, beneficiaries may retain more public benefits while having more flexibility and autonomy by covering support expenses from the ABLE account. This is another step in the planning process, and it may take some time to consider how to coordinate an ABLE account with the SNT.

However, some beneficiaries may never qualify for means-tested benefits. In those instances, it would be important to draft an SNT with flexibility, to draft a trigger trust, or to forego an SNT entirely for a trust with a more suitable distribution standard.

If a trust beneficiary has no legal status, she will not qualify for traditional Medicaid benefits. Since 1996, non-emergency Medicaid has generally been limited to citizens or "qualified immigrants." If a trust beneficiary has no legal status, she will not likely qualify for SSI or other means-tested programs. In many border states, it is common to find clients without legal status who are plaintiffs in a personal injury suit. It is often safer for the plaintiff to stay in the United States and risk being deported, than to return to a country without proper health care or without a stable safety net to keep her safe. The beneficiary will not be able to rely on public benefits to provide for on-going healthcare. In such circumstances, a Trustee may still be able to purchase private health insurance through the ACA. The ACA prevents non-lawfully present immigrants from enrolling in coverage through the exchanges.<sup>8</sup> 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. If an attorney knows this information prior to drafting, she could opt for a support trust or a distribution standard that allows for trust funds to be spent on items that would cause ineligibility for SSI.

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<sup>8</sup> See §1312(f)(3) available at <http://housedocs.house.gov/energycommerce/ppacacon.pdf>.

Another reason a beneficiary may not qualify for means-tested public benefits would be if her monthly income is over the income limit for SSI or a similar program. If a Beneficiary is receiving SSDI in an amount greater than the SSI limit, she may not ever be eligible for Medicaid. If a beneficiary is working and earning more than the amount for substantial gainful employment, she may not be receiving SSDI OR SSI. If a beneficiary has a disability that may lead her to qualify for SSI or Medicaid at some future time, it will be important to include trigger language that allows the trustee to pour trust funds into an SNT prior to the beneficiary reaching age 65, but it will make both the beneficiary and the Trustee happy to have flexibility in administering the trust while means-tested benefits are unobtainable.

A young beneficiary may have wonderful health coverage through a parent's employer. That parent, under the ACA, may be able to keep the beneficiary with health coverage through the age of 26 or beyond.<sup>9</sup> The parents' ability to have their adult child with a disability covered under their private health insurance until age 26 (or beyond) is a very important benefit. Most states have laws which allow parents to continue health plan coverage for their adult children with disabilities, even past the point at which a child's eligibility for dependent coverage would normally terminate because of their age. California law, for example, allows coverage to continue if the child can't support herself by work because of "mental retardation or physical handicap" and if the child is "chiefly dependent" on the insured parent for support and maintenance.

States usually require the insured parent to prove to the health plan that their child has a disability and is dependent on them. Some states require this proof within a specific number of days before the child would otherwise "age out." Other states require proof within a specific number of days after the child would otherwise "age out." There may be a further requirement of re-certifying the child's continuing disability. Even if there is a possibility that the beneficiary may need to rely on Medicaid at a future date, it may be in the beneficiary's best interest to have a trust with more flexibility and to modify, reform, or decant the trust into an SNT at some point in the future if Medicaid becomes more important.

In the past, an uninsured adult child with a disability was required to apply for Medicaid benefits, which often required a spend-down of assets and the establishment and funding of a special needs trust to hold the child's assets. Now, however, if the child does not need housing or day program supports and is ineligible for SSI, the special needs planner may advise the parents to defer applying for Medicaid benefits until such time that the child is unable to remain on the parents' health insurance. This determination should be based on the estimated additional premiums (if any) to stay on the parents' policy or whether Medicaid expansion, with no premium and no asset limit, is an option, as

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<sup>9</sup> The Affordable Care Act requires plans and issuers that offer dependent coverage to allow young adults to enroll in or remain enrolled in their parent's health coverage through age twenty-six. Many states and many health insurance providers do not apply maximum dependent ages to dependents with disabilities, so coverage may extend beyond age twenty-six under some policies.

opposed to the cost of establishing a special needs trust and bringing the trust's stringent disbursement restrictions into the beneficiary's day-to-day life.

In many catastrophic injury cases, a beneficiary may have a life expectancy that is greatly reduced. If coupled with a healthy trust funding, beneficiaries may choose to forgo public benefits so as to be able to spend money from the trust without the restrictions and requirements of an SNT. To make this determination, it will be necessary to survey the nature of the beneficiary's disability. Included in that survey should be a thorough cost comparison to the trust both if the beneficiary receives public assistance and if the beneficiary does not.

