

## Advice on Establishing a Special Needs Trust for a Family Member

*Summarized by Thomas T. Thomas*

How to care for a disabled son or daughter in the event of your death is a real concern for family members. On November 20, NAMI-East Bay's members heard from **Linda S. Durston, PhD**, an attorney at law who specializes in estate planning and elder law, which includes wills and trusts, conservatorships, trust administration, and disability benefits such as the Social Security Administration's Supplemental Security Income (SSI) program and the state's Medi-Cal program.

"A Special Needs Trust [SNT] is a legal means for a person to qualify for SSI and Medi-Cal," Durston said. "The income and resource rules for qualification are really confusing, and even lawyers who specialize in these benefits have to look up the details. So, instead of spending a lot of time on them, I want to focus on the big picture, which is that an SNT works around the complicated rules about money."



*LINDA S. DURSTON, PHD*

(For readers who wish to study the SSI rules first hand, log on to "<http://policy.ssa.gov>" and select "POMS." On that page, select "Table of Contents" and then "SI." In the resulting list of topics, "SI 008" addresses income rules and "SI 011" addresses resource rules.)

Unlike other Social Security programs, SSI is a needs-based benefit, not related to the person's work history or previous contributions. It provides \$750 per month to cover "basic needs," which include food, shelter, and clothing. If a person qualifies for SSI, then he or she automatically qualifies for Medi-Cal, which is a needs-based program in California that pays for medical treatment, medications, and long-term nursing care. Under SSI, any other money that the disabled person receives towards food, shelter, and clothing will usually reduce the \$750 benefit dollar for dollar.

"The good news is that there are caps," Durston said. "And this is about the only beneficiary-friendly part of the program." If a disabled person receives in-kind support and maintenance that meets these basic needs during a one-month period, then the maximum reduction in the SSI benefit for that month is capped at \$200, regardless of the actual value of the support.

A Special Needs Trust is set up to provide for a disabled person's needs that are not addressed by SSI, Medi-Cal, and other related programs for which the person qualifies, such as In-Home Support and Section 8 housing.

"The Social Security Administration does not consider assets set aside in an SNT as belonging to the beneficiary, and distributions from the trust are not

considered income,” Durston said. “This allows people who qualify for SSI and Medi-Cal to have a bucket of money to provide for their needs.” To meet these requirements, the trust must be set up correctly, and the beneficiary must qualify for SSI in the first place.

The basic elements of an SNT are:

- A corpus— the money or assets placed in trust.
- A beneficiary— who will make use of the funds.
- A trustee— who distributes the funds.
- A purpose— which guides how the funds will be distributed.

A new element that is starting to be used, Durston added, is a “trust protector.” This is someone other than the trustee who oversees the trust and has the power to hire and fire trustees.

The assets can originally be the beneficiary’s own money, which is called a “first party” trust, or they can come from someone else, which is a “third party” trust. The point is that, once placed in trust, the money or other assets do not— and never will— belong to the beneficiary. Upon the beneficiary’s death, the terms of the trust can assign any remaining amounts to a third person without restriction on their use.

The SNT, Durston explained, is a purely discretionary trust, meaning that the trustee has the power to distribute the funds or not. The role of the trustee is important, because it is assumed he or she will do a better job of handling the trust assets than the beneficiary could do him- or herself. However, the SNT is usually drafted with limits to the trustee’s liability— generally gross negligence and willful misconduct— because the trustee may not have the skills of a banker or financial manager. The SNT generally includes instructions for the trustee on how the money should be spent in order to comply with Social Security rules. It should also address what other resources the beneficiary may have and what programs he or she qualifies for.

If the SNT cannot provide for the beneficiary’s food, shelter, or clothing without jeopardizing benefits, then what can it pay for? Here are some options:

- Medical, dental, and vision care not covered by Medi-Cal.
- Rehabilitation programs and equipment, including workshops on dealing with the disability.
- Dietary supplements and special diet requirements.
- Nursing and custodial care supplemental to coverage under Alameda County’s In-Home Support. This can include housework, cooking, bathing, and other personal care.
- Professional grooming, such as haircuts, manicures, and skin care.
- Educational programs and equipment.
- Entertainment, including books, magazines, movies, plays, and athletic contests.
- Membership fees.
- Residential expenses beyond rent and utilities, such as furnishings and the costs of providing extra heat in the winter.
- Telephone and internet services.

- Travel costs, such as air fare and a traveling companion. Although meal and hotel costs while traveling are considered basic needs, they can be allowed if they are inseparable from the transportation, such as aboard a cruise ship.

“A lot of things are possible to enrich the beneficiary’s life if the SNT is constructed to provide them,” Durston said.

