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2022 Fundamentals of Special Needs Trusts Administration Webinar

Friday, May 20, 2022



**Stetson University College of Law
Gulfport, Florida**



2022 Fundamentals of Special Needs Trusts Webinar

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The Fundamentals of Special Needs Trust Administration Webinar

~Friday, May 20, 2022~

A half-day webinar that addresses challenging administrative issues faced by trustees, attorneys, financial planners and others involved in Special Needs Trust Administration.

12:30-12:40 pm EDT

Welcome and Announcements

Professor Roberta Flowers

12:40-1:30 pm EDT

What Do I Do Now? Questions a Trustee Should Ask When Administering a Special Needs Trust

Craig Reaves

This session will provide a framework for analyzing a special needs trust and the beneficiary's situation so the trustee can confidently know when and how to distribute from the trust in a manner that will help the beneficiary and not cause issues with means-tested public benefit programs.

1:30-2:20 pm EDT

Stop Talking and Start Doing: The Hows, the Whys, and the Ethics of Using a Client-Centered Approach in SNT Planning and Administration

Rebecca C. Morgan

This session will explain the client-centered approach to decision-making, review specific sections of the best practices guide, review the ethics rules and how they support the use of client-centered decision-making, and offer examples of how trustees can use the client centered process in making decisions.

2:20-2:30 pm EDT

Sponsor Break - *ElderCounsel*

2:30-3:20 pm EDT

Working With Litigation Counsel – A Guide to the Perplexed & Sometimes Frustrated

Stuart Zimring

You get a call late Friday afternoon from Murray the MedMal Maven telling you he needs a SNT with Medicare Setaside by 9 a.m. Monday or the judge will hold him in contempt. This presentation will discuss how we can work more efficiently and profitably to serve our joint clients when the end result of litigation will be a SNT.

3:20-4:10 pm EDT

Basic Trust Distributions...Nope!

Megan Brand and Yolanda Mazyck

From the most mundane to very complex distributions, all need to be evaluated using a framework inclusive of person-centered planning. We will address how we handle distributions from our varying perspectives.

4:10-5:00 pm EDT

Q&A Session

Craig Reaves, Rebecca Morgan, Stuart Zimring, Megan Brand, and Yolanda Mazyck

Join the webinar speakers for an interactive Q&A session.

2022 Fundamentals of Special Needs Trusts Administration Webinar

Speakers



Megan Brand

Executive Director

Colorado Fund for People with Disabilities (CFPD)

Megan Brand is the Executive Director of CFPD-Colorado Fund for People with Disabilities. Megan began her service at CFPD in 2003 and has been the Executive Director since 2010. Megan has a bachelor's degree in social work from the College of St. Benedict over 20 years of experience in working with people with disabilities, their families, service providers, attorneys, trustees, financial planners, guardians and other professionals. She leads a staff of 25 in administering the largest and longest-standing locally managed pooled trust in Colorado, as well as providing myriad of other services that offer protection, personalized attention, access to our network of organizations and services, and financial and benefit's guidance. In addition to leading the staff, Megan currently serves on the board for the National Planned Lifetime Assistance Network and is a frequent presenter in the community, both locally and nationally, on Special Needs Trusts and related topics.



Roberta K. Flowers

Professor of Law and Director,

Center for Excellence in Elder Law

Stetson University College of Law

Roberta K. Flowers is a professor of law at Stetson University College of Law. Within the Elder Law LL.M. program, Professor Flowers teaches Ethics in an Elder Law Practice. She also teaches Evidence, Criminal Procedure, and Professional Responsibility. While at Stetson, Professor Flowers has successfully coached trial teams, arbitration teams and moot court teams to national championships. She has served as the director of the Center for Excellence in Advocacy and as the William Reece Smith Jr. Distinguished Professor in Professionalism. During her time at Stetson, Professor Flowers has received the university-level Excellence in Teaching Award, Most Inspirational Teacher Award from the Student Bar Association, and an award from the Student Bar Association for supporting student life. She also has received the university-level Homer and Dolly Hand Award for Excellence in Scholarship, the Dean's Award for Extraordinary Service, and been awarded the Distinguished Service Award four times. In 2005, the Florida Supreme Court awarded Professor Flowers the Faculty Professionalism Award.

Professor Flowers has lectured worldwide on the topic of ethics. She won a Telly Award for Excellence in Educational Films for having produced a series of educational videos on the ethical issues faced by prosecuting attorneys. Along with Professor Rebecca Morgan, she created a video series used to train and educate attorneys nationwide on the ethical dilemmas faced by elder law attorneys. The Florida Supreme Court awarded Professor Morgan and Professor Flowers the Florida Supreme Court Professionalism Award for their video productions. Additionally, with Professor Morgan, Professor Flowers designed the nation's first "elder friendly courtroom," which serves as model for courtrooms of the future.



Yolanda Mazyck
Executive Director
Shared Horizons

Yolanda Mazyck, a native Pennsylvanian, and graduate of the University of Pittsburgh, relocated to the Washington, D.C. metropolitan area to manage Shared Horizons' Pooled Special Needs Trust in January 2005.

Yolanda has over 30 years of nonprofit experience, primarily in the fields of substance abuse, criminal justice, and disabilities. She worked as a certified addictions counselor and intervention specialist for nine years before accepting the position as Director of the Neighborhood-based Family Intervention Center (NBFIC) in Sharon, Pennsylvania. During her 12 years as Director, she developed new initiatives for delinquent youth, their families, and other "at-risk" populations, preserving and supporting families in crisis.

Yolanda is honored to work with a dedicated staff and committed Board of Directors that embrace Shared Horizons' person-centered trust management model and looks forward to expanding services to meet the needs of an increasingly diverse population of people with disabilities and their families.



Rebecca C. Morgan
Boston Asset Management Chair in Elder Law
Stetson University College of Law

Professor Morgan teaches a variety of elder law courses in the J.D. and LL.M. programs and is the Director of the M.J. in Health Care Compliance. She is the successor co-author of Matthew Bender's Tax, Estate and Financial Planning for the Elderly, and its companion forms book (Lexis), a co-author of Representing the Elderly in Florida, (Lexis), The Fundamentals of Special Needs Trusts (Lexis), Ethics in an Elder Law Practice (ABA), Planning for Disability (Bloomberg BNA Portfolio), co-author of Elder Law in Context and Bankruptcy in Context (Aspen), as well as Mastering Interviewing and Counseling (Carolina Academic Press). Professor Morgan has authored a number of articles on a variety of elder law issues and has spoken a number of times on subjects of elder law. She is the co-editor of the Elder Law Prof Blog, http://lawprofessors.typepad.com/elder_law/.

Professor Morgan is a member of the board of directors for the Center for Medicare Advocacy and currently serves as treasurer. She is a member of the board of directors for the American Society on Aging. She served as the eleventh president of the National Academy of Elder Law Attorneys and as past president of the board of directors of Justice in Aging. She served as chair for the American Association of Law Schools Section on Aging and the Law (twice) and of the Florida Bar Elder Law Section. She is on the faculty of the National Judicial College, a member of the American Law Institute (ALI), academic advisory board for the Borchard Center for Law and Aging, an academic fellow of the American College of Trusts & Estates Counsel (ACTEC), a NAELA fellow, and a member of NAELA's Council of Advanced Practitioners (chair 2012-2014). After a term on the Board of the ABA Commission on Law and Aging, she is a special advisor to the ABA Commission on Law and Aging.



Craig Reaves
Reaves Law Firm, PC

Craig C. Reaves has been Certified as an Elder Law Attorney (CELA) by the National Elder Law Foundation since the Charter class of 1995. Mr. Reaves is a Fellow and Past President of National Academy of Elder Law Attorneys (NAELA) and a Fellow of the American College of Trust and Estate Counsel (ACTEC). He has been selected for inclusion on the Kansas and Missouri Super Lawyers list for every year since 2005 and has been included in the current editions of The Best Lawyers in America since 2007. Mr. Reaves is the current Chair of the Board of Directors of the Kansas City Estate Planning Symposium. For the past twenty years he has been a lecturer and adjunct professor teaching an Elder Law course at the University of Kansas School of Law and also the University of Missouri-Kansas City School of Law.



Stuart Z. Zimring
Law Offices of Stuart D. Zimring

Stuart D. Zimring was born in Los Angeles, California, December 12, 1946. He was admitted to the Bar in 1972, and is admitted to practice in California and U.S. District Court, Central and Northern Districts of California and the U.S. Supreme Court. He received his B.A. degree in 1968 from UCLA and his J.D. degree in 1971 from the UCLA School of Law and is “AV” rated in Martindale-Hubbell. He is a member of the Los Angeles Superior Court Probate Volunteer Panel. Mr. Zimring is a Fellow of and Past President of the National Academy of Elder Law Attorneys (NAELA), and a Charter Member of NAELA’s Council of Advanced Practitioners (CAP). He is a Fellow of the American College of Trusts and Estate Counsel (ACTEC), is certified as a Specialist in Estate Planning, Probate and Trust Law by the Board of Legal Specialization of the State Bar of California and is one of the 7 California members of the Special Needs Alliance.

Mr. Zimring serves on the Boards of Directors of a number of non-profit organizations, including Justice In Aging (formerly the the National Senior Citizens Law Center and is past-president of ONEgeneration in the San Fernando Valley, on whose Board he continues to serve. He is also a member of the Estate Counselors Forum, San Fernando Valley Estate Counselors Forum, San Fernando Valley and Los Angeles County Bar Associations (of which he is a past Chair of its Trust & Estates Executive Committee), State Bar of California and Southern California Council of Elder Law Attorneys.



STETSON LAW

2022 Fundamentals of Special Needs Trusts Administration Webinar

**Friday, May 20, 2022
12:40 P.M. – 1:30 P.M.**

**What Do I Do Now? Questions a Trustee
Should Ask When Administering a
Special Needs Trust**

Presenter:
Craig Reaves

- Materials
- PowerPoint

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**What Do I Do Now?
Questions a Trustee Should Ask
When Administering a Special Needs Trust**

**Fundamentals of Special Needs Trust
Administration Webinar**

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**May 20, 2022**

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**What Do I Do Now?**  
**Questions a Trustee Should Ask**  
**When Administering a Special Needs Trust**

**Table of Contents**

|           |                                                                                                           |           |
|-----------|-----------------------------------------------------------------------------------------------------------|-----------|
| <b>1.</b> | <b>What Type of Special Needs Trust Is This? . . . . .</b>                                                | <b>1</b>  |
| A.        | Self-Settled Trust or Third Party-Settled Trust . . . . .                                                 | 2         |
| 1)        | Description of Self-Settled and Third Party-Settled Trusts . . . . .                                      | 2         |
| a.        | Self-Settled Trust . . . . .                                                                              | 2         |
| b.        | Third Party-Settled Trust . . . . .                                                                       | 3         |
| 2)        | How to Determine Whether Special Needs Trust Is<br>Self-Settled or Third Party-Settled . . . . .          | 3         |
| a.        | Read the Applicable Sections of the Trust Document . . . . .                                              | 3         |
| b.        | Determine Where the Assets Funding the Trust<br>Came From . . . . .                                       | 4         |
| c.        | Is There More Than One Beneficiary: . . . . .                                                             | 5         |
| 3)        | Distribution Rules for Self-Settled Trusts . . . . .                                                      | 5         |
| 4)        | Distribution Rules for Third Party-Settled Trusts . . . . .                                               | 6         |
| B.        | Strict or Discretionary Special Needs Trust . . . . .                                                     | 6         |
| 1)        | Two Types of Special Needs Distribution Standards . . . . .                                               | 8         |
| a.        | Strict Special Needs Distribution Standard . . . . .                                                      | 8         |
| b.        | Discretionary Special Needs Distribution Standard . . . . .                                               | 9         |
| 2)        | Know Which Type of Special Needs Distribution<br>Standard is in the Trust . . . . .                       | 10        |
| C.        | Is There an IRA Payable to the Trust? . . . . .                                                           | 10        |
| 1)        | Self-Settled Trusts and IRAs . . . . .                                                                    | 11        |
| 2)        | Third Party-Settled Trusts and IRAs . . . . .                                                             | 11        |
| <b>2.</b> | <b>What Public Assistance Benefits Is the Beneficiary Receiving? . . . . .</b>                            | <b>11</b> |
| A.        | Programs That Are Not Means-Tested - Do Not Be Concerned<br>About These . . . . .                         | 12        |
| B.        | Programs That Are Means-Tested - Be Concerned About These . . . . .                                       | 12        |
| 1)        | SSI (Supplemental Security Income) . . . . .                                                              | 13        |
| 2)        | Medicaid . . . . .                                                                                        | 13        |
| C.        | Chart Summarizing Four Primary Public Assistance Programs . . . . .                                       | 13        |
| D.        | Summary of Concerns About SSI . . . . .                                                                   | 14        |
| E.        | Do Not Rely On Verbal Description of Benefits Being Received . . . . .                                    | 16        |
| F.        | Obtain Proper Documentation of Benefits . . . . .                                                         | 16        |
| <b>3.</b> | <b>Does the Beneficiary Have an ABLE Account? . . . . .</b>                                               | <b>18</b> |
| A.        | Description of an ABLE Account . . . . .                                                                  | 18        |
| B.        | When to Consider Distributing From a Special Needs<br>Trust Into the Beneficiary's Able Account . . . . . | 20        |

|           |                                                                                                              |           |
|-----------|--------------------------------------------------------------------------------------------------------------|-----------|
| 1)        | Give the Beneficiary More Spending Money . . . . .                                                           | 20        |
| 2)        | Pay for “Shelter” When the Beneficiary is Receiving SSI . . . . .                                            | 21        |
| <b>4.</b> | <b>What are the Expectations or Immediate Needs of the Beneficiary and/or Family? . . . . .</b>              | <b>21</b> |
| <b>5.</b> | <b>What Does the Trust Document Say, Specifically? . . . . .</b>                                             | <b>23</b> |
| A.        | Specific Provisions . . . . .                                                                                | 23        |
| 1)        | Housing . . . . .                                                                                            | 23        |
| 2)        | Motor Vehicle or Transportation . . . . .                                                                    | 23        |
| 3)        | Travel . . . . .                                                                                             | 23        |
| 4)        | Payments to Others . . . . .                                                                                 | 24        |
| B.        | Must the Trustee Consider the Needs of Remainder Beneficiaries When Making Distribution Decisions? . . . . . | 24        |
| C.        | Chart for Reviewing Trust Document . . . . .                                                                 | 25        |
| <b>6.</b> | <b>Is the Trustee Required to Consult With Other People? . . . . .</b>                                       | <b>25</b> |
| A.        | Guardian or Conservator . . . . .                                                                            | 25        |
| B.        | Durable Power of Attorney Agent . . . . .                                                                    | 26        |
| C.        | Trust Advisor or Trust Protector . . . . .                                                                   | 26        |
| D.        | Directed Trust . . . . .                                                                                     | 26        |
|           | <b>Appendix A - Chart for Reviewing Trust Document . . . . .</b>                                             | <b>27</b> |

# **What Do I Do Now? Questions a Trustee Should Ask When Administering a Special Needs Trust**

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When a trustee receives a new special needs trust to administer, there are certain items that the trustee needs to know about the trust and its beneficiary before beginning to administer the trust. Without this information, the trustee may actually harm the beneficiary by making an incorrect distribution from the trust or otherwise mishandling the trust.

The following material outlines six general questions, along with followup questions, that a trustee should ask about a new special needs trust and the trust's beneficiary. By answering these questions and understanding the provisions of the special needs trust being administered and the circumstances of the beneficiary of that trust, the trustee will be better able to administer the trust in a way that provides needed assistance to help the beneficiary as much as possible without unintentionally jeopardizing any public assistance benefits the beneficiary is receiving.

## **1. What Type of Special Needs Trust Is This?**

The first question a trustee should ask about a new special needs trust is what type of special needs trust it is. There are two different issues this is referring to. One is whether the trust is “self-settled” or “third party-settled.” These are sometimes referred to as a “first-party trust” and a “third-party” trust. The other is whether the trust is a “strict” or “discretionary” special needs trust. Both of these are explained below.

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<sup>1</sup> Certified Elder Law Attorney by the National Elder Law Foundation. Neither the Supreme Court of Missouri, nor the Missouri Bar reviews or approves certifying organizations or specialist designations.

**A. Self-Settled Trust or Third Party-Settled Trust:** Generally speaking, trusts can be divided into two groups: self-settled and third party-settled. Every trust is one or the other. This is true for all trusts, including special needs trusts.

The "settlor" of a trust is not just the person who signs the trust to establish it and is referred to in the trust document as the settlor (or grantor, trustor, or some similar title). According to well-established law, a person is considered a settlor of a trust if the person's assets are used to fund the trust.<sup>2</sup>

### 1) Description of Self-Settled and Third Party-Settled Trusts

**a. Self-Settled Trust:** A "self-settled trust" is a trust that holds assets that were received from the beneficiary of the trust. This is true even if the beneficiary did not sign the trust as the person establishing it.<sup>3</sup> In other words, with a self-settled trust the settlor and beneficiary are the same person. In addition, for Medicaid and SSI purposes a trust is deemed to be self-settled if any assets of the beneficiary's

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<sup>2</sup> Restatement (Second) of Trusts, §3 and §17; 42 U.S.C. §1396p(d)(2)(A); POMS § SI 01120.200.B.2; Masterson v. Department of Social Services, Division of Family Services, 969 S.W.2d 746 (Mo. En Banc., 1998); Forsyth v. Rowe, 266 Conn. 818, 629 A.2d 379, (Conn., 1993); Cohen v. Commissioner of Div. of Medical Assistance, 423 Mass. 399, 668 N.E.2d 769, (Mass., 1996); Striegel v. South Dakota Dept. of Social Services, 515 N.W.2d 245 (S.D., 1994); Strand v. Rasmussen, 648 N.W.2d 95 (Iowa, 2002); In re Hertsberg Inter Vivos Trust, 457 Mich. 430, 578 N.W.2d 289 (Mich., 1998); In re Johannes Trust, 479 N.W.2d 25 (Mich.App. 1991).

<sup>3</sup> Guaranty Trust Co. of New York v. New York Trust Co., 297 N.Y. 45, 50, 74 N.E.2d 232, 234 (1947) ("There can be no doubt that the person who furnishes the consideration for the creation of a trust is the settlor, even though, in form, the trust is created by another."); Forsyth v. Rowe, 226 Conn. 818, 826, 629 A.2d 379, 384 (Conn. 1993) ("We conclude that the trust was established by Gregory because it was funded with the proceeds from the settlement of his tort claim even though the settlement was actually consummated by the plaintiff acting on behalf of Gregory."); Calhoun v. Rawlins, 93 Mass. App. Ct. 458, 463-64, 106 N.E.3d 684, 690, review denied sub nom. Shonna Calhoun v. Rawlins, 480 Mass. 1110, 113 N.E.3d 838 (2018) ("A trust is established by the person who provides the consideration for the trust even though in form it is created by someone else." Romo v. Kirschner, 181 Ariz. 239, 241-242, 889 P.2d 32 (Ct. App. 1995), quoting from Forsyth v. Rowe, 226 Conn. 818, 826, 629 A.2d 379, 384 (1993).").

spouse are transferred to the trust.<sup>4</sup> The only exception to this is if the spouse established the trust by the spouse's Last Will and Testament.<sup>5</sup>

**b. Third Party-Settled Trust:** On the other hand, if the assets in the trust did not previously belong to the trust beneficiary or their spouse, then the trust is a third party-settled trust.<sup>6</sup>

## **2) How to Determine Whether Special Needs Trust Is Self-Settled or Third Party-Settled**

**a. Read the Applicable Sections of the Trust Document:** In most special needs trust documents there is a section that describes the type of trust that is being established. Typically, this is near the beginning of the trust agreement.

If words such as "self-settled" or "42 U.S.C. § 1396p(d)(4)(A)," "OBRA '93,"<sup>7</sup> "FCIA '99,"<sup>8</sup> "42 U.S.C. § 1382b(e)(5) (Section 1613 of the

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<sup>4</sup> 42 U.S.C. § 1396p(d)(2) and § 1396p(e)(1); POMS SI 01150.110.E.

<sup>5</sup> 42 U.S.C. § 1396p(d)(2)(A); *Skindzier v. Comm. of Social Services*, 258 Conn. 642, 784 A.2d 323 (Conn. 2001).

<sup>6</sup> *In re Will of Kamp ex rel. Kamp*, 7 Misc. 3d 615, 618, 790 N.Y.S.2d 852, 855 (Sur. 2005) ("... a third party trust, that is, one created by someone other than the beneficiary . . .").

<sup>7</sup> Omnibus Budget and Reconciliation Act of 1993, Pub. L. No. 99-262. Among other things, this Act rewrote the laws concerning self-settled trusts for people who were applying for Medicaid assistance. A portion of this act contained what became 42 U.S.C. § 1396p(d)(4)(A).

<sup>8</sup> Foster Care Independence Act of 1999, Pub. L. No. 106-169. This law applied OBRA '93 to recipients of SSI (Supplemental Security Income).

Social Security Act)," or "POMS<sup>9</sup> SI 01120.201" are in the trust agreement, the trust is most likely a self-settled trust. This is also true if there is a reference that the beneficiary is under the age of sixty-five (65).

On the other hand, if the instrument says the trust is NOT any of the above phrases, then the trust is most likely a third party-settled trust.

**b. Determine Where the Assets Funding the Trust Came**

**From:** If the assets funding the trust are from the beneficiary or the beneficiary's spouse (with one exception), then the trust is a self-settled trust. The only exception to this is when a special needs trust established by the beneficiary's spouse is not deemed to be self-settled is because the trust is established by the provisions of the last will and testament of the deceased spouse.<sup>10</sup>

If the assets funding the trust are from a lawsuit settlement where the beneficiary was a plaintiff, or from an inheritance the beneficiary actually received (as opposed to being distributed directly into a trust), then the trust is a self-settled trust. This is true even if the beneficiary is intellectually disabled or in a coma and is not aware this is happening. It is also true if the assets are directed into the trust by a court or the beneficiary's guardian or conservator.<sup>11</sup>

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<sup>9</sup> Program Operations Manual System (POMS). It can be found at <https://secure.ssa.gov/apps10/>. This is an operations manual to guide Social Security Administration employees. It contains the Social Security Administration's interpretation of the laws relating to SSI and Social Security. It can be very helpful to trustees if a beneficiary is receiving SSI.

<sup>10</sup> 42 U.S.C. § 1396p(d)(2)(A); Skindzier v. Comm. of Social Services, 258 Conn. 642, 784 A.2d 323 (Conn. 2001).

<sup>11</sup> 42 U.S.C. § 1396p(d)(2)(A).

On the other hand, if all the assets funding the special needs trust are from anyone other than the beneficiary or the beneficiary's spouse, then the trust is a third party-settled trust. For example, a special needs trust established by a parent for the benefit of the parent's child that is funded with assets owned by the parent is a third party-settled trust. Other examples are a grandparent establishing a trust for a grandchild, or a person establishing a trust for the benefit of his parent, grandparent, sibling, or other relatives.

**c. Is There More Than One Beneficiary:** If there is more than one current income beneficiary of the special needs trust, then that is a good indication that the trust is a third party-settled trust. However, if a trust with multiple beneficiaries is funded with assets from the beneficiary, then the trust will not be an exempt trust for Medicaid and SSI eligibility purposes because it will not satisfy the provisions of 42 U.S.C. § 1396p(d)(4)(A).

**3) Distribution Rules for Self-Settled Trusts:** If the beneficiary of a self-settled special needs trust is receiving assistance from SSI or Medicaid (discussed below), then in addition to complying with what the trust document says, the trustee needs to comply with the provisions of 42 U.S.C. §1396p(d)(4)(A) and POMS SI 01120.201F. Among others, this requires the trust distributions be for the "sole benefit" of the beneficiary. A full description of the restrictions placed on distributions from a self-settled special needs trust are beyond the scope of these materials.

Also, keep in mind that when the beneficiary dies (or if the trust terminates while the beneficiary is living), every state Medicaid agency that provided assistance to the beneficiary for the beneficiary's lifetime is entitled to be repaid what the agency expended for the beneficiary's benefit. Other than

administrative expenses and taxes specifically relating to this trust, nothing can be distributed or spent after the beneficiary's death until Medicaid is fully repaid.

As a result, it is a good idea to make sure the beneficiary's funeral and burial or cremation expenses are prepaid and protected in an irrevocable plan. The trust can purchase these items during the beneficiary's lifetime, but not after the beneficiary's death.

**4) Distribution Rules for Third Party-Settled Trusts:** Third party-settled trusts do not repay Medicaid when the beneficiary dies and are not restricted to being used for the "sole" benefit of the beneficiary unless the trust document incorporates such language. The trustee of a third party-settled special needs trust does not have to comply with the sole benefit rules found in the POMS, although sometimes the POMS can provide some assistance when contemplating certain expenditures.

Instead, it is the provisions of the trust document that should primarily guide the trustee. The primary restriction to keep in mind is to not distribute money to the beneficiary or deposit money into the beneficiary's bank account. Also, if a trust beneficiary is receiving SSI, then the trustee needs to be careful to not distribute for the beneficiary's food or shelter expenses. This is further described below.

**B. Strict or Discretionary Special Needs Trust:** The second issue is whether the special needs trust is a "strict" special needs trust or a "discretionary" special needs trust. This is determined by reviewing the clauses in the trust agreement that describe how the trustee is to determine whether it is appropriate to make a distribution to or for the benefit of the beneficiary.



Every trust contains a section that tells the trustee when, what, and how to distribute from the trust for the benefit of the beneficiary. These materials refer to these instructions as a "distribution clause." Every distribution clause is based on a "distribution standard."

Generally speaking, there are four distribution standards that are commonly used in trusts. Two of them are a form of "support" that either requires the trustee to distribute for the support of the beneficiary (often referred to as a "mandatory support" distribution standard), or gives the trustee discretion to determine whether it is appropriate to distribute for the beneficiary's support (often referred to as a "discretionary support" distribution standard). In most states, neither of these should be used in a trust for the benefit of a person receiving means-tested public assistance, such as Medicaid or SSI.<sup>12</sup>

A third type of distribution standard is "pure discretion." This standard literally gives the trustee total discretion whether to distribute some, all, or none of the trust income or principal to or for the benefit of the beneficiary. For the past few years many attorneys have been using a pure discretionary distribution standard in trusts for beneficiaries who are receiving means-tested public assistance. They believe it provides more flexibility for the trustee than a special needs distribution standard. However, at least one state has enacted legislation making a pure discretionary trust an available resource for that state's Medicaid program. Instead, that state requires

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<sup>12</sup> However, there are exceptions. For example, the Texas Medicaid for the Elderly and Persons with Disabilities Handbook (MEPD) § F-6100 clarifies that a trust for a Texas Medicaid recipient is countable for Medicaid eligibility purposes only if the beneficiary "is the trustee and has the legal right to revoke the trust and use the money for his or her benefit. If he does not have access to the trust, the trust is not counted as a resource." As a result, even a trust that has a support distribution clause is an exempt trust for Texas Medicaid purposes, as long as the trust contains a spendthrift clause and limits the beneficiary's control over the trust assets. In addition, it is recommended that the trust allow the trustee to distribute to the beneficiary or to others for the benefit of the beneficiary (often referred to as a "facility of payment" clause).

a special needs distribution standard in order for a trust to be exempt for Medicaid purposes.<sup>13</sup>

The fourth type of distribution standard is “special needs.” A special needs distribution standard gives the trustee broad discretion to distribute trust income and/or principal for the “special needs” of the beneficiary. Special needs are usually defined as anything the beneficiary needs, or anything that would be useful or in any way helpful to the beneficiary, if it is not paid for or provided to the beneficiary from a public assistance benefit program or some other source. The trustee is typically directed to distribute from the trust in a manner that “supplements but does not supplant” any public assistance the beneficiary is receiving. Trusts that contain a special needs distribution standard (a “special needs trust”) are also sometimes referred to as “supplemental needs trusts,” “supplemental care trusts,” and similar titles.

**1) Two Types of Special Needs Distribution Standards:** There are two types of special needs distribution standards.

**a. Strict Special Needs Distribution Standard:** One type of special needs distribution standard expressly prohibits the trustee from making distributions from the trust that will cause a reduction or loss of the beneficiary’s public benefits. A trust that contains this distribution standard is referred to as a “strict special needs trust.”

An example of a strict special needs distribution clause is:

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<sup>13</sup> This state is Kansas. See, K.S.A. § 39-709(e)(3). If the trust beneficiary resides in Kansas, a pure discretionary trust cannot be used without jeopardizing the beneficiary’s eligibility for Kansas Medicaid.

“The Trustee shall not make a distribution for the beneficiary’s benefit that in any manner causes a reduction or loss of any public assistance the beneficiary may be receiving or entitled to receive.”

