THE PRACTICAL REALITIES OF LIVING WITH A SNT

Stetson University College of Law

The Center for Excellence in Elder Law

2010 Special Needs Trusts – The National Conference

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Nothing in this paper is to be construed as the rendering of legal advice.

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I. Introduction

The challenges in drafting and administering a Special Needs Trust (hereinafter "SNT") continue to be examined from a legal perspective as trust law evolves, such as with the enactment of the Uniform Trust Code in many states, and regulations pertaining to treatment of SNTs by the Social Security Administration (hereinafter "SSA") and Medicaid change. Many have authored materials regarding the foregoing and presented on the subject. Thus, this author is not going to attempt to add to or elaborate upon what may be considered a more academic discussion on the subject.

The focus instead will be on the practical reality of interpreting the language of both a SNT and peripheral documents, as well as administering the SNT, in such a way that the originator's intent is captured and the beneficiary's quality of life is enhanced. This is not

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always as easy as it sounds and hindsight is indeed twenty-twenty. So, this author has chosen to approach the topic by highlighting issues or raising questions and, by way of concrete example, discussing what appears to work and what arguably does not.

Note, given the wide variance in what is required in terms of the language and administration of self-settled or first party SNTs established pursuant to 42 U.S.C. § 1396p(d)(4), this discussion will not venture into this realm and will instead remain primarily focused on third party or non-grantor SNTs.

II. Drafting the SNT

> "The difference between the almost right word and the right word is really a large matter—it's the difference between the lightning bug and lightning." Mark Twain in a letter to George Bainton, 10/15/1888

A. Describing the Beneficiary and His Needs – General or Specific?

Many SNTs contain a general statement regarding the beneficiary and his disability, more often than not in an introductory provision that sets forth the Trustor or Settlor's intent and/or the purpose of the trust, such as the following:

> "The purpose of this Trust is to provide for the supplemental needs of **JOHN DOE,** who is disabled, and may be eligible for public or private financial assistance . . ."

Other SNTs may elaborate on the individual's disability as follows:

> "**JANE DOE** is disabled due to severe injuries, including a traumatic brain injury, from an accident that occurred on month date, year. Neither the degree of her recovery nor her future earning ability can be predicted at this relatively early point in time. **JANE DOE** is currently eligible for Medicaid and it is likely that in the future she will receive other types of public benefits . . ."

And yet other SNTs may provide even more detail regarding the beneficiary's disability, such as that which may be contained in a Letter of Intent. See discussion below in Section III.A.

When drafting a SNT, the question in this regard is how much information regarding the beneficiary's disability is too little, and how much is too much? The Settlor or Trustor, who more often than not is a parent, has intimate knowledge of the beneficiary's disability. But what about the nominated Trustee who is to succeed the parent? Those closer to the top of the line of succession, such as a sibling, presumably

have intimate knowledge but, mind you, from a different perspective than that of the parent who attended to the daily needs of the beneficiary while living and able.

One must consider who is at the end of the line of succession when describing the beneficiary and his disability or special needs, in most instances, is a Trustee appointed by the Court because no one else named is willing or able to serve. With this in mind, a general statement that the beneficiary is disabled seems inadequate. At a minimum, identifying the beneficiary's diagnosis provides the Trustee with enough information so that he can conduct some level of research to develop a better understanding of the beneficiary's condition and related needs. Too much detail or information regarding the beneficiary and his condition and needs, may raise concerns about confidentiality, and unintentionally constrain or tie the Trustee's hands. This author likes the approach taken with **JANE DOE** above as it highlights the dominant diagnosis and condition, and goes on to state that the beneficiary's future condition is unknown particularly as it relates to certain functions, such as earning potential, without revealing what may be considered confidential or sensitive information. The description sets the tone in terms of providing flexibility in administering the trust as the beneficiary's condition and needs possibly change.

B. Discretionary Language and Providing for Flexibility

The nature of a SNT, that is, its discretionary nature, suggests that language that places limits on or restricts distributions has no place in a SNT. A Settlor or Trustor may be overly fearful that the public benefit programs for which the beneficiary is or may be eligible will treat the trust as an available resource to the beneficiary, thereby disqualifying him from such assistance. Or, the Settlor or Trustor may be concerned with an abuse of discretion if parameters are not set forth in the document. In addition, the Settlor or Trustor may have strong feelings about making distributions for particular purposes. Obviously, the attorney needs to delve deep into the Settlor or Trustor's intentions and concerns. Once the attorney has an understanding of what these are and what lies at the root of them, the attorney can draft the SNT in such a manner that retains the level of discretion necessary to provide for both the anticipated and unanticipated needs of the beneficiary, while at the same time providing for checks and balances.

1. *Restrictive language*

Many SNTs unnecessarily contain some version of the following language out of an abundance of caution and concern that if such language is not contained therein, the trust will be considered an available resource to the beneficiary thereby disqualifying him from public benefits.

> "The trust cannot pay for food or shelter under any circumstances."
>
> OR
>
> "The Trustee may not expend any of the Trust principal or income for any property, services, benefits or medical care otherwise available to **JOHN DOE** from any governmental source or from any private insurance carrier required to cover **JOHN DOE.**"
>
> OR
>
> "The Trustee shall not make distributions that reduce or supplant governmental assistance of any kind."

What is crucial in ensuring that the trust is not considered an available resource to the beneficiary is to not name or nominate the beneficiary himself as trustee, and to limit the beneficiary, not the trustee's, ability to make the trust available for his maintenance and support. In that vein, the following qualifiers to the above language is advisable:

> ". . . unless the Trustee determines, in his or her sole and absolute discretion, that such expenditure would be in **JOHN DOE's** best interest."
>
> AND
>
> "The beneficiary has no ability to . . . direct the use of the Trust assets for his own support and maintenance."

