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Special Needs Trust Distribution

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Special needs planning is triggered by a person's health problems. A special needs trust (SNT) is usually part of the planning, designed to allow the potential beneficiary's publicly- funded health coverage (that is, needs-based Medicaid) to continue despite the existence of a trust for the person's benefit. The special needs trust funds are distributed to supplement state and federal cash income and medical coverage programs. If the trust terms fit the public program rules, the trust is not considered an "available resource" so as to disqualify the beneficiary.

The lawyer usually represents a family member or friend setting up a trust for the chronically ill beneficiary. Lawyers also represent a trustee of such a trust during administration, which is the focus of these materials today.

The toughest special needs trust administrative situations involve incapacity and disability of a trust beneficiary – often giving rise to chaotic life and care circumstances inordinate health care and supportive care costs for that beneficiary

Having health coverage means the beneficiary can get medical services. Supportive services (also known as long-term care) are not provided by private health coverage or Medicare. Some disabled individuals need day-to-day assistance to be safe in a home or apartment. Family members and friends provide some supportive services; some disabled individuals pay privately for supportive services in home or licensed facilities.

The trustee of any discretionary or mandatory support trust might spend down the trust corpus for health care premiums and uninsured costs, including supportive services in the home or facility care. The trustee of a special needs trust will limit distributions to supplemental needs if the public programs provide adequate medical coverage and supportive services including facility care.

Distribution Guidance

The chronic illness and potential or current disability of a trust beneficiary always affect how distributions from any discretionary or special needs trust are determined, and what those distributions are (dealt with in detail below).

To determine appropriate trust distributions, the trustee must obtain information about the settlor's intent and the particular beneficiary's circumstances. The trustee should then build in a periodic review.

The initial drafter can help greatly by setting out useful information in the instrument or associated documents, and building in some annual review process for the trustee. So in any special needs trust administration, look for a settlor's statement of intent (usually separate from the trust instrument itself), and determine if a trust advisor or regular care manager report is mandated.

Settlor's Statement of Intent

Most experienced SNT lawyers who help parents plan for disabled children request the parents create a "statement of intent" or "beneficiary information letter" to guide the trustee. Forms of these statements can be found on the Internet and in books about planning for special needs.

Trust Advisors

Special needs trust distributions are tricky, and loss of public benefits can ensue, so some trustees want to bifurcate trust distribution decisions from the safer trust administration and investment decisions, and foist the tough distribution decisions onto someone else.

Some trust drafters favor a co-trustee approach, with one trustee determining

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distributions and one trustee managing financial assets. Some drafters include "trust advisors" in a committee structure or single entity, to suggest distributions to the trustee who writes the checks.

The Uniform Trust Code and Oregon law contemplate trusts operated with "advisors." Some of the first party SNTs I draft include both trustees for basic investment management, and an independent (non-relative!) trust distribution entity to recommend appropriate distributions. The trust instrument should describe the advisor's role and how the advisor can be replaced and compensated.

Some older first party SNTs kept the personal injury lawyer involved after settlement, including him or her as a "trust advisor." Some older first party SNTs set up the parents or siblings as trust advisors, to recommend distributions to an institutional trustee. The professional fiduciary is worried about making disqualifying distributions, and wants to pass off that task to others. A trustee reasonably investigating the protected person's needs will solicit the input of those close to the beneficiary: family members or personal friends who consider themselves advocates, medical providers, or social service providers.

Administering a trust advisory committee is cumbersome. If the trust instrument is sketchy about the advisor role, compensation, or other details, review ORS 130.735 carefully and design procedures to try to make it work and reduce potential risk to the trustee. The most difficult trust advisor situations are when the disabled beneficiary lives with the advisor (often a parent or spouse), and the advisor seeks a distribution (i.e., purchase of a home, car or boat), which benefit both advisor and beneficiary.

I prefer a trust without formal advisors. I anticipate that the beneficiary will have a guardian, in most cases, and that the guardian can advocate for the beneficiary's best interests. If the trustee (who may be court supervised in a first party trust), and guardian get into a serious disagreement, I anticipate using the courts to resolve the dispute by either a petition for trustee instructions, or a petition to remove a guardian. I strongly recommend care manager reports to provide useful distribution-keyed information to a beneficiary's particular situation.

