

Special Needs Trusts: Powerful Planning Tools For Disabled Individuals

by Kate Dussault and Jeffrey R. Lauterbach, J.D.

Planning for individuals with disabilities will be one of the most demanding and rapidly growing areas of practice over the next 20 years, as parents of individuals with disabilities die and more members of the population become disabled. This article reviews types of special needs trusts, which can be a powerful planning tool. The authors also discuss trustee responsibilities, provide a due diligence approach to selecting a trustee for a special needs trust and describe a variety of design options for the ongoing management of the trust.

Kate Dussault is president of Settlement & Trust Consulting Services Inc. and Trust Management Services Co. specializing in serving the needs of individuals with disabilities with offices in Littleton, Colorado, and Seattle, Washington.

Jeffrey R. Lauterbach, J.D., is president and CEO of the Capital Trust Company of Delaware, which assists professional advisors nationwide in helping their clients achieve personal goals through trust strategies and the benefits of Delaware law.

Fifteen to 20 percent—that's a fair estimate of the number of individuals with a disability in the total U.S. population, according to Social Security and Department of Education incidence figures. This group includes everyone with some type of permanent disability, including developmental disabilities (such as mental retardation, cerebral palsy, Down syndrome and autism), acquired disabilities (such as traumatic brain injury or spinal cord injury), organic disabilities (such as multiple sclerosis, Parkinson's and Alzheimer's) and mental illness.

Thanks to steady advances in medical technology, ours is the world's first generation when children with disabilities will outlive parents and the first when many of our parents, albeit disabled, make it well into their nineties and over 100 years of age. This massive demographic change has spawned the need for legislative and regulatory changes to address the needs of individuals with disabilities. And the country faces a growing need for planners with the compassion and technical skills needed to work with individuals who experience disabilities.

Being an effective planner for individuals with disabilities starts with awareness. Communicating by using language that is sensitive to their concerns—no matter how awkward it may feel to you—is essential. Selective language demonstrates the honesty and empathy that will encourage them to see you as a truly caring professional. (We have incorporated such language in this article.)

Individuals with disabilities have special needs and may be eligible for a wide variety of public programs. Effective planning includes coordinating those public program benefits with private family or other resources. Critical to this coordination is the special needs trust, a unique planning tool that can substantially enhance the lifestyle of individuals who experience a disability.

Practitioners have employed special needs trusts (SNTs) throughout the United States since the early to mid-1970s. The SNT allows individuals who meet the Social Security disability criterion to maintain eligibility for critical public benefits available under 42 USC Title XVI (Supplemental Security Income, or SSI) and Title XIX (Medicaid) while at the same time preserving private assets in a qualifying trust to provide for services, items and activities not available through public programs. In addition to SSI and Medicaid, the individual with a disability also may be eligible for a wide variety of other state and federal benefit and service programs.

Eligibility for the essential medical benefits crucial to the long-term care and survival of individuals with disabilities requires that the individual meet rigid financial guidelines. SSI and Medicaid are means-tested programs. For initial eligibility for SSI and Medicaid, the individual may not earn more than \$740 a month (indexed annually) or have accumulated assets of more than \$2,000. A few exempt assets, such as a primary residence or accessible vehicle, do not count against the \$2,000 limit.

Each benefit program offers a different type of funding or service. SSI provides a small cash payment for support (approximately \$530 per month).¹ This payment is meant to provide food, clothing and shelter for the disabled individual. While such a small monthly income can provide only a menial existence at best, its preservation is

extremely important. SSI is the "gatekeeper" to Medicaid and other benefit programs, which are often critical to the health, welfare and long-term care of an individual with a disability.

With good advocacy, Medicaid is the most comprehensive "health insurance" program available to individuals with disabilities. Medicaid and Medicaid "waiver programs" provide payment for hospitalization, physician services, therapies (physical, occupational and speech), durable medical equipment, some rehabilitation services, medial transportation, prescription medications, home modifications, in-home custodial and respite care, and the majority of long-term care costs for assisted living facilities or nursing homes. Access to these benefits is crucial because many of the services provided under Medicaid may be unavailable or limited under private pay situations, Medicare or private health insurance policies. Preserving Medicaid benefits may be the only way to obtain lifelong-needed services.

Individuals who experience a disability almost never have enough funds available to pay for all of their lifetime needs. When family members cannot provide day-to-day supervision, costs for individuals with severe disabilities can easily reach \$10,000 a month. If a disabled individual depends solely on private assets available to him or her (whether family assets or assets obtained in a personal injury claim), the expense of custodial supervision, medical services or equipment can quickly exhaust those funds. Once private funds decrease to the \$2,000 eligibility level, the disabled person becomes eligible for, but solely dependent on, SSI and Medicaid benefits. No resources will be available to fund quality-of-life expenditures, such as social interaction, transportation, recreation and education.