Case in point is that of a SNT beneficiary who suffers from a mental illness, but no physical impairment. The SNT beneficiary's mental illness prevents her from being able to work and, thus, she is eligible for and receiving Supplemental Security Income (hereinafter "SSI") benefits at the federal maximum benefit rate, which is currently $674 per month. As a result of being eligible for SSI benefits, the SNT beneficiary is also eligible for Medicaid, which provides for the cost of her psychotropic medications and occasional inpatient

behavorial health treatment. This SNT beneficiary barely gets by on her SSI benefits and the SNT could substantially improve the beneficiary's quality of life by providing for the beneficiary's shelter expenses. This would result in a reduction of the beneficiary's SSI benefits of 1/3rd of her SSI benefit, but allow the beneficiary to expend her SSI benefits on things other than shelter, which is her most substantial expense. Unfortunately, the language of the SNT expressly disallows such distributions and the Trusee's hands are tied. Aside from providing for non-covered medical expenses, such as dental and vision, and providing for the beneficiary's clothing needs, the trust is able to do little else in terms of enhancing the beneficiary's quality of life.

Trustees are also often challenged by language limiting their ability to invest in certain assets, monetary limits or caps on distribution amounts, and/or prohibition from distributing trust funds to purchase or acquire certain assets. Rather than contain specific parameters or limits in the SNT, this author suggests a system of checks and balances that involves reporting or accountability to a third party other than the Trustee, such as a Trust Protector or other fiduciary, which is further discussed below in this Section. The following language alone should ameliorate any concerns related to abuse of discretion and excess or inappropriate distributions:

> "On an annual basis, the Trustee and Trust Protector shall develop an annual budget. The Trustee acting hereunder shall not make any distributions of income or principal in excess of such budget, and shall not make any single distribution in excess of $10,000.00, if not contemplated or included in such budget, except at the direction of, or with the approval of the Trust Protector."

Note, if no Trust Protector is contemplated then a Guardian, named family member, or other fiduciary or legal representative could just as easily be named and provide the desired checks and balances.

2. *Ability to Amend or Revoke*

Even with the best of drafting, no one has a crystal ball and only one thing is certain: Circumstances change and the rule of the various public benefit programs is constantly in flux. A SNT must be flexible, and that dictates the

inclusion of language that permits the tweaking of its language. This can be accomplished without putting the tax status or the beneficiary's eligibility for public benefits at risk. Clearly, the beneficiary can have no hand in the ability to amend or revoke. Arguably, neither should the trustee. However, an independent third party, such as a Trust Protector, Independent Trustee, or Special Trustee, may do so. The following provides options and language in this regard:

> "A special Trustee meeting the requirements of an Independent Trustee, as set forth herein, appointed by the then acting Trustee, may amend the Trust to carry out the intention of the parties hereto in the event that the law or regulations concerning needs-based public benefits or benefit programs change hereafter.
>
> Independent Trustee, including a Corporate Trustee, if used herein, shall mean a Trustee who is neither of the following:
>
> **(1)** A Beneficiary of any trust established under this document;
> **(2)** A person who has transferred or joined in the transfer of property to such Trust; nor
> **(3)** A related or subordinate party to any person described in numbers 1 and 2 above.
>
> If a general power of appointment held by a Beneficiary of a trust may only be exercised with the written consent of an Independent Trustee, the term "Independent Trustee" also means a person who does not have a substantial interest in the property subject to the power which is adverse to the exercise of the power in favor of the Beneficiary, his estate, his creditors, or the creditors of his estate."
>
> OR
>
> "The Trust Protector shall have the authority to amend the Trust to conform with later changes, interpretations, or state variations in federal or state law involving public benefits to better effect the purposes of the Trust."

Even in the worst case scenario, an out or remedy exists. So, in the event the language in the SNT and the reality of the beneficiary are incompatible, and the SNT does not provide for the limited ability to amend the SNT, the Trustee may have one or two options. In those states that have enacted the Uniform Trust Code, the Trustee may have the ability to "decant" the existing SNT to a new SNT without court intervention. Alternatively, the Trustee could apply to the court to modify or reform the SNT based on, hopefully, what is known to be the intent of the Settlor or Trustor.

C. Providing for Eventualities – A Prime Example: The Home

The penultimate drafter will attempt to provide for most, if not all, eventualities, such as successor trustees and what if none is named, to whom the trustee must report or be accountable in the case of a mentally incapacitated beneficiary, who is to provide for the care of the beneficiary when the family caregiver is no longer able to do so himself, etc. However, one specific area that is often lacking in foresight in SNT drafting is the disposition of the home, which is often times the home of the Settlor or Trustor and has also served as the home of the beneficiary during the Settlor or Trustor's lifetime. This author is of the opinion that in the case of most third party or non-grantor SNTs, title to the home should remain in trust so as to provide for its protection and distribution to ultimate beneficiaries.

That being said, the question that is often not realistically examined in the drafting context is whether it is realistic for the beneficiary to continue to live and be cared for in the home on the death of the Settlor or Trustor, who is typically the beneficiary's primary caregiver, i.e., the parent. Examining what is realistic in this regard begins with an honest assessment of whether the beneficiary can live in the home independently or whether he requires substantial caregiver support, and then a projection of the cost associated not only with maintaining the home but the necessary support structure to enable the beneficiary to continue to reside there.