“In general, the trustee shouldn’t give cash to the beneficiary, because that’s considered income. Instead, you can buy things for him or her. Pay the phone bill. Buy a television. Then open a bank account for the beneficiary and put the SSI benefit in it for spending money.”

While a \$500 gift certificate to Macy’s would be considered “clothing,” she said, if given in a single month it would only reduce the SSI benefit by the \$200 cap and could be considered a good deal. The SNT can be set up to pay for the things that are allowed and so maximize the SSI benefit.

One problem, Durston explained, concerns dual beneficiaries and the state’s payback requirement. If the SNT is set up *after* the beneficiary has acquired the trust assets— say, from a rich uncle’s bequest— then upon the beneficiary’s death the state will want the remaining value in the trust as reimbursement for *all* medical benefits received under Medi-Cal, not just those enjoyed during the life of the trust. This can eat up the trust assets and leave nothing for a second beneficiary. One solution is to set up the SNT to receive the bequest *before* it goes to the beneficiary. But if that’s not possible, then the bright side is that Medi-Cal services are usually provided at lower cost than would be available under other circumstances, so they are still a good deal.

A court will be required to oversee the SNT unless the trust is:

- Established by a third party using that party’s funds.
- Established by a parent or grandparent using the beneficiary’s own funds.

If a sibling or other relative or friend stands in for the parent or grandparent in the latter case, then the SNT will have to be established in court. And, of course, the beneficiary cannot set up an SNT for him- or herself.

When the court is involved, there is an automatic \$4,000 in fees. In addition, the court will want an accounting of distributions in the first year (imposing \$1,500 in audit fees) and then every two years after that (with similar audit fees every time). “Avoid having the trust in court if at all possible,” Durston recommended.

An SNT can be created as a component of another vehicle, such as a will or a living trust. In this case the SNT does not become funded and effective— and so remains revocable— until the trust maker dies or, under a living trust, becomes incapacitated. “It’s better to set the SNT up in a living trust,” Durston said, “because then it does not go through probate.”

An SNT can also contain a share of a piece of property, such as an undivided interest in a house. However, the requirement for state reimbursement, as described above, can complicate such an arrangement.

Choice of the trustee is important. It can be a sibling or other relative, or a corporation such as a bank (although they may not be interested in handling assets of less than \$200,000), or one of the new private professional fiduciaries, who handle trusts for a fee and might take on a trust with assets of \$100,000. It is also

possible to have co-trustees. The terms of the SNT should spell out rules for how trustees are evaluated and removed and successors appointed. If the trust is established by a court, then the trustee may also have to report to an advisory committee.

At the close of her remarks, Durston suggested resources to help a parent get started with an SNT:

- National Academy of Elder Law Attorneys ([www.naela.org](http://www.naela.org)).
- California Association for Nursing Home Reform ([www.canhr.org](http://www.canhr.org)).
- The Hawkins Center for Law and Services for People with Disabilities (2500 Bissell Avenue, Suite 101, Richmond, CA 94804, 510/232-6611), which is a not-for-profit law firm specializing in Social Security and SSI claims.
- East Bay Community Law Center (3130 Shattuck Avenue, Berkeley, CA 94705, 510/548-4040), which is similar to the Hawkins Center but serves low-income only.
- Alameda County Bar Association (510/893-7160).
- Contra Costa County Bar Association (925/825-5700).

Linda Durston then answered questions from the audience.

**What happens if the SSI rules change after the SNT is established?**

In the past, the government has let the old trusts operate under the old rules, while only new ones had to comply with the new rules. But there is no guarantee that this pattern will continue.

**Can SNT funds come from an Individual Retirement Account (IRA)?**

They can, but the tax implications are complicated. It's best to work them out with an attorney.

**What happens if the beneficiary moves out of California. Is he still covered?**

Yes, but different states have different benefit programs that work with SSI, as Medi-Cal does. The trust language should say something like "Medi-Cal or other appropriate benefits."

**If I put my house into the SNT, does it affect the SSI rules about shelter?**

This is covered in the Social Security rules. A house that's used as a place of residence is an exempt resource, so it does not have to be included in the SNT— unless that would protect the house from the beneficiary. There is no SSI impact and the house does not become part of any payback to the state.

**Can I give my son on SSI \$50 for walking around money? Say for cigarettes and hamburgs?**

You don't need an SNT to make payments that are within the Social Security rules while you're alive. The trust is for his protection after you're gone. But rather than giving him the \$50 directly, buy him the cigarettes.

**What are the costs of setting up an SNT?**

That depends. Usually \$1,500 to \$2,000 in fees if you set it up for your child with your own money. At least \$4,000 if set up through a court. You should also review your estate planning every ten years or so, because of changes in the law and regulations.