Gathering Information About Needs, Programs

The SNT beneficiary's circumstances will change over time, as the underlying medical/cognitive conditions and care providers change. In some cases, the trustee is also the guardian, caregiver, or family member closest to the beneficiary, and intimately aware of all necessary data. But where the trustee is not in close contact with the beneficiary, the trustee needs to find a way to regularly update the initial information guiding distribution decisions, and solicit input from those most familiar with the beneficiary's current needs.

The trustee can rely on regular contact or reports from the beneficiary's guardian or case manager for guidance. Some special needs trusts provide for an advisory committee or "trust advisor" to guide a trustee in making special needs distributions.

The trustee will develop a set of practices to permit these other players to give input about distributions, so that information flow is a two-way street.

Usually, the trust provides that a guardian or conservator is an interested person to receive annual trust accountings. A trust advisor will also receive accountings, and the trust will outline which decisions (usually distribution matters) require advisor input.

Guardian Advocacy: If a disabled beneficiary is incapacitated, and has a guardian, then the trustee should review the annual guardian report, and talk to the guardian about anticipated changes. The guardian is expected to act as an advocate, pushing the trustee to make distributions to improve the quality of the beneficiary's life. Where the guardian is not acting as advocate, or is overwhelmed by care giving responsibilities, the trustee should consider hiring a case manager to get good information.

Special needs trust often exist in tandem with a protective proceeding. In some cases, a guardian-only protective proceeding has been set up to make residential and medical decisions for a disabled beneficiary. In some cases, a conservator is appointed for a disabled beneficiary to administer some non-trust assets, and perhaps to set up and fund a first party payback trust with a personal injury settlement or unprotected inheritance.

First Party Trust: In first party, self-settled payback trust administration, the SNT trustee may also be a conservator; there may be a family member or professional fiduciary serving as guardian. The petitioner to set up a court-approved payback 42 UCS 1396p(d)(4)(A) trust will sometimes be the ultimately appointed

conservator/trustee.

Third Party Trust: The third party SNT may be setup while there is a conservator to manage a spend down of disqualifying assets. The conservator and trustee will coordinate the closing of the conservatorship with the application for any needs based benefits, and the commencement of distributions from the special needs trust.

A relative may fund the third party SNT with inter vivos gifts, and/or at death through the will, revocable trust, and life insurance, or retirement accounts. If at funding the beneficiary is not yet receiving needs-based benefits, the third party SNT may be treated as a "trust in waiting" - preserved for the beneficiary's future supplemental needs. But in some cases, the pre-public benefits SNT actively makes distributions to ease the beneficiary's economic straits prior to eligibility (for example, paying health care costs, for supportive services, a case manager, or other assistance deemed appropriate).

If the third party SNT has been set up so that the parent/initial trustee can establish a pattern of distributions that is intended to guide successor trustees, then distributions commence immediately, even while a conservator spends down the disabled protected person's remaining assets.

No Court –Appointed Guardian for Minor; May Have Conservator: Where a minor disabled person lives with a parent (the so-called "natural guardian"), there will be no court-appointed guardian. When a minor living with parents settles a personal injury claim, the particular court forum's settlement process may require appointment of an independent guardian ad litem to approve the court's establishment and funding of a special needs trust. In Oregon litigation, the courts typically require appointment of a conservator to approve the settlement, establish the payback SNT, and transfer the plaintiff's funds to the special needs trust.

Guardian for Disabled Minor Trust Beneficiary Turning Age 18: When a disabled minor beneficiary turns age 18, the SNT trustee might be approached by a relative seeking to become the guardian and asking the trustee to fund the protective proceeding. Perhaps the trust beneficiary is a self-advocate, and does not want –or perhaps does not even need - a guardian. After evaluating the situation and the suitability of the proposed fiduciary, the SNT trustee will fund a guardianship if needed, and adds both the beneficiary and guardian to the annual account list of interested persons.