A Trustor or Settlor with limited ability to fund the SNT aside from the home and whose beneficiary requires 24-hour care and supervision, may not be able to do as he or she wishes or intends with respect to enabling the beneficiary to reside in the home. One option may be to work with appropriate state programs, such as those that provide services to individuals with developmental disabilities, to structure a situation where the trust retains title to the home (or rather, the trust has an interest in a limited liability company that holds title to the home) and provides room and board to several residents, including the beneficiary, who are comparable in age and disability. In exchange, the residents would pay the trust room and board, presumably from their respective Social Security benefits, and the state would provide the necessary care and habilitation in the home via a waiver program through Medicaid. If this is an option, and the only way in which the home can be retained for the benefit of the beneficiary, then this should be set

forth in the SNT. The circumstances pursuant to which such a structure cannot be formed or maintained should be clearly identified, thereby permitting the trustee to opt out of this endeavor. Licensing or regulation requirements, liability issues or concerns, budget cuts or service reductions in Medicaid waiver programs, as well as the time and cost associated with forming such a structure are all factors that the Trustee should be able to consider and rely upon in exercising his discretion as to this option.

What is more often the norm is a beneficiary whose ability to live independently is in question, but who clearly does not require 24-hour care and supervision, and the beneficiary for whom a potential caregiver has been identified who would enable the beneficiary to continue to reside in his home. In the former instance, a mechanism by which to independently assess or determine the beneficiary's ability to live independently needs to be set forth in the SNT. For example, see the following in the case of a beneficiary who suffers from mental illness:

> "**JOHN DOE's** ability to continue to live independently shall be determined by the majority of a psychiatrist, the Trust Protector, and his Guardian. Should Co-Guardians be appointed, they shall share a single vote as to the foregoing. In the event it is determined that **JOHN DOE** can no longer live independently in the subject real property, such property shall be sold and the proceeds held in trust for the benefit of **JOHN DOE** as set forth herein."

In the latter instance, it is assumed or clear that the beneficiary cannot live independently and, whether the beneficiary may be able to continue to reside at home may be contingent on a particular caregiver, such as is the case with the following:

> "Because **JOHN DOE** is disabled and unable to maintain and support himself independently, he needs someone to help him with his Activities of Daily Living ("ADLs") and to provide for his general care and supervision (hereinafter referred to as a "Caregiver"). I hereby nominate **ADAM SMITH** to be **JOHN DOE's** Caregiver, upon my death. Upon acceptance, **ADAM SMITH** may move into the real property located at address or any other property I own at the time of my death that serves as **JOHN DOE's** primary residence, with **JOHN DOE**, and assist **JOHN DOE** with his ADLs and provide for his general care and supervision as I did while I was alive and not incapacitated, and as may be further described by me in a separate writing which I incorporate herein by reference. . . . In the event **ADAM SMITH** is unwilling, unable, or ceases to act as **JOHN DOE's** Caregiver before **JOHN DOE's** death, I direct **JOHN DOE's** Guardian to make proper provisions for **JOHN DOE** to live at designated care home, located at address."

Or, it may be dependent on not only whether a caregiver exists, but to what extent such arrangement is funded by public assistance.

> "**JANE DOE** shall have the right to occupy the Property, for so long as she desires and is able to do so. **Jane's** special needs require constant supervision and assistance; therefore, if it is **Jane's** desire to occupy the Property, her Guardian, or such other person selected by her Guardian to care for **Jane**, shall also have the right to occupy the Property with her, free of rent, while caring for **Jane**. In the event **Jane** no longer wishes to reside in or no longer occupies such Property, or it is determined that she can no longer occupy such Property for whatever reason, the Property shall be sold and the proceeds from the sale be made payable to the trustee of "**The Jane Doe Discretionary Supplemental Care Trust,**" and deposited to such trust. If **Jane** is not occupying said Property for whatever reason, it is Trustor's desire to hold the Property for at least two (2) years before listing the Property for sale in the event **Jane's** circumstances change within such time, and **Jane**, or her legal Guardian, decide to again reside in such Property. While the Property is not being occupied by **Jane,** the Trustee may rent the Property to offset the expense to the Trust; however, the Trustee is not required to do so."

If the beneficiary is to have the "right to occupy" real property, then watch out for standard trust language or provisions that may wreak havoc in administering the trust in this regard, such as the following:

> "Trust assets consisting of residential real estate may be occupied by a beneficiary as part of his or her current benefits to which he or she might be entitled; provided that, during the legal or mental capacity of the beneficiary, and until such time as the real property is distributed free and clear of trust to the beneficiary, the beneficiary shall have responsibility for and the Trustee shall have no responsibility for taxes, assessments, insurance coverage, maintenance and general running and upkeep of the property or the payment of any of these costs and expenses and the Trustee is relieved from liability for losses resulting from failure of the beneficiary to meet his or her responsibility."

A beneficiary who is disabled and eligible for needs-based public benefits presumably has limited financial means to maintain the home in which he or she lives. It is not practical to make him or her primarily responsible for maintaining the home, and likely not the intent of the Trustor or Settlor. Therefore, language such as the above should be removed or expressly made inapplicable to the beneficiary who is disabled.

D. <u>The Players</u>

The idiom "too many cooks in the kitchen" holds true and applies in many contexts, including that of SNT administration. However, in the SNT context, not enough cooks can prove just as harmful. Picture this: On the one hand, a non-family member trustee, maybe a corporate trustee or professional fiduciary who is new on the scene and has no personal knowledge of or experience with the beneficiary, with little to guide the trustee but the trust document itself. On the other hand, you have the beneficiary, who is disabled and unable to advocated for himself. He may or may not

have a Guardian whose role in relation to the trust was not contemplated or addressed in the SNT. This picture is not ideal and in this author's humble opinion, there is room for at least one more "cook," so to speak, whose role should be expressly addressed in the SNT (and cross-referenced in other relevant documents) and in relation to that of the Trustee.

