

# The Special Needs Trust

## *Planning for the Future of Your Loved One with a Disability*

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IMAGINE FOR A MOMENT—HORRIBLE AS IT IS TO THINK OF— THAT ONE EVENING, ON YOUR WAY HOME FROM A MOVIE OR A DINNER PARTY, YOU AND YOUR SPOUSE ARE KILLED IN AN AUTOMOBILE ACCIDENT. WHILE YOU WERE ALWAYS PLANNING TO WRITE A WILL, YOU NEVER ACTUALLY GOT AROUND TO IT, SO YOUR MODEST ESTATE, INCLUDING SOME LIFE INSURANCE, IS DISTRIBUTED BY THE LAWS OF YOUR STATE. YOU HAVE TWO SONS, ONE WITH A DISABILITY AND ONE WITHOUT. EACH OF YOUR SONS INHERITS \$100,000.

Your older son, Frank, who does not have a disability, uses his inheritance to pay off some of his mortgage and splurges on a new car. In contrast, your younger son Johnny gains nothing and loses much. Johnny, who has multiple disabilities, does not work and relies solely on government benefits for housing and medical care. The inheritance causes Johnny to lose those benefits. He must now provide for his own medical care, which includes the considerable cost of medicine, personal care attendants, physical therapy and doctor visits. The group home in which he lives begins to charge him for residency and the services he receives.

Within two years, all but \$2,000 of the inheritance is gone. At this point, Johnny again becomes eligible for government benefits and is re-instated after a waiting period of several months—a period in which he uses up the last of his inheritance. Now

there are no funds left to pay for whatever supplemental needs Johnny might have: education, over-the-counter medicines, dental care beyond what is covered by government benefits, trips to see his brother or other family members, reading materials, and basic supplies such as razors, soap and shampoo. Government benefits do not cover these types of expenses, and Johnny's parents are no longer here to do so. The irony of the situation is that, while an inheritance ordinarily improves a person's lifestyle, in this scenario, it has worsened Johnny's.

## The Question of Relying Only on Government Benefits

Fairness is a primary question when something like this happens. Should the government continue to subsidize someone who has "money?" On the one hand, standard government programs such as Social Security and Medicaid were established to help the elderly and disabled living at the poverty level. On the other hand, government benefit programs are paid for out of tax dollars, and eligible individuals are entitled to receive these benefits.

When families consider this question, they should be aware that, while the services available through government benefit programs may be substantial (e.g., medical coverage through Medicaid), the actual cash benefits generally are quite small and force the person to live far below the poverty level. In 1992, the maximum federal Social Security monthly payment was \$422 for an individual. So for someone with a disability to have any type of meaningful lifestyle, the family or local charities must provide supplemental assistance.

With recent changes in the Social Security Administration, the primary government benefit programs are recognizing that family contributions to the person's well-being can only improve his overall quality of life. As long as the family's contributions are supplementary in nature, as opposed to duplicating government benefit programs, they are permitted. Thus, the current government benefit programs permit the family to provide some supplementary income and resources to the person with a disability. However, the government regulations are very strict and carefully monitored.

## Special Needs Trust

A reliable method of making sure that an inheritance reaches a person with a disability is through a legal device known as a special needs trust (SNT). The SNT is developed to manage resources while maintaining the person's eligibility for public assistance benefits. The family leaves whatever resources it deems appropriate to the trust, and it is managed by a trustee (manager) on behalf of the person with the disability.

While government agencies recognize special needs trusts, they have imposed very stringent rules and regulations on them.

This is why family members contemplating using an SNT should consult an experienced attorney—not just one who does general estate planning, but one who is knowledgeable about SNTs and current government benefit programs. One wrong word or phrase can make the difference between an inheritance that truly benefits the person with a disability, and one that causes the person to lose access to a wide range of needed services and assistance. To illustrate, suppose the trust instructs the trustee to pay the person with the disability \$100 a month for life. Such a mandatory income might jeopardize government benefit programs, which only allow the person to have \$70 of earned income each month.

Families who have experience with government benefits know that the government says a person with a disability cannot have a trust. This is correct. However, the special needs trust does not belong to the person with a disability. The trust is established and administered by someone else. The person with the disability does not have a trust. Instead, he is nominated as a beneficiary of the trust and usually is the only one who receives the benefits. Furthermore, the trustee is given the absolute discretion to determine when and how much the person should receive.

Given the government's stringent requirements, covered subsequently, it is critical that the trust be carefully worded and clearly show that it:

- 1) Is established (by grantor, settlor) by the family (persons other than the person with the disability);
- 2) Is managed by a trustee (and successor trustees) other than the person with the disability;
- 3) Gives the trustee the absolute discretion to provide whatever assistance is required;
- 4) Never gives the person with the disability more income or resources than permitted by the government;
- 5) Is used for supplementary purposes only; it should add to the things provided by the government benefit program, not replace them;
- 6) Defines what it means by supplementary/special needs in general terms, as well as in specific terms related to the unique needs of the person with the disability;
- 7) Provides instructions for the person's final arrangement (families should assume that when the person with the disability dies, no relatives will be alive who know what the mother and father would have wanted);
- 8) Determines who should receive the remainder of the trust after the person with the disability dies;
- 9) Provides choices for successor trustees, people or organizations that might be able to take a personal interest in the welfare of the person with the disability; and
- 10) Protects the trust against creditors or government agencies trying to obtain funds to pay for the person's or family's debts.