We have recently had a few cases where a beneficiary is injured later in life and has been supporting others. That beneficiary still has a desire—and sometimes a duty—to support others: spouse, children, etc. If the trust can afford it, a beneficiary may choose to transition off of public benefits so that a trustee can use trust funds to support other family members or to replace support that the beneficiary once provided. In some circumstances, this type of trust is only used until minor children reach adulthood, and then the trust can be transitioned into an SNT prior to the beneficiary's sixty-fifth birthday. By delaying the use of an SNT for several years, the beneficiary has the advantage of continuing support for immediate family, but then transitioning to an SNT when that support terminates so that the trust funds last for the remainder of the beneficiary's lifetime.

If drafting a trust that may provide support or distributions to someone other than the primary beneficiary, there are many other factors to consider that are beyond the scope of this paper. However, before drafting such a trust, an attorney should be familiar with any ways in which tax and family law may impact the trust. As with any public benefits practice, a portion of drafting an appropriate trust includes playing therapist, social worker, and fortune teller. A drafting attorney must be familiar with the family dynamics and must ultimately draft a trust with the worst-case scenario in mind. If everyone around the beneficiary can believe that a spouse may not stick around after the trust is funded, it is the drafting attorney's job to plan for and protect the beneficiary.

## **VIII. What to Do with an SNT When There Are No Public Benefits**

Regularly, we get calls from trustees who have beneficiaries with wonderfully crafted special needs trusts where the beneficiary isn't receiving public benefits—and likely won't for the foreseeable future. The Sections II through VI can be used as a road map for considering what type of trust to draft if trustees and attorneys have the benefit of early involvement. However, most often, trustees and drafting attorneys do not have that benefit. We get calls at the last hour and are expected to draft an appropriate trust with little information and even less time to gather the necessary information. In those cases, we do the very best we can, usually operating conservatively and providing the most protection for public benefits eligibility that we can.

It may be days, weeks, months, or years after a trust is first funded that we truly have the information to fully understand the beneficiary's situation and to be able to make a determination as to the appropriateness of the trust. Trustees can feel constrained by the distribution restrictions in an SNT. Beneficiaries often do not understand the reasons for the restrictions. This leads to tension in the fiduciary relationship that can ultimately lead to a breakdown that costs thousands of dollars for a removal action or other litigation between trustee and beneficiary.

While we cannot go back to pre-funding and re-draft, it does not mean that trustee and beneficiary are destined for failure. Trustees who are looking for solutions to make distributions, may find they have several options.

### **A. Read the Document!**

When in doubt, read the document! To avoid creating countable income for SSI purposes, trusts cannot make distributions for food or shelter. But the language of the document is important. What *isn't* included in the trust document may also be important. Rather than an all-out prohibition against support distributions, many special needs trusts prohibit the trustee from making a distribution that would reduce or eliminate a beneficiary's eligibility for means-tested public benefits when the beneficiary is *otherwise qualified* for or is *actually receiving* such benefits. These trusts may not expressly allow for distributions that are not in compliance with the SSI rules; however, a trustee may find implied authority for such distributions. A trustee may seek a legal opinion from a special needs trust attorney that making distributions for support when a beneficiary is not eligible for or is not receiving public benefits is not a violation of the terms of the trust agreement. Coupled with an affidavit from the beneficiary or guardian for a beneficiary that states she is not eligible for or has declined public benefits may be satisfactory for the trustee.

### **B. Modify, Amend, Restate, or Decant the Trust.**

When a trust document does not allow for deviation from a distribution plan that allows a beneficiary to be eligible for means-tested benefits, a trustee may seek to Modify, Amend, or Restate the trust. Many states have enacted one or more statutes that expressly permit the modification of irrevocable trusts. Although there are many variations among the states, most statutes fall into one of four general categories: (1) decanting statutes, (2) trust merger statutes, (3) consent modification and similar statutes, and (4) nonjudicial settlement agreements and similar statutes.

By using any one of these techniques, a trustee may be able to correct a drafting attorney's mistake. Sometimes, these changes can be done with little time and investment. Other times, it may be costly. However, if the outcome is that a

beneficiary has a trust that more closely aligns with her abilities, goals, and expectations, the cost associated with the amendment is likely worth it.

## **IX. Conclusion**

We all know that public benefits provide some basic benefits. As attorneys and trustees, we are sometimes so quick to protect public benefits eligibility, that we fail to evaluate whether those public benefits are in our clients' best interests. Our clients may never qualify for some means-tested programs. Some clients have the ability to work and a trust that support that goal—even at the expense of eligibility for some programs—may be best. We may have beneficiaries who have adequate health insurance coverage that allows for independence from SSI and Medicaid.

It is the job of the drafting attorney and the trustee to ensure that a distribution plan meets the needs of the beneficiary. When those needs do not involve public benefits, it is best to start early to gather the necessary information and draft a trust that has flexibility. If we do not have the opportunity for a thorough investigation and drafting of a distribution plan prior to funding, though, we still have an opportunity to promote distribution planning. By taking steps to formulate a suitable distribution plan and properly implement it, we are aligning the trust with the beneficiary's best interests.