1. *Trust Protector*

From a practical standpoint (fiduciary obligations aside), this author views the Trust Protector as the individual who serves as the eyes and ears of the beneficiary, and who keeps the Trustee accountable. A Trustor or Settlor often sees the need to incorporate a Trust Protector in the SNT in the event a non-family member, such as a corporate trustee or professional fiduciary serves as Trustee. In the foregoing instance, the Trust Protector provision can be drafted to become effective only in such event. However, the need for a Trust Protector may not be apparent to a Trustor or Settlor when they have nominated a family member to serve as Trustee until such time as it is pointed out to them that someone other than the Trustee may be serving in multiple roles, such as Guardian and caregiver, which provides for no checks and balances. On the flip side, even when someone other than the Trustee is serving as Guardian, the Trustee may not feel it necessary to involve the Guardian or be of the opinion he or she is accountable to the Guardian unless the Guardian's role in relation to the SNT is formalized. In drafting for whether a Trust Protector is to be appointed and who is to serve in that role, make sure that at no time is the Trustee serving in that dual capacity, or that the Beneficiary is able to appoint himself in such capacity. See the following language:

> "The Guardian of **Jane,** and if someone other than the Trustee, shall serve as Trust Protector. In the event the Guardian is unable to serve, the then acting Conservator, and if someone other than the Trustee, shall serve as Successor Trust Protector. In the event the Trustee is also serving as Guardian and Conservator, the subsequent Successor Trustee named herein shall serve as Trust Protector. In the event no Successor Trustee is named to serve as Trust Protector, then the Guardian shall nominate and appoint a Trust Protector other than himself or herself. Said appointment shall be made by delivering instruments in writing, executed in duplicate, one copy to the Trustor, one copy to the **Jane** or her legal representative, one copy to the Successor Trust Protector, and one copy to the Trustee. In the event

> a Successor Trust Protector has not been named, the Trustee then serving shall apply to the Court to appoint a Successor Trust Protector, preferably a member of the **Jane's** family, or the then acting Guardian; provided that the then acting Guardian is not the then acting Trustee."

So what powers or duties should the Trust Protector have? Those states that have enacted the Uniform Trust Code may have statutory powers to rely upon; however, the SNT itself can and arguably should set forth powers that are tailored to the SNT and its beneficiary. The following are samples of Trust Protector powers that are commonly included in a SNT:

> The authority to amend administrative and technical provisions as well as to amend the Trust to conform with later changes, interpretations, or state variations in federal or state law involving public benefits.
> The authority to remove and replace a Trustee with someone other than the beneficiary or Trust Protector.
> The requirement to develop an annual budget with the Trustee and requiring prior approval of the Trust Protector if distributions in excess of the budget are to be made.
> The requirement that the Trustee consult with the Trust Protector at least annually to determine a general investment policy.
> The authority to resolve conflicts between Co-Trustees and/or the Trustee and beneficiary.
> The ability to determine the appropriateness of accessing insurance or governmental benefits for a beneficiary and the impact of distributions on the beneficiary's eligibility for such assistance.

Additionally, this author recommends including an alternative dispute resolution clause in the SNT to facilitate the resolution of any conflict between the Trustee and Trust Protector. Although, a Trust Protector is likely to remove a Trustee with whom the Trust Protector is in conflict assuming the Trust Protector has the authority to do so.

2. *Other Fiduciaries, such as a Guardian*

In many instances, a beneficiary of a SNT will have a legal Guardian appointed for his person (and/or his estate). The Trustor or Settlor may have nominated the Guardian in his Last Will & Testament. If that is the case, then it is important for the Will and SNT to cross-reference each other where relevant,

and to be consistent and compatible with each other rather than at odds. The Guardian may even be named in the SNT to serve as Trust Protector.

For example, see the following language contained in a SNT which clearly delineates the role of the Guardian as compared to the Trustee, and provides direction to the Trustee in terms of making distributions that facilitate and are in support of the Guardian exercising his duties and powers:

> "Trustor has nominated XYZ as Guardian with the authority to consider and investigate options for the placement of the Trustor's disabled daughter, . . . and the Trustor has requested that the Guardian visit her periodically to monitor her progress and see that her needs are being met. These visits will be required to assist the Trustee in determining what disbursements of the trust to or for the benefit of the Trustor's disabled daughter are necessary or beneficial. The Trustee is further directed to reimburse the Guardian for any costs related to the investigation of placement options, including possible placement with the sister of Trustor, NAME, and/or her family who reside in England, and any costs involved in visiting Trustor's daughter in the event she is required to transitionally live with the Guardian. A monthly payment shall be made to the Guardian that is equivalent to that required at another facility, or for a comparable level of care, in that community."

Checks and balances may be provided for not only insofar as the Trustee is concerned, and ensuring that the Trustee fulfills his duties and responsibilities, but also insofar as the Guardian is concerned. The Settlor or Trustor may give the Trustee and/or Trust Protector authority to remove and replace a Guardian in the Settlor or Trustor's Last Will & Testament.