Care Manager Report to Trustee: Some trustees engage a care manager familiar with both public benefits and the medical conditions suffered by the beneficiary. That case manager could do an initial evaluation, and then follow up with an annual review. The trustee could ask the case manager to:

- *meet the beneficiary,
- *talk with family members,
- *talk with care providers,
- *review social service and medical records,
- *talk with the public benefit case worker about the existing programs and likely cutbacks in the next year,
- *review the annual or most recent public benefit review materials sent in by the beneficiary or SSA representative payee, and
- *review available health care coverage and options if public benefits are lost.

The beneficiary or guardian must, of course, sign a release to permit the case manager to talk to medical providers or public benefits caseworkers. The case manager can report on the beneficiary's needs and the likely changes in his or her medical condition or support system and benefits during the next year, to prepare the trustee for coming changes in a distribution pattern. For example, if the beneficiary has lost function, and will likely move to assisted living from an independent community apartment in the coming year, the trustee will stop making a distribution for cleaning the beneficiary's apartment. If the beneficiary is getting better, and will work enough to lose SSD and eventually lose Medicare, then the trustee will need to determine whether to make distributions for private health plan coverage.

Basic "Safe" Distributions

Most trustees want to know some basic "safe" distributions, so they can pay for items for the beneficiary immediately. These safe distributions include:

- *Telephone
- *Cable/Satellite TV
- *Paper products (TP, tissues, paper towels)
- *Laundry and cleaning supplies

- *Eyeglasses
- *Dentures and dental work
- *Transportation
- *Out of pocket medical expenses
- *Cameras
- *Trips and vacation
- *Membership in gym, book club
- *Newspaper and magazine subscriptions
- *Athletic training and exercise costs
- *Materials for hobbies
- *Tickets for recreational and cultural events
- *Computer or electronic equipment
- *Television or radio
- *Tuition and educational or training costs
- *Guardianship fees and costs for court advocate
- *Cell phone
- *Yoga classes

Practice Tip: Provide the trustee with a list of basic safe distributions, and then meet 60 days later to review the checkbook for problem distributions or recordkeeping issues. For example, one of my trustees recorded a restaurant meal prepayment as a "food gift card" instead of "monthly entertainment – meal out." Gifts from the beneficiary to others are disqualifying; distributions for food and shelter reduce a SSI grant. Having the trust pay for an occasional restaurant meal out for the disabled beneficiary and a necessary companion is "entertainment" - not a potentially disqualifying food distribution.

Resources for Trustee Client

Trustees of special needs trusts will scour the Internet for information about what they can or should be doing. My trustee clients have probably already reviewed online material raised by a Google search for special needs trusts. I recommend the websites of the Academy of Special Needs Planners, the Special Needs Alliance, and Tucson, Arizona lawyer Robert Fleming. Most diagnosis-specific advocacy groups will have publications or conference materials on special needs trusts.

I recommend a new trustee buy *Managing a Special Needs Trust: a Guide for Trustees*, by Barbara Jackins, Richard Blank, Ken Shulman and Harriet Onello, DISABILITIESBOOKS, Inc. (2010), available on Amazon. The attorney-authors practice in Massachusetts, so the book has some Massachusetts-specific material, but is the best resource for trustees available.

My family trustees rely on my initial guidance about distributions appropriate for that beneficiary and a checkbook review about 60 days out. Trustees who are also guardians or court-supervised conservator/trustees will see me annually for their court reports and I review their trust distribution patterns at that time.

Patterns of Trust Distributions

The trustee will administer some trusts intensively, making many small distributions monthly. Some trustees make very few distributions. Some trusts are basically quiescent and can be considered a legitimate "trust in waiting." You should determine what distribution pattern your trustee exhibits and why.

Many Distributions: Beneficiary Living Independently in a Private Home or Apartment With SSI/Medicaid. Does the trust beneficiary live independently in a private home or apartment and receive public benefits, such as food stamps, HUD housing, and/or SSI (federal Supplemental Security Insurance of \$674/month) with SSI-linked Medicaid health coverage? In this situation, there are many opportunities for small distributions to enhance life quality, such as restaurant meals, cable or Internet service, cigarettes, clothing, pet care, subscriptions, bus passes or gas card payments, car repairs, vitamins, supplements, and hair/nail care. Some beneficiaries are helped by intensive supportive distributions, to try to ensure a stable period of existence to get back on mental health medications and break a pattern of homelessness.

