Finding More Funding for Your Child's Special Needs Trust

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A special needs trust (SNT) is a wonderful gift to a child with special needs, however, there is much more that parents and other benefactors can do.

There are two basic funding principles: (1) use what you have wisely, and (2) be creative in searching for more funds. The three phases of funding help attain the set goals: (1) preparing the SNT and special needs plan to leverage existing resources, (2) ensuring that resources are properly directed into the SNT, and (3) looking for additional funding sources.

Mapping the events that alter public benefits is a key step to finding more funds by not wasting funds or opportunities.

Phase I: Prepare the SNT and Plan

An SNT and special needs plan with serious flaws may never have enough funds. The SNT can be much like a bucket with holes in the bottom. The best way to secure more funds for the SNT is often by preventing waste of what the family already has.

Find the Right Attorney. Special needs planning is not yet a standardized area of law. The attorney's knowledge base will make a big difference in identifying resources and strategies to leverage family funds and find more funding. The most experienced attorneys will often be those who have written or spoken about SNTs to other attorneys and professionals.

Focus on the SNT Beneficiary First. Focus first on the individual's likely future needs, such as employment and housing options, medical or assistance needs, and personal and social needs. One mental health professional noted that most individuals with disabilities are no longer satisfied with minimal activities in their lives but, instead, want a house, a car, a job, and a date on Saturday night.

Almost everyone will need housing, transportation, activities, and a social structure. For many, employment is a goal. But employment brings the risk of lost benefits, by losing the quantitatively-determined "disabled" label for Social Security Disability Insurance (SSD) or Supplemental Security Income (SSI), by building the individual's own Social Security work credits, or by hitting the SSI income limit. Lost benefits usually reduce funds available for the SNT.

Examine Existing Resources. There are three primary types of resources, each of which supports the others: paper (the planning), people (individual with special needs, family, benefactors, advocates, professional providers), and money. Careful planning with realistic reliance on the people resources is likely to leverage money resources, keeping more funds for the SNT. But it is also important to plan to protect the irreplaceable people resources.

Develop a Road Map. It is important to know what types of public benefits the individual beneficiary is likely to receive, and if and how those benefits are impacted by changes throughout time. Such profiles and plans may be developed in discussions and informal assessments, or by written reports.

SSD and SSI benefits may change due to life events. Under age 18, parents' income and resources are often deemed to their child. Benefits such as SSI secured after age 18 can be disrupted later by a parent's retirement, disability, or death. An SSI or SSD recipient's eligibility is affected by how much they work. Trust distributions can cause the loss of SSI, as can marriage or divorce, in some cases.

Many of the changes in benefits eligibility surprise individuals. But the details and quirks of public benefits translate into significant funding sources. Mapping the events that alter public benefits is a key step to finding more funds by not wasting funds or opportunities.

Select an Excellent Trustee. A corporate trustee with extensive SNT administration experience is often a wise choice due to the paperwork, accounting records, investment requirements, and general risks that are involved.

Select Good Trustee Appointers and Advisors. Devoted family members who have authority to remove and replace corporate trustees and to advise trustees on appropriate distributions will help save funds by monitoring SNT distributions.

Require SNT Annual Reports and Distribution Plans. Just like budgeting, accounting, and auditing for a million-dollar business, it is important to have outside auditors and reporters who have a process for compiling information about the SNT that is, in turn, useful for creating or modifying a distribution plan. Without such a review, there is greater risk of losses to the trust value through disputes or loss of public benefits. Annual reports and distribution plans can make SNT dollars work harder for the benefit of the SNT beneficiary.

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Phase II: Ensure That Funds Get to the Trust

Good estate planning that directs one's property at death is the most important step to insure that funds make it to the SNT. But there are other important steps as well.

Analyze Each Asset. One way to analyze assets is to develop a grid with all assets listed, and then review the options for transferring each asset. For example, when an individual owns a house or a life estate outright, he or she may be entitled to disability tax exemptions from a variety of taxing authorities. Each element of reduced cost or money saved translates into more money staying in the SNT.

Prepare for Pre-Death Transfers. Pre-death incapacity is a major risk to SNT funding. When parents or grandparents need Medicaid, transfers for the benefit of an individual who meets the definition of disabled may be exempt from Medicaid transfer penalties. But if there are not powers of attorney that permit transfers to an SNT at that time, it is possible that there will be nothing left to fund the SNT at the parent's or grandparent's death. See more about this in Phase III.