3. *Care Manager*

What if no Trust Protector is named or provided for in the SNT and no Guardian has been appointed for the Beneficiary? This may suggest that the Beneficiary is mentally capable and able to be his own advocate. That being said, it may be beneficial to both the Trustee and beneficiary to hire a private care manager to monitor the beneficiary's circumstances and needs, and report back to the Trustee with recommendations. This is particularly beneficial in those instances where a non-family member such as corporate trustee or professional fiduciary is serving as Trustee, and has little or no personal knowledge of or experience with the beneficiary. The following provides for such an assessment:

"The Trustee may, but is not required, to arrange for an annual evaluation of **JOHN DOE** addressing his needs and circumstances such as physical condition; educational, residential, vocational and training opportunities; recreational, leisure and social needs; appropriateness of existing programs and services; and the availability of governmental financial assistance and private contractual benefit programs. The Trustee is requested to personally visit **JOHN DOE** at his residence, or retain a private care manager to do so at periodic intervals determined appropriate by the Trustee, to assess **JOHN DOE's** living conditions, and to assess the treatment given to him by caregivers, if applicable. Reasonable compensation and expenses incurred in relation to the annual evaluation and/or the personal visits of Trustee, and/or a private care manager may be charged against the Trust estate."

III. Interplay Between the SNT and "Non-Legal" or Other Than EP Documents

At one time, all a Trustee had to work with was the trust document or agreement itself, and as had been discussed, the trust document or agreement can be very general in terms of describing who the beneficiary is and what his needs are or may be in the future. What were once peripheral documents, such as the letter of intent (hereinafter "LOI") and life care plan (hereinafter "LCP"), are becoming more integral to the overall estate plan as those who establish a SNT for the benefit of a loved one who is disabled, realize that transmittal of the information they have will only increase the odds that the SNT will be administered as they intended, and the Trustee welcomes any and all information that will facilitate ease of administration.

A. The Letter of Intent ("LOI")

When establishing a SNT for a loved one who is disabled, the Settlor or Trustor, who more often than not is the parent, takes for granted the information that he or she has about his or her loved one's condition, needs, and desires. Is this information important to the effective administration of a SNT? Most definitely! It is additional evidence of the Settlor or Trustor's intent, and provides information that minimizes questions regarding the appropriateness of particular distributions, as well as further ensures the beneficiary's needs are being met. Should it be contained in the SNT document or agreement itself? As discussed earlier, concerns with confidentiality may dictate against including the level of detail or sensitive information in the trust document or agreement itself. Moreover, much of the information is not legal in nature, and although it aids the Trustee in

administering the SNT, it does not necessarily belong in the SNT. It belongs somewhere, though, hence the LOI!

The LOI allows a parent to transmit detailed information concerning the care of a child with a disability upon the parent's death. In many instances, the beneficiary, even other family members, are unable to provide meaningful or detailed information regarding the beneficiary's condition, needs, and preferences to those who enter into his life for the first time upon the death of a parent, such as a caregiver, Guardian, Trustee. How helpful is a SNT when it states that which is set forth above in Section II.A, that is, "the purpose of this trust is to provide for the supplemental needs of the beneficiary who is disabled"?

The LOI need not take any particular form. It can be handwritten and in narrative form. Many clients find it helpful to have a form to work with and they are relatively easy to come by.[2] The LOI is not a static but an evolving document. It needs to be updated as the beneficiary ages and his condition changes. To the extent the beneficiary is able to participate in the process of completing and updating the LOI, he should be encouraged to do so.

The following is an outline of the critical information that should be contained in the LOI:

> Personal information of the beneficiary, his parents, involved family members, Guardian, Trustees;
> Contact information of individuals or organizations that provide or coordinate services for the beneficiary;
> Current and future living situation in terms of who the beneficiary lives with, where he lives, and who he would like to assist him;
> General overview of the estate plan, including SNT, Power of Attorney, Guardianship;
> Financial information including cash benefits for which the beneficiary is eligible, as well as the beneficiary's own earnings and assets;
> Medical coverage information, including private health insurance, Medicare, Medicaid;
> Contact information for financial professionals such as financial advisors or planners and accountants;
> Medical and emergency information, including contact information for doctors, dentists, specialists, therapists, psychiatrists, etc.;

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[2] See Appendix 5-3 of the "Special Needs Trusts Handbook" by Thomas D. Begley, Jr. and Angela E. Canellos (Aspen Publishers 2010).

Medical history;
School information;
Employment information;
Personal possessions;
Personal care, such as what the beneficiary can do on his own versus what he requires assistance with, as well as use of personal care items and the beneficiary's personal care routine;
Food and eating, such as abilities, likes and dislikes;
Leisure and recreation, such as favorites activities/places to go and friends to go with, exercise programs or activities;
Special interests/abilities;
Religion;
Family culture and tradition;
Community participation, such as voting, clubs, volunteer activities;
Habits/routines;
Disposition, i.e., the beneficiary's temperament, what may upset him, and how to calm him down or comfort him; and
Communication.

B. The Life Care Plan ("LCP")

If the beneficiary was rendered disabled as a result of someone else's negligence, and a lawsuit ensued as a result, a life care plan may have been developed in that context with the objective of quantifying damages. The LCP can be useful in other contexts as well, particularly that of administering a SNT. What the LCP does is provide a general overview of the medical history of the individual beginning with the time of the incident or accident that rendered the individual disabled, and the anticipated future costs associated with treating and caring for the individual for his lifetime.

A LCP originally developed for the purposes of quantifying damages in a negligence lawsuit may have to be revamped if it is to prove useful to the Trustee of a SNT. A LCP may have been developed by both plaintiff and defendant. Not surprisingly, their respective plans will be at odds in terms of life expectancy, treatment and care needs, and their estimated costs. Because the defendant's life care plan is presumably that of the minimalist, it may be best to rely upon the LCP of the plaintiff. Of course, dollars will drive how much of the plan may be implemented. Another good place to start is to identify the services and products that other sources may cover, such as private insurance, Medicare, Medicaid, state mental health/developmental disability programs or services, and special education, to name a few.