Does the chronically ill beneficiary have secure basic health coverage (i.e., through Medicare because SSD or DAC/CIB, or private coverage through a parent, that will continue until age 26 and then convert to HIPAA portability) and live in a stable nonfacility setting?

Few Distributions: There are several situations where the trustee makes few distributions. Two are legitimate; one is questionable.

The beneficiary may live in a licensed facility, where most needs are provided and the trust accessed only for vacations, tickets to events, and occasional video games or movies. The beneficiary may be able to use a substantial portion of the monthly Social Security or Railroad Retirement child's benefit for these small expenditures, making access to the trust for help infrequent.

The beneficiary may have several trusts in place, and be intentionally draining one trust before the other trust, so that the secondary trust remains a "trust in waiting." See discussion of multiple trusts below. A quiescent trust may be perfectly legitimate – waiting for a later decline in the beneficiary's condition to be activated, or waiting until other countable resources of the beneficiary are exhausted.

Finally, the hoarding trustee situation may exist (where an ignorant corporate fiduciary or eventual remainder beneficiary trustee resists distributions that reduce corpus). Where the hoarding trustee resists distributions, then the trustee's exercise of discretion may be challenged by an advocate for a living beneficiary.

Practice Tip: Avoid the Hoarding Trustee

If a lawyer is approached for representation by a trustee making no distributions and basically hoarding the funds for remainder beneficiaries, I suggest you reject the engagement. Do you want to be defending a trustee for breach of duty to the life beneficiary, or dealing with an aggressive state claim on some theory against a discretionary third party trust? Oregon and other states get exercised when a large trust exists, no distributions for the life beneficiary are made, the taxpayer supports the ill beneficiary, and the corpus passes at trust termination to the relatives. Representing the hoarding trustee is risky – he or she will likely turn on the trust administration lawyer when later challenged.

Multiple Support and/or Special Needs Trusts

In some special needs planning situations, the relatives may set up multiple trusts designed to operate with a payback first party trust for unprotected assets.

One inter vivos SNT may be set up to allow the parents to "practice" administering a SNT for the disabled beneficiary and establish a pattern of distributions they want followed by successor trustees. There may be an old discretionary support trust in existence established by a grandparent, to be administered as an "as if" SNT if public benefits are needed. There may be an IRA receptacle SNT in existence, to be funded with large retirement accounts at the second parent's death. There may be a payback 42 USC 1396p(d)(4)(A) trust established through a court with the disabled beneficiary's unprotected inheritance or injury claim settlement funds. Finally, there may be a testamentary SNT to be funded with the probate assets at the second parent's death.

In multiple trust situations, the trustee of all trusts may be the same individual – but there may be different trustees of each bucket of assets. Ideally, the trustees cooperate to drain an "as if" discretionary support trust or payback trust first, and then to dip into the long term trusts. As program eligibility rules toughen over time, the goal may be to reserve safer third party trusts for the long-term needs. The legitimate "trust in waiting" can be explained cogently to relatives, advocates and state agencies.

Four Common Distribution Errors

The most common distribution errors I see are:

- 1. Giving the beneficiary more than \$20 in cash – the SSI program allows the beneficiary to receive up to \$20/month in cash, but every dollar over \$20 reduces the cash grant dollar for dollar.**
- 2. Depositing the Beneficiary's Extra Funds in the Special Needs Trust bank account. This commingling of trust and non-trust funds could disqualify the entire trust from being exempt, and greatly confuses both public benefit agency reporting and tax reporting.**
- 3. Writing a check to the trustee himself or herself – even reimbursement checks are improper. Trustees routinely pay for something with their personal credit or debit cards and then write a trust check payable to that card company or to themselves. It is impossible to get this practice stamped out, but the lawyer has to try. Records supporting the reimbursement and showing the distribution purpose help but do not remove the taint of self-dealing.**

4. Writing a check to a guardian or other person close to the beneficiary, without noting what the funds are for or getting receipts for reimbursement, leading to an inquiry about whether the trust is "for the benefit" of the disabled beneficiary, or gifts or theft of funds from the trust

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