The special needs trust allows the disabled individual to preserve eligibility for Medicaid benefits while the assets in the trust go for other needs not provided by public programs. These include supplemental attendant care, home maintenance, transportation, schooling, job training and coaches, social interaction and recreation—all aspects of life taken for granted in the nondisabled world. In addition, trust funds may be used to enhance quality of life by paying for respite care for family caregivers, basic home furnishings, cable television, telephone service, computers, Internet access and even some vacation opportunities. Finally, SNT assets may supplement Medicaid services with additional therapy, respite or custodial care, and may provide payment for cutting-edge medical advances or therapies not paid for by Medicaid. In many cases, only the coordination of public benefits and SNT assets allows individuals who experience a disability to live "normally."

Types of Special Needs Trusts

There are four types of special needs trusts, all of which will preserve crucial public benefit programs if properly drafted and managed.

Settlement/litigation special needs trusts. These trusts are established with proceeds obtained on behalf of a disabled individual from a personal injury action. Settlement special needs trusts have been used throughout the United States since the late 1970s, but a few states did not accept these trusts as a device to preserve public benefits until the Omnibus Budget Reconciliation Act (OBRA '93) permitted their use nationwide. Since OBRA '93, each state has developed corresponding laws. These trusts should be drafted by qualified counsel with specific knowledge of the entire disability benefit delivery system and the requirements under federal law noted at 42 USC 1396p(d)(4)(A), as follows:

1. The trust beneficiary must be under the age of 65 when the trust is established.
2. The beneficiary must have a condition that meets the definition of disability under the Social Security Act (Title II).
3. The trust may be established by a parent, guardian, next friend or court. (We recommend the trust be established by the court.)
4. The trust must be drafted to expressly state it is supplemental to various public benefits and does not supplant the benefits.
5. The trustee must have full discretionary authority over all trust distributions.
6. The trust cannot be subject to the trust beneficiary's control.
7. The trust language should state that no distributions may be made for "food, clothing or shelter" expenses as defined by the Social Security Administration's Program Operations Manual System (POMS).
8. The trust must contain provisions for a Medicaid lien reimbursement at the termination of the trust or death of the beneficiary.

The planner and drafting attorney must be aware that this type of trust is not a parallel to "elder law" Medicaid trusts. The eligible population is under age 65 and the trust preserves eligibility for benefits that reach far beyond those available to seniors. The trust language must be specific to qualify the beneficiary for SSI and Medicaid as well as other state and federal benefits.

Pooled or "c" special needs trusts. The federal law establishing these trusts is found at 42 USC 1396p(d)(4)(c), thus one of their names: the "c" trust. They are also called "pooled" trusts, referring to the pooling of assets for investment purposes. This type of trust is the only trust that will preserve SSI and Medicaid benefits for disabled individuals over age 65 whose own assets are used to fund the trust. The trust also may be used for individuals under 65 if appropriate.

Management of these trusts must be through a nonprofit organization set up in each state. The trust assets of disabled individuals are pooled for investment management but distributed for each individual's use during his or her lifetime. Pooling for investment management costs less for smaller accounts than it would in an individually managed SNT of the same size. For smaller estates and settlement awards (under \$100,000), a pooled trust is often more cost effective for the trust beneficiary.

The SNT requirements outlined above must be met, except that the individual may be over age 65 and any funds remaining in the individual trust account at the trust beneficiary's death will remain in the pooled assets of the nonprofit agency to benefit other individuals with disabilities. Some difficulties to be aware of when using pooled trusts include states that have not set up nonprofit agencies for this purpose or inefficient management of funds by a nonprofit agency.

Third-party special needs trusts. Interested parties may create a special needs trust to benefit a disabled individual. Remember, SNT beneficiaries must not own assets. These SNTs are used in special situations involving contributions or donations by unrelated third parties. For example, after the Columbine High School shootings in April 1999 in Littleton, Colorado, a "Healing Fund" was established for the families and survivors of this violent incident. Several of the teenagers who sustained permanent disabilities as a result of the shootings received funds that were placed into SNTs to preserve their SSI and Medicaid benefits. Like the pooled trust, a third-party trust must meet the provisions outlined above, except no age restrictions apply and no Medicaid lien reimbursement provisions are required at the termination of the trust.