In addition, some strict special needs distribution clauses prohibit the distribution of trust assets for the “food or shelter” of the beneficiary. Others add “clothing” to this list. This language is drawn from SSI regulations.<sup>14</sup> The purpose of prohibiting the trustee from distributing for any of these items is to make sure the trust does not cause a reduction in the beneficiary’s SSI. Unfortunately, this restriction is often included in trusts for beneficiaries who are not receiving SSI. Also, SSI regulations that became effective March 9, 2005, removed “clothing” from this list. This means that many trusts drafted prior to this regulation change (and even some drafted after the effective date) include this now needless restriction.

**b. Discretionary Special Needs Distribution Standard:** The other type of special needs distribution standard gives the trustee discretion to make distributions for the benefit of the beneficiary that may reduce or cut off public assistance benefits, if the trustee deems such distributions to be in the best interests of the beneficiary. A trust that contains this distribution standard is referred to as a “discretionary special needs trust.”

An example of a discretionary special needs distribution clause is:

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<sup>14</sup> 20 C.F.R. § 416.1102, “Income is anything you receive in cash or in kind that you can use to meet your needs for food and shelter. Sometimes income also includes more or less than you actually receive (see §§ 416.1110 and 416.1123(b)). In-kind income is not cash, but is actually food or shelter, or something you can use to get one of these.” 70 FR 6344, Feb. 7, 2005.

“It is preferred that the Trustee not make distributions from the trust that cause a reduction or loss of any public assistance the beneficiary is receiving or entitled to receive. However, if the Trustee, in its sole discretion, determines that any distribution from this Trust will benefit the beneficiary and is in the beneficiary’s best interest, then the Trustee may make that distribution even if doing so will cause a reduction or loss of public assistance benefits the beneficiary would otherwise receive or be entitled to receive.”

**2) Know Which Type of Special Needs Distribution Standard is in the Trust:** If the trust contains a special needs distribution clause, then it is important that the trustee understand which type of special needs standard it is. It is much preferred that the clause be discretionary rather than strict; it provides much more flexibility for the trustee and often allows the trust assets to better provide for the beneficiary.

For example, if the beneficiary is receiving SSI, a discretionary special needs distribution standard will allow the beneficiary to live rent free in housing paid for by the trust, even though this will cause a reduction of the beneficiary’s SSI because the payment of rent is deemed to be “in-kind support and maintenance.” On the other hand, if the trust contained a strict special needs distribution clause, the trustee would be prohibited from providing or paying for any of the “shelter” items because doing so would cause a reduction in the beneficiary’s SSI, which is prohibited with a strict special needs distribution standard.

**C. Is There an IRA Payable to the Trust?** The trustee should clarify if there is an IRA payable to the trust or currently held by the trust. How these are treated differs depending on whether the trust is self-settled or third party-settled.

**1) Self-Settled Trusts and IRAs:** If an IRA inherited from another person is payable to the beneficiary, then Private Letter Ruling 200620025 issued by the IRS on May 19, 2006, allowed a person to transfer an inherited IRA into a self-settled special needs trust and not only keep the assets in the IRA, but stretch the IRA distributions over the life expectancy of the beneficiary. Since this is a Private Letter Ruling, it cannot be relied on by any others. However, it provides an outline of how the IRS may treat such transfers of inherited IRAs.

If the new special needs trust is currently holding an IRA, then the Private Letter Ruling described in the prior paragraph may provide assurance to the trustee that it is acceptable to hold the IRA. The trustee will need to comply with all rules relating to Required Minimum Distributions.

**2) Third Party-Settled Trusts and IRAs:** The rules regarding holding an inherited IRA in a third party-settled special needs trust are beyond the scope of these materials. However, the trustee needs to know if the trust is holding an IRA and, if so, then the trustee needs to comply with the applicable rules. If the IRA was received after January 1, 2020, then the special needs trust may be a Type II Applicable Multi-Beneficiary Trust and be subject to special rules. Refer to I.R.C. § 401(a)(9) and proposed regulations § 1.401(a)(9), *et seq.* for guidance.

## **2. What Public Assistance Benefits Is the Beneficiary Receiving?**

A second question a trustee needs to ask is whether the beneficiary is receiving public assistance benefits, and if so, which ones. If the special needs trust beneficiary is receiving “means-tested” public assistance from a government agency, then the trustee must be careful to distribute assets from the trust in a manner that does not disqualify the beneficiary from receiving assistance from those programs.

Government public assistance programs in the United States can be divided into two categories: those that are "means-tested" (sometimes referred to as "needs-based") and those that are not. Means-tested public assistance programs require that a person have low income and few assets (usually referred to as "resources") in addition to being sufficiently blind, old, disabled, or otherwise eligible for assistance from the program. Other public assistance programs that are not means-tested only require that the participant be sufficiently blind, old, or disabled and, in some cases, able to tap into the Social Security or Railroad Retirement systems. For these programs, it does not matter if the person is wealthy or has high income.

A trustee needs to know what types of public assistance the beneficiary of the special needs trust is receiving so the trustee will know when to, or not to, distribute for the benefit of the beneficiary.

**A. Programs That Are Not Means-Tested - Do Not Be Concerned About**

**These:** A trustee does not need to be concerned about disqualifying a beneficiary from public assistance programs that are not means-tested. Some of the most common of these programs are: (i) Social Security, whether retirement, disability, or survivors; (ii) Medicare; and (iii) compensation from the Veterans Administration or a branch of the United States military.

**B. Programs That Are Means-Tested - Be Concerned About These:** The programs a beneficiary may be participating in that should cause the trustee to be cautious in making distributions from the special needs trust are: (i) Supplemental Security Income (SSI); (ii) Medicaid (which goes by different names in some states); (iii) public housing, such as Housing Choice vouchers (often referred to as "Section 8"); and (iv) a pension from the Veterans Administration. Two of these are further discussed below.

**1) SSI (Supplemental Security Income):** The means-tested program that causes the most concern for a trustee of a special needs trust is Supplemental Security Income (“SSI”). This is because the purpose of SSI is to provide a minimum amount of income for a recipient to spend on food and shelter. If the beneficiary receives money, or if the beneficiary receives actual food or “shelter” from some other source, such as a trust, then the beneficiary’s SSI will be reduced. This is further explained below.

**2) Medicaid:** The second means-tested program that causes concern is Medicaid. This is because Medicaid usually is the primary source of care and non-financial support for the beneficiary, and losing Medicaid could be devastating for the beneficiary.

The chart below summarizes the four primary government benefit programs and whether they are means-tested or not.

**C. Chart Summarizing Four Primary Public Assistance Programs**

|                                         | <b>Not</b> Means-Tested or Needs-Based                                                                      | <b>Is</b> Means-Tested; Needs-Based                                  |
|-----------------------------------------|-------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------|
|                                         | <b>Need</b> Social Security or Railroad Retirement Connection                                               | Do <b>not</b> need Social Security or Railroad Retirement Connection |
| Money Only;<br>No services or benefits  | <b>Social Security Disability (SSD), Social Security Retirement, and Railroad Disability and Retirement</b> | <b>Supplemental Security Income (SSI)</b>                            |
| Benefits and services Only;<br>No money | <b>Medicare</b>                                                                                             | <b>Medicaid</b>                                                      |

**D. Summary of Concerns About SSI:** If the beneficiary is receiving SSI, then the trustee needs to be extra careful when making trust distributions. While both SSI and Medicaid eligibility will be negatively impacted if the trustee distributes money to the beneficiary, or transfers money into the beneficiary's personal bank account or onto a debit card the beneficiary can use (other than a card such as one offered by TrueLink<sup>15</sup>), SSI is the only public benefit program that counts "in-kind support and maintenance" as "income" to the beneficiary and will reduce the beneficiary's future SSI payments.

Basically, for SSI eligibility purposes, "in-kind support and maintenance" (often referred to as "ISM") is actual "food or shelter" that is provided to the beneficiary by another person or entity (such as a special needs trust) without the beneficiary paying fair market value for the items. This includes both physically providing food or shelter (such as delivering food to the beneficiary or allowing the beneficiary to live rent free in a house) and paying the food or shelter expenses of the beneficiary.

"Shelter" for SSI purposes is defined as ten specific items.<sup>16</sup> These are listed in the POMS at SI 00835.465D.1<sup>17</sup> as payments made towards a beneficiary's:

- Mortgage
- Property insurance on the residence required by a mortgage lender
- Real property taxes (less any tax rebate/credit)
- Rent
- Heating fuel

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<sup>15</sup> See POMS SI 01120.2011.1.e; True Link's website <https://www.truelinkfinancial.com/card/true-link-card>.

<sup>16</sup> 20 C.F.R. § 416.1130(b).

<sup>17</sup> POMS SI 00835.465D.1.



- Gas for the residence
- Electricity
- Water
- Sewer
- Garbage removal.

Condominium and homes association fees in themselves are not “shelter.” However, these fees may include charges which are classified as “shelter,” such as garbage removal. To the extent that these charges are identifiable, they will be deemed to be “shelter” for calculation of in-kind support and maintenance.

Any distribution from any trust, including a special needs trust, for any of these shelter items will be deemed to be in-kind support and maintenance and will cause the beneficiary’s SSI to be reduced. Although the full details are beyond the scope of these materials, the reduction is usually equal to the lesser of (i) the actual amount paid towards “shelter” expenses, or (ii) one-third of the currently payable maximum SSI amount, plus \$20 (the “Presumed Maximum Value rule”). In 2022, this is \$300.33 ( $\$841 \div 3 = 280.33 + 20 = \$300.33$ ). This means the beneficiary’s SSI amount will be reduced to \$540.67.

Keep in mind that there are many items the beneficiary may need or want that the special needs trust can pay for that are not food or one of the specific items of “shelter.” Examples include, mobile phone and telephone provider costs, computer, internet, furniture and furnishings, clothing, cleaning and maintenance of the beneficiary’s house and grounds, travel, and education, just to name a few.

Also, if the beneficiary has an ABLE account, this can be used as a mechanism for the special needs trust to assist with shelter expenses. This is explained later in these materials.

**E. Do Not Rely On Verbal Description of Benefits Being Received:** Do not rely on what someone says are the benefits being received by the beneficiary. Often the beneficiary or someone speaking on behalf of the beneficiary will be mistaken about exactly what type of benefits are being received. For example, SSI and Social Security Disability (SSD) look very similar. Both provide monthly income directly deposited from the Social Security Administration. However, SSDI is not a means-tested program, so its distributions from a special needs trust will not negatively impact the amount of SSDI being received by the beneficiary.

**F. Obtain Proper Documentation of Benefits:** Ask the beneficiary or someone assisting the beneficiary to provide written documentation of the exact benefits being received. They will either already have this in their possession or can contact the public agency providing assistance and obtain a written description.

**1) Social Security - Recent Benefit Statement:** Towards the end of every year, the Social Security Administration sends a written benefit statement to every person receiving Social Security benefits. This statement advises the recipient how the benefit and any deductions will change in the coming new year. Ask for the most recent benefit statement from the Social Security Administration. If this cannot be located, ask the beneficiary to set up a (or access their existing) “my Social Security” account. This allows them online access to this information, which can then be printed out. See <https://www.ssa.gov/myaccount/>.

**2) SSI - Recent Benefit Notice:** Any time there is an award of SSI or a change of the SSI amount, the Social Security Administration will send written notice of this to the recipient. Ask to see a copy of the initial letter notifying the beneficiary of becoming eligible for SSI, along with a few of the most recent notices received by the beneficiary.

**3) Medicaid - Benefit Notice or Letter:** Medicaid is a partnership between the Federal government and each state. The Federal government oversees the Medicaid program on a national level (the agency that does this is the Centers for Medicare and Medicaid Services (CMS)), but it is the state where the beneficiary resides that actually administers the benefits the beneficiary receives. Ask for the letter from the state Medicaid agency notifying the beneficiary of becoming initially eligible for one or more of the programs offered by Medicaid, or of the most recent reauthorization of benefits. In many states this information can be obtained online by the beneficiary. It is possible the beneficiary may be receiving services from one or more waiver programs offered by the state Medicaid agency.

**4) Public Housing Assistance - Letter or Notice of Approval:** Public housing programs are administered by local Public Housing Authorities. These agencies will notify a recipient in writing when they are approved for assistance. Ask for a copy of these letters.

**5) Make Copies of All Identification Cards:** Most of the public agencies offering assistance will issue an identification card and assign a number to the people receiving services. In addition, private health insurance companies typically issue identification cards verifying the coverage being provided. Ask for copies of all these cards, and copy both the front and back of each card. At the very least, get the identification numbers assigned to the beneficiary.

**6) Recent Bank Statements:** Ask for a copy of the past three months of bank statements for each of the beneficiary's accounts. Look for the amounts being deposited by SSA (the Social Security Administration). There may be multiple deposits each month. Some people receive monthly

deposits from SSI, Social Security on their own earnings record, and Social Security based on someone else's earnings record (such as a parent or spouse). In addition, there may be money being deposited from the Veteran's Administration, the federal government, or a state or municipality. Not all of these deposits are public assistance, but knowing the income the beneficiary is receiving will help the trustee know when it may be appropriate to make a distribution from the trust.

### **3. Does the Beneficiary Have an ABLE Account?**

The third question the trustee should ask is whether the beneficiary has, or may be eligible for, an ABLE account. If so, the trustee can choose to distribute to it from the trust, if that is appropriate. This is authorized by POMS SI 01120.201I.1.h, which says,

“Funds transferred from the trust into an account established by the trust beneficiary under the ABLE Act are excluded from income to the trust beneficiary. For treatment of deposits into an ABLE account, see SI 01130.740.”

**A. Description of an ABLE Account:** While a full discussion of ABLE accounts is beyond the scope of these materials, a brief description of the key provisions will help make what is suggested below more understandable.

ABLE accounts are authorized by the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014 (the “ABLE Act”), enacted on December 19, 2014 as part of The Tax Increase Prevention Act of 2014.<sup>18</sup> The ABLE Act allows a state, or state agency or instrumentality, to establish and maintain a tax-advantaged savings program (an “ABLE program”) that benefits certain individuals who have a disability.

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<sup>18</sup> Pub. L. No. 113-295.

Qualified individuals can establish and own an account (an “ABLE account”) managed under an ABLE program.

In order to be eligible to have an ABLE account, the beneficiary must satisfy a few requirements. These are:

- 1) The beneficiary must have been “sufficiently disabled” prior to age 26.
- 2) The beneficiary can have only one ABLE account.
- 3) The ABLE account can only receive cash, not other assets.
- 4) The maximum amount of money that can be received into an ABLE account from all sources (with one exception allowing a portion of the beneficiary’s earnings if certain conditions are met) in a calendar year is the then-current per donee annual exclusion authorized by I.R.C. § 2503(b),<sup>19</sup> or in other words, the amount that can be given away without incurring a taxable gift. This is \$16,000 in 2022.
- 5) With some restrictions, contributions can be made to an ABLE account, and distributions made from an ABLE account, without adverse tax consequences or causing the beneficiary to be disqualified from public benefit programs. In addition, the money in an ABLE account grows income tax free.<sup>20</sup>

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<sup>19</sup> I.R.C. § 529A(b)(2)(B); POMS SI 01130.740.B.2.

<sup>20</sup> I.R.C. § 529A(a).

Upon the death of the beneficiary, any money remaining in the ABLE account, after the payment of the beneficiary's bills and last expenses (including, but not limited to, funeral and burial) must first be used to repay any Medicaid benefits the beneficiary received after the date the ABLE account was established.

**B. When to Consider Distributing From a Special Needs Trust Into the Beneficiary's Able Account:** Whether it is appropriate for a special needs trust to make a distribution to the trust beneficiary's ABLE account depends on the circumstances. However, there are at least two times when transferring money from a special needs trust to an ABLE account have been appropriate and helpful.

**1) Give the Beneficiary More Spending Money:** One of these times is when the beneficiary has sufficient intellectual capacity to appropriately spend money, but the amount of money the beneficiary can have access to at the end of a month is limited because the beneficiary is receiving means-tested public assistance, such as SSI or Medicaid.<sup>21</sup> The trustee can distribute from the special needs trust to the beneficiary's ABLE account. However, be careful that the ABLE account does not receive too much money within a calendar year; remember that in 2022 it is limited to \$16,000 per year from all sources.

Also, because an ABLE account will repay Medicaid upon the death of the ABLE account owner, it is more appropriate to distribute to an ABLE account from a self-settled special needs trust than a third party-settled special needs trust. This is because the self-settled special needs trust will also repay

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<sup>21</sup> The available resource limit imposed by SSI and most Medicaid programs is \$2,000. However, some states have a different limit for their Medicaid program.

Medicaid upon the death of the beneficiary. Therefore, with one exception,<sup>22</sup> it does not matter whether there is money in an ABLE account or a self-settled special needs trust upon the beneficiary's death - both will be required to repay Medicaid. A third party-settled special needs trust, however, will not be repaying Medicaid upon the beneficiary's death.

**2) Pay for “Shelter” When the Beneficiary is Receiving SSI:** Another time when distributions to the beneficiary's ABLE account are appropriate is when the beneficiary is receiving SSI and needs help paying for “shelter” expenses. Any money the trust pays towards “shelter” expenses for the beneficiary is deemed to be “in-kind support and maintenance” and will cause a reduction in the beneficiary's future SSI. On the other hand, payment of these expenses from an ABLE account does not cause a reduction in the beneficiary's SSI.<sup>23</sup> Also, transfers from the trust to the ABLE account do not have any negative effect on the beneficiary's eligibility for SSI or Medicaid.

#### **4. What are the Expectations or Immediate Needs of the Beneficiary and/or Family?**

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<sup>22</sup> The exception has to do with what amount of Medicaid is repaid from a self-settled special needs trust that complies with 42 U.S.C. § 1396p(d)(4)(A) and an ABLE account. The assets remaining in a self-settled special needs trust upon the death of the beneficiary must repay all Medicaid the beneficiary received during the beneficiary's entire lifetime. In contrast, the assets that remain in an ABLE account upon the death of the account owner only repays Medicaid received by the account owner since the date the ABLE account was established. Medicaid received prior to the establishment of the ABLE account is not repaid from the ABLE account, but would be repaid from the self-settled special needs trust.

<sup>23</sup> This is because “housing” expenses, which include the exact same list as “shelter” for SSI purposes, are “qualified disability expenses” under the ABLE Act and do not cause a reduction in SSI. See POMS SI 01130.740.C.4, which says, “Do not count ABLE account distributions as income. A distribution from an ABLE account is not income but is a conversion of a resource from one form to another, see SI 01110.600B.4.

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

The third question the trustee needs to ask is what the beneficiary and the beneficiary's family members are anticipating or expecting to receive from the special needs trust, and when they expect to receive it.

This is particularly true if the assets funding the special needs trust are coming from a personal injury award. Often family members have been skimping, doing without, and spending all available money on the beneficiary for many years. Now that the lawsuit is over and money is available, there is can be strong pressure to use that money to help family members in addition to the beneficiary.

More importantly, the beneficiary often has immediate needs that can and should be addressed with the money in the special needs trust. Some of these may be realistic and legitimate, and others may not be legal or possible. It is helpful to know what the beneficiary and/or family members are thinking about these topics.

Some of the items that are often important for a beneficiary of a special needs trust include things such as providing housing, transportation, education or training, therapies or medical or dental care Medicaid or Medicare may not be paying for, items needed or wanted for the beneficiary's home, and travel the beneficiary would like to take. There may also be a need to pay for other people to travel to visit the beneficiary.

While the details of what type of housing, transportation, and other items are appropriate for the beneficiary and are beyond the scope of these materials, the point of this question is to make sure the trustee is having these conversations with the beneficiary and appropriate family members so that expectations are realistic and there are no big surprises for either party. Also, if it is possible that any of these expenditures will actually be made, the trustee needs to maintain sufficient liquidity in the trust assets so money will be available when needed.



## 5. What Does the Trust Document Say, Specifically?

The fifth question is to ask has to do with what the trust document actually says. Obviously, it is important for the trustee to be very familiar with the written trust document that describes the trust established for the beneficiary. However, it is not unusual for there to be unique provisions in a special needs trust, particularly if it is a third party-settled trust.

**A. Specific Provisions:** There may be specific provisions in the trust document regarding:

**1) Housing:** There may be directions to retain or purchase a house for the beneficiary to live in and the trust to own. This may or may not include provisions allowing or requiring the trustee to contract with an agency to provide Independent Supported Living services, which may require other people with a disability or staff member also living in the house. There may also be directions, or prohibitions, regarding neighborhoods, cities, or states where the trustee is authorized, directed, or prohibited from paying for housing for the beneficiary to live in.

**2) Motor Vehicle or Transportation:** There may be specific instructions in the trust document relating to retaining a certain vehicle already owned, or purchasing and paying the ongoing expenses for a motor vehicle for the beneficiary. This may be an adapted van or a more traditional car or SUV.

**3) Travel:** There may be specific instructions regarding paying for the beneficiary to take trips, and who can travel with the beneficiary and have their expenses also paid by the trust. Or there may be specific prohibitions relating to this. In addition, often special needs trusts will instruct the trustee

to pay for other family members or trust advisors to travel to visit the beneficiary on a regular basis.

**4) Payments to Others:** There may be provisions directing the trustee to make annual distributions to whoever is serving as the beneficiary's guardian or serving as a trust advisor. Typically, these are meant to be gifts to those people as a thank you for looking out for the beneficiary, and not compensation for doing the requesting job. However, these could be structured as payments for work performed, which may require the trustee to withhold taxes.

**B. Must the Trustee Consider the Needs of Remainder Beneficiaries When Making Distribution Decisions?** The trust document will instruct the trustee where to distributed any assets remaining in the trust when the beneficiary is no longer living. The people or entities to receive these remaining assets are often referred to as the "remainder beneficiaries."

Usually governing law requires the trustee to take into consideration that there are remainder beneficiaries when deciding how to invest and distribute trust assets during the beneficiary's lifetime.<sup>24</sup> This means the trustee should be thinking about making sure there are assets left when the beneficiary dies so there is something to distribute to the remainder beneficiaries. This may cause the trustee to not make a distribution for the beneficiary's benefit unless it is absolutely necessary to do so.

Often special needs trust will contain a clause clarifying that the trustee should only look to the current beneficiary when determining whether to make a distribution, and not be concerned about preserving assets for the remainder beneficiaries. The clause often will look something like this:

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<sup>24</sup> See for example, Uniform Trust Code § 803.

My child is the primary beneficiary of this trust. The Trustee is directed to use the trust assets to provide amply for my child, and the preservation of principal for the remainder beneficiaries is entirely secondary to this objective.

The trustee should carefully review the trust document to see what restrictions, if any are placed on the trustee's ability to distribute all the trust assets for the current beneficiary.

**C. Chart for Reviewing Trust Document:** As a suggestion, Appendix A is a chart that may be helpful when reviewing the special needs trust.

## **6. Is the Trustee Required to Consult With Other People?**

The sixth question the trustee should ask is whether the trustee will need to consult with other people before making distributions from the trust. This may depend on the beneficiary's circumstances or provisions in the trust document.

**A. Guardian or Conservator:** If the beneficiary has a guardian or conservator of the person that has been appointed by a court (for ease of reference, only referred to in this section as a guardian), the trustee will need to include that person in discussions about what is appropriate, or not, for the beneficiary. Typically, the guardian will not have the authority to direct what the trustee does or override a decision made by the trustee. However, the guardian is responsible for the well being of the beneficiary, and as such, needs to be involved in the decision process regarding what distributions to make from the special needs trust for the beneficiary's benefit.

**B. Durable Power of Attorney Agent:** If there is no guardian, but the beneficiary does not have sufficient capacity to understand what the trustee may be asking nor have the cognitive ability to make or communicate decisions, then there may be an agent appointed by a durable power of attorney signed by the beneficiary prior to the beneficiary losing cognitive capacity. If so, the trustee will need to know who that agent is and involve them in discussions and decisions as appropriate.

**C. Trust Advisor or Trust Protector:** It is possible the trust document appoints a person or group of people as trust advisors or trust protectors. If so, then the trustee needs to carefully read the trust provisions to understand when the trustee will need to consult with these people regarding the trust. Most trust advisor clauses direct the trustee to listen to and consider what a trust advisor is saying, but leave the ultimate decision to the trustee. However, sometimes a trust advisor is given the authority to override or veto a trustee's decision. Also, some trusts require the trustee to get the consent of the trust advisor before making distributions. The trustee needs to know what, if any, requirements are imposed on the trustee's traditional authority. Typically, a trustee will not be required to consult with a trust protector about distributions, but the trustee should confirm what the trust document actually says about when a trustee must communicate with a trust protector.

**D. Directed Trust:** It is not unusual for a special needs trust give authority to a person or entity to direct the trustee to make, or not make, distributions from the trust.<sup>25</sup> Typically, these clauses also relieve the trustee from liability for actions the trustee takes when directed to do so. If this type of clause is in the special needs trust document, then it is important for the trustee to clearly understand its authority and responsibilities, along with the authority and responsibilities of the person or entity who is directing the trustee's actions.

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<sup>25</sup> See, for example, Uniform Trust Code § 808.

## Appendix A - Chart for Reviewing Trust Document

As a suggestion, the following are some of the items the trustee should clarify about the trust.

| Question                                                                                           | Answer | Location in Document | Notes/Thoughts                                                                                                       |
|----------------------------------------------------------------------------------------------------|--------|----------------------|----------------------------------------------------------------------------------------------------------------------|
| Is the trust self-settled?                                                                         |        |                      |                                                                                                                      |
| Is the trust third party-settled?                                                                  |        |                      |                                                                                                                      |
| What is Settlor's intent in establishing the trust?                                                |        |                      |                                                                                                                      |
| Who is the beneficiary?                                                                            |        |                      |                                                                                                                      |
| Is there more than one beneficiary?                                                                |        |                      | If yes, make sure trust is third party-settled                                                                       |
| Is there authority to spend all money on the beneficiary and ignore remainder beneficiaries?       |        |                      |                                                                                                                      |
| Is there a requirement to hold back money for remainder beneficiaries?                             |        |                      |                                                                                                                      |
| Is there a requirement to payback Medicaid upon the trust termination and/or death of beneficiary? |        |                      | If so, make sure this is a self-settled trust; Medicaid does not need to be repaid from a third party-settled trust. |

|                                                                                        |  |  |                                                                                                        |
|----------------------------------------------------------------------------------------|--|--|--------------------------------------------------------------------------------------------------------|
| What distribution standard is used?                                                    |  |  |                                                                                                        |
| - Special Needs?                                                                       |  |  |                                                                                                        |
| - Discretionary or Strict?                                                             |  |  |                                                                                                        |
| - Pure Discretion?                                                                     |  |  |                                                                                                        |
| - Will beneficiary live in Kansas?                                                     |  |  | A discretionary trust in Kansas is deemed available for KanCare eligibility purposes. KSA 39-709(e)(3) |
| - Support or discretionary support?                                                    |  |  | Probably will have issues with SSI and Medicaid                                                        |
| Are there specific instructions to make, or not make, any distributions?               |  |  |                                                                                                        |
| Are there restrictions on how to title vehicles and housing?                           |  |  | If self-settled SNT, must be titled in name of trust or beneficiary. POMS SI 01120.201F.2              |
| Are there special investment powers?                                                   |  |  |                                                                                                        |
| - To invest in non-income producing assets, such as housing?                           |  |  |                                                                                                        |
| Is there a trust protector, trust advisor, or other person who can direct the trustee? |  |  |                                                                                                        |
| - If so, who is it?                                                                    |  |  |                                                                                                        |
| - What authority do they have                                                          |  |  |                                                                                                        |

|                                                                 |  |  |  |
|-----------------------------------------------------------------|--|--|--|
| Does anyone have input or oversight over distributions?         |  |  |  |
| - If so, who?                                                   |  |  |  |
| - Must they be informed before or after a distribution?         |  |  |  |
| - Is their approval needed before making a distribution?        |  |  |  |
| Can the trust be amended?                                       |  |  |  |
| - If so, by whom?                                               |  |  |  |
| - Must a court approve an amendment?                            |  |  |  |
| - Must anyone or any agency be informed of an amendment?        |  |  |  |
| - If so, before or after the amendment is made?                 |  |  |  |
| - If so, is their consent required before making the amendment? |  |  |  |
| Are there restrictions on what can be amended?                  |  |  |  |
| - If so, what are they?                                         |  |  |  |
|                                                                 |  |  |  |

# What Do I Do Now?

## Questions a Trustee Should Ask When Administering a Special Needs Trust

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Stetson University School of Law

Fundamentals of Special Needs Trust Administration

**Craig C. Reaves, CELA**  
**Reaves Law Firm, P.C.**



# Questions That Need To Be Answered



1. What type of special needs trust is this?
2. What public assistance benefits is the beneficiary receiving?
3. Does the beneficiary have an ABLE account?
4. What are expectations or immediate needs of the beneficiary and/or family?
5. What does the trust document say, specifically?
6. Is the trustee required to consult with other people?