A LCP can be developed outside of the personal injury context and for purposes other than to quantify damages. It can be a costly venture, but where the financial means exist, the Trustor or Settlor should be encouraged to map out his desired or intended plan for the future care of his loved one who is disabled. A LCP can answer what may be a threshold question and that is whether private resources are sufficient to provide for the care and treatment of the beneficiary, or whether future anticipated costs dictate a marriage between private and public resources to ensure that the beneficiary is provided for throughout his lifetime. If a LCP does not exist at the time a Trustee assumes responsibility for administering a SNT, it is never too late to formulate such a plan. The LCP is a more elaborate version of the "annual evaluation" discussed above in Section II.D.3, and serves as a good foundation for future evaluations.

C. Guardianship Orders

This discussion has repeatedly made reference to a Guardian as an individual with whom the Trustee must coordinate efforts in administering a SNT for the benefit of a disabled beneficiary. What has not been discussed and bears mention is that the Guardian, whether of the person or estate, may be subject to certain orders of the court. These orders may impact administration of a SNT for the benefit of an individual who is subject to guardianship. Thus, it is important for the Trustee to have access to and be mindful of relevant court orders. For example, guardianship orders may address whether the beneficiary can own property such as a home or vehicle outright, the beneficiary's living and caregiver arrangements, the role of various fiduciaries and court-appointed legal representatives and how they are to be compensated. Being mindful of relevant court orders is not to say that they should be blindly abided by in contradiction to the terms of a SNT. In such event, the Trustee may need to enter an appearance in the guardianship matter as an interested party, or initiate a trust action to resolve issues concerning administration of a SNT when court orders appear to be at odds with the terms of the SNT and the Settlor or Trustor's intent.

IV. Coordination of Resources

A. Public Benefits

An overview of the various public benefits for which an individual who is disabled may be eligible will not be provided here other than to stress the importance for

the Settlor or Trustor in establishing a SNT, and the Trustee in administering it, to know the benefits for which the SNT beneficiary is or may be eligible, and whether they are based on financial need or not.

To the extent eligibility for public benefits is *not* based on financial need, the SNT is a non-issue insofar as the beneficiary's continued eligibility for such assistance is concerned and can be administered more flexibly. For example, a child who has been disabled since before age 22 and has been eligible for and receiving SSI benefits well into his adulthood, may be eligible for Disabled Adult Child (hereinafter "DAC") benefits upon his parent's death. The DAC benefits typically are of such amount that the adult child is no longer eligible for SSI benefits. Eligibility for SSI benefits is based on financial need whereas eligibility for DAC benefits is not. The existence of the SNT and its distributions become irrelevant insofar as the adult child's eligibility for Social Security benefits (and, later, Medicare coverage) is concerned.

To the extent eligibility for public benefits *is* based on financial need, it is incumbent on the Trustee of the SNT to know the applicable eligibility requirements. Most public benefit programs have an income and resource limit. Some public benefit programs are income-sensitive only and have no resource limit. All public benefit programs have an income limit. With respect to the applicable resource limit, many, if not most public benefit programs, exclude the value of certain resources such as a home and car. With respect to the applicable income limit, all public benefit programs count as income cash distributions to a SNT beneficiary or anyone on behalf of a SNT beneficiary, such as an agent or Guardian. Some public benefit programs count as income vendor payments for food and shelter. Other public benefit programs do not count vendor payments for any purpose as income.

The other reason it is important for a Trustee to know the public benefits for which the beneficiary is or may be eligible is to minimize the trust having to pay for items or expenses that are otherwise provided for unless doing so is in the best interest of the SNT beneficiary. For example, although a beneficiary may be eligible for and receiving SSI benefits of the federal maximum benefit rate, the SSI may be insufficient to provide for the beneficiary's shelter costs. A SNT can make distributions to provide for the beneficiary's shelter costs with the understanding that the SSI benefit will be reduced

accordingly, and, as long as the beneficiary continues to receive at least $1 of SSI, he remains eligible for Medicaid, which is often considered the more valuable benefit.

B. Private Resources

1. *Private health insurance – Health Care Reform*

The enactment of the Affordable Care Act factors into the decision as to whether or not to establish a SNT and, if one is established, how it is administered. Oftentimes, a SNT is primarily established to allow an individual who is disabled to obtain or maintain medical assistance via Medicaid because no other source of coverage exists, and once established, it is administered in such a manner to ensure such eligibility is maintained.

Under the Affordable Care Act, individuals with pre-existing conditions may no longer be excluded from private health insurance coverage in 2014. In the meantime, temporary coverage known as the "Pre-Existing Condition Insurance Plan" is available either in an individual's state of residence or through the federal government if the individual has been denied coverage or premiums are unaffordable due to a pre-existing condition, and the individual has been without insurance for the six (6) months prior to enrollment.[3]

In addition, beginning this fall, insurance companies cannot deny children under the age of nineteen (19) coverage due to a preexisting condition, and individual and group insurance plans are now required to extend dependent coverage to adult children until age 26 if they are ineligible for another employer-sponsored group health plan.