Protect Against Later-Life Losses. Poor planning may result in the need for a guardianship for a parent or grandparent. Once subject to guardianship, funds can be depleted rapidly, like a melting block of ice. Prior to incapacity, there may also be times of waning capacity when an individual has poor judgment. This is the time when individuals are more susceptible to scams and other poor decisions that can rapidly—indeed, almost instantly—deplete their resources. Planning in advance can reduce many risks to those who may otherwise direct their funds to an SNT.

Protect Against Daily Depletion from Disorganization: Get a Bookkeeper. Working with a bookkeeper can be a very valuable investment. The paperwork one faces when there are family members with disabilities can be enormous. For the parents of a special needs child, especially full-time caregivers or parents working outside the home, there are simply not enough hours–and there never will be. Good bonded and insured bookkeepers are hard to find, but can produce a great return on investment.

Phase III: The Search for More Funding Sources

Funding sources can be low-tech or complex. Consider the following options:

File for SSI as Soon as Possible. Parents often delay filing for SSI due to their then-current ability to pay expenses. But filing for SSI and having access to Medicaid-funded services can free up other funds for long-term planning or more life insurance. The SSI check ($564 in 2004) will be reduced by one third if the child is still living at home, but parents may prevent this one third reduction by establishing rental or expense sharing arrangements.

Charitable Planning. IRS Revenue Ruling 2002-20 provides that a charitable remainder trust (CRT) can make payments to an SNT for an individual who qualifies as “financially disabled.” CRT payments can continue throughout the individual’s lifetime, creating a replenishment funding stream for the SNT.

Retirement Funds. Working with retirement funds and SNTs is challenging. When it is possible, consider swapping assets with other heirs; for example, leave the retirement benefits to the other children and put more of the cash assets in the SNT.

Child Support. Child support payments belong to the child; if those funds go into an SNT, the SNT is self-settled and must meet pay-back requirements under 42 U.S.C. § 1396p(d)(4)(A). Consider using child support for regular expenses and using the parent’s other funds to purchase more insurance on the parent’s life, or getting a court order to direct the funds to an SNT rather than to child support payments.

Exempt Transfers of a House. An individual’s house can be transferred to a qualifying person (meeting the disabled definition) or to a qualifying trust for that individual. A mother, father, grandmother, grandfather, or any other benefactor, can make a gift of their house without incurring a Medicaid transfer penalty by either a direct transfer from parents, under 42 U.S.C. § 1396p(c)(2)(A)(ii), or a transfer to an SNT from parents or others pursuant to 42 U.S.C. § 1396p(c)(2)(B)(iii) or (iv). There are many technical requirements, so find an attorney who has gone down this road before.

Other Exempt Transfers. As noted earlier, parents, grandparents, and other benefactors have the opportunity to make transfers that are exempt from Medicaid penalties at a time when they need long-term care themselves. This technique can generate significant funds for an SNT under appropriate circumstances, and many older relatives may want to consider this option. See 42 U.S.C. § 1396p(c)(2)(B)(iii) and (iv).

Life Insurance Policies. Many older individuals have multiple small life insurance policies that are time-consuming and sometimes costly to liquidate if that individual later needs to apply for Medicaid. It would, in most cases, be more practical to liquidate and transfer the proceeds earlier.

Insurance on Multiple Lives. It is especially helpful to insure the lives of multiple caregivers and advocates to generate funds that will help replace the personal services that such caregivers and advocates provide.

Insurance Trusts. Insurance trusts reduce the risk of losing an insurance policy if the person who is insured experiences medical events that result in his or her need for public benefits, or if the insured experiences serious financial difficulties. These events may result in the liquidation and loss of the insurance policy.

Establish an SNT and Tell Family Members How to Direct Funds to It. Many benefactors leave assets directly to individuals with serious disabilities. In order to have such funds end up in an SNT, consider establishing an SNT to be funded by others, and providing instructions to family members on how to use it. By establishing an SNT for use by other family members, not only will some of the pre-designated funds end up in the SNT, but other family members may put the SNT higher on their distribution list once they know there is something they can do to help.

No Perfect Guidance System.
There is not an ideal guidance system to help parents and other benefactors do good special needs planning and seize all opportunities, so it helps to recognize the challenges that families face in trying to do good planning.

Much like the Serenity Prayer, we as parents and planners should do what we can, make peace with what we cannot do, and carefully focus on which is which. We usually cannot fix all the problems or fully fund all future possible needs. What we can do, however, is work at developing a great plan and, once that is done, put it aside with less anxiety and a clearer understanding of what to watch for in the future.

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