**Special  
Needs  
Trust**

# 1. What Type of Special Needs Trust Is This?

This is actually two separate questions

**A**

- Self-Settled or Third Party-Settled Trust?

**B**

- Strict or Discretionary Special Needs Trust?

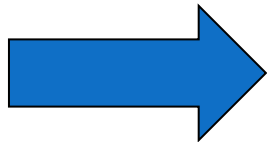


**Special  
Needs  
Trust**

# Question A: Self-Settled or Third Party-Settled Trust?

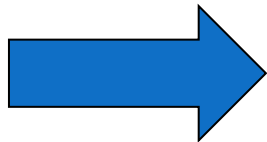
## Whose Assets Are In the Trust?

1. The beneficiary's assets (or from beneficiary's spouse)



**Self-Settled Trust**

2. Someone else's assets



**Third Party-Settled Trust**

A decorative scroll graphic on the left side of the slide, partially unrolled, with the text "Special Needs Trust" written on it.

**Special  
Needs  
Trust**

# How to Determine Whether Trust is Self-Settled or Third Party-Settled

1. Read the applicable sections of the trust document
2. Determine where trust assets came from
3. Is there more than one beneficiary?



**Special  
Needs  
Trust**

# Look in trust document for words such as...

## **Self-Settled**

- Repay Medicaid upon death
- POMS SI 01120.201
- Beneficiary is under age 65
- OBRA '93
- 42 U.S.C. § 1396p(d)(4)(A)
- FCIA '99
- 42 U.S.C. § 1382(e)(5)
- Section 1613 of the Social Security Act

## **Third Party-Settled**

# What are the POMS?

## Program Operations Manual System (POMS)

- SSA manual to guide employees
- Very helpful for attorneys and trustees
- Available online
- <https://secure.ssa.gov/apps10/>.
- POMS SI 01120.201

# Look in trust document for words such as...

## **Self-Settled**

- Repay Medicaid upon death
- POMS SI 01120.201
- Beneficiary is under age 65
- OBRA '93
- 42 U.S.C. § 1396p(d)(4)(A)
- FCIA '99
- 42 U.S.C. § 1382(e)(5)
- Section 1613 of the Social Security Act

## **Third Party-Settled**

- Does not repay Medicaid
- POMS SI 01120.200
- If there is more than one current income beneficiary, the trust will be a 3<sup>rd</sup> party trust
- Trust is NOT any of these



# Determine Where Trust Assets Came From

## When Self-Settled SNTs are Used

- Personal injury award payable to person who has a disability and needs Medicaid and/or SSI
- Inheritance received by the person
- Child with disability turns 18 years old and has excess assets
- Adult who has assets becomes disabled and needs Medicaid



Special  
Needs  
Trust



# Determine Where Trust Assets Came From

## When Third Party-Settled SNTs are Used

- When someone other than the beneficiary is leaving assets in trust for the beneficiary's benefit. Use when someone is establishing a trust for the benefit of another person.
  - Parent for Child
  - Grandparent for Grandchild
  - Child for Parent, Grandparent, or Sibling



**Special  
Needs  
Trust**

# Special Needs Trusts



```
graph TD; A[Special Needs Trusts] --> B["$ from someone other than Beneficiary (Third Party-Settled)"]; A --> C["$ from Beneficiary (Self-Settled)"]; B --> D[Third Party-Settled Special Needs Trust]; C --> E[d4A Trust]; C --> F[d4C Trust (Pooled Trust)];
```

The diagram is a flowchart titled "Special Needs Trusts". It branches into two main categories: "\$ from someone other than Beneficiary (Third Party-Settled)" and "\$ from Beneficiary (Self-Settled)". The first category leads to a "Third Party-Settled Special Needs Trust". The second category branches into two sub-categories: "d4A Trust" and "d4C Trust (Pooled Trust)". The "Third Party-Settled Special Needs Trust" and "d4A Trust" boxes are circled in red.

\$ from someone other than  
Beneficiary  
(Third Party-Settled)

Third Party-Settled  
Special Needs Trust

\$ from Beneficiary  
(Self-Settled)

d4A Trust

d4C Trust  
(Pooled Trust)

# Effect of Self-Settled Trust on Medicaid & SSI Eligibility

Trust assets are available resources for SSI and Medicaid (*i.e.*, will disqualify the beneficiary from these programs) unless trust complies with

- OBRA '93 (42 U.S.C. § 1396p(d)(4)(A) & (d)(4)(C))
- Applied only to Medicaid eligibility, and
- FCIA '99 (applied OBRA '93 provisions to SSI eligibility)



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# Effect of Third Party-Settled Trusts on Medicaid & SSI Eligibility

- Does NOT have to comply with OBRA '93 or FCIA '99
  - Does NOT have to comply with “sole benefit” rules
  - Can be more than one income beneficiary
  - Does NOT repay Medicaid upon death of beneficiary
- Will NOT disqualify from Medicaid or SSI
  - IF correct distribution standard used



Special  
Needs  
Trust

# Question B: Strict or Discretionary SNT?

Generally, there are four trust distribution standards

1. Support (mandatory support)
2. Discretionary Support
3. Pure Discretion
  - Exempt for Medicaid in most states, but not Kansas
4. Special Needs – Exempt for Medicaid and SSI in all states
  - Discretion to distribute for “special needs” of beneficiary
  - Generally, anything not paid for by public benefits

# Two Types of Special Needs Distribution Standards

- Strict – Prohibited from distributing for any food, shelter, or anything provided from public benefits; Cannot cause loss or reduction of public benefits
- Discretionary – Trustee has discretion to distribute for food, shelter, or items provided by Medicaid if the trustee deems it in the beneficiary's best interest, even if reduces benefits.



Special  
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Trust

# Is There an IRA Payable to the Trust?

- Self-Settled SNT –
  - Private Letter Ruling 200620025
  - Allows person to transfer inherited IRA to self-settled SNT
- Third Party-Settled SNT –
  - IRC § 401(a)(9) and Prop. Reg. § 1.401(a)(9)
  - If IRA received after SECURE Act (January 1, 2020), the SNT may qualify as a Type II Applicable Multi-Beneficiary Trust

## 2. What Public Assistance is Beneficiary Receiving?

There are two types of public assistance programs

### Not Means-Tested

To qualify for these, a person must be

- blind,
- sufficiently old, or
- have a permanent and total disability,

AND be able to connect to Social Security or Railroad Retirement benefit programs

### Means-Tested (Needs-Based)

In addition to being blind, having a permanent and total disability, or being sufficiently old, a “means-tested” public assistance program bases eligibility on financial need, such as:

- Low income, and
- Low assets (“available resources”)

Do not need a connection to Social Security or Railroad Retirement



# Another View of Means-Tested Programs

|                                            | Not Means-Tested (or Needs-Based)<br>But need connection to Social<br>Security or Railroad Retirement      | Means-Tested (Needs-Based)<br>Do NOT need connection to Social<br>Security or Railroad Retirement |
|--------------------------------------------|------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|
| Money Only;<br>No Benefits or<br>Services  | Social Security Disability (SSD), Social<br>Security Retirement, and Railroad<br>Disability and Retirement | Supplemental Security Income<br>(SSI)                                                             |
| Benefits and<br>Services Only;<br>No Money | Medicare                                                                                                   | Medicaid                                                                                          |

# Special Concerns About SSI and Medicaid

---

If beneficiary receiving SSI or Medicaid, Trustee should not:

Distribute cash to beneficiary, make deposits into beneficiary's bank account, or add money to debit card that is not restricted

- Will cause dollar-for-dollar reduction in beneficiary's SSI
- Will increase beneficiary's monthly spenddown requirement for Medicaid



Special  
Needs  
Trust

# Special Concerns About SSI

---

If beneficiary receiving SSI, Trustee should not:

Pay for beneficiary's food or "shelter," or give food or shelter to beneficiary

- Referred to as "in-kind support and maintenance" or "ISM"
- Will cause SSI reduction pursuant to "Presumed Maximum Value Rule"
  - Lesser of (i) actual value of ISM, and (ii) one-third of maximum SSI + \$20
  - $\$841 \div 3 = \$280.33 + \$20 = \$300.33$  reduction. Leaves \$540.67 of SSI (at most)



Special  
Needs  
Trust

# Special Concerns About SSI

---

“Shelter” expenses are:

|                                                            |                     |                 |
|------------------------------------------------------------|---------------------|-----------------|
| Mortgage (including property insurance required by lender) | Real property taxes | Rent            |
| Heating fuel                                               | Gas                 | Electricity     |
| Water                                                      | Sewer               | Garbage removal |

# How Types of Special Needs Distribution Standards Affect Trustee's Decision

**Example:** Beneficiary receiving SSI & needs a house, trust has \$3,000,000 in assets.

Distributing for housing is “shelter” and causes reduction in SSI.

- Strict – Cannot provide housing; will reduce SSI
- Discretionary – Can provide housing if the trustee deems it in the beneficiary's best interest, even though causes reduction of SSI.

# Do Not Rely on Verbal Description of Benefits Being Received

SSI and any other money from SSA look similar –

- They all pay money monthly directly deposited from the Social Security Administration (SSA)
- A person could be receiving
  - SSI,
  - SSD from the person's own account,
  - SSD from a parent's account, and/or
  - retirement SS from their own account.



Special  
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Trust

# Obtain Documentation of Benefits

## 1. Social Security

- Recent Benefit Statement

## 2. SSI

- Recent Benefit Notice

## 3. Medicaid

- Benefit Notice or letter

## 4. Public Housing

- Letter or Notice of Approval

# Obtain Documentation of Benefits

## 5. Copy all Identification Cards

- Front and Back
- Make sure have assigned ID numbers

## 6. Copy recent bank statements

- For all accounts in name of or controlled by beneficiary or someone on beneficiary's behalf



**Special  
Needs  
Trust**



### 3. Does Beneficiary Have an ABLE Account?

If so, the trustee can distribute money from the special needs trust to the beneficiary's ABLE account without penalty



**Special  
Needs  
Trust**

# ABLE Accounts – What Are They?

## **Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014 (the “ABLE Act”)**

An investment vehicle where a limited amount of money can be contributed and accumulated without disqualifying the beneficiary from means-tested public assistance.

But a person has to qualify to be able to use an ABLE account, and there are restrictions on how money in an ABLE account can be used without adverse consequences.

# ABLE Account – Some of The Requirements

1. Must be sufficiently disabled prior to age 26
2. Can be only **one** ABLE account per person
3. Only cash can be given to an ABLE account
4. Maximum of \$16,000/year contribution (in 2022) from all sources
5. Must repay Medicaid upon death of beneficiary
  - But only for Medicaid received AFTER account is established

# ABLE Accounts – Some of The Details

1. Earnings compound income tax free
2. Assets in ABLE account are not “available resource”
3. Contributions not “income” to beneficiary for tax or means-tested benefits

# ABLE Accounts – Some of The Details

4. Distributions for “qualified disability expenses” do not adversely impact beneficiary’s means-tested public benefits

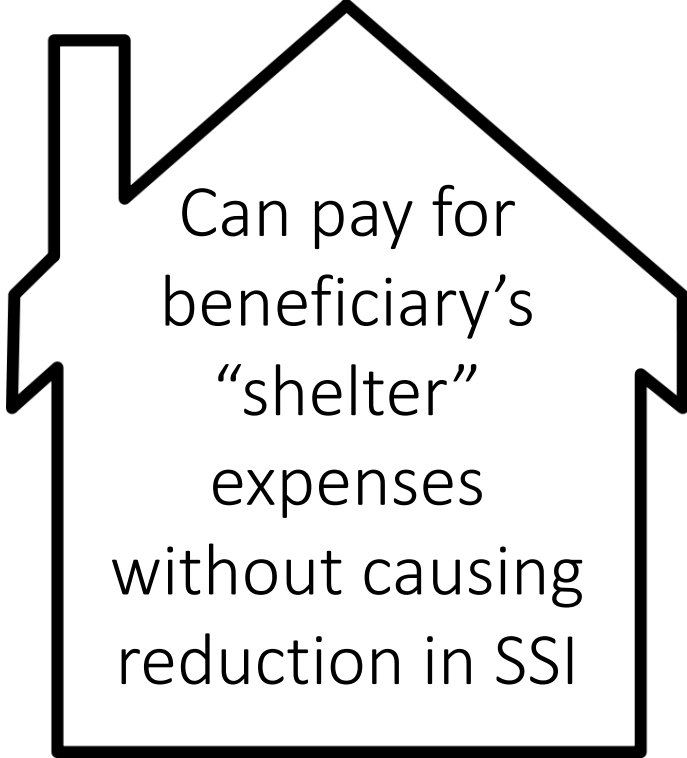
|                                                    |                                       |                             |                                                  |
|----------------------------------------------------|---------------------------------------|-----------------------------|--------------------------------------------------|
| Education                                          | Housing (“shelter”)                   | Transportation              | Employment training and support                  |
| Assistive technology and personal support services | Expenses for oversight and monitoring | Prevention and wellness     | Financial management and administrative services |
| Legal fees                                         | Health                                | Funeral and burial expenses | Other approved expenses                          |
| Basic living expenses (added by POMS)              |                                       |                             |                                                  |

# How a SNT Can Coordinate With an ABLE Account

The SNT can distribute money to ABLE account without penalty



Can give beneficiary more  
spending money



Can pay for  
beneficiary's  
"shelter"  
expenses  
without causing  
reduction in SSI



## 4. What Are Expectations or Immediate Needs?

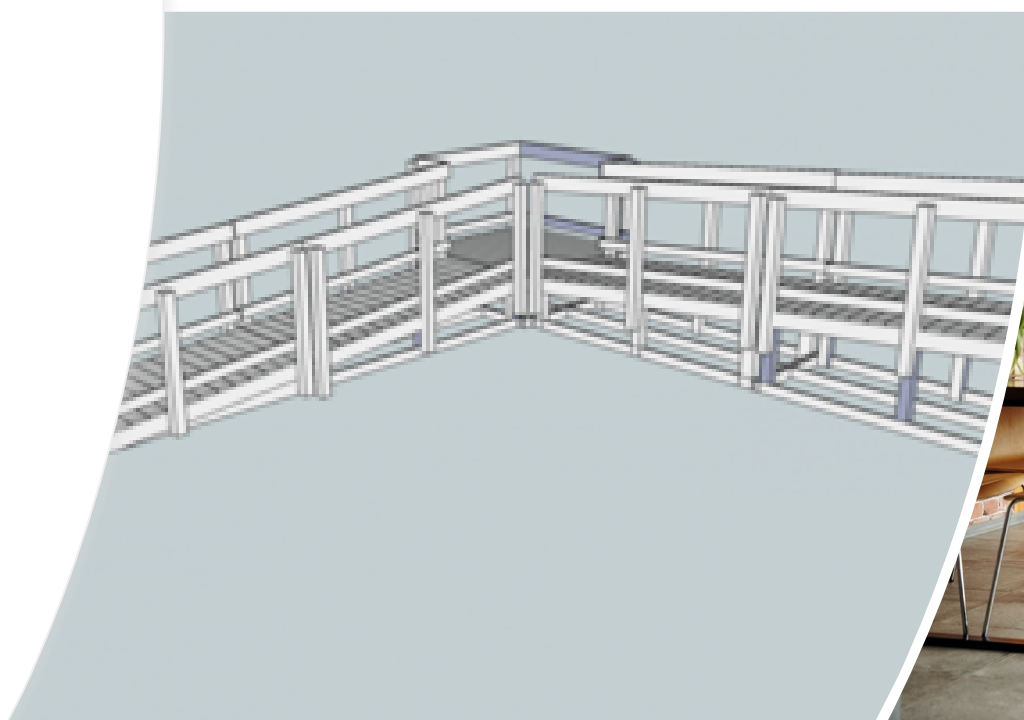
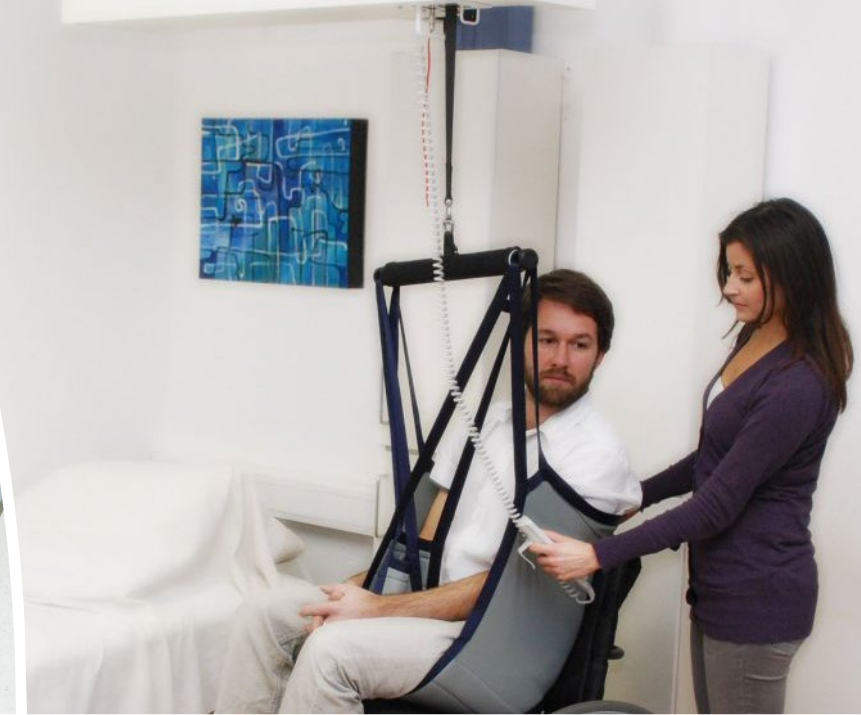




## 5. What Does the Trust Say, Specifically?

### Housing

- Adapt current house to accommodate
- New house or condo
- Add pool
- Other requirements





# What Does the Trust Say, Specifically?

## Transportation

- Adapted vehicle to drive
- Own a vehicle to transport
- Arrange for transportation services
- Pay for use of Uber or Lyft





# What Does the Trust Say, Specifically?

## Travel

- Pay for trips where beneficiary would like to go
- Pay for companions to accompany beneficiary
- Pay for family and friends to travel to beneficiary to visit
- Be careful if self-settled SNT; must be for “sole benefit” of beneficiary



# What Does the Trust Say, Specifically?

## Payments to Others

- Guardians
- Trust Advisors
- Care Managers or providers

## Examples

- Reimbursing Expenses
- Give money annually as a thank you
- Or pay for services

## 6. Is the Trustee Required to Consult with Other People?

1. Guardian or Conservator
2. Durable Power of Attorney Agent
3. Trust Advisor or Trust Protector
4. Directed Trust



**Special  
Needs  
Trust**

# App. A-What Are Important Provisions of This Trust?

Carefully read the trust document to find key provisions

| Question                            | Answer | Location in Doc. | Notes/Thoughts                                           |
|-------------------------------------|--------|------------------|----------------------------------------------------------|
| Self-settled?                       |        |                  |                                                          |
| Third party-settled?                |        |                  |                                                          |
| More than 1 bene?                   |        |                  | If yes, make sure trust is 3 <sup>rd</sup> party-settled |
| Payback Medicaid?                   |        |                  | If yes, make sure trust is self-settled                  |
| What distribution standard is used? |        |                  | If not special needs, my be issues                       |

# App. A-What Are Important Provisions of This Trust?

| Question                                    | Answer | Location in Doc. | Notes/Thoughts                                                          |
|---------------------------------------------|--------|------------------|-------------------------------------------------------------------------|
| Restrictions on titling house and vehicles? |        |                  | If d4A, must be titled in name of bene. or trust – POMS SI 01120.201F.2 |
| Trust protector or trust advisor?           |        |                  |                                                                         |
| - If so, who and what authority?            |        |                  |                                                                         |
| Can trust be amended?                       |        |                  |                                                                         |

# What Do I Do Now?

## Questions a Trustee Should Ask When Administering a Special Needs Trust

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Fundamentals of Special Needs Trust Administration

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**Reaves Law Firm, P.C.**



STETSON LAW

# **2022 Fundamentals of Special Needs Trusts Administration Webinar**

**Friday, May 20, 2022**

**1:30 P.M. – 2:20 P.M.**

**Stop Talking and Start Doing: The Hows,  
the Whys, and the Ethics of Using a  
Client-Centered Approach in SNT**

Presenter:

Rebecca C. Morgan

- Materials
- PowerPoint

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Center for Excellence in Elder Law

ACCESS AND JUSTICE FOR ALL®





## **Aspirational Standards for the Practice of Elder Law and Special Needs Law**

Second Edition, April 24, 2017

### **Preamble**

The National Academy of Elder Law Attorneys (NAELA) was founded in 1987 to support attorneys in meeting the complex legal needs of elderly individuals and individuals with special needs. These Aspirational Standards for the Practice of Elder and Special Needs Law are core to NAELA's mission. NAELA requires all members to support these Standards. This condition of membership distinguishes NAELA from all other legal associations.

Given the dynamic and evolving nature of elder and special needs law, attorneys should and often must represent their clients "holistically," adapting and applying information and insight obtained from a wide range of legal and social disciplines. When assisting clients with planning or the implementation of plans, elder and special needs law attorneys often represent clients who have diminished or lack of capacity. Family members and other persons with fiduciary responsibilities also may be involved. The attorney-client relationship in elder and special needs law is not always as clear-cut and unambiguous as in other areas of law. Questions relating to end-of-life planning, self-determination, exploitation, abuse, long-term care planning, best interests, substituted judgment, and, fundamentally, "Who is the client?" present issues not regularly faced by attorneys in other fields. These Standards are designed to assist attorneys to provide high-quality counsel, advocacy, and guidance to clients in this unique and specialized area.

These Aspirational Standards:

- Assist attorneys to navigate the many difficult ethical issues that often arise when representing elderly individuals and individuals with special needs;
- Raise the level of professionalism in the practice of elder and special needs law; and
- Assist attorneys to effectively meet the needs of their clients.

This second edition of the Aspirational Standards is the product of 3 years of study and deliberation by NAELA's Professionalism and Ethics Committee. While each state's professional responsibility rules mandate the minimum requirements of conduct for attorneys to maintain their licenses, the Aspirational Standards build upon and supplement those rules.

These Standards do not define or establish a legal or community standard nor are they intended to be used to support a cause of action, create a presumption of a breach of a legal duty, or form a basis for civil liability. Those matters are governed by the statutes and rules of professional responsibility of the state in which the attorney practices.

Following these Aspirational Standards helps attorneys make the lives of clients better. As Clifton Kruse, NAELA Past President and member of the Professionalism and Ethics Committee at the time the Committee drafted the first edition of the Standards, so aptly said:

[C]lients are hesitant to share without invitation. There is a threshold that we must assure them that we want them to cross. And we do this with questions. And we do it as lawyers. We are the elders' lifeline. ... Our licenses make this possible. They give us status and credibility, and after meeting us — hopefully, trust. The legal answers are comparatively easy — the job we are called in to do is done — but along the way, the more important, the more valuable service occurs as well. We listen. We invite a monologue. We establish this by our demeanor and by our questions that invite unloading — and in the process we extend the joy that elders' memories bring. And on those days, we earn the accolade — professional — one who serves others. That is our privileged role as lawyers; we can make others' lives, if even for a few moments, better than they were before.

The following are the NAELA Aspirational Standards. If you are a NAELA member or prospective member, you can [access the full version with commentary here](#).

#### **A. Holistic Approach**

The elder and special needs law attorney:

1. In applying a holistic approach to legal problems, works to consider the larger context, both other legal consequences as well as the extra-legal context in which the problems exist and must be solved.
2. May consider using nonlegal services to accomplish the goals of the representation when appropriate and the client consents.
3. Encourages the use of family members and other third parties to support the client in the legal representation when appropriate and the client consents.
4. Explains to the client seeking estate planning services how conflicts among family members may develop and, if desired by the client, recommends harmony-enhancing measures consistent with the client's estate planning goals to minimize these conflicts.
5. When conflict between family members or other interested parties arise, evaluates whether nonjudicial conflict resolution is appropriate and encourages noncourt resolution when appropriate.
6. Takes actions to help prevent current and future financial exploitation, abuse, and neglect of the client.

#### **B. Client Identification**

The elder and special needs law attorney:

1. Identifies the client and the individuals who will assist the client at the earliest stage of the representation, obtains the client's agreement on these identifications, and communicates this information to the persons involved.
2. Recognizes the unique challenges of identifying the client when a fiduciary is acting on behalf of a protected individual.

3. Meets with the prospective client in private at the earliest practicable time to help the attorney identify the client and assess the prospective client's capacity and wishes as well as the presence of any undue influence.

### **C. Engagement Agreements and Document Drafting**

The elder and special needs law attorney:

1. Uses an engagement agreement, letter, or other writing that will:
  - a) Identify the client;
  - b) Describe the scope and objectives of the representation;
  - c) Disclose potential material conflicts of interest between the attorney and client;
  - d) Explain the attorney's obligation of confidentiality;
  - e) Confirm, when there are joint clients, that the attorney will share information and confidences between them and may withdraw if one client requests that the attorney not disclose a secret to the other client or if the clients cannot agree on how to proceed;
  - f) Disclose potential material conflicts between joint clients;
  - g) Address (and possibly waive) nonmaterial conflicts of interest between joint clients;
  - h) Confirm, when representing a fiduciary, the fiduciary's obligations to the protected individual, clarify whether the attorney may speak directly to the protected individual, and state that the attorney may withdraw if the fiduciary violates a fiduciary or other duty to the protected individual and does not take timely corrective action;
  - i) Set out fee arrangements (hourly, fixed fee, or contingent); and
  - j) Explain when and how the attorney-client relationship may end.
2. Drafts documents reflecting the client's intentions and informed choices that:
  - a) An attorney-client relationship has been established (except in certain exigent circumstances described in Standard C. Engagement Agreements and Document Drafting, Section 4(a);
  - b) The client has sufficient capacity to sign the documents;
  - c) The documents reflect the client's intentions and informed choices as opposed to the choices of others; and
  - d) If the client is a fiduciary, the fiduciary appears to have authority and the proposed documents either reflect the choices of the protected individual if known or, if not known, are in the protected individual's best interests.
3. Recognizes the unique challenges in drafting documents at the request of a fiduciary.
4. Exercises caution when:
  - a) Drafting documents in exigent circumstances for a prospective client before the attorney-client relationship is established;
  - b) Drafting documents for a new client at the request of an existing or former client related to the new client;
  - c) Drafting a special needs trust for a person with special needs; and
  - d) Drafting documents to be signed by nonclients.

5. The elder and special needs law attorney ensures that documents are properly executed.

#### **D. Conflicts of Interest**

The elder and special needs law attorney:

1. In the initial meeting when multiple prospective clients are present, ensures that the prospective clients understand whether the representation will be individual, concurrent, or joint.
2. Undertakes joint or concurrent representation, as permitted by relevant state rules of professional conduct and these Aspirational Standards, only after obtaining the consent of the parties and having reviewed with them the advantages and disadvantages of such representation, including the relevant foreseeable conflicts of interest and risks of such representation, in a manner that will be best understood by each person to be represented.
3. Treats family members who are not clients as unrepresented persons and accords them involvement in the client's representation only to the extent that the client consents to their involvement with a signed waiver or, if the client no longer has the capacity to consent, to the extent that their involvement is consistent with the client's wishes and values if known and, if not known, the client's best interests.
4. Accepts payment of client fees by a third party only after:
  - a) Determining that payment by the third party will not influence the attorney's independent professional judgment on behalf of the client;
  - b) Securing the client's informed consent to the payment by the third party in writing; and
  - c) Ensuring that all the parties understand and agree to the ethical ground rules for third-party payment.
5. Subject to state regulations, may serve as a fiduciary for a client upon the request of a client who has capacity if it is in the client's best interests and if the client gives written informed consent after full disclosure.

#### **E. Confidentiality**

The elder and special needs law attorney:

1. Carefully explains to the client and others involved, as early in the representation as possible, the attorney's duty of confidentiality to the client in order to avoid misunderstandings and to ascertain and respect the client's wishes regarding the disclosure of confidential information.
2. Explains how the rules of confidentiality are applied to different forms of representation, including individual representation and joint representation.
3. Establishes as a prerequisite to joint representation a clear understanding and agreement that the attorney will keep no client secrets from any other client in that joint representation.
4. Strictly preserves client confidences, especially in situations that involve frequent contacts with family members, caregivers, or other trusted third parties who are not clients.