Family special needs trusts. These trusts are tools in traditional estate planning for families with disabled individuals. As with third-party trusts, the funding assets cannot be owned by or available to the trust beneficiary. Restrictions regarding the supplemental nature of the trust and the discretion of the trustee must be carefully drafted to avoid jeopardizing benefit eligibility. Counsel may also want to include specific language regarding protection from claims of creditors.

Any assets given directly to the disabled family member or included in a court-established guardianship/conservatorship will disqualify the disabled individual for all public benefits if the assets exceed \$2,000 (with some exemptions for housing and a vehicle). The use of an SNT allows family members who are not disabled to pass on personal assets to enhance the lifestyle of the individual and thus preserve his or her benefit eligibility. The trust may be established during the lifetime of the family member/grantor via a "living SNT" or through an individual's will that funds the SNT at death. SNTs may be funded through outright gifts or through gifts used to purchase life insurance on the grantor. It is possible to coordinate the special needs aspects of these trusts with traditional estate tax planning, but such planning is extremely complex. Traditional *Crummey* power trusts will most likely eliminate benefit eligibility unless secondary and tertiary beneficiary provisions are included. Family SNTs must meet the general SNT provisions outlined above except there are no age restrictions and no Medicaid lien provisions are required.

The four SNTs may be referred to as supplemental or special needs trusts, settlement SNTs, disability trusts, Dussault trusts, "d(4)(A)" trusts (referring to the federal statute), or simply by the name of the disabled individual (for example, John Doe irrevocable trust). Regardless of how the trust document is named, a trust properly drafted under the above criteria will preserve various public benefits for individuals with disabilities.

Proper Management Critical To Benefit Preservation

Planners who suggest SNTs must be cautious to ensure that the trust not only is drafted correctly but also that the trustee (whether a corporation or individual) has the expertise necessary to manage the trust properly.

An SNT trustee has three distinct duties:

1. To be custodian of the assets and perform various accounting functions
2. To invest the assets prudently
3. To distribute the assets on behalf of the trust beneficiary without compromising benefit eligibility

Institutional trustees typically perform the duties of custodian and investment manager well (or adequately), but they seldom have the expertise needed to distribute assets properly to preserve public benefits. An inappropriate trust distribution may result in the loss of critical public benefits, violating the basic purpose of the trust. Improper trust distributions are quickly becoming an area of liability for those involved in the management of SNTs.

The trustee must be aware and have knowledge of the Social Security Administration's POMS and state Medicaid agency rules and regulations. The Medicaid rules and regulations vary significantly from state to state, change frequently and are extraordinarily complex.

Basically, if the trustee provides direct cash payments to the trust beneficiary or provides distributions that may be construed as "food, clothing or shelter," public program benefits for the beneficiary who is disabled will be reduced and may be completely lost.

But there are exceptions. For example, even though expenditures for "shelter" are restricted, a trustee may purchase a primary residence outright as an exempt resource to provide stable housing. The home could even be "rented" to the beneficiary, which could allow the beneficiary to qualify for an additional federal benefit (a HUD rental subsidy). SNT trustees also may make distributions for an accessible vehicle, personal property (such as computers, televisions and furniture), recreational activities, vacations, education, additional therapy, supplemental respite and custodial care, and other items/services, but only if the distributions are provided to a third-party vendor and not in cash directly to the trust beneficiary (or parent of a minor child receiving SSI and Medicaid benefits).

Some states closely monitor all distributions made from SNTs by requiring an annual accounting to the state department that oversees the Medicaid programs. The Social Security office also may "audit" the trust to ensure no inappropriate distributions have been made.

In addition to understanding various public benefit rules and regulations, the trustee must also understand the unique needs of each disabled individual. Individuals with disabilities are not a homogeneous class. Each case requires individualized customization.

SNT trustees must clearly understand their fiduciary duty. Many SNT situations involve requests from various family members of the individual who is disabled. The trust beneficiary may have difficulty communicating his or her wants and needs. The family members may be the primary caregivers of the individual and will have significant impact on that person's life. Some trust distributions may provide a benefit to the family member(s) as well as to the trust beneficiary. Some requests for distributions may have little to do with the needs of the beneficiary and more to do with the comfort or convenience of the family. Distributions to or for the benefit of the family in general, rather than specific to the disabled beneficiary, may subsequently be viewed by a court as not being in the trust beneficiary's best interest. This will unquestionably expose the trustee to liability if a future challenge is made by the beneficiary, the trustee's legal representative, or by a court.

Many states require annual accountings to an overseeing court. The court may question whether distributions are in conflict with the terms of the trust and the needs of the person who is disabled. The trustee must be prepared to justify and prove that all distributions made from the trust were made in the best interest of the disabled individual and did not jeopardize any public benefit programs.