A SNT can certainly pay the cost of any premiums associated with obtaining or maintaining private health insurance, and associated deductibles and co-pays. Private health insurance may afford the Trustee substantially more flexibility in administering a SNT. For example, a SNT may have been established for the purpose of maintaining the beneficiary's eligibility for Medicaid as he has no other medical coverage available. The only way in which

[3] Go to www.healthcare.gov for more information.

the beneficiary has been able to remain eligible for Medicaid was by virtue of the fact that he was eligible for SSI benefits. So, the Trustee was administering the SNT in such a manner so as to ensure the beneficiary remained eligible for SSI benefits. Although the Trustee was making distributions that covered most of the beneficiary's shelter-related costs, the beneficiary was left with nominal funds, i.e., his SSI benefit after a 1/3rd reduction, to provide for his other support needs, namely, food, and discretionary cash. In 2014, when the beneficiary is able to obtain private health insurance without regard for his condition, he can forego the SSI benefits and Medicaid, which will enable the SNT to make more substantial cash distributions to the beneficiary and further enhance his quality of life.

2. *Beneficiary's own resources*

A beneficiary may have resources of his own in addition to having a beneficial interest in a SNT. For example, the beneficiary may own resources that are excluded, such as a home and car, for purposes of his financial eligibility for public benefits, such as SSI and Medicaid. However, he may not have the financial means to maintain those resources. A beneficiary may own a home, which necessarily means he has property taxes and homeowners insurance to pay. And what if the home requires substantial repairs? The Trustee of the SNT can coordinate efforts with the beneficiary or his legal representative so as to minimize any potential impact on the beneficiary's benefits. For example, let's again examine the case of an SSI recipient who owns his own home and who has incurred debt. The Trustee could make a single annual lump sum distribution to vendors or even the beneficiary to pay such expenses and, as long as the beneficiary does not retain more than the countable resource limit the following month, the beneficiary will not be disqualified from SSI and will only be required to repay the SSA the equivalent of one month's worth of benefits. In fact, the SNT rather than the beneficiary can repay this amount so that the beneficiary himself is not out-of-pocket. You could have a situation whereby the beneficiary's SSI is reduced by a mere one-third for one month in exchange for thousands of dollars of trust funds being utilized to maintain the beneficiary's home, pay off debts, etc.

If the beneficiary is eligible for a public benefit program that has no resource limit but is only income-sensitive, such as the case with respect to some state's Medicaid programs, then the beneficiary may have liquidity of his own, such as a bank or investment account. In such a case, whether the beneficiary should expend his own funds before tapping into the SNT becomes the question. In most instances, it probably is not an all or nothing answer. The beneficiary's individual circumstances and needs must be carefully considered, as well as what is available in the SNT to provide for the beneficiary throughout his lifetime. Of course, the interests of the ultimate beneficiaries, that is, the beneficiaries of the SNT upon the death of the primary beneficiary who is disabled, weigh in, particularly if they do not mirror the heirs or beneficiaries of the disabled individual's own estate. But these interests should not be paramount.

If a disabled beneficiary has a condition that is progressive resulting in a need for a higher level of care that potentially qualifies him for other needs-based public benefits, it may make sense to do some "spend down" planning with respect to the disabled beneficiary's own estate and then look to the SNT for ongoing care and support. If the beneficiary's condition is expected to remain constant and he is not likely to require the assistance of other public benefit programs that limit the resources he can have available, then more coordination may be involved in terms of who pays what. It may be a function of who owns the asset, such as a home, the beneficiary or the trust. Or, it may become a question of needs versus wants, particularly if the Trust is limitedly funded. Of course, the Trustee must look to the language of the SNT itself for guidance, and, to the extent other fiduciaries are involved, such as a Trust Protector, the job of the Trustee is made that much easier in such instances.

3. *First party or self-settled SNT*

If the beneficiary is the beneficiary of a SNT established pursuant to 42 U.S.C. §§ 1396p(d)(4)(A) or (C), as well as a third party or non-grantor SNT, the issue of which trust pays for what is more straightforward in this author's opinion. In the case of a first party or self-settled SNT, particularly one established pursuant to 42 U.S.C. § 1396p(d)(4)(A), there is the obligation to reimburse

Medicaid the cost of medical services it has provided to the beneficiary upon termination of the trust, which is typically at the time of the beneficiary's death. This requirement creates a disincentive in terms of preserving these trust funds as opposed to those of a third party or non-grantor SNT. If the first party or self-settled SNT is a pooled trust established pursuant to 42 U.S.C. § 1396p(d)(4)(C), then funds may be retained in the pooled trust to benefit other pooled trust beneficiaries or to support the charitable activities of the non-profit who is managing the pooled trust. The beneficiary and his family may feel strongly about the foregoing, but that is often not the case and, therefore, the incentive to preserve funds in that instance over that of the third party or non-grantor trust remains less.

Aside from who benefits from what is remaining in a SNT on the death of the primary beneficiary, the other question that dictates which SNT to turn to in the beneficiary's time of need is often a function of what d(4)(A) or (C) trust distributions are permitted by a state's Medicaid program. Many states place restrictions on the use of d(4)(A) or (C) trust funds and, in such instances, it is nice to have a third party or non-grantor SNT to fall back on. Restrictions may also exist in terms of what the probate court, which often authorizes or establishes self-settled or first party SNTs, allows. With the foregoing in mind, this author suggests that the self-settled or first party SNT be the primary source of funds to provide for the beneficiary and, if a distribution is not permitted or it is too cumbersome to obtain approval or implement, that the third party or non-grantor SNT be tapped into.