5. Ascertains the wishes of the client as to whom, if anyone, the attorney may disclose confidential information and explains the potential consequences of such disclosure.
6. Carefully maintains client confidentiality to the extent possible while also meeting the requirements of laws, regulations, or court orders imposing a duty to disclose.

#### **F. Competent and Diligent Representation**

The elder and special needs law attorney:

1. Has a wide range of professional skills unique to the practice of elder and special needs law and continually demonstrates a commitment to addressing the individual needs of each client.
2. Diligently and competently handles all client matters.
3. Regularly pursues continuing professional education and peer collaboration in elder and special needs law and related subjects, including the physical, cognitive, social, and psychological challenges of elderly individuals and individuals with special needs and the skills needed to serve individuals facing those challenges.
4. Adequately trains and supervises legal and nonlegal staff members to ensure that they have the knowledge and skills needed to best serve individuals facing the challenges associated with aging and having special needs.

#### **G. Client Capacity**

The elder and special needs law attorney:

1. Continues to respect the right to self-determination and confidentiality of a client with diminished capacity.
2. Develops and uses appropriate skills and processes for making and documenting preliminary assessments of client capacity to undertake the specific legal matters at hand.
3. Adapts the interview environment, timing of meetings, communications, and decision-making process to maximize the client's ability to understand and participate in light of the client's capacity and circumstances.
4. Takes appropriate measures to protect the client when the attorney reasonably believes that the client (a) has diminished capacity; (b) is at risk of substantial physical, financial, or other harm unless action is taken; and (c) cannot adequately act in his or her own interest.
5. Uses appropriate measures to protect the client, including (a) considering the wishes and values of the client if known or, if not known, the client's best interests; (b) minimizing intrusion into the client's decision-making autonomy; (c) respecting the client's family and social connections; and (d) considering a range of supportive actions other than court proceedings and adult protective services.
6. Preserves client confidences to the extent possible by only divulging that information necessary or appropriate for protective action.
7. Seeks guardianship or conservatorship only when no other viable alternatives exist.

#### **H. Communication and Advocacy**

The elder and special needs law attorney:

1. Works to minimize barriers to effective communication with clients.
2. Maintains direct communication with the client, whether in person, by telephone, or through correspondence, even when the client chooses to involve others (including an agent under a durable power of attorney).
3. In order to obtain informed consent, advises clients of their options, explaining the possible consequences of each option.
4. Advocates for the courses of action chosen by the client.
5. When developing a plan to secure and pay for long-term supports and services should:
  - a) Strive to determine the client's wishes and values in order to achieve the client's objectives concerning living options, health care, loved ones, and property;
  - b) Endeavor to preserve and promote the client's dignity, self-determination, and quality of life;
  - c) Counsel the client about the full range of long-term services options, risks, consequences, and relevant costs;
  - d) Counsel the client in light of the client's needs, personal values, wishes, best interests, and the alternatives available; and
  - e) Counsel the client on the estate planning and tax implications of the client's choices for long-term services on his or her property.

## **I. Marketing and Advertising**

The elder and special needs law attorney:

1. Should consider marketing and advertising as an opportunity to educate the public and promote the profession of elder and special needs law.
2. Ensures that no materially false or misleading information is communicated in connection with a seminar, presentation, marketing, or advertising activity.
3. Should communicate in a manner that considers the intended audience's potential lack of sophistication or vulnerability to overly aggressive or fear-based marketing communications.
4. Communicates the attorney's education and experience to distinguish the attorney's practice and refrains from suggesting the attorney's superiority to or advantage over other attorneys.
5. Uses endorsements and testimonials in a truthful, nondeceptive, and transparent manner.

## **J. Nonlegal Services**

The elder and special needs law attorney:

1. May consider using nonlegal services to accomplish the goals of the representation with the client's informed written consent and ensures that the client's rights and attorney's ethical duties are maintained.
2. Considers alternative ways to deliver nonlegal services.
3. Discloses in writing and obtains the client's informed written consent to any relationship between the provider of the nonlegal service and the attorney, the attorney's law firm, and the attorney's immediate family members.

4. Maintains appropriate licenses and complies with state bar ethics rules when selling insurance and investment products.

#### **K. Pro Bono Legal Representation and Public Service**

The elder and special needs law attorney:

1. Recognizes the need for pro bono legal representation, provides pro bono representation to elderly individuals and individuals with special needs who cannot afford to pay, and participates in and supports pro bono referral programs.
2. Financially supports organizations that meet the needs of elderly individuals and individuals with special needs.
3. Participates actively in, and provides ongoing leadership for, efforts to improve the law to meet the changing needs of elderly individuals and individuals with special needs.

#### **About NAELA**

Members of the National Academy of Elder Law Attorneys (NAELA) are attorneys who are experienced and trained in working with the legal problems of aging Americans and individuals of all ages with disabilities. Upon joining, NAELA member attorneys agree to adhere to the [NAELA Aspirational Standards](#). Established in 1987, NAELA is a non-profit association that assists lawyers, bar organizations, and others. [The mission of the National Academy of Elder Law Attorneys](#) is educate, inspire, serve, and provide community to attorneys with practices in elder and special needs law. NAELA currently has members across the United States, Canada, Australia, and the United Kingdom. For more information, visit [NAELA.org](#), or to locate a NAELA member in your area, please visit [NAELA.org/findlawyer](#).

## LIFE PASSAGES<sup>1</sup> PSNT BEST PRACTICES GUIDELINES

*“It is one of the most beautiful compensations of life that no man can sincerely try to help another without helping himself.” Ralph Waldo Emerson*

### Introduction

The area of Pooled Special Needs Trusts (PSNT) has seen tremendous growth over the last two decades. With that growth comes great challenges including: the challenge of keeping the beneficiary central to all services provided, the challenge to face and incorporate new technologies, and the need to balance growing the entity with assuring that the humanity of the clients is never lost. The purpose of this guide is to provide PSNT Executive Directors, Administrators and Boards of Directors with suggestions on how to operate their PSNT in a way that balances all of the competing factors.<sup>2</sup>

We recognize that PSNTs come in all different shapes and sizes,<sup>3</sup> and we were trying to write guidelines that would cover the landscape, realizing that in doing so, not all of these guidelines would apply to every PSNT. A PSNT wishing to follow any of these best practices guidelines may need to pick those that would apply and modify them to fit their own special circumstances. These best practices can be adopted in their entirety, in part or modified to suit the specific needs of the PSNT.<sup>4</sup>

This guide is not intended to create a duty of care or standard that would be used in litigation against a PSNT but rather a guide that will be reviewed, edited, and expanded. Thus, this is why the document uses guide or guidelines rather than standard.

The mission, purpose and intent of PSNTs, is to serve beneficiaries and families, and continue to earn the support and trust of the government and the public. As the National Pooled Trusts Standards Committee (NPTSC) Guidelines offer, the “[m]ission [of a PSNT is] [t]o provide pooled trust services with integrity. The pooled trust program’s mission and primary purpose should be adherence to its fiduciary duties and the sole benefit status of each trust beneficiary’s account.”<sup>5</sup>

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<sup>1</sup> The authors of these guidelines are Stephen Dale, John Dickerson, Professor Roberta K. Flowers and Professor Rebecca Morgan (referred to as the Team). The Team uses life passages to mean the various stages of life through which an individual passes and how individuals with special needs and PSNT administrators need to plan for these stages for the individuals. These guidelines were created as part of a project funded by the May and Stanley Smith Charitable Trust.

<sup>2</sup> These materials are designed to guide the day to day operations of a PSNT and are not intended to aid in the establishment of a PSNT.

<sup>3</sup> “While effective pooled trusts share a broad range of best practices, variation still exists, indicating that a successful trust can take numerous shapes and forms.” See, ***Pooled Special Needs Trust Best Practices***, by True Link Financial, available at <https://truelink-wordpress-assets.s3.amazonaws.com/wp-content/uploads/Pooled-Special-Needs-Trust-Best-Practices.pdf> at 16. True Link notes variations amongst PSNTs on various items, including whether to provide “case management in-house, providing extensive hands-on support to the families they serve,” *True Link* at 17, and fees, with some using flat fees, others asset-based fees, still others based on time/resources used. *True Link* at 18.

<sup>4</sup> Many of these practices can apply to stand alone accounts for those PSNTs that also administer stand-alone trusts.

<sup>5</sup> National Pooled Trust Standards Committee, *Guidelines for Pooled Trust Organizations*, Guideline 1, Mission (06/21/2019), referred in this document as NPTSC, and available at [http://nationalplanalliance.org/wp-content/uploads/2019/08/GuidelinesForPooledTrustOrganizations\\_v2\\_2019\\_06\\_21-rev.pdf](http://nationalplanalliance.org/wp-content/uploads/2019/08/GuidelinesForPooledTrustOrganizations_v2_2019_06_21-rev.pdf). © NPTSC. “These [NPTSC] Guidelines were developed as part of an informal working group, the “National Pooled Trust Standards Committee”, comprised of members listed below, all stakeholders in non-profit organizations providing pooled trust services for beneficiaries with disabilities. Each author holds an undivided ownership interest in and to the final product in perpetuity until such right is extinguished by assignment back to the National Pooled Trust Standards Committee. It is the intent of the Committee that these Guidelines will be used in future academic, professional and industry publications, so as to



This mission requires a commitment to the highest standards of ethical conduct. Defining standards for ethical practice requires a thorough dissection of all the difficult and varied circumstances faced by trust personnel. This guide may seem at times lengthy; but hopefully, it addresses the most difficult situations faced by PSNT and provide steps that will help PSNTs prevent those situations. The length and complexity of the best practices is directly related to the complexity of taking the responsibility to recognize and facilitate a lifetime commitment to the beneficiaries. Some of the examples are based upon actual policies in use by a certain PSNT and provided to us with permission to reprint. In those instances, acknowledgement is provided. If the reader wishes to incorporate those examples into their publications, the reader should contact the PSNT for reprint permission.

These best practices are the compilation of a review of policy and procedure manuals that currently are used by some PSNTs, conversations with a number of PSNT administrators, and editing by a group of experts in the field of PSNT. There are several sources that we used in this Best Practices Guide. We have relied on True Link Financial, *Pooled Special Needs Trust Best Practices* (2016) (referenced as True Link);<sup>6</sup> National Pooled Trust Standards Committee, *Guidelines for Pooled Trust Organizations* (06/21/2019) (NPTSC) and Plan of New Jersey's *Service Coordinator Handbook* (referenced as Plan of New Jersey).<sup>7</sup> We also spoke with a number of leaders of PSNTs both as a group and individually, and with the members of the project's think tank.

The authors wish to thank the members of the project's think tank for their invaluable input.<sup>8</sup> The authors particularly wish to thank the May and Stanley Smith Charitable Trust and the Poses Family Foundation for their financial support, which made this project possible.

### *The Life Passages Plan Team*

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advance and aid in standardizing the practices of pooled trust administration and management. To the extent these Guidelines are adopted or incorporated into subsequent publicly accessible third- party publications, proper attribution must be made to the National Pooled Trust Standards Committee and its authors.”

<sup>6</sup> True Link, in its *Introduction*, explained the genesis of its PSNT Best Practices guide:

Through True Link's ongoing work with pooled special need trusts, we have found that the most successful trusts distinguish themselves in one or more of the following ways: how they communicate with beneficiaries, use technology, develop administrative processes, manage financial assets, and build their teams. These trusts develop advantages—often thorough a time- intensive and iterative process—and overcome the odds to thrive in a resource-constrained environment.

How do we know when something is a “best practice”? Trust leaders tell us. When it comes to technology, for example, people's own descriptions range from “Digitizing our documents has completely transformed our practice,” to “We succeed despite our technology—it's terrible.” Our hope is that by collecting and publishing best practice, effective trusts will learn from the innovations of others and continue to break ground in the field, and newer trusts will be more likely to succeed.

True Link Financial, *Pooled Special Needs Trust Best Practices*, available at <https://truelink-wordpress-assets.s3.amazonaws.com/wp-content/uploads/Pooled-Special-Needs-Trust-Best-Practices.pdf>), at 1-2.

<sup>7</sup> Plan of New Jersey's *Service Coordinator Handbook* is an internal document.

<sup>8</sup> Those involved and providing information are full time pooled trust administrators from various parts of the country.

## Table of Contents

|             |                                                          |    |
|-------------|----------------------------------------------------------|----|
| <b>I.</b>   | Financial Management of the Trust.....                   | 4  |
| 1.          | Distributions.....                                       | 4  |
| 2.          | Investments.....                                         | 7  |
| 3.          | Insurance .....                                          | 8  |
| 4.          | Audits .....                                             | 9  |
| 5.          | Record Keeping.....                                      | 9  |
| 6.          | Communications.....                                      | 11 |
| 7.          | Fees.....                                                | 13 |
| 8.          | Tax Exempt Status .....                                  | 14 |
| 9.          | Transfers from one PSNT to Another .....                 | 14 |
| 10.         | Financial Provisions for PSNT.....                       | 15 |
| 11.         | Retained Funds.....                                      | 16 |
| 12.         | Confidentiality.....                                     | 16 |
| 13.         | Contracting with 3rd Parties and the Use of Agents ..... | 17 |
| <b>II.</b>  | Trust Management Best Practices.....                     | 18 |
| 14.         | Policies and Procedures.....                             | 18 |
| 15.         | Strategic Partnerships.....                              | 22 |
| 16.         | Media.....                                               | 22 |
| 17.         | Technology.....                                          | 22 |
| 18.         | Real Estate.....                                         | 23 |
| <b>III.</b> | Personnel and Physical Plant.....                        | 24 |
| 19.         | Hiring and Firing: Employees and Vendors.....            | 24 |
| 20.         | Training .....                                           | 25 |
| 21.         | Distribution of Duties.....                              | 27 |
| 22.         | Physical Plant .....                                     | 27 |
| <b>IV.</b>  | Emergency Planning.....                                  | 27 |
| 23.         | Disaster Planning.....                                   | 27 |
| 24.         | Emergency Procedures .....                               | 28 |
| <b>V.</b>   | Beneficiary-Related Best Practices .....                 | 28 |
| 25.         | Beneficiary-Centered Processes .....                     | 28 |
| 26.         | Considering the Entire Person .....                      | 28 |
| 27.         | Employment Opportunities for Beneficiaries .....         | 29 |
| 28.         | Focus on the Beneficiary .....                           | 29 |
| 29.         | Beneficiary Budgets .....                                | 32 |
| 30.         | PSNT Providing Additional Services to Beneficiaries..... | 33 |

## I. *Financial Management of the Trust*

Trustees are fiduciaries and have duties to the beneficiaries. Each state has its own Trust Code that sets out the duties of the trustees. Many of the state trust codes are based on the Uniform Trust Code. Article 8 of the UTC provides the duties and powers of trustees. These include:

|                                          |                                                    |
|------------------------------------------|----------------------------------------------------|
| Duty to administer the trust             | Recordkeeping and identification of trust property |
| Duty of loyalty                          | Enforcement and defense of claims                  |
| Impartiality                             | Collecting trust property                          |
| Prudent administration                   | Duty to inform and report                          |
| Costs of administration                  | Discretionary powers, tax savings                  |
| Trustee's skills                         | General powers of trustee                          |
| Delegation by trustee                    | Specific powers of trustee                         |
| Control and protection of trust property | Distribution upon termination                      |

It is important to remember that a Pooled Special Needs Trust is still a trust and the PSNT trustee is still a trustee. As a result, those administering PSNTs must comply with the applicable rules of their state's trust codes. What follows is our take on some of the duties of the trustee that have unique applicability to a PSNT. As always, the PSNT should consult their state's trust code.

### 1. **Distributions<sup>9</sup>**

- a. The PSNT should have a regular schedule for routine and recurring distributions.
  - i. The beneficiary and any authorized representative should be provided with the distribution schedule when the account is created and whenever there is a change to the schedule.
  - ii. Vendors with whom the PSNT makes recurring distributions for beneficiaries should also be apprised of the distribution schedule.
  - iii. The executive director (or other member of the leadership team) should be authorized to make limited exceptions to the distribution schedule.
  - iv. Every distribution should have at least one supervisory approval beyond the initial staff approval. There should be a third level for amounts above an amount set by policy.

**Example:** *NPTSC Guidelines, Guideline 6(c) provides that “[t]he beneficiary or that person’s representative as applicable should be informed of the pooled trust program’s typical time frame for processing distributions.”*

- b. The PSNT should identify who can routinely approve distributions, any limit on the amount of distribution and who can approve a distribution over the approved amount.

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<sup>9</sup> As the UTC § 801 notes, the trustee has a duty to administer the trust. In the case of PSNTs, the duty would include making distributions.

**Suggestion ☹ :** A PSNT should consider approving a certain limit for discretionary distributions that an account manager is authorized to expend per beneficiary for the calendar year without further approval. The account manager must keep a record to track these distributions vis a vis the limit. If there is a request that would exceed the approved amount, the manager would seek approval of the supervisor. The PSNT should have a form for the account manager to use to document the distribution and the supervisor should do regular reviews of these discretionary distributions to make sure the process is correctly followed.

- c. The PSNT should have an internal review process for every (non-discretionary see-above) distribution that requires at least a two-step process.
  - i. First the account manager should determine the appropriateness of the expenditure.
  - ii. Second, the account manager should get approval from the Trust Director.
  - iii. Finally, the associate executive director (if any) or the Executive director approves the check request, examining the request for any anomalies.
- d. The PSNT should have a documented appeal process if a distribution request is denied. The appeal process should have reasonable time frames and allow for oversight of the process and a fair review. Any time a request is denied, the beneficiary and legal representative should be notified in writing of the appeals process.

**Suggestion ☹ :** The following (1-5) are a documented denial process from a successful PSNT with 30 years of experience. We would suggest that you develop the appropriate written denial process that fits your organizational structure and provide that to beneficiaries. Here is the example:

- 1. If the beneficiary requests a review of the denial of the request, then the account manager forwards the request and the denial to the Executive Director.
- 2. If the Executive Director agrees with the denial, then the beneficiary is notified.
- 3. If the beneficiary requests further review, then the request and denial are submitted to the Trust Advisory Committee for Review. Note: We suggest a committee like this be made up of volunteer lawyers well informed about what is and is not admissible.
- 4. If the Trust Advisory Committee supports the denial, the beneficiary is notified.
- 5. If the beneficiary requests further review, then the request and the denial are submitted to the PSNT's board of directors for review. The board recommends either approval or denial. The board's decision is final.

**Suggestion ☹ :** The Trust Advisory Committee could be made up of volunteer attorneys who understand what is and is not appropriate.

- e. Each distribution decision should be made and communicated to beneficiary within a reasonable time.
- f. Before a distribution is approved, the PSNT should confirm that the necessary documentation has been received.

- i. For example, the PSNT should obtain a copy of the court order that established or otherwise approved the creation of a (d)(4)(C) trust.
- g. The PSNT should keep a real time accounting of the beneficiary's budget so the PSNT can determine the impact of the distribution on the beneficiary's budget.
- h. The PSNT should provide regular accountings for the beneficiary at least quarterly.
- i. The PSNT should require original receipts before making a disbursement except in emergency situations, with a requirement that receipts be submitted within a specific time.
  - i. The PSNT should develop a written procedure that beneficiaries and third parties can use to submit receipts, and what forms of transmission of receipts are accepted (Example: mail, fax, etc.).
  - ii. The PSNT should examine every receipt prior to making a disbursement to ensure the receipt contains the necessary information.
  - iii. The PSNT should move toward a system of scanning every paper receipt and file it in the electronic folder for the individual beneficiary along with any electronic receipt.
- j. The PSNT should have a process in place to verify the legitimacy of reimbursements, requiring original receipts to avoid forged receipts.
- k. PSNTs should take precautions to prevent beneficiaries or family members from improperly using bank routing numbers.
- l. The PSNT may wish to use a debit card system for beneficiaries or a credit card system (The PSNT may wish to use a debit or credit card system for beneficiaries as allowed by, See POMS SI 01120.201I.1.e).
- m. The PSNT should establish a standardized and formalized process for discretionary disbursements and follow the process. The PSNT should always handle reimbursement requests and disbursements in the same way and always require the documentation prior to the disbursement.
- n. The PSNT should establish a policy on the timeliness of handling distribution requests and publish that for all beneficiaries.

**Commentary:** For routine, recurring distributions, such as paying the beneficiary's rent, the drafters believe that two working days is sufficient time to process the request. More time may be needed for unique requests.

- i. If the PSNT cannot grant the request the beneficiary should timely be informed of the decision in writing, along with the reason for the denial.
- ii. The PSNT should have a clear policy of internal review of disbursement requests including the person completing the initial request and document review, a secondary review and a final review.
- iii. The PSNT should establish a random process to check their distribution protocol and let all participants know that any disbursement may be subject to review at any time as part of this process.
- iv. The PSNT should have an appeal process in writing to give a beneficiary a chance to have a request that has been denied by the PSNT reviewed upon appeal.

**Commentary:** Perhaps no other place than here is process so important. There is a balance to be struck between attention to detail and prompt processing of distributions. Since mistakes can occur, the process needs to be clearly understood by all staff. True Link offers this best practice: “Strike a balance between diligence and efficiency in reviewing disbursement requests.”<sup>10</sup> How does a PSNT accomplish this? Designate a small number of certain staff to undertake the reviews and invest in technology that allows for online review and approval, such as a web-based system.<sup>11</sup>

## 2. Investments

- a. The PSNT should have a written investment policy that complies with their state’s version of the Prudent Investor Act and should follow that policy.<sup>12</sup> The policy should be given to the beneficiary when the account is created and be available thereafter on request.

**Example:** *NPTSC Guidelines, Guideline 8(a) provides that “[p]ooled trust programs should develop written investment policy statements that are available for review by the beneficiary or that person’s representative as applicable and consider prudent investments and risk tolerance.”*

- b. When creating the investment policy, the PSNT should be cognizant of the potential for tension between what may be good for the overall PSNT or for one beneficiary may not be good for all beneficiaries.
- c. The goal of the investment policy should be reflected in a board resolution setting the policy for the investment decisions. One very successful PSNT states their goal is to operate the trust as they would for a client that is already retired and needs the income – rather than a 30-year-old starting a retirement fund they will not need for 35 years.
- d. A copy of the investment policy should be provided as part of the materials for prospective beneficiaries or authorized representatives.

**Example:** *NPTSC Guidelines, Guideline 8(a) provides for making the investment policy statement available to beneficiaries and Guideline 8(d) provides that “[p]ooled trust programs should, upon request, make written investment policy statements available to each beneficiary or that person’s representative, if applicable.” Additionally, 8(e) calls for “provid[ing] information to teach a beneficiary or that person’s representative as applicable regarding who manages investments” on request.*

- e. The Investment policy should be reviewed at least annually.<sup>13</sup>
- f. The PSNT should rely on a team of investment advisors in developing and updating the policy, as well as formulating an appropriate asset allocation and the selection of individual marketable securities within the portfolio. The PSNT should also reduce an

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<sup>10</sup> True Link at 9.

<sup>11</sup> True Link at 9. True Link in its commentary offers that “pooled trusts with streamlined multi-person approval systems stay focused on the task at hand: documenting discretion and ensuring appropriate disbursements are made.” *Id.*

<sup>12</sup> For example, NPTSC Guidelines, Guideline 8(b) provides that “[I]nvestment managers should comply with the organization’s investment policy statements. See also Article 9 of the Uniform Trust Code.

<sup>13</sup> The NPTSC Guidelines, Guideline 8(c) provides that “[p]ooled trust programs should conduct regular investment performance reviews of the performance of the investment manager and should provide a written report of the findings of such reviews to the organization’s Board of Directors.”

- asset or sector concentrations that are identified during the review, as well as ensure appropriate cash/liquidity is available for distributions.
- g. The Board of Directors of the PSNT should complete an annual conflict of interest statement and it should be kept on file.

**Commentary:** In order for the investment advisors to give the PSNT informed advice, the PSNT will need to provide them with appropriate context regarding beneficiaries (such as life expectancy, likely distribution rate, nature and extent of disabilities and attendant costs, etc.). This in turn will better position the advisors to assess risk, develop a diversification strategy and create investment options.<sup>14</sup>


- h. The PSNT should require fee transparency from investment advisors.<sup>15</sup>

### 3. Insurance

- a. The PSNT should have adequate and appropriate insurance.
- i. The various types of insurances to consider include: premises (whether owned, or rented), key person (director), directors and officers, errors and omissions, workers' compensation, health insurance for employees, cyber security insurance, employee theft, liability, business interruption, disaster insurance (floods, fires, mudslides, tornados, sink holes, etc.), appropriate riders if employees use their cars, an umbrella policy and insurance against employee theft.

**Example:** *NPTSC Guidelines, Guideline 4(h) directs that the PSNT have “directors and officers and professional liability insurance.”*

- b. The PSNT should ensure the beneficiary's property, including as appropriate renter's insurance, homeowner's insurance (which would include flood, wind and wildfire riders, if necessary), casualty insurance, automobile insurance and personal property insurance. The PSNT should confirm that any valuable personal property is scheduled separately if required by the policy. The premiums would typically be paid from the beneficiary's funds held by the PSNT. In the event the beneficiary has insufficient funds, the PSNT may pay the insurance premiums from the retained funds (if the joinder agreement so provides).<sup>16</sup>

**Suggestion** : Suggest the beneficiary video the property to establish the pre-loss condition of the property. The PSNT may need to provide the beneficiary with the video equipment.

<sup>14</sup> *True Link* at 12.

<sup>15</sup> See *True Link* at 12, discussing the need for the PSNT to “[b]e aware (and beware) of expenses ratios and internal fees.” (inquiring about “the fully loaded cost”).

<sup>16</sup> The UTC requires the trustee to control and protect the trust property. See UTC § 809.

#### 4. Audits

- a. Each year the PSNT should arrange for outside audits: (1) internal financial operations; (2) trust procedures, internal controls and activity, (3) Information Technology (IT) security and (4) the investment management of the fund.
- b. The PSNT should post its state-filed financial documents on its website and comply with standard nonprofit practices.

**Suggestion** ¶: A PSNT might consider having a periodic programmatic audit with one firm and an annual financial audit by another firm. This allows the PSNT to identify and respond earlier to trends and problems.

**Example:** *NPTSC Guidelines, Guideline 4(g) provides that “[o]rganizations should have regular audits of the organization, including internal financial operations, trust activity and Information Technology (IT) security.”*

**Example:** *Each state has requirements for reporting. In some states, the PSNT may have to file a report with the state’s Secretary of State.*

**Suggestion** ¶: Copies of the audit reports should be provided to beneficiaries or authorized third parties. The PSNT should also consider whether to post the reports, or summaries of them, on their website—either the public side or available through client portals.

**Suggestion** ¶: Any audit findings/exceptions should be timely remediated. The audits should be presented to and confirmed by the PSNT board.

#### 5. Record Keeping<sup>17</sup>

- a. The PSNT should get originals or copies of original beneficiary documents that the beneficiary has received from government agencies such as SSA, Medicare, or Medicaid, as well as court orders, wills, trusts, settlement agreements, insurance policies, etc.
- b. If administering an MSA for a beneficiary, the PSNT should keep track of any MSAs for beneficiaries, including a policy for sufficient set asides to satisfy the MSA.
- c. The PSNT should regularly report to Medicaid, Social Security and any other required state agencies disbursements and comply with all reporting requirements of the state.

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<sup>17</sup> See, e.g., UTC § 810 (Recordkeeping and Identification of Trust Property).



**Suggestion ♀:** The PSNT should use tickler/calendar reminders for mandatory, annual reporting requirements.

**Suggestion ♀:** The PSNT should get a copy of any correspondence to CMS regarding the MSA amount and calendar any relevant dates regarding payments to CMS when a PSNT is administering an MSA.

- d. The PSNT should operate with transparency in the creation and operation of the PSNT, including record keeping.
- e. The PSNT should have a document retention policy that covers how original documents will be handled, stored and destroyed. Original documents kept in the PSNT office should be securely maintained in a way that protects the documents from theft, damage, or destruction.

**Example:** *NPTSC Guidelines, Guideline 6 TRUST CREATION TRANSPARENCY, especially 6(a) “[t]he pooled trust program should disclose the operational features of its Trusts to each prospective beneficiary or that person’s representative as applicable to set expectations of how the Trust may assist the beneficiary...”<sup>18</sup>*

*Also, Guideline 2(m) directs that “[t]he organization’s program trust operations ....be reasonably transparent for a beneficiary or that beneficiary’s representative as applicable for that beneficiary’s account.”*

- f. PSNT employees should document each transaction with supporting documentation and each beneficiary contact.
  - i. Every call should be logged and noted to the appropriate beneficiary account.
  - ii. An action report (to-do list) should be created as a result of a beneficiary’s request.
  - iii. The PSNT should make a decision on a routine recurring distribution request within a reasonable time and note the decision in the beneficiary’s file. Every contact with the beneficiary, whether initiated by the PSNT or the beneficiary should be noted in the beneficiary’s file.