Trustee Selection

The complexity of the regulatory requirements coupled with the human dynamics of SNT cases mandates an experienced and knowledgeable trustee. Four types of trustees may be appointed to manage a SNT:

1. A traditional bank trustee
2. Corporate/professional trustee or trust company
3. Professional individual fiduciary
4. Nonprofessional/nonprofit individual trustee

This decision should be made with caution, and at least the following questions should be reviewed:

- Does the trustee have experience or expertise in SNT trust management?
- What is the corporate trustee's investment experience? What are their historical three-, five- and ten-year rates of return? Is the trustee open to outsiders managing the assets in the trust?
- What are the trustee and investment fees? Are these charged separately or bundled? Are there any hidden transaction or other fees? Are there break points related to fees?
- What types of investments are used?
- Does the trustee understand the tax treatment of SNTs?
- Does the trustee understand how structured annuity payments (if used as part of a personal injury settlement) directed into the trust are treated for tax purposes and in the overall investment portfolio of the trust?
- What bonding and professional liability coverage is carried?
- Does the trustee have experience working with individuals with disabilities?
- Does the trustee have expertise in the Social Security Administration and state Medicaid rules and regulations, or access to this expertise?
- Will there be continuity for the trust beneficiary? Is there turnover of trust officers? If the trustee is an individual, who will act if the appointed person is unable or unwilling to act?
- Is the trust officer who works directly with the disabled person empathetic, compassionate and knowledgeable about the disabled person's needs?
- Is the trustee domiciled in the state where the beneficiary lives? If not, is the trustee able to legally act in the beneficiary's state of residence? Will the trustee submit to the court with jurisdiction over the beneficiary?
- What is the capitalization of the corporate trustee? Does it meet the beneficiary's state of residence requirements, if any? Will the trustee provide certified financials? Management letter, if any?
- What is the quality of the trustee's relationship with its regulatory authority? What results has it had on examinations?
- What is the overall quality of the trustee's management? Does it have a coherent business plan that is being carried out? What about its directors and their expertise and capabilities?

Advisors may be placed in a precarious situation when working with SNTs. The family may want the advisor to be the investment advisor/manager of the trust, but generally this is only possible if (1) a corporate trustee does not offer investment services, or is willing to work with outside advisors or (2) a nonprofessional or professional individual trustee does not manage money. Knowledgeable corporate trustees offer tremendous value, in addition to the administration of SNTs, but few of them willingly cooperate with independent investment advisors.

In many family-established SNTs, the advisor may be asked to assist the family/friend trustee with investing the account. The advisor should be cautious in this situation to ensure he or she is fully aware of the potential liability. The advisor should review the following areas:

1. The nonprofessional trustee may look to the advisor for all investment and tax planning advice. Therefore, the advisor must be aware of any special requirements for investment of SNT funds and tax issues.
2. The advisor may become aware of a situation where the trustee is mismanaging or misusing the trust funds. In this situation, advisors must determine who the client is. Is it the trustee or the trust beneficiary? What is the advisor's liability and fiduciary duty upon learning that a trustee is victimizing a beneficiary?
3. The advisor should inquire about the individual trustee's knowledge of the various rules and regulations

- covering public benefits. If the individual trustee does not have this expertise, will he or she have access to it?
4. Who will serve as trustee if the initial individual trustee is not able or willing to serve? Who will be responsible for notifying the relevant parties? Will the advisor's role as investment manager be preserved?
 5. The advisor should fully disclose all fees associated with management of the trust investments to the trustee and the trust beneficiary or guardian. Many courts closely scrutinize all disclosed and undisclosed fees and may not look kindly on situations where nonprofessional, inexperienced trustees are "taken advantage of" by professional investment advisors.
 6. In situations where there is a corporate trustee the advisor and the trustee, should fully disclose each of their fees to the court, trust beneficiary or the legal guardian for the beneficiary. Total management fees may vary significantly in this type of situation. It will be critical to the individual who experiences a disability that fees are reasonable because it is likely their trust assets will be the only substantial assets they will obtain during their lifetime. Additionally, the individual has a significantly reduced ability to earn additional funds. A reasonable trustee/investment management combined fee should range between one and two percent annually.

The advisor may want to consider a written agreement outlining what his or her duties and responsibilities are in the management of the special needs trust. The advisor should also recognize the special risk in any contested situation where there is no required bonding or insurance for the trustee. A court may look to the deepest pocket in an effort to recover any damages for the individual who is disabled.