4. *More than one third party or non-grantor trust*

The situation where an individual who is disabled is the beneficiary of more than one third party or non-grantor SNT happens more often than expected. This is less surprising when relatives in addition to the parent want to provide for a loved one who is disabled, and given the fact that many families do not openly discuss their estate planning. Thus, unbeknownst to a parent, the grandparents or an aunt or uncle may have established a SNT for the benefit of that parent's child

who is disabled, just as the parent has done. In such instances, it may be prudent to keep the SNTs separate and administer them accordingly given that the ultimate dispositive provision on the death of the disabled beneficiary may vary. However, how to coordinate distributions as between the two SNTs remains an issue. Which SNT takes the position of the primary source of providing for the beneficiary's needs? Again, the language of the respective SNTs, their relative size, and ultimate beneficiaries all are factors in deciding this issue. Maybe one splits the baby and looks to both or all of the SNTs equally. In this situation more than others, particularly if the SNTs have different Trustees, it is important to identify a third party, such as a Trust Protector if provided for in the SNT document or agreement or legal Guardian, to be the point person and coordinate administration between the SNTs.

Dual or multiple SNTs may have been established by the same Settlor or Trustor and, following the death of the Settlor or Trustor, it may not be clear which of the SNTs is to be funded and administered. If similar in their terms, the SNTs can be merged either pursuant to the terms of the SNT, the Uniform Trust Code, or court order. This author includes the following merger clause in her SNT documents or agreements to provide for this possibility:

> "Notwithstanding any and all of the other provisions of this Trust, in the event identical or similar trusts are in existence for one or more of the beneficiaries under this Trust for which a new trust is to be created, then the Trustee may, . . . in the Trustee's sole discretion, either distribute the assets designated for a Trust to be created hereunder to the Trustee of the corresponding Trust already in existence, or may accept a distribution of assets from the Trustee of the existing Trust for any Beneficiary under this Trust and distribute such assets into the corresponding Trust for such Beneficiary created hereunder."

As has already been discussed, whether to merge dual or multiple SNTs is a function of who are the respective Trustees and ultimate beneficiaries on the death of the primary beneficiary who is disabled. Of course, the merged trusts can be tracked separately for accounting purposes, and this is advisable if the ultimate beneficiaries are not the same. The question again becomes which "sub-trust" to tap into first or whether to have them equally provide for the disabled beneficiary's needs.

Last, but not least, is the scenario of the "sole benefit" trust established by a spouse or parent not only to provide for a loved one who is disabled, but to also facilitate the Settlor or Trustor's own eligibility for public benefits, namely, SSI and/or long term care assistance through Medicaid. This particular trust would be funded during the Settlor or Trustor's lifetime, presumably not unless or until the Settlor or Trustor is in need of public benefits and must dispose of assets to financially qualify for such assistance. The "sole benefit" trust must either be actuarially sound, that is, provide for distribution of the entire corpus of the trust within the beneficiary's lifetime based on the SSA's life expectancy tables, or payback to Medicaid on the death of the beneficiary for the Settlor or Trustor's transfer of assets to the trust to not be penalized and result in the Settlor or Trustor being financially disqualified from public benefits. With the foregoing in mind, it is prudent for the Settlor or Trustor to also establish a standard or typical SNT, i.e., one that is *not* a "sole benefit" trust, that is designated in the Settlor or Trustor's Last Will & Testament or his own trust to receive assets designated for a disabled beneficiary upon the Settlor or Trustor's death.

V. Conclusion

If nothing else, one thing this discussion has highlighted is that even in the world of SNTs, circumstances can vary widely from one SNT and its beneficiary to the next. Who the beneficiary is, the nature of his disability, and his care and treatment needs, as well as his support system factor greatly into how a SNT and peripheral documents are drafted, and how a SNT is administered. Documents such as a Letter of Intent and Life Care Plan can aid the Trustee in administering a SNT to meet the needs of a beneficiary throughout his lifetime and do such a way that the beneficiary's quality of life is enhanced.

A beneficiary's circumstances and the eligibility requirements, as well as services provided by public benefit programs, do not remain static and, as such, a SNT should be drafted with the utmost flexibility. As long as the beneficiary has no control over the trust, a SNT that is drafted to allow for flexibility is not likely to run afoul of public benefit eligibility requirements. And, if it does, providing for the limited ability of someone other than the trustee or beneficiary to amend the trust can readily resolve the situation.

Drafting for flexibility also means drafting with foresight. As much as a parent may want to provide a home for his disabled child, and allow him to continue to reside and be cared for in such a setting, the possibility that such an arrangement may not be feasible or cost effective must be considered. Identifying the circumstances pursuant to which a home will not continue to be maintained and instead, be sold and the proceeds made a part of the SNT should be set forth in the SNT document or agreement.

At the same time, the SNT should steer clear of prohibiting the purchase of certain items or assets, or setting monetary caps or limits on distributions. If checks and balances are the goal, then that can be accomplished with the appointment of a third party, such as a Trust Protector or Guardian, to whom the SNT Trustee is accountable and with whom the Trustee must coordinate efforts to ensure the needs of the beneficiary are being met.

Finally, the Trustee should be mindful of the totality of resources available or potentially available to a beneficiary in administering a SNT. Obviously, the public benefits for which a SNT beneficiary is or may be eligible comes into play, and their varying eligibility requirements. Private resources, such as health insurance under the Affordable Care Act, may now be available thereby minimizing the beneficiary's dependence on public assistance. The beneficiary may have resources of his own, whether owned outright or held in a first party or self-settled SNT, that the third party or non-grantor SNT can supplement, or vice versa. And, not surprisingly, an individual who is disabled may be a beneficiary of more than one third party or non-grantor SNT. When other resources exist, the Trustee must be mindful of such resources and seek to coordinate efforts to ensure the needs of the beneficiary are comprehensively met and met in such a way that no single resource is under or over-utilized.