**Suggestion ♀:** What is a reasonable time is fact specific. A routine recurring distribution could be determined appropriate or rejected within two working days and a check received within 5-7 days, whereas a request that needs to be taken to the PSNT committee would take more longer but still should be reasonable.

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<sup>18</sup> Guideline 6(b) covers information about any balance in a beneficiary’s account on the beneficiary’s death, 6(c) deals with the time to process a distribution and 6(d) recommends that a proposed beneficiary be encouraged to seek the advice of an attorney.

- iv. Decisions and other dispositions should be noted in the file, along with the date and method of communication to the beneficiary of the decision or disposition.


**Example:** *NPTSC Guidelines, Guideline 4(l) requires that each PSNT prepare “a brief trust summary of each trust under management which could include names and contact information for grantors, trustees, beneficiaries and remainder beneficiaries, unusual provisions, financial restrictions and examples of permissible purchases.”*

## 6. Communications

- a. The PSNT should have a policy that covers both the methods of communication with the beneficiary and the time frame within which a communication will be returned.<sup>19</sup> This information should be conveyed orally and in writing to the beneficiary and any authorized third parties.
- b. The PSNT should consider security of email and when conveying personal or financial information, consider encrypted or other secure communications.
- c. Every contact from a beneficiary, whether in person, phone, email, or other, should be logged into the file for the beneficiary that includes the date, time, method of communication and summary of it.<sup>20</sup>
- d. Every PSNT employee who has contact with anyone outside the organization should be trained on effective communication skills, including both verbal and non- verbal communications.

**Commentary:** Building relationships is critical for a PSNT organization and to that end, communication is just as important as the services provided. As True Link explains in best practice standard 1 Beneficiary Communication, “understand, communicate, review and reach out,” the “[h]igh-performing pooled trusts” approach their difficult balancing act of “protecting [the beneficiary’s] government benefits eligibility” while still purchasing items for the beneficiary “that enhanced [the beneficiary’s] quality of life” by a three-pronged approach of “understand[ing] the beneficiary’s situation, communicat[ing] critical information—especially restrictions— early on in the relationship, and maintain[ing] ongoing, regular contact.”<sup>21</sup>

True Link notes that communicating with prospective beneficiaries about the trust and its operation allows the PSNT a chance to “learn about the beneficiary’s situation, goals, and needs, and to lay the foundation for a transparent, productive relationship. Rather than just answering questions as they come in, trusts can proactively provide information about things that might need a little explaining, like the onboarding process, fee schedule, and disbursement guidelines.”<sup>22</sup>

**Suggestion**  Use prospective beneficiary conversations not only to be hired, but use these talks to manage expectations, educate beneficiaries about limits on the use of the money and develop rapport with the beneficiary.<sup>23</sup>

<sup>19</sup> A trustee has a duty to inform and report. See UTC § 813.

<sup>20</sup> The NPTSC Guidelines, Guideline 4(c) is somewhat applicable to this point. It provides that the “organization should have systems for tracking information and processes for accurate and timely availability of the needed information.”

<sup>21</sup> *True Link* at 2.

<sup>22</sup> *Id.* at 3.

<sup>23</sup> *Id.*

**Suggestion ♀:** Consider this example from Plan of NJ, known as the “Contact Note Format”:

**A. Contact Note Format**

The acronym “S.O.A.P.” can serve as a mnemonic device to help you remember what to address in your contact notes. **You should not write the letters S - O - A - P**, but you can use this guide to make sure you include all of the components in body of your note.

**S** = Service provided – What was the purpose of the contact?

**O** = Observations – Describe objectively what you see and hear.

**A** = Assessment – How is the person doing with what you came to check out?

**P** = Plan – What is your follow up and next step together.

**B. Sample Contact Note**

(S) This writer visited BJ at her home on August 1, 2008 to get acquainted and to assess her general health and well-being. The visit included a discussion with Iwach Overu, BJ’s residential sponsor, conversation with BJ, and transporting BJ to Fridays for lunch and back.

(O) BJ’s residential sponsor, Iwach Overu, reported that her health problems include diabetes, Parkinson’s, Alzheimer’s, high blood pressure, scoliosis, and psychiatric conditions. Ms. Overu showed this writer how B’s medication is tracked and discussed a wheelchair that was recently purchased through Medicare for her. Ms. Overu requested a therapeutic chair with lumbar support to ease BJ’s discomfort from scoliosis and indicated that BJ needed clothing that could be purchased through Sears. Ms. Overu also reported that BJ had not attended her day program since November after she broke her ankle and spent time in rehabilitation.

(A) BJ ordered food consistent with her required diet. She was able to answer questions and express her interest in following the Yankees and the Giants. BJ expressed contentment with her living situation and her daily routine. However, BJ did state that she missed her day program and particularly the Bingo. BJ did not comment on the need for a therapeutic chair.

(P) This writer will

1. Research the need for and acquisition of a therapeutic chair and clothing through the trust fund and initiate action accordingly.
2. Get a release for the doctor and follow up on the day program issue.
3. Make an appointment to visit BJ the beginning of September.<sup>24</sup>

- e. The PSNT should train employees on responding to beneficiaries who frequently call. The PSNT should also train employees on tips for de-escalating an interaction with an aggressive or upset beneficiary (especially when a distribution request is denied).
- f. When communicating with third parties, whether family of beneficiaries, service providers, or others, the PSNT must first have the consent of the beneficiary or authorized representative and every communication should be documented and then filed within the file of the beneficiary with whom the contact is concerned.
- g. The PSNT should have an efficient process for handling all incoming phone calls and emails. The PSNT should decide whether there will be one person who answers the phone and directs calls, or whether direct lines for each employee will be used.
- h. The PSNT should have a reliable process for handling emergency and after-hours calls.

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<sup>24</sup> *Plan of New Jersey* at 15-16.

- i. The PSNT should have a clear policy for communicating with the originators of unfunded third-party trusts that have been established. This is an important relationship to foster and build and should not be lost in daily communication with beneficiaries. It is suggested that at least annually, the PSNT update the information with the originators of the third-party trust.

**Suggestion** ♀: Communication with beneficiaries is an ongoing process and the quality of communication goes a long way toward the effectiveness of the relationship. Frequent, transparent, and clear communication with beneficiaries is crucial. The PSNT should routinely ask beneficiaries about any changes in the beneficiary's circumstances. For those beneficiaries who regularly reach out, the PSNT should always ask the beneficiary "what's new with you?" For those beneficiaries who do not regularly communicate with the PSNT, the PSNT should schedule routine check-ins with those beneficiaries just to get a status update.<sup>25</sup>

- j. Communication is a two-way street. The beneficiary should be given an opportunity to provide feedback to the PSNT in whatever manner the beneficiary feels most comfortable. One example might be a beneficiary satisfaction survey or questionnaire. Another is to just ask the beneficiary.

## 7. Fees

- a. The PSNT should create a published fee schedule that is adopted or approved annually by the PSNT board. The Board should confirm that the fee schedule is reasonable under the applicable state law.<sup>26</sup>
- b. Any fee structure changes should be determined at least six months in advance and be published to all beneficiaries affected and to any potential enrollees considering enrollment.

**Example:** *NPTSC Guidelines, Guideline 9(a) provides that "[f]ees charged by the pooled trust program should be reasonable" while 9(b) provides for "[t]he executive director in consultation with staff should develop a fee schedule that is reviewed and approved by the board of directors on a regular basis to see whether the fees are reasonable and are sufficient to meet basic organizational expenses..."*

- c. The PSNT should be transparent about its fee structure and be sure to provide it to potential clients at the first meeting.

**Example:** *NPTSC Guidelines, Guideline 9(c) directs that the organization give the proposed beneficiary or the beneficiary's authorized "representatives or grantors as applicable" a copy of the fee schedule for that beneficiary "and ... indicate that fees are subject to change upon advance notice."*

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<sup>25</sup> See, e.g. *True Link* at 4-5 which suggests "[s]etting a needs-based engagement calendar for each beneficiary with reminders scheduled immediately following the onboarding call, can be an effective strategy. Calendar items can include regular check-ins with beneficiaries themselves, as well as advocates and service providers."

<sup>26</sup> See, e.g., UTC § 708 (compensation of trustee).

- d. The PSNT should create a policy on exceptions to the fee structure.
  - i. For example, if a beneficiary runs out of money, will the PSNT continue to cover the beneficiary's (basic) expenses out of retained funds?
  - ii. The policy should explain how an exception is requested, the supporting information needed and who makes the decision about the exceptions.
- e. The PSNT in its organizational structure should clearly identify who has decision-making authority to waive or reduce any fees.
- f. The PSNT should make sure the allocation of fees between principal and income for trust accounting complies with state law.
- g. The PSNT should determine whether the fee structure is all encompassing or a la carte.

## 8. Tax Exempt Status

Each PSNT or their umbrella organization should obtain tax exempt status as a 501(c)(3) charity from the IRS.<sup>27</sup> All federal and state filings for a not-for-profit organization should be carried out in a timely manner. The PSNT should annually confirm that its tax-exempt status is in good standing and that all required reporting requirements have been met.

**Example:** *The NPTSC Guidelines, Guideline 2(b) directs the PSNT to “provide charitable services and seek donations and grants as needed in keeping with their charitable non-profit status.” Further, Guideline 4(o) directs that “[b]oard members and officers should serve without compensation (other than expense reimbursement) except to the extent they are employees of the pooled trust organization.”*

## 9. Transfers from one PSNT to another

- a. A PSNT should determine whether it will accept a transfer of a beneficiary's account from another PSNT or a standalone SNT that authorizes decanting to a PSNT.
  - i. If the PSNT does accept the transfer, the PSNT should create a list of items/information it will need from the transferring PSNT before accepting the transfer. This information could include a list of any outstanding expenditures, an accounting, any tax returns filed for the last 3 years, any applicable court orders or pending petitions, and a copy of the transferring PSNT's assessment/budget/plan.
  - ii. The receiving PSNT should not assume liability for any wrongdoing by the transferring PSNT by accepting the transfer.
  - iii. Except in limited circumstances, the request for the transfer should come from the beneficiary or the beneficiary's authorized representative.
- b. A PSNT whose beneficiary has requested the transfer of the beneficiary's account to another PSNT should
  - i. Accept the decision to move the trust but also seek to learn more from the decision. Inquire as to the reasons for the transfer and attempt to resolve any issues presented by the beneficiary as the basis for the transfer.

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<sup>27</sup> NPTSC Guideline, Guideline 2(a) directs that the PSNT “be qualified as a charitable entity by the Internal Revenue Service under Section 501(c)(3) of the Internal Revenue Code.”

- ii. Advise the beneficiary and authorized family members of the potential impact of an out-of-state transfer. For example, if the transfer is to a PSNT located in another state, the beneficiary may or may not be eligible for public benefits under that state's rules and it is possible that the state's Medicaid agency may not approve the PSNT even though the current state's Medicaid agency in fact approved it.
  - iii. If the beneficiary insists on the transfer after the disclosure, the PSNT should have the beneficiary sign an acknowledgment of the potential negative consequences of the transfer and give informed consent for the PSNT to proceed with the transfer.
  - iv. Only after the beneficiary has been advised of the potential consequences of the transfer should the PSNT cooperate fully with the beneficiary and the receiving PSNT to timely accomplish the transfer.
  - v. The beneficiary's request for transfer should be made in writing and kept as part of the PSNT's file.
- c. In the event another PSNT is deemed unable to continue its role and the PSNT is asked to assume support to an entire PSNT, the receiving PSNT shall require a court order that clearly states there is no liability for any actions prior to the court order, and no responsibility to pay any outstanding bills that are not acknowledged by the court order. Such an order will include an immediate audit of all incoming accounts paid for by the PSNT being terminated.
  - i. The PSNT should provide the beneficiary with a written explanation regarding the effect, if any, of the transfer and require the beneficiary to provide a written acknowledgment of receipt of the explanation.
  - ii. The transferring PSNT should provide the beneficiary or authorized representative with copies of any documentation provided to the receiving PSNT and receive a written acknowledgment of receipt of the documents from the beneficiary or authorized representative.
  - iii. If a court order is required to approve the transfer, the PSNT should file a petition with the court having jurisdiction over the beneficiary's PSNT for court approval of the transfer.

**Example:** *NPTSC Guidelines, Guideline 4(k) provides that: [l]ateral transfers to and from another similar pooled trust should not be unreasonably denied to promote choice and options for beneficiaries, as appropriate."*

#### **10. Financial Provisions for PSNTs**

- a. A PSNT should have unrestricted reserves of one-year operating expenses in case no new beneficiaries enroll for a year.
- b. In creating a new PSNT, the founders should have accumulated enough initial capital for 2-3 years of operational costs before starting the PSNT via cash, grants and donors.
- c. The PSNT should have additional provisions in place to ensure long-term financial sustainability.

## 11. Retained Funds

- a. The PSNT should have a policy on remainder funds, complying with the applicable laws.
  - i. The policy should describe the circumstances when funds remain, the uses of the remainder funds (whether for operations or for other beneficiaries), any time limit on terminating the joinder agreement, etc.<sup>28</sup>
  - ii. The policy should be included in the joinder agreement, written in plain language, be noted prominently and require initials of the beneficiary or authorized third party.
  - iii. If a PSNT has too large an amount of remainder funds, the PSNT should review its budgeting process.

**Suggestion** ¶ : Every year the PSNT should review the accounts of any beneficiaries who died that year with remaining funds, to see if the beneficiary's death was earlier than anticipated or due to an accident, or whether the PSNT should have done something differently regarding the oversight of that beneficiary's account, especially when the beneficiary has not been accessing money from the PSNT.

**Commentary:** The PSNT administrators and Board should understand that remainder funds are not the same as reserves for operating expenses.

**Example:** *NPTSC Guidelines, Guideline 10(a) provides that “[f]unds retained by the organization upon the death of a pooled trust beneficiary should be used to benefit people with disabilities and to further the mission of the organization.”*

## 12. Confidentiality

- a. Having a policy on confidentiality alone isn't enough. As part of mandatory training for all employees, the PSNT should train employees on confidential information and confidentiality.
  - i. Information that is confidential just does not include the client's financials, but includes any information at all about the client, including that the client is a client of the PSNT.
- b. Clients should consent to the release of information prior to its release. The release of information should only be for appropriate business purposes.
- c. If it is necessary to provide any client information to any agencies, the client's consent should be obtained at the beginning of the representation, as part of the joinder agreement.
- d. In cases where a client's health information is obtained (including in situations where the client is evaluated for disability), the PSNT must ensure that each employee with access to such information is trained on the applicable laws and regulations and the

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<sup>28</sup> In discussing remainder interests, True Link notes variations amongst PSNTs on this issue. “Some pooled trusts have strict policies that prevent the retention of any remainder interest. Others retain remainder interest and use it to run charitable programs, support operations or subsidize fees for lower-income beneficiaries.” *True Link* at 17.

employee signs a statement of completing the training and abiding by the requirements of the laws and regulations.

- e. An intentional breach of client confidentiality should be treated as a firing offense.

**13. Contracting with 3rd Parties and the Use of Agents:<sup>29</sup>**


- a. If a PSNT contracts with a third party, the PSNT should do the following before hiring the third party:
  - i. If the third party is an individual rather than a company, the PSNT should conduct a background check, obtain references and check the references. If the third party is a company, the PSNT should ensure that the company is regularly performing background checks of its employees.
  - ii. The PSNT should obtain and check references.
  - iii. The PSNT should get three bids—choose the most appropriate, not necessarily the lowest bid
  - iv. The PSNT should conduct interviews—over the phone is acceptable.
  - v. The PSNT should make sure that the 3rd party selected is licensed, bonded and insured. The PSNT should make a copy of the license number and certificate of insurance and keep in the file.
- b. The PSNT should not pay the 3rd party the entire amount up front, but instead may contract to make installment payments on achievement of certain benchmarks.
  - i. The PSNT should not make any payment to the third party at the beginning of the contract, but if the 3rd party insists on some payment up front, then the PSNT should only agree to a small amount, with discretion to the executive director to negotiate a higher amount, but no more than 50% of the contract price.
  - ii. The PSNT should confirm the job is completed before making the final payment. This may include having another inspect the premises or confirm the job completion.
    - 1. The PSNT should be sure to obtain and file any release of liens filed by the 3rd party at the inception of the contract.
    - 2. If the job isn't completed to the satisfaction of the PSNT, the PSNT should withhold final payment until the contract is fulfilled.
  - iii. When hiring a third party, the PSNT should enter into a written contract with the third party that clearly sets out the scope of work, the start and completion dates, the payment schedule, non-discrimination clause, as well as any boilerplate clauses required by law or on advice of counsel. The beneficiary or authorized third party should be given a copy of the executed contract.
- c. The PSNT should deal at arm's length with third parties. For example, the PSNT should not hire families or friends or an unlicensed handyman to make repairs to the beneficiary's home.

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<sup>29</sup> See, e.g., UTC § 807, Delegation by Trustee.



**Commentary:** Although a friend of the family may offer to do the work a lot cheaper than a professional, the potential for things going wrong could outweigh any savings.

**Suggestion**  : In the event that a professional is not available to do the work, or it is in any other way not feasible to hire a professional, then when dealing with a family member or friend, the PSNT should follow similar procedures to hiring a professional, include language in the contract limiting liability and withholding payment until the job is completed to the PSNT's satisfaction. In all events a written contract must be obtained, rather than making an agreement on a handshake.

## ***II. Trust Management Best Practices***

### **14. Policies and Procedures**

- a. Each PSNT should, with the input and contribution of the board, develop a comprehensive set of policies. The finalized policies should be adopted by the PSNT board of directors.<sup>30</sup> This set of policies should be provided to staff in a compilation that is regularly updated and able to be referred to in print or electronically.

**Commentary:** Since no two PSNTs are alike, some policies may be more appropriate for some PSNTs than others. The PSNT should be sure to develop all the policies needed for the PSNT to fulfill its goals.

- b. Every PSNT should have policies required by local, state and federal laws, such as wage and hour laws, workers compensation, and the Americans with Disabilities Act, to name a few.
- c. Every PSNT should have a policy on who has access to a beneficiary's personal identifying and financial information. Access should be limited to only those who need the information in order to do their jobs and the officers of the PSNT (if necessary).
- d. Every PSNT should have a policy on social media that covers, among other things, prohibitions on using the PSNT technology for an employee's **personal** use, and employee posting to the employee's **personal** social media from the office, even during personal time, and the prohibition against personal posting the employee's personal social media site any information about beneficiaries, co-workers and others with whom the PSNT staff interact in any way. The policy should also prohibit employees using the PSNT's logo or any other trademark in personal postings.
- e. The PSNT should have an internal conflict of interest policy approved by the PSNT board that applies to employees, administrators, officers and board members.
- f. In the event the PSNT is part of a larger not-for-profit organization; there must be clear firewalls between the PSNT, their donors, beneficiaries and key people and the not-for-profit. For example, the umbrella not-for-profit should not have access to the donors to the third-party trusts for the purposes of fund-raising.

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<sup>30</sup> For example, NPTSC Guidelines, Guideline 4(a) provides that "[o]rganizational policies should be approved by the board of directors."

**Example:** *NPTSC Guidelines, Guideline 4(n) provides that “[t]he Pooled Trust Program ... have a conflict of interest policy. The pooled trust organization should require all board members and officers to disclose any real or potential conflict of interest at the time it arises and, in any event, should annually request disclosure of such real or potential conflicts. Where an individual has a conflict of interest, the board should take appropriate steps to protect the pooled trust organization from injury or undue influence arising from the conflict.”*

- g. The PSNT should have an external conflict of interest policy approved by the PSNT board that applies to employees working or volunteering part-time for other agencies, for anyone employed by or in governance of the PSNT serving on boards of organizations or doing business with entities when doing so creates an actual conflict or the appearance of a conflict of interest. The policy should require the disclosure of such outside business activity at the inception of the activity and with annual updates as long as the activity continues.

**Example:** *NPTSC Guidelines, Guideline 4(o) prohibits officers or members of the board from being paid or receiving any kind of compensation “from any entity doing business with the pooled trust organization.”*

- h. Each PSNT employee, administrator, officer and members of the board must sign an acknowledgment regarding the conflict of interest policy.
- i. Each PSNT should have a policy that prohibits an employee, administrator, officer or board member from having any involvement with a beneficiary outside of work-related duties.<sup>31</sup>
- j. Each PSNT should have a policy for employees on when to call law enforcement or 911 when a beneficiary or interested third party is acting out of control, rather than trying to handle the matter. The failure to comply with the policy should be considered a disciplinary infraction because doing so puts individuals at risk of harm.
- k. Each PSNT should have a policy that requires reporting of suspected abuse, neglect and exploitation when a beneficiary reports to them that they have been abused by any provider, caregiver, community member or family member and provide documentation that policy is followed in each case. The policy should have specific steps based upon the situation, *i.e.*, an allegation of rape has very specific steps that should be taken.
- l. Each PSNT should also have a policy that requires reporting of suspected self-harm by the beneficiary. PSNT staff should be trained on steps to take in such situations.
- m. Each PSNT should have a policy on steps to be taken if staff believe a guardian or key person involved with a beneficiary is acting in a way that is harmful or dangerous to the beneficiary, including steps in extreme cases to seek legal recourse to seek removal of that person’s legal status.
- n. Each PSNT should have a policy to address when it might be necessary for the PSNT to petition for the appointment of a guardian, conservator or guardian ad litem, or for instructions from the court.

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<sup>31</sup> See, e.g., NPTSC Guidelines, Guideline 7(a): “[t]he pooled trust program should maintain a professional relationship with the beneficiary....”

- o. Each PSNT should have a policy and process on notifying the appropriate individuals and authorities when beneficiaries describe behavior that is indicative of bullying, taunting, etc. The policy should cover whom to report and the responsibility of staff to respond.
- p. Each PSNT should have a policy on remainder funds and on reserves that is approved by the board and reflected in the joinder agreement.<sup>32</sup> The policy should be disclosed to and acknowledged in writing by the prospective beneficiary at the creation of the account.
- q. Each PSNT should have a strong and clear policy on confidentiality. The policy should address (1) with whom can the PSNT share information, whether family members of beneficiaries, vendors or others, (2) the type and amount of information to be shared, and (3) the circumstances under which the sharing of information would be appropriate.
- r. PSNTs should always follow their own policies and procedures and include a statement in the employee handbook on the ramifications for failing to do so. If an employee doesn't know the policy, the employee should know to ask the supervisor, rather than making up an answer on the fly.
  - i. If a beneficiary can give informed consent, the PSNT should obtain such consent from the beneficiary regarding the sharing of information. The consent should be in writing and clearly note that the beneficiary can revoke this consent at any time. The beneficiary should be given a copy of the consent.
    - 1. The scope of consent should be clearly laid out in the document.
  - ii. If a 3rd party has legal authority to provide consent for the beneficiary, if the beneficiary is still capable of giving consent, the PSNT should look to the beneficiary for consent.
  - iii. If a 3rd party has legal authority to provide consent, the PSNT should require the 3rd party to provide a copy of the document (if any) authorizing the 3rd party to provide consent. The document should be kept in the beneficiary's file.

**Example:** *The NPTSC Guidelines, Guideline 4(b) provides that “[t]he organization should have policies and procedures for the confidentiality of information and the privacy of beneficiaries.*

- s. The PSNT should recognize that its employees are fiduciaries and have a policy that outlines the performance of fiduciary duties.
  - i. As a routine matter, on hiring of an employee, each PSNT should provide the employees with information about being a fiduciary and how to discharge their duties as fiduciaries.
- t. If employees of the PSNT use their personal cars for company business, the PSNT should have a policy on mileage reimbursement, insurance, liability and appropriate uses of personal cars.
  - i. The employee must provide the PSNT with written proof of ownership or documentation they are allowed to use the vehicle as well as written proof of

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<sup>32</sup> See, e.g. NPTSC Guidelines, Guideline 4(f) which directs that “[o]rganizations and their boards of directors should actively and regularly evaluate their operating reserves.”

- insurance; and road worthiness and safety of the vehicle before the employee can use the employee's personal vehicle for PSNT business.
- ii. If an employee transports a beneficiary in the employee's car, the transportation should only be for authorized activities. The PSNT should obtain a rider on insurance to cover any harm that might occur to a beneficiary when riding in an employee's personal vehicle. The employee should not assist or lift the beneficiary to/from/in/out of the vehicle. Transporting a beneficiary for non- authorized activities is a firing offense.
- iii. Reimbursement for mileage should be no more than the federal allowable rate.
- u. PSNTs should use secure time keeping-billing methods and keep accurate, detailed records.
  - i. To determine the appropriateness of an expenditure, the PSNT should make sure that the expenditures contain enough detail that the beneficiary or authorized 3rd party will have sufficient information about the expenditure.
  - ii. Entries should be made contemporaneously with an expenditure or no later than the next business day.
  - iii. Supporting documentation should be obtained for each expenditure.
  - iv. If the time/billing records are kept electronically, the PSNT should be sure to have adequate firewalls and cybersecurity systems in place.
  - v. Those individuals who have authorized access to a beneficiary's funds should be bonded.
  - vi. The PSNT should have an internal audit system to ensure appropriateness of time, billing and approval of expenditures.<sup>33</sup>
  - vii. The PSNT should have an external review of financial policies at least once every three years as part of an independent audit of the PSNT.
- v. A PSNT should have a policy on who is to respond when the beneficiary has an emergency.
  - i. The beneficiary and authorized third parties should be given a copy of the policy and the names and emergency contact information for the PSNT.
  - ii. Those employees on call after hours should understand the necessity of being reachable at any time in the event of an emergency.
  - iii. If an on-call employee fails to make him/herself available during an emergency, absent good cause, the employee should be terminated.
  - iv. The PSNT should consider the provision of a safe place for employees during a disaster that has backup generators and supplies so the employees can continue to be reached by beneficiaries (*See*, § 21 on Disaster planning).

**Commentary:** There are two scenarios that should be addressed in an emergency preparedness policy. The first is when a disaster strikes that effects the PSNT's ability to conduct business. The PSNT needs to be sure that it can continue operations after the emergency has abated. The second is when a vendor requires an up-front payment from the PSNT before providing services to a beneficiary during or right after an emergency. For example, in the case of evacuation, the PSNT may need to pay for lodging for the beneficiary and the vendor may require an upfront payment or guarantee from the PSNT.

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<sup>33</sup> See, e.g., NPTSC Guidelines, Guideline 4(g) noting the need for "regular audits of the organization, including internal financial operations...."

## 15. Strategic Partnerships

- a. The PSNT should identify organizations and agencies that would be beneficial to the PSNT with which to have a working relationship.
  - i. These could include an elder law section of a local or state bar association, local government agencies (such as permitting), state agencies (such as Medicaid), federal agencies such as SSA or HHS or charitable organizations.
- b. The PSNT should identify employees who might be available to serve on boards of such agencies or organizations and encourage them to seek such leadership positions.
- c. The PSNT should include a marketing line item in its operating budget that includes sponsorships for charitable fundraising activities.

**Caution:** In creating strategic partnerships, the PSNT should be cognizant of actual or potential conflicts of interest, or even the appearance of a conflict of interest.

## 16. Media

- a. A PSNT should have a policy on dealing with the media. As part of the policy, an individual should be identified who will handle all media inquiries. Others should be trained to refer all media inquiries to the individual and not try to respond to the media. The policy should ensure that employees understand confidentiality of beneficiary information.

## 17. Technology

- a. Every PSNT should make sure it has secure firewalls, antivirus and other cybersecurity systems in place.
- b. Every PSNT should be sure to train employees on the appropriate use of technology and the risks of inappropriate use of it. The PSNT employee manual should address security concerns while working remotely.

**Suggestion** 💡: The manual should address the risks of accessing unsecured or public Wi-Fi, using a laptop in public, business continuity and technology accessibility for business continuation in the event of a natural disaster or emergency.

- c. The PSNT should have a tracking system that requires each employee to log-on in order to track the transactions for individual beneficiaries.
- d. The PSNT should use accounting software that allows the PSNT to track transactions for individual beneficiaries.
- e. The PSNT should have adequate cybersecurity insurance.

**Commentary:** Technology has become ubiquitous and its use widespread. However, the PSNT needs to examine technology as it supports the mission of the PSNT. Technology is a tool, but not a replacement for humans. When determining methods of communication, a PSNT may choose to use email as a primary method of communication. There are many conveniences and advantages to email, but it may not always be the best method for communication.