When a corporate trustee is used, the advisor should ensure that the trustee has expertise and knowledge in the required areas. The advisor also should carefully review and outline who is responsible for which trustee duties (custodian/accounting, investment, distribution). Advisors should avoid being liable for any decisions made by the trustee and should verify that the trustee carries adequate bonding and insurance coverage. Finally, the advisor should ensure that all trustee and advisor fees are fully disclosed to the trust beneficiary or guardian.

Management Design Options

Several management models work well for SNTs. The most traditional design is a sole trustee to perform all three basic trustee duties: to (1) hold, (2) invest and (3) distribute the funds. A sole trustee for most SNTs is not ideal unless the trustee has experience and knowledge in all areas. The most problematic of these is competence in the benefit compliance/disbursement issues. Where a sole trustee lacks the required expertise, a co-trustee model may be used to allocate responsibilities between respective parties. If this model is selected, make sure drafting counsel understands the duties to be assigned to each participant and clearly allocates responsibility in the trust document. Alternatively, under the laws of some states, trusts may specify trust investment advisors, trust protectors and other roles.

In most litigation settlement SNTs, a court reviews the terms of the settlement and the trust document. Typically, the court will require a corporate or professional trustee as a sole trustee or co-trustee. However, in family-established SNTs, the family member creating the trust may designate another family member or trusted friend as the sole trustee.

In addition to the co-trustee models, advisors should consider using a three-party model, which includes (1) a corporate/professional trustee responsible for custodial/accounting functions, (2) an investment advisor who selects and oversees the trust investments, and (3) a co-trustee committee to make disbursement decisions. The co-trustee committee might consist of several individuals, each holding one vote for disbursement decisions, which are made by majority rule. In cases of tied votes or conflicts of interest, the administrative trustee may be required to make the disbursement decisions.

Committee members should have intimate knowledge of the trust beneficiary and his or her needs, or possess expertise in a specific area, such as public benefit rules and regulations. Generally, one member is a parent or spouse with knowledge of the disabled individual and his or her needs. More than one family member may participate on a committee, but to avoid conflicts of interest family members should not have voting control. A second member of the committee should have expertise in the federal and state SSI/Medicaid benefit rules and regulations. The third member may be any other interested party, such as an attorney, physician, schoolteacher or family religious leader. A representative from the administrative trustee should not be designated to serve on the co-trustee committee. It would result in a transfer of significant liability risk for disbursement decisions to the trustee. Protection from liability for

decisions in areas where the trustee is not familiar is one of the reasons to use a co-trustee committee. Family members on the committee generally should not charge fees for the time they expend on the trust committee. Other committee members may volunteer their participation and knowledge. However, most professional members will charge for their time and effort.

Conclusion

The population of individuals who experience disabilities is aging and growing. Planning for this group requires special planning tools and niche expertise. Advisors with clients who are disabled, or who have dependents who are disabled, must be aware of the use, implementation and management issues surrounding special needs trusts. In addition, they should have basic knowledge of how to preserve essential public benefits and how to apply the different types of SNTs.

In planning work with clients who are disabled, or who have disabled family members, advisors should ensure proper drafting of the trust document, including effective design. Due diligence in selection of trustees should include assessing competence, bonding/insurance coverage, and all fees and charges. Advisors also should consider their potential professional liability when recommending trustees or participating in the management of an SNT.

Ideally, advisors will work with clients to implement a properly drafted, designed and managed SNT that will preserve critical public benefits, manage the trust assets to provide for the disabled beneficiary's immediate, ongoing and future expenditure needs, protect the individual from exploitation and allow him or her to lead a "normal" life, without depending solely on menial public benefits. This is truly an opportunity for advisors to "do well by doing good."

Endnote

1. Reflects 2001 maximum federal benefit amount. Some states also add supplements to the federal programs increasing the SSI cash benefit. SSI cash benefits are adjusted each year via a cost-of-living increase adjustment (COLA).

Sidebar: Checklist for Advisors Wishing to Work with Special Needs Trusts

1. Learn as much about the use and implementation of special needs trusts as possible through attending educational seminars and reading relevant materials.
2. Network with attorneys and other experts who specialize in the area of special needs trusts and disability planning for individuals with disabilities. This is a fairly small community of practitioners, and only a handful are national experts in this area.
3. Begin to look for qualified trustees before the need arises so that you are prepared to make appropriate recommendations.
4. If you hope to work in the area of personal injury settlements, understand what structured settlement annuities are, how they are used, and the pros and cons of their use.
5. Volunteer for local nonprofit organizations that serve and advocate for individuals with disabilities so that you truly understand the needs of this population.