Further, the PSNT should remember that not all beneficiaries have access to, or the ability to use, technology for communication. To that end, the PSNT should recognize that multiple methods of

communication are important, and in some instances a phone call, a fax, or even snail mail may be the better way to proceed for a particular beneficiary.<sup>34</sup>

Even though the PSNT may need to use alternative methods of communication with certain beneficiaries, the PSNT should still recognize the value of technology as a tool for more effective operations and efficiencies. To that end, the PSNT should strive to become paper-less (that is, less paper, not paper-free) so the PSNT will need a high-volume scanner and other technology that allows for efficiencies. For example, True Link observed that

Paperless pooled trusts employ a range of tools to digitize documents. Instead of collecting signatures via paper and pen, they use services like HelloSign, eSignLive, or DocuSign, which offer electronic signature technology as well as comprehensive audit trails. These systems can be used to expedite communication with beneficiary advocates and external partners, and facilitate internal authorization when multiple approvals are required.<sup>35</sup>

True Link analyzed the advantages of a PSNT going digital noting the potential for growth, efficiencies, cost and time savings and better inter-agency communications. The report also noted that 3rd parties found advantages to digital documents when requesting them from the PSNT.<sup>36</sup>

**Suggestion** ¶ : Use technology to make the PSNT operations more efficient and better able to serve beneficiaries. Technology can lead to better record-keeping, an electronic paper trail for reporting and timelier responses to beneficiary requests. Recognize that there will be up-front costs and a learning curve, but the end result will lead to efficiencies and improved effectiveness.

## 18. Real Estate

The PSNT should have a policy on whether to use the beneficiary's funds to buy the beneficiary a house or whether to accept title to real estate on behalf of a beneficiary. In determining whether to do so, the PSNT should keep in mind the unique issues that real estate ownership presents, the additional costs associated with real estate ownership, the Sole Benefit Rule and the POMS regarding real estate ownership.

**Commentary:** The POMS notes that the sole benefit rule comes into play regarding home ownership. See POMS SI 01120.201.F.2. If others live in the house with the beneficiary, the sole benefit rule is implicated, and these other occupants will need to pay rent to the trust.

**Commentary:** Other issues implicated by ownership of real estate include maintenance, taxes, depreciation (or appreciation), insurance, liability issues and more. The PSNT should consider a budget for ownership before deciding whether to purchase or take title to real estate.

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<sup>34</sup> See *True Link* at 8, noting that “offer[ing] ... beneficiaries multiple ways to submit requests [can lead to] greater compliance, fewer hours spent fielding calls, and addressing concerns, and quicker disbursement turnaround times.” The takeaway, according to True Link: “it’s easier to teach ... staff to do the same task multiple ways through good technology than it is to persuade all beneficiaries to do the same task the same way.” *Id.*

<sup>35</sup> *True Link* at 6.

<sup>36</sup> *True Link* at 7.

### **III. Personnel and Physical Plant**

#### **19. Hiring and Firing: Potential Employees, Employees and Vendors**

- a. Potential Employees
  - i. As a matter of routine, a PSNT should complete a criminal background check, fingerprinting, a reference check, a drug test and a credit check for each prospective employee.<sup>37</sup> Each prospective employee should provide a valid and current photo ID. If the employee is going to ever be transporting a beneficiary a current driver's license and insurance card must be provided. It is the responsibility of the employee to notify the PSNT of any loss of driving privileges or insurance coverage.
- b. Vendors
  - i. A PSNT should check references for any vendor and confirm that the vendor is licensed and insured. A reference check should also be conducted before hiring a vendor.
  - ii. Before doing business with any vendors that will have access to physical space of the PSNT, the PSNT should determine whether any employees of vendors have been screened, bonded, etc. by the vendor and if not, then the PSNT should consider conducting a criminal background check, fingerprinting, a reference check, a drug test and a credit check for each such vendor or have a policy that each PSNT employee must secure files and log off computers so anyone not employed by the PSNT who has access to the space will not have access to confidential information.
- c. Employees
  - i. Each new employee should have a stated probationary period and this should be clearly noted in a letter of employment.
  - ii. Each employee should be provided with an employee manual that includes information about policies and procedures (including technology policies), penalties for violation of policies and procedures, and actions that could lead to immediate termination.
    - 1. Employees should sign an acknowledgment of the policy manual.
    - 2. Employees should confirm in writing that they have read the manual.
    - 3. Employees should be required to undergo an initial and then periodic training on the PSNT policies and procedures.<sup>38</sup>

**Commentary:** The PSNT may hire a cleaning service, and if that is the case, before engaging the service ask about the employee screening used by the cleaning service. If instead of a service, the PSNT hires individuals to clean the office space, then the PSNT needs to do its own check of the individual before hiring the individual. Further if any PSNT employees might be working late when the individual is on the premises, screening the individual before hiring will help ensure the safety of the PSNT employees.

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<sup>37</sup> See, e.g., *Plan of New Jersey* at 4.

<sup>38</sup> NPTSC Guidelines, Guideline 3(a) provides that “[o]rganizations ... hire competent staff and provide staff with ongoing training.”

- iii. The PSNT should offer practices and incentives to employees to encourage retention. It is critical to maintain continuity of staff both for beneficiaries to have confidence and knowledge of the staff they work with and for program integrity.
  - 1. The PSNT should develop a regular “stay interview” with staff focusing on their contribution to the organization, their personal goals for development and the mission of the organization. For new employees this should be done within the first 30 days, repeated at six months and then become an annual event separate from any annual evaluations.
  - 2. Every employee of the PSNT should have an annual evaluation with review of mutually set goal, requests for training and direct feedback on performance from their supervisor.
  - 3. The PSNT should have an annual training program for staff that is focused on the needs of individuals – employment goals for example – so, they become more knowledgeable about the ways they can support beneficiaries.
  - 4. The PSNT in conjunction with their staff should develop a series of incentives that recognizes continuity and longevity. The incentives can be tailored to the individual PSNT and can take a variety of forms other than monetary incentives.

**Example:** *A PSNT may allow a casual dress day or bring in puppies from a local rescue for an afternoon break.*

- iv. The PSNT should ask staff to define professionalism and customer service and create its definition of professionalism with the staff input.
  - 1. The PSNT board should adopt a professionalism and customer service policy that applies from the top down.
  - 2. Staff should be asked for examples of professional conduct and unprofessional conduct, with those examples incorporated into the policies and procedures manual.

## 20. Training

- a. The PSNT should have a required training program for all new employees and then regular continuing required training for all employees.
  - i. Required topics should include the mission of the PSNT, the role of the PSNT, supporting a quality of life of beneficiaries, history of the PSNT, Governance of the PSNT, their role and responsibilities, HIPAA, confidentiality and informed consent, implicit biases, employee attitudes, POMS, sole benefit, policies and procedures, and record keeping
  - ii. Topics for continued training could include building natural supports, building relationship and effective methods of communication, handling beneficiaries who are angry or demanding, assessment tools, various disabilities, government programs and benefits, dealing with an angry beneficiary or



- family member, dealing with local agencies, cyber security, what happens when a beneficiary runs out of money, etc.<sup>39</sup>
  - iii. Additional training should be related to program areas like vocational opportunities, health and wellness, and developing community interactions as outlined in the BEST Tool.
  - iv. The PSNT should regularly share success stories with staff of critical steps taken by the PSNT that effectively changed the lives of the beneficiary for the better.
  - v. Employees should be given an opportunity to evaluate a training session, suggest topics for future trainings and to serve as trainers or facilitators.
  - vi. The PSNT should keep a record of each staff member's participation in training, and this should be part of their annual evaluation.
- b. Every PSNT should conduct annual employee reviews, using a written tool that employees can either use to self-evaluate or read prior to evaluation.<sup>40</sup> The review process should also give employees a chance to confidentially evaluate supervisors.
- c. Every PSNT should develop a plan for employee retention and incentives for engagement.
- d. Every PSNT should have an exit interview process to learn from any staff leaving what caused them to leave and what if anything can be learned to improve the work environment for all.

**Commentary:** Well-trained and dedicated staff are the most valuable asset a PSNT has. The PSNT should be sure that staff education is a priority and staff retention an ongoing goal.<sup>41</sup>

**Suggestion** ¶ : A PSNT should consider the creation of a “retention strategy”<sup>42</sup> and benchmarks for employees who strive for greater responsibility within the organization. Promotion from within can have great advantages, but the PSNT also needs to recognize that they need to provide appropriate training, professional opportunities and support for employees, so the employees are not promoted only to fail.

- e. The PSNT should also offer training to family caregivers, professional caregivers and beneficiaries, including topics such as financial literacy (especially for beneficiaries), record keeping, receipts, sole benefit rule, etc.
- f. As a value added, a PSNT might consider offering additional training for family caregivers and professional caregivers should also focus on their personal well-being in the role they have undertaken.

<sup>39</sup> See, e.g., NPTSC Guidelines, Guideline 3(b) which directs that employees “possess or know where to obtain knowledge of trust laws specific to the applicable state, Medicaid laws and regulations specific to the applicable state; Social Security laws and regulations; HUD Section 8 laws and regulations; laws pertaining to other major programs; and law changes. 3(c) directs that employees have “or know where to obtain knowledge of the population served and receive ongoing training regarding the population served and changes in disability services.”

<sup>40</sup> The NPTSC Guidelines, Guideline 3(d) calls for regular employee evaluations.

<sup>41</sup> See, e.g., *True Link* at 15, discussing that top performing PSNTs “invest in staff development and retention because they know that institutional knowledge is invaluable.” *Id.* at 15.

<sup>42</sup> *True Link* at 16.

## 21. Distribution of Duties

- a. Each staff member should have discrete responsibilities and a job description.
- b. Staff should be cross-trained so that operations continue even if an employee is on vacation, ill, etc.
- c. A member of the leadership team should monitor the workload of each staff member and redistribute the cases as needed.
  - i. Case load numbers are not always a good indicator of workload, in that some beneficiaries need more time and attention while others need little.

|                                                                                       |
|---------------------------------------------------------------------------------------|
| <b>Suggestion</b> ♀ : Regular reports and group meetings can help with workload flow. |
|---------------------------------------------------------------------------------------|

## 22. Physical Plant

- a. The PSNT should decide whether to have a location to meet with beneficiaries that is part of the PSNT physical plant or a separate facility.
- b. All physical parts of the PSNT should be fully accessible, ADA-compliant and meet state/local building codes.
- c. The PSNT should have adequate security for people (employees, vendors, beneficiaries and business invitees) and for information. Thus, the PSNT should consider the use of keycard or biometric entries, emergency call buttons, cameras and lighted parking.
  - i. If cameras are used on the premises, appropriate notices should be posted regarding the use of cameras.
  - ii. The PSNT should consider the issues presented by the storage of video, including security and length of storage and who can access the stored video.

## IV. Emergency Planning

### 23. Disaster Planning

- a. A PSNT must have a disaster plan and policy for both the organization and for the beneficiaries.
  - i. A PSNT must have a disaster plan for the organization that recognizes the need to secure the equipment, data, and original documents; protect employees and beneficiaries; and allows for ongoing operations.
- b. Although the physical space may not be available for some time, the PSNT must be able to continue business or resume business as soon as possible.
- c. Beneficiaries dependent on the PSNT for paying bills and arranging services will need to have that support continued even though the physical location of the PSNT is inaccessible.
- d. The disaster plan must contemplate that when a natural disaster strikes, all entities and individuals will be scrambling for services, infrastructure repairs, and basics, such as food, clothing and shelter.
  - i. The plan needs to arrange for adequate provisions prior to the natural disaster and for at least three weeks post-disaster.

- ii. The PSNT should assume that electricity, cell service, water, gasoline, and food supplies will be interrupted and have a plan in place to respond to beneficiaries' needs during these outages.
- e. A PSNT must have adequate insurance that includes property and casualty, business interruption, and liability insurance.
- f. A PSNT should ask each facility where one of the PSNT beneficiaries resides for a copy of the facility's disaster plan and review it for adequacy.
- g. The PSNT should have an alternative means of communication available until local governments and cell providers are able to restore standard communications.

## 24. Emergency Procedures

**Suggestion** ☹: The PSNT should distinguish between emergencies and disaster preparedness and train employees on each.

- a. The PSNT should train employees on how to respond if a beneficiary has a medical emergency in the presence of the employee.
- b. The PSNT should have backup files offsite-whether in a physical location or cloud storage.
- c. The PSNT should have a business interruption plan to allow the PSNT to resume operations as soon as possible.
- d. The PSNT, in developing its emergency response plan, needs to balance employee safety and security with the needs of and supports for beneficiaries.
- e. The PSNT should provide every beneficiary, authorized caregiver and authorized family member with an emergency phone number and ensure that a PSNT employee is available at any time to answer that number.

## V. Beneficiary Related Best Practices

### 25. Beneficiary-Centered Processes

The Beneficiary Experience: How does the operation of the PSNT look from the viewpoint of the beneficiary, the family, and others who care about them?

### 26. Considering the entire person

- a. **The goal of the PSNT should be to consider the entire person and their quality of life.** The PSNT should be an effective organization providing support to the beneficiary with timeliness, accountability and transparency. In addition, the PSNT should be an effective partner with the beneficiary in building a better life looking to critical areas that often have been overlooked in the past. The PSNT should have a process to regularly engage all beneficiaries in developing their plan for a quality life in critical areas.

## 27. Employment<sup>43</sup> Opportunities for Beneficiaries

One of the areas that has most often been overlooked by the PSNT in the past has been employment opportunities for beneficiaries. As a result, our best practices guide recommends a renewed approach for all beneficiaries to explore employment opportunities.

- a. As part of the assessment of the beneficiary, the PSNT should inquire of the beneficiary the beneficiary's interest in employment opportunities, whether for pay or as a volunteer. These interests should reflect the beneficiary's interests and desires for work, not just available jobs.
- b. PSNT staff should be trained on the various vocational opportunities for beneficiaries.
  - i. For those beneficiaries who need support, the PSNT should include in the beneficiary's budget a job coach or job companion in the budget if there is no federal, state or local government funding for such positions.
  - ii. The budget may also need to include transportation, clothing and other expenses associated with vocational opportunities.
- c. Staff of the PSNT should familiarize themselves with vocational training, college programs, and employment resources in their community, their state and nationwide, such as the Association of People Supporting Employment First (APSE); state specific vocational rehabilitation services funded under the Rehabilitation Services Administration (<https://www.careeronestop.org/ResourcesFor/WorkersWithDisabilities/vocational-rehabilitation.aspx>), The Arc, U.S. Department of Labor Office of Disability Employment Policy and the World Institute on Disability.

## 28. From the beginning to the end, the PSNT should have processes in place that ensure that the focus is on the beneficiary in all facets of the administration of the beneficiary's account in the PSNT.

- a. The PSNT should learn as much as possible about the beneficiary, not just the benefits for which the beneficiary is or may become eligible and the beneficiary's needs, but what gives the beneficiary joy and provides the beneficiary with a quality of life.<sup>44</sup>
- b. A PSNT should use a routine process for learning about the beneficiary that allows the PSNT administrator to know the beneficiary as a person, rather than as a case.
- c. As much as possible, the PSNT should emphasize the beneficiary's autonomy and quality of life rather than focus on the task at hand.
- d. The PSNT should strive to empower each beneficiary when making decisions about expenditures and other matters and make decisions in a way that allows a beneficiary autonomy.<sup>45</sup> Whenever possible, the PSNT should use tools that allow the

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<sup>43</sup> We use the word employment to indicate paid or volunteer employment, and in this document consider it synonymous with vocational opportunities.

<sup>44</sup> True Link Best Practices suggests that PSNT staff "take detailed notes on the beneficiary's needs, living situation, capacity, spending habits, anticipated future purchases, and government benefits..." and use the information to determine "a monthly spending plan to help the beneficiary, as well as the trust, budget appropriately." True Link notes that all information gathered should be "entered electronically into an internal client database." In fact, True Link notes the most efficient trusts "enter data in real time" during the meetings with the beneficiaries. *True Link* at 3.

<sup>45</sup> See, e.g., NPTSC Guidelines, Guideline 7(a): "[t]he pooled trust program should maintain a professional relationship with the beneficiary and that person's representative as applicable, consider the needs of the beneficiary and respond to requests for trust distributions."

beneficiary's participation in decision-making, such as supported decision-making. Key to this process is spending time insuring to the extent possible beneficiaries understand the resources available to them and the limits of those resources.

- e. A beneficiary's request should not be denied just because the PSNT fears the possibility of liability.
- f. When creating a budget for the beneficiary, the PSNT should consider those expenditures and matters that provide a beneficiary with joy and, whenever financially feasible, include those in the budgeting process, even though the PSNT administrator may consider the items to be frivolous or unnecessary. However, the PSNT administrator should take the beneficiary's long-term needs and safety against such expenditures. It is essential for the PSNT to distinguish between the importance to the individual beneficiary rather than the PSNT or other's opinions.
- g. The PSNT should obtain the informed consent of the beneficiary (if the beneficiary is capable of giving informed consent and if not, the representative of the beneficiary), including a HIPAA consent. Consent should be obtained before any information about the beneficiary is shared with a third party.
- h. PSNT staff should never assume that the inability to verbally communicate precludes any other form of communication. In the case of persons who are nonverbal, the PSNT staff must develop alternative means to engage the beneficiary. The PSNT staff should have auxiliary aids and other effective (and ADA compliant) communication devices available to assist in communicating with the beneficiary. The PSNT should also arrange for interpreter services for those whose primary language is not English.
- i. The PSNT should always remember that the individual beneficiary is just that---an individual and ensure that staff are trained to understand this and have operating procedures that are designed to treat the beneficiary as an individual.
- j. The mission of the PSNT should incorporate a focus on the quality of life of the individual beneficiary rather than just on the provision of services.
- k. When meeting with a prospective client/beneficiary, the PSNT should explain how decisions are made, the information needed under BEST to provide an accurate profile of the beneficiary, explain operating procedures and ascertain beneficiary expectations.<sup>46</sup> As well, the PSNT should explain the investment management part of the PSNT, such as how the funds are invested within the PSNT, who manages the investments, personal tax reporting requirements/tax liability considerations, etc.

**Suggestion<sup>Q</sup>:** In meeting with the prospective client/beneficiary, the PSNT representative should be careful to not mislead the prospective beneficiary or over-promise programs and services. The prospective beneficiary should have specified a cooling off period between the time of signing the joinder agreement and the time the check is deposited.

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<sup>46</sup> For example, NPTSC Guidelines, Guideline 6(b) requires that the PSNT give "a prospective beneficiary or that person's representative as applicable ... the details of how remaining funds are distributed on upon the beneficiary's death, including the possibility of payback of funds to Medicaid agencies and retention of remaining funds by the organization pursuant to" federal law.

- l. The PSNT should have a specific timeframe for processing requests that is shared with all beneficiaries. For example, a request is processed and a check prepared or a beneficiary is notified that a request is denied within two full working days.
- m. The PSNT should have an electronic means for beneficiaries to access their accounts, check balances and see amounts available to them for disbursements.
- n. The PSNT staff or representatives should visit every beneficiary in person or virtually through telecommunication at least semi-annually and provide a record of a contact. Any change of status should initiate a personal visit.

**Commentary:** When visiting a beneficiary, the PSNT representative should prepare in advance for the visit and use a checklist (contained in BEST) to ensure the maximum and best information is gathered during the visit. The checklist would include observations regarding surroundings, the beneficiary's appearance, health care and treatment, etc. If appropriate, the PSNT representative visit should include observation during mealtime.<sup>47</sup>

In person visits are critical but the frequency may depend on the needs of an individual beneficiary, the amount in the beneficiary's trust and the costs incurred in visiting the beneficiary (especially those where lengthy travel is required). For some beneficiaries, semiannual visits may be enough. For others, more often visits may be needed due to critical changes occurring with the beneficiary, although the frequency may change depending on the beneficiary's situation. It is our opinion that an annual in-person visit is insufficient.

**Commentary:** In some instances, especially in rural areas where the PSNT staff may be several hours away from the beneficiary, the PSNT might consider the use of technology for real time visits as a substitute for some in-person visits.

**Example:** *NPTSC Guideline 6 covers Trust Creation Transparency. In particular Guideline 6(a) states that "[t]he pooled trust program should disclose the operational features of its Trusts to each prospective beneficiary or that person's representative as applicable to set expectations of how the Trust may assist the beneficiary. The program should provide information related to trust irrevocability, sole benefit restrictions, in-kind support and maintenance restrictions, Trustee discretion, and restrictions on direct payments to beneficiaries."*

*Further, Guideline 6(d) recommends that "[t]he pooled trust program ... encourage a prospective beneficiary or that person's representative as applicable to meet with independent counsel to discuss trust features and specific circumstances of Trust creation.*

*Finally, Guideline 5 Practices, especially 5(b) cautions the PSNT that it "not make a warranty of eligibility for public benefits."*

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<sup>47</sup> See, *Plan of New Jersey* at 7-9.

**Suggestion ¶** : Consider carefully the documents used by the PSNT as well as the content of the PSNT website. Those each communicate a specific impression of the PSNT with prospective beneficiaries and involved third parties. The documents and the website should be written in clear, understandable and informative language.<sup>48</sup>

- o. Each PSNT should operate in such a way as to keep humanity in their services.

**Suggestion ¶** : A PSNT may send individualized birthday, anniversary and appropriate holiday greetings to beneficiaries. A PSNT may choose to hold a party for beneficiaries or in some way acknowledge and celebrate individual beneficiaries. If the activity is benefitting all beneficiaries, the PSNT should not charge the cost of the activity against the beneficiary's account.

A PSNT should develop tools to engage and support beneficiaries in understanding the funds available, share documents and their goals and life plans. This tool should be accessible to Trust staff working with beneficiaries when making decisions about expenditures. The BEST tool is one a PSNT might consider. The BEST Tool will provide the PSNT an interactive and real time tool to use with their beneficiaries for their benefit not as another assessment and will provide the PSNT with a planning tool that also support financial literacy skills of the beneficiary.

## 29. Beneficiary Budgets

- a. The PSNT should create a budget for each beneficiary.<sup>49</sup> The goal of the budget is to build a quality life for the individual to the extent possible and to expend all funds prior to death of the beneficiary.
- b. Before creating a budget for the PSNT beneficiary, the PSNT should complete an assessment (BEST) to determine the beneficiary's goals, expectations, dreams and factors that provide the beneficiary with a quality of life.
- c. The budget that the PSNT creates should be based on the amount of money the beneficiary deposits with the PSNT but taking into account the beneficiary's life plans. The PSNT should recognize that the money is to be spent on the beneficiary's behalf, and not saved for future generations. The PSNT reserves the right to go beyond the annual budget for special circumstances and this should be communicated in writing to the beneficiary. The budget should also take into consideration any outside income/assets or any government or private benefits received by the beneficiary.
- d. The budget should also take into account the beneficiary's life expectancy as determined by the life expectancy tables which includes flexibility for people with

<sup>48</sup> True Link offers examples of "high-performing trusts" describing "the quality and clarity of [those] materials. Trusts that create user-friendly forms, easy checklists, visual resources, and documents geared toward the population served... reported higher success rates with the onboarding process. Some trusts take this even further, sending duplicate materials to advocates, loved ones, and service providers so everyone is on the same page. Still others create customized packets for beneficiaries depending on the type of benefits received." *True Link* at 4.

<sup>49</sup> *But see* NPTSC Guidelines, Guideline 7(b) which provides that

The pooled trust program should have full discretion to decide if a beneficiary should have a written spending plan for each beneficiary that is provided to each beneficiary and that person's representative as applicable. This may include review of prior year spending, anticipated life of the trusts, and considerations of principal and interest spending.

multiple disabilities, the beneficiary's health and disability. This table should be reviewed periodically and adjusted as needed. A key determinant of effectiveness should be a review of the number of beneficiaries who die before their trust is expended.

- e. Once the budget is created, the PSNT should review and explain the budget with the beneficiary, if the beneficiary is capable of comprehending, as well as anyone else the beneficiary chooses to be part of the discussion. When considering whether a beneficiary is comprehending the discussion, the PSNT should recognize that a beneficiary with diminished capacity may still comprehend the information depending on the form in which the information is presented, as well as the time of day and location of the conversation. If the beneficiary is unable to comprehend the conversation, then the PSNT should have the conversation about the budget with the individual(s) legally authorized to speak on the beneficiary's behalf.
- f. Once the budget is final, the beneficiary or authorized third party should sign an acknowledgement of the budget and be given a copy.
- g. The budget is a living document and should be periodically updated, especially in the event of a significant occurrence.

**Example:** *NPTSC Guidelines, Guideline 4(d) recommends the provision of "individual trust accountings.... on a regular schedule."*

PSNT staff should remember that a budget balances the beneficiary's needs against the amount of money in the account. However, the PSNT should never let the potential for remainder funds guide any decision to approve or deny a request. PSNT staff should support the goals of the person, follow the law on allowable expenses, and consider each situation individually. Their personal values about an expenditure as being too lavish or too cheap, should not impact their decision to allow or deny any request.

**Example:** *NPTSC Guidelines, Guideline 7(c) directs that a "pooled trust program ... not take retention by the organization into consideration when making distributions."*

- h. In situations where it appears likely that the beneficiary will exhaust the funds in the PSNT, the PSNT should prepare a phase-out or "weaning" budget.

### **30. PSNT Providing Additional Services to Beneficiaries**

- a. A PSNT may decide to offer services beyond that of administration of the pooled trust. Any fees for wrap-around services and extraordinary fees should be clearly listed on the published fee schedule.

**Commentary:** Some PSNTs that offer additional services may serve as a representative payee for a person receiving Social Security benefits, as a fiduciary for someone receiving Veterans benefits, or care management services.

- b. A PSNT needs to recognize the potential for conflicts of interest when deciding whether to hire a third-party to provide case manager/care manager or to provide those services in house.



**Commentary:** Assume a beneficiary needs a care manager to arrange for services for the beneficiary. If the PSNT offers expanded services, the PSNT may choose to use an in-house care manager to arrange for these services. But what if a third-party care manager can provide those same services cheaper than what the PSNT would bill the beneficiary? The PSNT may be tempted to keep the transaction in-house, since it would benefit the PSNT's bottom line, but it would cost the beneficiary more.

There may be valid reasons for the PSNT to keep the transaction in-house. For example, the PSNT may be able to arrange the services for the beneficiary faster than the third-party service provider. If there is a reason to justify the higher expenditures for services provided by the PSNT, the PSNT should be sure to document the beneficiary's file to reflect this. In order to avoid the perception of self-dealing, written authorization to provide in-house care management services should be provided prior to delivery of the service. The authorization can be a Life Plan document, a Joinder Agreement or other writing evidencing the request. The PSNT should have and follow a policy that public support services will be utilized prior to private trust assets being used. A competent beneficiary or authorized representative may make a written request that trust assets be used in lieu of public support services.

### **Summary**

These guidelines are designed to be comprehensive, but we recognize that not all of these guidelines will fit every PSNT. We hope that these guidelines will be used by PSNTs in the U.S. to the extent appropriate and feasible. These guidelines may be reproduced with attribution to the Life Passages Planning Project and the May & Stanley Smith Charitable Trust. In reproducing these guidelines, we ask that edits or changes be reviewed by the Life Passages Planning Project to avoid attributing a contrary position to the Project.

Sept. 30, 2019

First Revision January 25, 2020

**Stop Talking and Start  
Doing: The Hows, the  
Whys, and the Ethics of  
Using a Client-Centered  
Approach in SNT Planning  
and Administration**

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Rebecca C. Morgan  
Boston Asset Management  
Chair in Elder Law



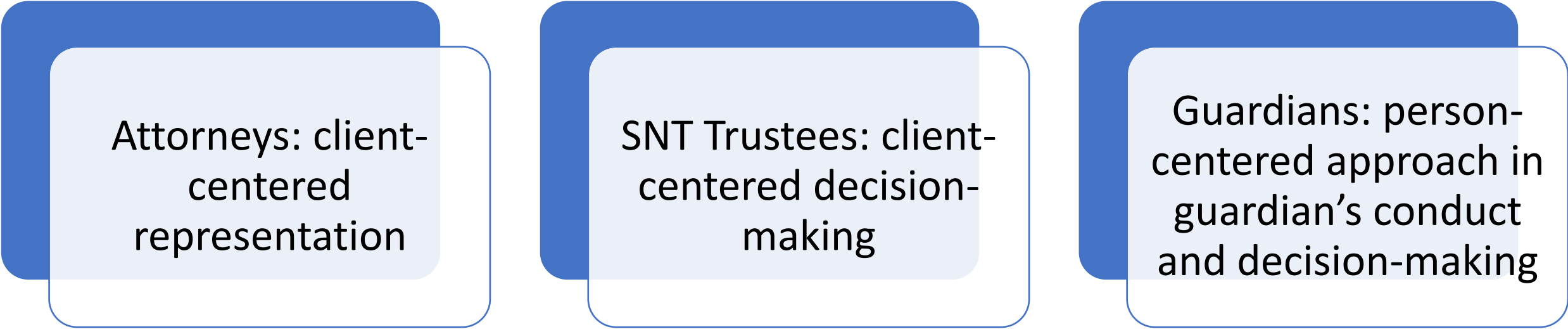
# Learning Objectives

- This session will
  - Explain the client-centered approach to decision-making
  - Review specific sections of the best practices guide for PSNTs.
  - Review the Model Rules of Professional Conduct and how they support the use of client-centered decision-making, and
  - Offer examples of how trustees can use the client centered process in making decisions.

# Resources

- Model Rules of Professional Conduct
- Life Passages Planning Best Practice Guidelines (in the materials)
- NAELA Aspirational Standards (2d ed) (in the materials)
- Assessment of Older Adults with Diminished Capacities: A Handbook for Lawyers (2d ed. 2021);  
<https://www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>
- Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act;  
<https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=17c2bb02-86d8-fa14-df3a-ac9e720b7ecd&forceDialog=0>

# Client-Centered Approaches



The diagram consists of three identical graphic elements arranged horizontally. Each element features a dark blue rounded rectangle in the background, with a light blue rounded rectangle centered on top of it. The text is contained within the light blue rectangle. The first element on the left describes the role of attorneys, the middle one describes SNT trustees, and the right one describes guardians.

Attorneys: client-centered representation

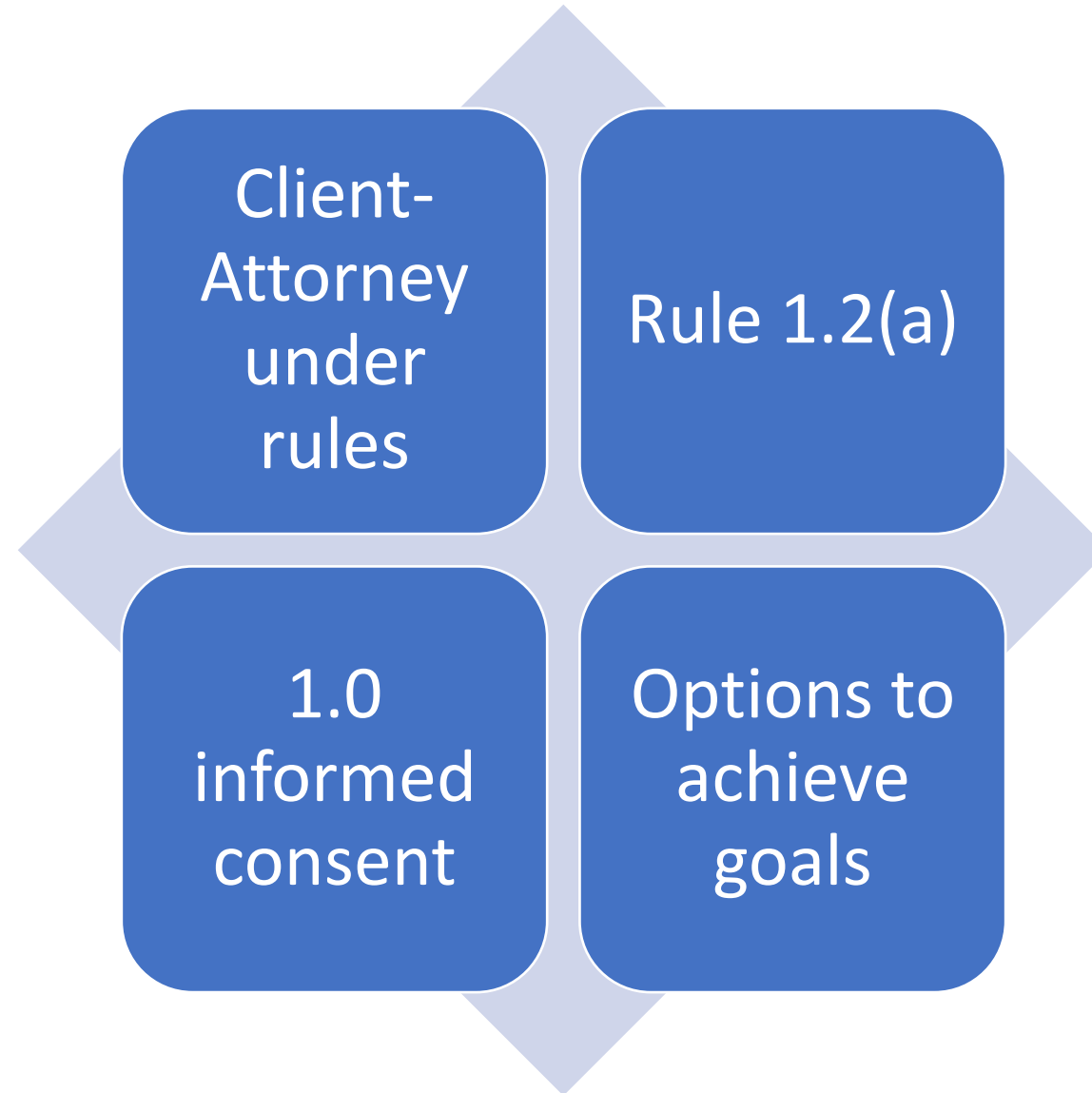
SNT Trustees: client-centered decision-making

Guardians: person-centered approach in guardian's conduct and decision-making

# Client- Centered Lawyering



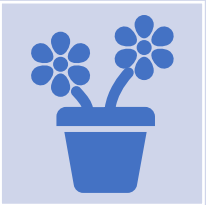
# Client-Centered Lawyering



# Client-Centered Lawyering



Note that Rule 1.4 is all about the client. The attorney shall promptly inform, reasonably consult, reasonably inform, consult ... with the client.



As Professor Flowers says, the attorney needs to mind their two T's: time and talk.



Rule 1.14 client-centered lawyering, noting obligation of atty to maintain normal client-atty relationship & only if can not be maintained, might atty consider protective action ....



# SNT Trustee: Beneficiary- Centered Decision Making

Using the Life Passages  
Project Best Practices  
Guidelines (materials),  
specifically Part V. Note  
these two:

#28 “From the beginning to the end, the PSNT should have processes in place that ensure that the focus is on the beneficiary in all facets of the administration of the beneficiary’s account in the PSNT.”

## #26: Consider the Entire Person

- “The goal of the PSNT should be to consider the entire person and their quality of life. The PSNT should be an effective organization providing support to the beneficiary with timeliness, accountability and transparency. In addition, the PSNT should be an effective partner with the beneficiary in building a better life looking to critical areas that often have been overlooked in the past. The PSNT should have a process to regularly engage all beneficiaries in developing their plan for a quality life in critical areas.”

# Guardians

- Fiduciary, like trustee; Authority from court's order; but still person-centered.
- UGCOPAA prefatory note: “[I]t aims to reflect the person-centered philosophy ... approach is evidenced in the act’s updated terminology. ... The person-centered approach is also evident in new provisions requiring that individuals ... be given meaningful notice of their rights...; ... involving individuals ... in decisions about their lives; requirements that guardians and conservators create person-centered plans; and provisions to facilitate court monitoring of compliance with those plans. ”

# Guardians: UGCOPAA § 311: statement of rights

- 311(b) lists various notice requirements.
- 313(b) guardian required to promote adult's self-determination and support adult's decision-making
- (b) A guardian for an adult shall promote the self-determination of the adult and, to the extent reasonably feasible, encourage the adult to participate in decisions, act on the adult's own behalf, and develop or regain the capacity to manage the adult's personal affairs.
- (d) make the decision the adult would make, with some caveats



# What About Supported Decision- Making?

# Supported Decision-Making

- Furthers individual's autonomy
- Client-centered
- Is it recognized in your state?
- Obstacles to using?

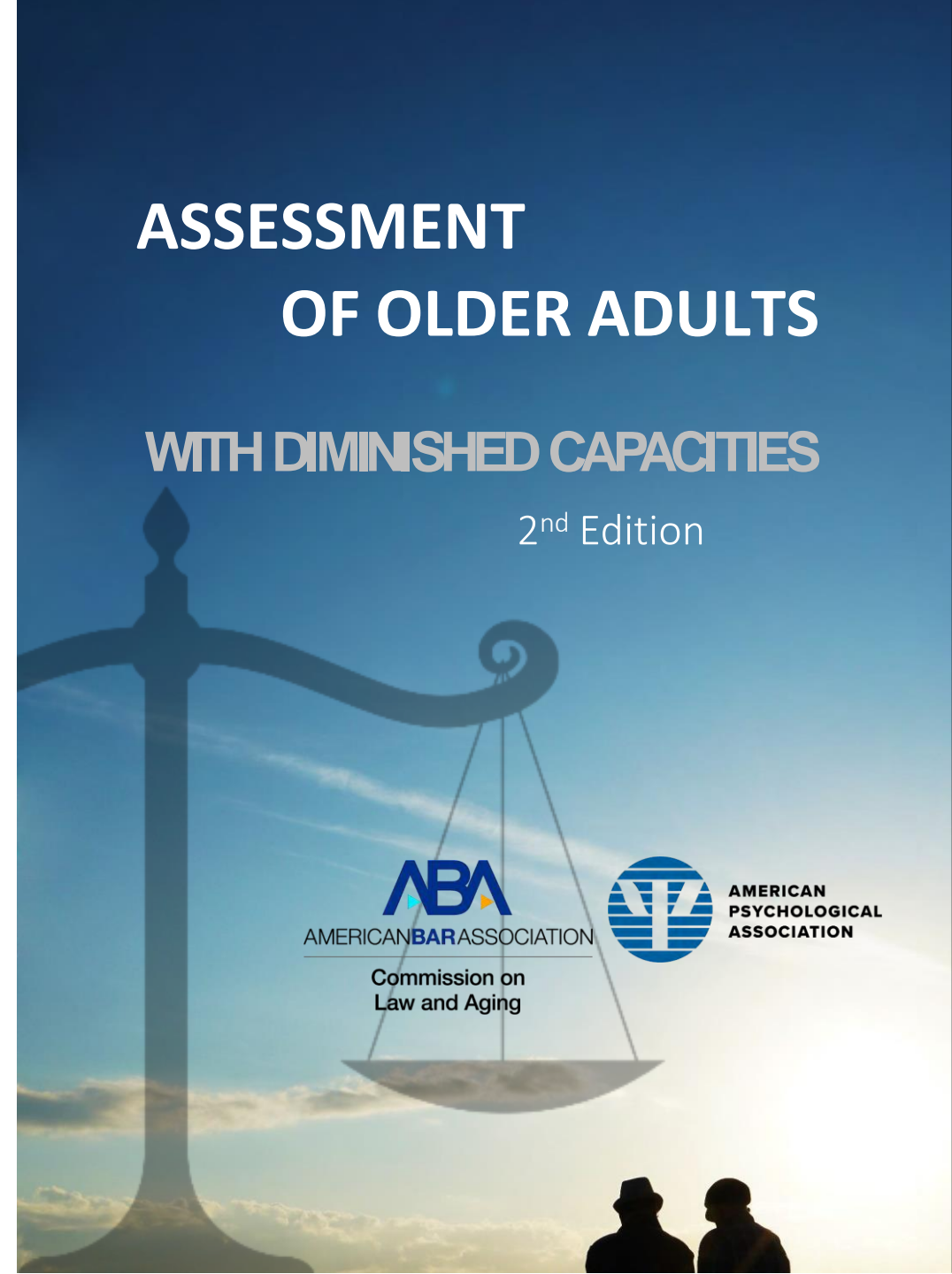
## Client-Centered and Capacity

- For lawyers, client needs capacity to make decisions.
- Trustees, guardians, and more: can client express preferences, etc.
- Facilitating client decision-making
- Model Rule 1.14 guidance

# Assessment of Older Adults With Diminished Capacities (2<sup>nd</sup> ed.)

- Medical conditions affecting capacity
- Capacity for different legal actions
- Decision supports
- Worksheet

- Medical conditions affecting capacity
- Capacity for different legal actions
- Decision supports
- Worksheet





STOP TALKING

JUST  
DO IT!

Start

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# THANK YOU



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STETSON LAW

# **2022 Fundamentals of Special Needs Trusts Administration Webinar**

**Friday, May 20, 2022  
2:30 P.M. – 3:20 P.M.**

**Working With Litigation Counsel – A  
Guide to the Perplexed & Sometimes  
Frustrated**

Presenter:  
Stuart D. Zimring

- Materials
- PowerPoint

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***Working With Litigation Counsel - A Guide to  
the Perplexed and Sometimes Frustrated***

a presentation for

**The Fundamentals of Special Needs Trust  
Administration Webinar**

by

**Stuart D. Zimring**

May 20, 2022

## **Working with Litigation Counsel - A Guide to the Perplexed and Sometimes Frustrated**

### 1. Introduction - Setting the Scene

It's 4p.m. on a Friday afternoon. You are just beginning to close your briefcase and head out for the weekend when your phone rings. It's Marvin the Med-Mal Maven, an attorney whose advertisements you've seen and heard but have never met. He informs you that he has just settled the biggest case of his career. It's a multimillion dollar settlement of a personal injury case involving a 16 year old young woman, Giselle, a ballet prodigy who was hit by car rendering her a paraplegic. She has decision making capacity and is firmly convinced she will dance again and wants the settlement funds directed towards making that happen. Marvin, the defendants, the structured settlement brokers, life care planners and the young girl's mother,(who is her Guardian ad Litem (GAL)) had all agreed on the terms when the mother informed him that her best friend had asked why they monies weren't going into a Special Needs Trust? Marvin consults with the structured settlement brokers and the life care planner who all agree that's not a bad idea (especially given the kind of long term therapy and surgeries Giselle may need if it appears she can dance again), and why didn't they think of it first, and suggest Marvin contact you to send him one of those "special needs trust things" so he can take it to the Judge on Monday (when they've all been ordered to appear to put the settlement on the record.)

You explain to Marvin that it's not quite that simple and suggest that he get the matter continued so that you can meet with his client and the other players involved so that you can do your job as well as Marvin has done his. With some grumbling Marvin agrees and a meeting is set for the following week.

## 2. The Cast of Characters

### A. First Steps

You need to decide who should be involved in this first meeting. In a SNT arising out of litigation, it may be appropriate for you to meet with Marvin first, without anyone else present, to get the background information and “lay of the land.” However, unless Marvin is the one who is going to employ you (and even if he is) you are still going to want to meet Giselle, her mother/GAL and quite possibly confer with the structured settlement brokers and the life care planners. A Warning bell should go off and you should consider withdrawing from the matter if Marvin insists on shielding his client from you. You should consider requesting copies of pleadings and discovery and especially any life care plans that have been created in advance of the meeting.

### B. The Players

1. The Attorney: As noted, Marvin may well insist on being part of the planning process even though he knows nothing about SNTs. Usually, this is because he believes (and rightly so) that Giselle is dependent on him for advice and counsel therefore Giselle needs him as part of the planning process. In other cases the litigation attorney may fear that you are going to “steal” the client notwithstanding the fact that you do no personal injury or medical malpractice litigation.

In either case, participation by the litigation attorney should be welcome since she or he is more familiar with the legal issues involved and condition of the plaintiff/beneficiary than almost any other person and will be able to communicate

the information to you in terms appropriate to the legal issues involved in the drafting process.<sup>1</sup>

## 2. The Beneficiary, Guardian ad Litem and/or Guardian

It goes without saying (but sometimes needs to be said) that the plaintiff who is going to be the Beneficiary of the SNT should participate in the drafting of the SNT if she is able to do so. In our hypothetical, Giselle has capacity (other than still being a minor), so she should definitely be part of the process.

If you are told that the Beneficiary lacks capacity to participate in the planning process in a meaningful way, you should make an independent investigation to verify the accuracy of this conclusion. On the other hand, if a GAL or Guardian has been appointed, that is the person with whom you should be dealing, keeping in mind (and constantly reminding the GAL/Guardian) that she/he stands in the shoes of the person with the disability and in legal reality it is that person who may well be your client.<sup>2</sup>

Where the GAL or Guardian is a family member you should analyze whether the relationship raises the possibility of a potential conflict of interest. The easiest example is where one spouse is the GAL for the other and there is a claim for loss of consortium. In such cases, when the case settles, can the spouse/GAL fairly negotiate the allocation of the settlement between the ward and the spouse/GAL? In my experience this issue is rarely addressed during the settlement process by the litigation attorney, but it is a critical ethical issue for all when the time

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<sup>1</sup> See Neal Winston, *The Role of the SNT Attorney or Trust Administrator in Working with Probate, Personal Injury and family Law Attorneys and Their Clients*, Stetson University College of Law 2021 National Conference on Special Needs Planning and Special Needs Trusts (Oct. 2021).

<sup>2</sup> Model R. Prof. Conduct 1.14; NAELA Aspirational Standard, 2nd Ed. B.2.

comes to determine the amount of the settlement to fund the SNT. If the issues are not addressed early on, all of the attorneys involved may find themselves with serious conflict-of-interest problems necessitating their withdrawal from the representation.<sup>3</sup>

### 3. Life Care Planners & Other Experts

Life Care planners, health care professionals and social welfare professionals involved in the litigation can be invaluable resources in obtaining the information necessary to draft the SNT. Both sides in a case may have prepared Life Care Plans and it is useful for you to review both. Keep in mind these are advocacy pieces but they all have common goals: dealing with and predicting the present and future needs of the Beneficiary, albeit from differing perspectives. Having access to these analyses will enable you to create a better structure in your SNT to cover the cost of care over the Beneficiary's lifetime.<sup>4</sup>

### 4. Structured Settlement Brokers

A "structured settlement" refers to a settlement of a litigated matter in which the settlement amount is to be paid out in a series of period payments over a period of time rather than in a lump sum. A structured settlement can be and often is combined with a lump sum payment. Virtually all structured settlements are funded through the purchase of one or more Structured Settlement Annuities, negotiated

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<sup>3</sup> Model R. Prof. Conduct 1.7(a)(2) (*see* comment 29); NAELA Aspirational Standards, 2<sup>nd</sup> Ed, D.2; Home Ins. Co. v Wynn, 493 S.E. 2d 622 (Ga. App. 1997).

<sup>4</sup> For more information about Life Care Plans, see [www.aanlcp.org](http://www.aanlcp.org) and [www.rehabpro.org/sections/ialcp](http://www.rehabpro.org/sections/ialcp).  
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by Structured Settlement Brokers and issued by insurance companies.<sup>5</sup> While you may not need or want to be part of the negotiating process for a structured settlement, you should at least verify that the proposed stream of payments off the structure are properly going into the SNT and that remainder beneficiary designations in the SNT coincide with Court Orders or settlement agreements providing for the disposition of the remaining funds in both the structured settlement and the balance remaining in the SNT on the death of the Beneficiary or other termination of the SNT.

## 5. Family Members

It is almost axiomatic that family members will want to be involved. This can create serious ethical issues for you since the family members do not want to hear about “attorney-client privilege” - they want to be part of the decision making process and unfortunately, frequently believe they have not only a right to be part of that process but an economic interest in the settlement or award.

There is nothing wrong with having family involved and in fact it can be very useful since these people constitute (hopefully) a built in support system for the Beneficiary. However, you need to be vigilant to make sure everyone understands who the client is (and note, that is a subject we have yet to address in this paper!), and to whom you can provide information and advice. All too frequently friends and family believe that you “represent” them as well as your client. When these people are participating in the discussion, regardless of the

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<sup>5</sup> For a more complete description of Structured Settlements and the process, see Stuart D. Zimring, Rebecca C. Morgan, Bradley J. Frigon and Craig C. Reaves, *Fundamentals of Special Needs Trusts*, §4.08 (Lexis Nexis 2022) (hereafter “Fundamentals”).

amount of their involvement, you must obtain appropriate waivers of the attorney-client-privilege together with disclosure authorizations when the client wants you to discuss the case with others.<sup>6</sup>

6. The Trustee

If the identity of the Trustee is known, the Trustee should be a participant in the discussions. The ultimate decision as to whom the Trustee is going to be is up to the client (or in some cases), the Court. However, you, by virtue of your experience are in a position, and may well have a duty to advise the client regarding the choice of Trustee.<sup>7</sup>

3. The Drama Unfolds - We Deal with the Elephant(s) In the Room

A. The Elephant in the Room - Who is the Client?

The various parties are assembled around your conference table (on in their separate little “Hollywood Squares” boxes in your zoom call). The first and most pressing question is: Who is your client? Secondly, an equally pressing question is: How and by whom are you going to get paid?

B. Identifying the Client

1. “Who is the client?” may well be the most important question you ask during this or any representation. The answer will govern much of what happens

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<sup>6</sup> Model R. Prof. Conduct 1.14 (see comment 3), NAELA Aspirational Standard, 2<sup>nd</sup> Ed. E.1, B.2. See also John B. Henry, III, *SNT Planning: A Family Matter*, Stetson University College of Law 2021 National Conference on Special Needs Planning & Special Needs Trusts (oct. 2021).

<sup>7</sup> See *Fundamentals*, §404[1][f]. See also David S. Banas, *Trustee School! How to Train Family Member Trustees*, Stetson University College of Law 2019 National Conference on Special Needs Planning and Special Needs Trusts (Oct. 2019) and Peter Wall and Prof. Roberta Flowers, *Multi-disciplinary Liability and Defining the Trustee’s Role*, Stetson University College of Law 2020 National conference on Special Needs Planning and Special Needs Trusts (Oct. 2020).

later in terms of the scope of your representation, the source of payment for your services, to whom you owe a duty of loyalty and the scope of the attorney-client privilege and waivers of it. Given the list of players in a litigation context the answer is not necessarily simple. It therefore behooves you to ask the question as early as possible. And, you should answer the question (or drive the answer to the question) in a way you want it to be answered, rather than the way someone else may want it to be answered.

2. In making this decision it is critical that you consider all the usual criteria that an attorney uses in agreeing to represent a client:

- a. Does the person have the capacity to retain counsel?<sup>8</sup>
- b. Are there existing or potential conflicts of interest that must be disclosed and if so, can they/should they be waived?<sup>9</sup>
- c. Is there mutual respect and an ability to work together within the context of the attorney-client relationship?<sup>10</sup>
- d. Is Court approval required to enter into the attorney-client relationship?
- e. Is the Beneficiary/plaintiff the one creating the SNT?

In our hypothetical, the GAL, mom would most likely be the client on behalf of Giselle. Does your state law require prior court approval of the retention? If so, who is responsible for obtaining court approval? You or Marvin? These issues must be addressed and answered before the relationship commences.

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<sup>8</sup> See in particular Model R. Prof. Conduct 1.14 regarding an attorney's duties in dealing with clients with diminished capacity and NAELA Aspirational Standards 2<sup>nd</sup> Ed. Standard G.

<sup>9</sup> Model R. Of Prof. Conduct 1.7, 1.8, 1.9; NAELA Aspirational Standards 2<sup>nd</sup> Ed., Standard D.

<sup>10</sup> NAELA Aspirational Standards 2<sup>nd</sup> Ed. Standard H; Model R. Prof. Conduct 1.14, 2.1.

### C. Conflicts of Interest

Litigation is, by definition, a stress-filled process. Add to this a mix of familial relationships, emotions and lives torn apart by the underlying trauma that is the reason the litigation exists and it is easy to see how and why various types of conflicts can and will occur over the course of the litigation and its resolution.

Conflicts of interest are often subtle and therefore a potentially invidious element and create a real trap for the unwary. From the very outset you must be vigilant in identifying the areas of potential or actual conflict of interest and respond to them in a professional and ethical manner. In some cases you will find that the potential conflicts are waiveable in accordance with the applicable Rules of Professional Conduct<sup>11</sup> and in other cases, while the potential conflict may be theoretically waiveable, the practical reality is that the game is not worth the candle. That said, the key points to remember here are that (a) the fact that there may be potential conflicts does not mean you cannot be involved in the representation as long as they are properly disclosed and acknowledged; and (b) if there is a real conflict even though the Model Rules state that it can be waived does not mean it should be waived. Where a real conflict exists or arises after the representation begins, the safest course is probably to withdraw from the representation.<sup>12</sup>

### D. Determining Client Capacity

Once you have determined who the client will be, you need to determine whether that person has the capacity to (a) enter the attorney-client relationship and (b) whether the potential client has the capacity to knowingly and intelligently participate in the representation? In this regard your analysis will be no different than how you deal with any other potential client. Thus,

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<sup>11</sup> Model R. Prof. Conduct 1.7(b)(4); NAELA Aspiration Standards 2<sup>nd</sup> Ed. Standard D.2. For deeper discussion of conflicts of interest in this context *see* Fundamentals, §2.05

<sup>12</sup> Model R. Prof. Conduct 1.7(a).

as you would do in any other case, if necessary and appropriate reference to Model Rule of Professional Conduct 1.14 and the cases and ethical opinions cited therein will be useful along with a review of the ABA Commission on Law and Aging publication “*Assessment of Older Adults with diminished Capacities: A Handbook for Lawyers*” (2nd Ed.. 2021)<sup>13</sup>

E. Duties to Non-Clients

The soon-to-be-Beneficiary of the soon-to-be-created SNT is often surrounded by a constellation of family members, friends, caregivers, and others all of whom believe they should be involved in every aspect of the Beneficiary’s life. As a result, maintaining the attorney-client privilege barrier as well as the duty of undivided loyalty to the client can often be difficult and can require a good deal of diplomacy and tact (and sometimes that’s not enough, unfortunately). Third parties need to understand (and you can try to help them to understand) that they are not your client, you owe them nothing, and you have no obligation to protect their interests (and are therefore not liable to them for professional negligence.)

However, there are exceptions to this rule. The most applicable exception in the SNT world is that you may well have a duty to a non-client where the basic purpose of your representation is to create benefits for a third party. In our hypothetical, if Marvin was consulting you in connection with the case and he retained you to draft the SNT on behalf of his client (rather than the GAL), your duty would flow to Marvin’s client even though she was not your client.<sup>14</sup> Of course, if the client wishes to waive the attorney-client privilege, she is free to do so and can authorize you to disclose as much or as little information to whomever she wishes. A form Disclosure Authorization is attached to these materials.

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<sup>13</sup> Available from the ABA at [www.americanbar.org/pruducts/inv/book/411701219](http://www.americanbar.org/pruducts/inv/book/411701219). See also, Fundamentals §§2.06 *et seq.*

<sup>14</sup> See A. Frank Johns, *Fickett’s Thicket: the Lawyer’s Expanding Fiduciary and Ethical Boundaries When Serving Older Americans of Moderate Wealth*, 32 Wake Forest L. Rev. 445 (1997); Fundamentals §209.

F. Getting Paid

1. As in any other representation, good practice requires that your fee arrangement be in writing so not only the client, but in this case, everyone involved in handling the economics (Marvin, the GAL, the Structured Settlement Broker, etc.) clearly understand what it is you are going to do for the client, how much you are going to be paid and how that fee is calculated.<sup>15</sup> In particular, I think it is important for you to set forth in your Retainer Agreement (and in subsequent correspondence and pleadings as appropriate) who is responsible for negotiating and seeing to the payment of Medicaid liens due and payable out of the settlement proceeds prior to funding the SNT, contacting Medicare regarding appropriate Medicare set-aside arrangements and proper funding amounts and subrogation rights that any insurance companies may have in the matter. In my experience, this is something litigation counsel sometimes loses sight of when their eye is on the prize.

2. In the litigation context, it may turn out that the person paying your fee is not your client. This is permissible as long as the appropriate disclosure, waivers and consents are observed and obtained. For example, in our hypothetical, assume the GAL, with Court approval has retained you to prepare the SNT for Giselle. However, Marvin has agreed that he will pay your fees out of his contingent fee award (it does happen and therefore your fee should not be subject to court approval since it's not part of the settlement!). In cases like this, you need to make specific disclosures to the GAL and consents must be obtained from both the GAL and Marvin acknowledging that by agreeing to pay your fees, Marvin does not acquire any rights to be involved in your representation, and/or to direct your actions or obtain information regarding the case that may be in your files rather than his. On the

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<sup>15</sup> Model R. Prof. Conduct 1.5(a).

other hand, your well drafted third-Party Payer Agreement and Retainer Agreement will also have the GAL acknowledge that she is primarily responsible for the fees and if Marvin fails to pay, she remains liable. A form Third-Party Payer Agreement and corresponding language for the Retainer Agreement are attached.<sup>16</sup>

3. In situations where your fees are going to be paid out of the settlement or judgment, you must check your State's relevant statutes, Court Rules and Local Rules since any or all of them may require that your fees (separate and apart from the GAL's initial approval to retain your services) be approved by the Court.<sup>17</sup> When fees are going to be paid from the SNT itself, upon its creation, the Court Order should specifically authorize payment of legal fees for its creation. You should also ascertain beforehand whether such orders and payment provisions do not run afoul of your local Medicaid regulations.

4. Be aware that while many of us use a "fixed fee" methodology in creating SNTs, this may not sit well with a Court that is used to basing fee awards on "reasonable value" based on hours worked, etc. So even if you have agreed to a fixed fee arrangement, I suggest you keep detailed time records just in case the Court asks for them. Also consider having two (2) fee arrangements: (a) a fixed fee for the drafting of the SNT (if that's what you want) and (b) an hourly rate for time you may have to spend in Court explaining the SNT structure to the Judge or even handling the preparing of the pleadings dealing specifically with the approval of the SNT by the Court.

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<sup>16</sup> Model R. Prof. Conduct 1.8(f), 1.6; NAELA Aspirational Standards (2<sup>nd</sup> Ed. 2021) Standard D.4.

<sup>17</sup> See for example Cal. Prob. Code §§2580 *et seq.* regarding court authorized petitions for substituted judgment in conservatorship proceedings and Cal. Prob. Code §3604 specifically dealing with court authorization of SNTs created in connection with litigated matters.

#### 4. A Successful Outcome

Being prepared is half the battle. Understand that at your meeting you will be the most knowledgeable person in the room; the only one with a total grasp of every aspect of the case, the “big picture” and probably the only one (or one of the few) whose sole interest is protecting the plaintiff by seeing to it that not only will she be receiving compensation for her injuries (keeping in mind she will never be made whole) but that you and you alone are the one who is safeguarding that fund for her future.

#### 5. A Final Thought

The focus of this paper has been on protecting litigation settlements and judgments through the use of SNTs. However, you should keep in mind that the exact same tools, skills and concepts apply in Domestic Relation matters. Spousal and Child Support payments as well as an individual’s property allocated during a dissolution of marriage proceeding can be used to fund SNTs. This is especially critical in cases where the award of Spousal Support or allocation of property could cause a termination in SSI or Medicaid benefits.<sup>18</sup> From a “marketing” standpoint I think this is an untapped area of potential business for SNT drafters and planners and a perfect application of NAELA’s maxim of “doing well by doing good.”

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<sup>18</sup> 20 C.F.R. §4.16.1121(b), POMS SI 01120.200G.1.d, Fundamentals §3.06. *See also* Kim Martin, *Divorce and the Special Needs Child: How to Save the Day by Knowing A Lot About A Little*, Stetson University College of Law 2021 National Conference on Special Needs Planning and Special Needs Trusts (Oct. 2021).



## **DISCLOSURE AUTHORIZATION**

I have retained the services of the Law Offices of Stuart D. Zimring as my attorneys. I understand that all communications between me and the Law Offices of Stuart D. Zimring are confidential and that any facts or other information that I give to my attorneys will not be revealed to any person or persons without my express permission. With full knowledge of this right, I specifically authorize the Law Offices of Stuart D. Zimring to take the following steps (check the appropriate boxes):

☒ [ X ] To answer questions presented by the person(s) listed below and to otherwise share any and all:

☒ [ X ] Information

☒ [ X ] Copies of correspondence

☒ [ X ] Documents requested by such person(s).

☐ [ ] To answer questions presented by the person(s) listed below and to otherwise share any and all information, copies of correspondence and documents requested by such person(s) ONLY in the event that such person(s) indicates that there is, in such person(s) judgment, an emergency with regard to my financial and/or physical well-being.

I further understand that I will be billed for the time and costs incurred to respond to such questions, calls and other inquiries at the then prevailing rates.

Dated: \_\_\_\_\_, 2020

\_\_\_\_\_

FRED FLINTSTONE

Authorized Person(s)

BARNEY RUBBLE

Third Party Payer:

You have requested that we accept payment for the services to be rendered to you from your \_\_\_\_\_. By initialing this paragraph, you indicate your understanding that you are primarily responsible for the fees and costs described and that you will be liable for them if \_\_\_\_\_ fail or refuse to pay. (\_\_\_\_). (\_\_\_\_\_).

We are not aware of any conflicts or potential conflicts that exist or may exist in connection with the payment by \_\_\_\_\_ of our fees and by initialing this paragraph and signing this Agreement, you indicate that you have given your informed consent to payment by them. (\_\_\_\_). (\_\_\_\_\_).

Third Party Payor:

Client has requested the Firm accept payment for the services to be rendered to Client from \_\_\_\_\_ who is the Client's \_\_\_\_\_.

Client understands that the Client is primarily responsible for fees and costs incurred under the Agreement and will be liable for same if \_\_\_\_\_ fails or refuses to pay.

Client acknowledges Client has been informed in writing of any potential conflicts that may exist in connection with the payment by \_\_\_\_\_ and the Client has given his/her/their informed consent to payment by \_\_\_\_\_.

# Working With Litigation Counsel -

A Guide to the Perplexed  
and Sometimes Frustrated

# Setting the Scene

- 4 p.m. Friday. You're out the door.
- Marvin the Med Mal Mavin (he of many billboards and late night TV) calls.
- It's the case of a lifetime – Poor Giselle!
- Can you send him one of those “Special Needs Trust Things” before you leave?

# The Cast of Characters

- Who's In the Room Where it Happens?
  - ◆ Marvin
  - ◆ Giselle
  - ◆ GAL
  - ◆ Structured settlement folk
  - ◆ Life care planners
  - ◆ Trustee (?)

# Dealing With the Elephant(s) In the Room

Who is the client?

- Identifying the client

- Determining client capacity

Conflicts of Interest

Duties to non-clients



# More Elephants

Getting paid (very important!)

By whom (3<sup>rd</sup> party payor?)

From Where?

How to calculate?

The Devil is in the details

Medicaid/Medicare/Subrogation issues-  
who's responsible?

# Success!

- Being prepared is half the battle.
- You are probably the only one who see the entire picture, *i.e.* Giselle in 30 years.
- A perfect example of NAEELA's motto:
  - ◆ Doing Well by Doing Good

# A Final Thought

- Domestic Relations, Spousal & Child support and SNTs – the Next Frontier?



STETSON LAW

# **2022 Fundamentals of Special Needs Trusts Administration Webinar**

**Friday, May 20, 2022  
3:20 P.M. – 4:10 P.M.**

**Basic Trust Distributions...Nope!**

Presenters:

Megan Brand and Yolanda Mazyck

- Materials
- PowerPoint

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# Basic Trust Distributions...Nope!

STETSON'S 2022 FUNDAMENTALS OF SNT ADMINISTRATION WEBINAR

MEGAN BRAND AND YOLANDA MAZYCK

## **Nothing For Us Without Us: A Person-Center Approach**

We begin this paper and presentation with this statement: THERE IS NOTHING BASIC ABOUT THE PROCESS OF MAKING DISBURSEMENTS FROM A SPECIAL NEEDS TRUST. The organization serving as trustee is accountable to the beneficiary, government entities and their public programs, the IRS, the board of directors, and their adopted policies and procedure. One wrong disbursement decision can impact the beneficiary and the organization. This paper aims to provide a framework for the practitioner to consider in their trust management journey.

We believe that every trust account is unique to the person for whom it was created and should be engaged using a person-centered-like model. Most of us have heard the term person-center service or some iteration. The Journal of the American Geriatrics Society offered this definition of person-centered care after assembling 14 experts in diverse disciplines, including public health, medical, social work, and health policy and finance:

*"Person-centered care" means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires. An individualized, goal-oriented care plan based on the person's preferences. Volume 64, Issue 1 of January 2016*

We adapted the definition to better align with the populations we serve to read: "the beneficiary is placed at the center of service and treated as a person first, allowing the team to

focus on identifying their desires. Adopting this model can establish a more customized approach to the disbursement process because deciding which disbursements to approve from a beneficiary's trust can be complicated. There are multiple factors to consider before disbursing funds. However, before making any distributions, we strongly suggest engaging the beneficiary and their support network, if applicable, in a trust planning process. Each organization may assign a different name to the process from Quality of Life Plans, Trust Plans, and Trust Assessments, to name a few. That planning process aims to give the beneficiary a voice focused on how the trust can enhance their lives. The planning process also gives the trustee critical information when developing the beneficiary's budget. Lastly, the trust planning process can prevent confusion, misunderstandings, and disgruntled beneficiaries during the trust management process—and we have yet to encounter a Trust Administrator seeking disgruntled beneficiaries or their support network.

### **The Trust Planning Process**

We shall use the term Quality of Life Plan (QLP) for this paper. As fiduciaries, we are responsible for the assets and how they are managed and distributed. That can be an arduous task, and we must ensure the beneficiary is part of the planning process. While it is true that the trustee has "sole discretion," we must consider the needs and, yes, even the desires of the beneficiary before developing a budget. At a minimum, as trustees, we should acquire an understanding of the beneficiaries' lifestyle related to housing, care, and needs. Then, ask the beneficiary and their support network how the trust can enhance their overall quality of life. Acquiring this information is part of developing a Quality-of-Life Plan and often the first step to adopting a person-centered trust management model.

What a perfect plan, except the beneficiary most likely has at least one public benefit that the trustee must consider when developing their QLP for distributions. Though we may engage in a person-centered-like model, Social Security's Supplemental Security Income (SSI), State Medicaid, and Subsidized Housing programs do not. They each have their own set of rules that must be followed to avoid interruption or termination of benefits. This creates an additional layer; however, it is an integral part of the beneficiaries' whole care plan. It is our responsibility to share, provide supporting documentation of the governing rules, and reshare and attempt to manage the beneficiary's expectations and their support network.

Once the QLP is completed, the trustee can then create a budget. The approach to budgeting is contingent on the information gathered at the planning meeting, the amount in trust, and its life expectancy. Our experience extends from generic (cell phone and internet bills only) to moderated (monthly bills, card uploads, and vacations) to detailed (all of the above and housing, medical and debt management), requiring more investment of time for research and possibly even negotiations in some cases.

Regardless of where on the spectrum a plan or budget falls, the process will assist with managing expectations for the beneficiary and create a guide for the trustee as they begin to receive requests for distributions. Lastly, because QLPs and Budgets are living documents, the trustee should review them annually for "high touch" accounts, bi-annually for moderate to limited use, or when a life event occurs.

### **Requests and the evaluation of them:**

It is important that requests are accepted in multiple formats to accommodate how people with disabilities may communicate. A trustee will likely require additional information once the initial request has been made, but an in-person meeting could accept the first inquiry, phone or



video call, fax, text, or email. The staff member of the trustee may do an initial review and ask for documentation of the request (ex: invoice, estimate, bill, link to an online store, etc.) From there, a trustee will begin evaluating the request.

#### Case Decisions:

Before we review the framework for evaluation, it is important to look at a few decisions that have been made regarding distributions from Supplemental Needs Trusts. The department of Public Welfare of the Commonwealth of Pennsylvania attempted to require that a pooled trust must meet expenditure requirements additional to the federal statute in that "all distributions from the trust must be for the sole benefit of the beneficiary" and "must have a reasonable relationship to the needs of the beneficiary." Further, they defined special needs as "items, products or services...[that] assist in and are related to the treatment of the beneficiary's disability." *Lewis v. Alexander*, 685 F.3d 325 (3<sup>rd</sup> Cir. 2012). Thankfully, *Lewis v. Alexander* found that pooled trusts cannot be limited to treating one's disability.

Similarly, there was a case in MN in which the District Court in MN denied distributions for a snowmobile and Brittany Spears tickets while approving a bike and other outings. Jennifer Collins was then a teenager with down syndrome and had a trust from a personal injury suit. Jennifer's father was her trustee. In 2004, the court of appeals reconsidered and responded to "Whether Brittany Spears concert tickets are an appropriate expenditure for a 14-year-old" the court wrote, "requires an exercise of discretion: parents of disabled and non-disabled children are constantly faced with such discretionary decisions...we conclude that [Mr. Collins] exercised but

did not abuse his "sole discretion" in providing a child's snowmobile and concert tickets for Jennifer."<sup>1</sup>

Most courts use the "Abuse of Discretion" standard, and the appellate court in MN was no different. Thankfully for trust administrators, there is now a standard that the trustee can use their discretion and approve unique and individual requests for beneficiaries.

Framework:

Any trustee needs to have a formula or framework for evaluating requests. Establishing and then following a framework for evaluating requests by a pooled trust administrator is especially critical in maintaining consistency, organization, and fairness. It is important to note that a framework does not necessarily mean that similar requests from different beneficiaries (or even the same beneficiary at other times) will result in the same outcome. Each beneficiary and their unique circumstance and reasoning for the request must be evaluated.

#### 1. Appropriateness for the Individual

With each request, one of the first steps that should be analyzed is the appropriateness of the request for the individual. The trustee must know the beneficiary and their circumstance well. Suppose the trustee cannot evaluate the needs of the individual personally. In that case, they could employ a case/care manager, trust advisor, or, in some cases, rely on the requests from a family member or close friend whom the trustee has come to know and trust. The pre-planning, which is person-centered, discussed earlier, aids the trustee even further in understanding the appropriateness for the individual.

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<sup>1</sup> *In re Irrevocable Supplemental Needs Trust of Collins*, A04-1018, 2004 WL 2858079 (Minn. Ct. App. Dec. 14, 2004)

a. Identify the need

When a trustee first receives a request, especially a unique request, it is important to document the *who*, *what*, *where*, *when*, *why*, and *how*. One of the most telling pieces of information is who made the request. Suppose a new "player" suddenly enters the life of the beneficiary. In that case, this could be one of the first signs of exploitation or undue influence, which must be in the back of the trustee's mind when considering requests for a vulnerable population. The *what* and *why* are equally important factors. Consider this example from a trust administrator:

A trust beneficiary calls the trustee and asks for a sex change operation. Rather than just saying "no," the trustee began to ask some questions. She learned that the trust beneficiary wanted to become a female because he wanted to live on the main floor of his home. The trust officer was surprised to hear this because the trust beneficiary had always lived on the main floor of his home. When she talked with him further, she learned that he had recently taken in two roommates, both females, and they had relegated him to the basement. (Mind you, this was a **trust-owned** property). The roommates told this beneficiary that he couldn't live on the main floor because he wasn't a woman. So, his solution—have a sex change operation. Thankfully, a sex change operation and further abuse from the roommates was averted when this trustee asked the right questions.

When the request is made, or how frequently it is made, is another important factor. One of the best tools in the tool belt of the trustee is time. Following an initial conversation re: a request, the beneficiary often calls to change his/her mind or rescind the request. Further, there are some beneficiaries, due to the nature of their disability, who make requests so frequently that the trustee learns to only follow up on the requests that are consistently reiterated by the beneficiary.

b. Discuss how it relates to the person's disability

Thankfully, *Lewis v. Alexander*, 685 F.3d 325 (3<sup>rd</sup> Cir. 2012), found that pooled trusts cannot be limited to the treatment of one's disability. However, this decision does not mean that the disability of the individual should not be considered when making a decision. Consider the following example:

When considering if firearms should be purchased from a special needs trust, one must consider the disability of an individual. A trust beneficiary who has a mental illness and is unstable and has recently filed a complaint with her mental health provider and then comes to the trustee asking for a Glock pistol for "self-defense", should not be given the gun. Conversely, when a young man with cerebral palsy asks his trustee to pay for a rifle so that he can do target shooting with his brother, father and uncle at a shooting range, the response will likely be different.

- c. Is it recommended by a professional? Or could it be?
  - i. Medical Professional/Doctor/Therapist, etc.
  - ii. Social Worker/Case Manager
  - iii. Mental Health Professional

The recommendation from a professional working with the beneficiary can be a great resource to the trustee. A medical professional, for instance, has a much different relationship with the beneficiary than a trustee and can provide insight into the person's needs. This opinion or recommendation can be very helpful when the trustee is faced with a difficult decision. Further, this documentation from a professional can go a long way in justifying an expenditure from a trust. Conversely, if a professional does not recommend something for a trust beneficiary and the trustee was leaning toward not approving it, the trustee now has the backing of another person on the "team" for denying the request.

- d. How does the request impact the individual's government benefits?

The entire purpose of a Supplemental Needs Trust is to protect a person's governmental benefits while still giving them access to the funds held in trust. It is, then, the primary focus of a trustee to maintain these critical benefits that provide income, food, shelter, and medical care. As with any request, there must be a comparison of the request to the individual's government benefits. This is not a cookie cutter approach, as Medicaid offers several different programs with different income and resource limits. And of course, these Medicaid programs vary from state to state.

One of a trustee's most significant challenges with government benefits with atypical or controversial requests is the differentiation between federal and state laws. For example, marijuana for recreational and medicinal use is legal in many states, but marijuana is not legal federally. A trustee must consider these rules and a trust beneficiary's reliance on Federal benefits such as Section 8 or Food Stamps when deciding if the trust will purchase medicinal marijuana. While it may be legal in the state where the beneficiary lives, the trustee approving the medicinal marijuana may inadvertently make the beneficiary ineligible for a federal government benefit.

e. Is the request in line with the financial plan/budget for this individual's trust?

No matter what the request, a trustee must always consider the balance of the trust, other expenditures of the trust, the request at hand and the overall goals of the trust beneficiary and the trustee. When looking specifically at a pooled trust, it is more common that pooled trust sub-accounts will not outlive the trust beneficiary. However, this is not an excuse for a trustee to be frivolous with expenditures. A trustee who is making a difficult decision that has a heavy financial outcome may be able to "let the numbers do the talking" when explaining the reason for denying a particular request.

2. Sole or 3<sup>rd</sup> party benefit

Another requirement of a Pooled Supplemental Needs Trust is that the trust is for the sole benefit of the person with a disability.<sup>2</sup> Due to the individuals served by a pooled trust, they are often vulnerable to exploitation. Again, as with any trust request, a trustee must evaluate who benefits from the request at hand.

3. Review of the request alongside any federal or state laws

The federal and state laws must be evaluated with any request, but the due diligence of the trustee when it comes to "atypical" beneficiary requests is especially important. For example, the laws regarding the requests of Marijuana, Firearms, Fireworks, Prostitution and Sex Change Operations vary from state to state. Further, Medicaid benefits, in particular, vary from state to state and can provide a lot of guidance when it comes to trust distributions in consider of eligibility from an income and resource standpoint.

4. Review the request alongside the Trust, Policies, and Procedures

In addition to the state and federal government benefits and the state and federal laws, the trust document must be considered. The master pooled trust document may certainly prohibit a particular item or expense from the trust for a pooled trust. It may be more likely for the non-profit administering the trust to have a policy prohibiting or allowing a particular expenditure or setting certain requirements for the expense (Ex: policy requiring certification of medicinal marijuana or a certain procedure relating to the purchase of a home). Policies must be considered by the governing board and staff carefully so as to set the necessary limitations but not to lock one into an inability to

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<sup>2</sup> 42 U.S.C. §1396p(d)4(C)(iii)

approve a request (Ex: a complete prohibition of firearms may prevent the young adult in the earlier example from going to a shooting range with his family if the trust cannot purchase the firearm).

5. The trustee must do a "values check"
  - a. Personal Experience
  - b. Religious or Moral framework
  - c. Evaluate if we are acting paternalistically

The trustee (in the case of the pooled trust, the individual staff member making the decision) needs to be aware of their own bias in making a decision, especially when it comes to controversial issues. For example, a trustee may come from a background or belief that any sexual activity outside of marriage is immoral and would never consider approving prostitution. The trustee can also easily slip into a paternalistic position of approving or denying a request simply on what *they* think is best.

The best way to avoid this is to have at least two parties involved with every request. A case manager or trust administrator may make the request and advocate the desires of the beneficiary. The supervisor then decides based on the information presented and the other components of the framework discussed above. Another consideration is to draft policies that may pose conflict (ex: abortion or End of Life Medication) for a staff member with the option not to participate. Finally, an internal committee or board committee should be available when a supervisor is unsure of what to do or for certain predefined parameters (Ex: requests over a certain threshold or any request that could be considered for a third party's benefit).

**The Beneficiary: Too Many Rules, I Want What I Want...NOW**

So, you've created a clear QLP that addresses a variety of needs and wishes of the beneficiary. You developed the perfect budget and reviewed it annually. You updated the QLP bi-annually or in response to life events. You provide government benefits and organizational rule changes as needed. Your trust management is impeccable. Then out of nowhere, a beneficiary is disgruntled; they want what they want and do not care if the distribution jeopardizes their benefits.

What do you do? First, meet with the beneficiary and their support network, if applicable. Listen to their concerns. Provide documentation supporting your decision. Make sure your organization is well represented—consider meeting with them as a team. If unresolved, provide them with your grievance process. Every trust organization should have a grievance process outlined in the procedural trust manual and the beneficiary welcome packet. Once presented with an official grievance, FOLLOW YOUR PROCEDURE. Do not skip a step. A skipped step can result in unnecessary litigation—that we all want to avoid. These processes are an integral part of managing a person-center trust—the beneficiary is always the focus because there should be nothing for them without them...especially when they are disgruntled.

### **Distribution Fulfillment:**

Once the decision is made to approve the request, additional factors must be considered in how the distribution will be fulfilled. There are various ways to purchase the requested items. Again, even the most mundane forms of payment can propose problems or risks.

#### **1. Checks**

Most distributions are made via check. Typically, the check is made and mailed to the vendor directly for payment. Still, there are instances in which a check may be made to the beneficiary directly if it is permissible with their types of benefits.



It is important that the trustee, especially a trustee with multiple staff, employ as many checks and balances as possible in the check writing process to follow best accounting practices and reduce opportunities for embezzlement. For example, one person enters the information into the system, another person approves it and a final person mails the check. Some trustees utilize vendors that are offsite to mail the process and mail the checks and this method is best at covering all of the checks and balances.

Finally, a system such as Positive Pay that is offered by banks is a great tool to prevent fraudulent activity with checks. This system requires the trustee to send a file of all checks being cut to the bank so that the bank can verify as checks are presented for payment. This prevents people taking the routing and account number and attempting to use the account for electronic payments.

## 2. Credit Cards

Credit cards can be an excellent tool for the trust staff to fulfill requests. Credit cards can be used online, in person, and over the phone. The trustee will need to determine the criteria they use for allowing staff to have credit cards and the available credit allowed. It will be critical to document the beneficiary's name, address, or other identifying information for such purchases and confirm with the vendor that they will send a receipt (especially for phone purchases). The trustee should ask the beneficiary to sign the receipt or other document when given items in person.

## 3. True Link Cards

True Link Debit cards can be another great aide to the trustee in making distributions. The Program Operations Manual System (POMS) is the primary source of information used by Social Security Employees to process claims for Social Security

benefits. POMS SI 01120.201.I.1.e. specifically addresses the True Link restricted debit cards used by a trustee for trust distributions. The POMS states that the trustee must be the owner of the account (not the beneficiary) for it to be allowable.

The trustee fully controls True Link cards. Further, the trustee can determine the amount on the card, where the funds can be used (by categories), lock or suspend the card, and pull back the funds at any time. The categories can also be changed at any time so the trustee may choose to use the True Link card very restrictively (fuel only for example) most of the time and then lift limitations when the beneficiary is traveling.

#### 4. PEX

PEX is another prepaid card option that allows the trustee to set limits, track spending, pull back funds in the account, and block the card in real-time. The card program operates with the same parameters as True Link cards, offering an administrator and cardholder platform. The PEX Cardholder platform allows the beneficiary access to their transactions and card statements; they can upload receipts, make fund requests, and other communication tools. Both cards are a fantastic compassionate management tool for the trustee, offering a sense of dignity and independence for beneficiaries living in a means-tested system of constraints.

#### 5. Gift Cards

Gift cards to stores are another option for distributions that must be used with caution. The POMS (POMS SI 01120.201.I.1.f) gives guidance in re: gift cards and certificates. A gift card that can be used to buy food or shelter items is countable as

unearned income in the month of receipt. A card for a store that does not sell food or shelter items may be permissible, but the card must have a legally enforceable prohibition on the individual's selling the card for cash. If it does not, then it will be counted as unearned income. Gift cards may be best used along with a Limited Power of Attorney.

#### 6. Limited Power of Attorney

A trustee may choose to make a trusted family member or friend an agent of the trust through a Limited Power of Attorney document. The document can specify the amount of funds to be given and the method (check, gift card, etc.), the purpose for the funds, and the length of time the Limited POA is in effect.

#### 7. Reimbursement

So long as an item is approved in advance, a trustee may also consider reimbursement to a family member or friend for their payment of a good or service. This reimbursement should require excellent documentation and proof that it was for the beneficiary. In certain circumstances, it may be acceptable to reimburse a beneficiary, but a trustee should proceed with extreme caution and in consideration of the individual and their benefits, as it could be construed as income.

### **Conclusion:**

As we have shown the reader, THERE IS NOTHING BASIC ABOUT THE PROCESS OF MAKING DISBURSEMENTS FROM A SPECIAL NEEDS TRUST. The requests our beneficiaries make are as unique as they are and must be handled with care while taking into consideration the quality of life needs of the beneficiary and the fiduciary duties of the trustee. Decisions made will need to be documented along the way and hopefully result in happy and fulfilled beneficiaries.





# BASIC TRUST DISTRIBUTIONS... NOPE!

Megan Brand, ED, CFPD  
Yolanda Mazyck, ED, Shared Horizons



# Agenda

- Person Centered Planning
- Requests and evaluation
- Making the Decision
- Distribution Fulfillment

# OUR CLARIFYING STATEMENT

**There is nothing basic about the process  
when making disbursements for beneficiaries  
from a special needs trust.  
NOTHING.**



# PERSON-CENTERED PLANNING

# WHAT IS A PERSON-CENTERED APPROACH?

The beneficiary is placed at the center of service and treated as a person first, allowing the team to focus on identifying their desires.



Nothing For Us Without Us:  
A Person-Center Approach



# WHY DO WE NEED A PLANNING DOCUMENT?

- It gives the beneficiary an opportunity to express their needs and wishes
- It provides critical information to the trustee
- It prevents, or at least reduces, misunderstandings

What's the point of engaging in a trust plan if we [trustee] have "sole discretion?"



# What is included in the Trust Plan?

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Benefits

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Support Network

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Housing

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Care Needs

---

Wants and Wishes

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Trust Representative – if applicable

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Beneficiary of Residual



# REQUESTS, EVALUATION & DECISION

# How requests are made:

- in-person meeting
- phone or video call
- fax
- Text
- Email
- \*Important to accommodate

# Case Decisions to guide our deliberation:

## 1. Lewis v. Alexander, 2012

- State Medicaid in Pennsylvania attempted to narrow the allowable distributions from a pooled trust to "disability specific".
- The beneficiaries of the pooled trust formed a class action suit against Pennsylvania and won.

# Case Decisions to guide our deliberation:

## 2. In re: Irrevocable Supplemental Needs Trust of Jennifer Collins

- Jennifer was a teenager with down syndrome and had a trust from a personal injury suit.
- Jennifer's father was her trustee.
- District Court in MN denied distributions for a snowmobile and Brittany Spears tickets while approving a bike and other outings.
- In 2004, the court of appeals reconsidered and wrote "Whether Brittany Spears concert tickets are an appropriate expenditure for a 14 year old" the court writes, "requires an exercise of discretion: parents of disabled and non-disabled children are constantly faced with such discretionary decisions...we conclude that [Mr. Collins] exercised, but did not abuse his 'sole discretion' in providing a child's snowmobile and concert tickets for Jennifer."
- Most courts use the "Abuse of Discretion" standard.

# Framework for Evaluation

## 1. Appropriateness for the Individual

- Identify the need
- How does this relate to the person's disability?
- Is it recommended by a professional? (Or should it be?)
- Impact on Government Benefits
- Consider the financial plan/budget and other distributions.



# Framework for Evaluation

2. Sole or Third Party Benefit?

3. Review request alongside any federal or state laws

4. Review the request against the Trust, Policies and Procedures of the Trustee

# Framework for Evaluation

5. Trustee must do a “values check”

- a. Personal Experience

- b. Religious or Moral framework

- c. Evaluate if we are acting paternalistic

# THE DENIAL AND APPEAL PROCESS



# **The Beneficiary: Too Many Rules, I Want What I Want...NOW**

- **Meet**
- **Listen**
- **Provide Support**
- **Documentation**
- **Then Meet Again With Support Network**

# STILL UNRESOLVED?

Time to Engage  
the Grievance  
Process

Follow Your  
Procedure

A row of wooden figures, resembling pawns, arranged in a line on a light blue surface. The figures are mostly light-colored, but one figure in the center is a vibrant red. The figures are slightly out of focus as they recede into the background, creating a sense of depth. The red figure stands out prominently as the focal point of the composition.

STILL PART  
OF THE

PERSON-CENTERED  
APPROACH



# REQUEST FULFILLMENT

# Distribution Fulfillment

1. Checks
2. Credit Cards
3. True Link Cards
4. PEX Cards
5. Gift Cards
6. Limited Power of Attorney
7. Reimbursement



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