Since the trust is a legal arrangement regulated by state laws, there will be other sections that your attorney may need to insert. Be aware that while the majority of public assistance funds come from the federal government (which provides guidelines for SNTs), each state government is responsible to regulate trusts and administer federal benefits. As long as the federal guidelines are followed to the letter, the state will accept the SNT, and the trust will fulfill its function.

## SNTs and the Social Security Administration

The Social Security Administration's publication, "Understanding SSI," discusses special needs trusts as follows:

- How do resources in this type of trust count in the Social Security Income (SSI) program?
- Money or property in this type of trust for an SSI beneficiary...does not count toward the SSI resource limits of \$2,000 for an individual.
- How does money from the trust affect the individual's SSI payments?
- Money paid directly to the providers for items other than the person's food, clothing and shelter does not reduce SSI payments. (Items that are not "food, clothing, or shelter" include medical care, telephone bills, education, entertainment.)
- Money paid directly to the providers for food, clothing, and shelter does reduce the individual's SSI payments— but only up to a limit. No matter how much money is spent for these items, no more than \$155.66 (in 1991) is subtracted from the individual's SSI check.
- Money paid directly to the individual from the trust reduces the SSI payment.

(U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, 1990, P. 46)

## Testamentary Trust vs. Intervivos Trust

At one time, the average attorney simply advised parents of an individual with a disability to prepare their last wills and testaments and include a testamentary special needs trust. Upon the death of the parents, the wills would be probated (established as authentic or valid), and the special needs trust would be created. In simpler days, this was pretty good advice.

Today, most attorneys experienced in estate planning for persons with disabilities will advise the family to prepare an intervivos or living special needs trust. Intervivos means that the trust functions now, while the parents are still living. As a "living" trust, it should not be confused with the modern estate planning tool for the family's main estate—the family revocable living trust. These are two very separate trusts. The sole function of the intervivos special needs trust is to look after the future of the person with the disability.

Parents need not wait until their child is 18-years-old to establish such a trust; they can establish it now. The trust is set up as a checking account at a local bank. Families can place funds into the trust every month and use these funds to cover the normal supplementary expenses of the person with the disability, as well as save for the future.

Using the intervivos special needs trust fund to pay for the person's supplementary expenses also is an excellent way of recordkeeping, because these expenses are tax-deductible. By paying for supplementary items from the checkbook, the family shows future trustees the types of things that are appropriate to the person's needs and that have passed government scrutiny. The typical government challenge to an SNT comes when a trustee pays for nonsupplementary items. The checkbook with stubs can help future trustees use the trust properly and avoid expensive challenges.

Sometimes, relatives (e.g., aunts, uncles, grandparents) would like to leave an inheritance to the person with the disability but are concerned that he will lose government benefits or mismanage the funds. Relatives like the concept of a trust, which is a legal way to make sure the person actually receives the full gift. With a testamentary trust, the parents of the person with the disability must pass away and their estate probated before a trust is created. Once established, relatives then can leave money to the trust. The better option is to create a living special needs trust, permitting relatives with tax concerns (i.e., those who need to give money each year to avoid large estate taxes upon their death) to give money to the trust now, rather than only upon their deaths.

Another consideration is that, according to current estimates, 40%-60% of the population will go into a nursing home before they die. The average family's total estate likely will be used up in one year to cover nursing home costs. In their wills, parents may have generously given everything to the testamentary trust. Unfortunately, after nursing home care and Medicaid expenses, there may be no estate left for the testamentary trust. And even if a portion of the estate remains after the parents die, there may be a six-month to six-year waiting period while the estate is being probated. A testamentary trust would not be created or funded during this waiting period, so supplementary needs would be unmet.



Having a living special needs trust creates a more secure scenario for the person with the disability. The parents would have saved money each month for the future and may have purchased life insurance or transferred assets into the trust. Should they suddenly pass away or enter a nursing home, the living trust continues to function without interruption. The successor trustee designated by the parents would begin to administer the trust funds within one to two hours. Supplementary assistance to the person with the disability would continue without a break.

## Revocable vs. Irrevocable

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Once the basic details of the trust have been agreed upon, you have to decide whether to lock the door and throw away the key, making it impossible to change the trust (irrevocable), or to hold the key just in case you want to make some changes (revocable). With a revocable trust, you retain the right to add and subtract assets as you go along. With this right, however, there are some potential consequences. The first and major consequence is that the government considers the trust to be part of your estate. Therefore, when you die, everything in the special needs trust is included in your estate for tax purposes and for potential lawsuits. If someone sues your estate after you are gone, for example, the assets in your special needs trust could be lost in such a lawsuit.

By creating an irrevocable trust, any assets you place in it will remain there solely for the benefit of the person with the disability. Even if you need some of these assets later on for your own care, you cannot take them out. Any assets placed in the trust cannot be touched by your creditors for debts, taxes, etc. Neither can the trust be touched by creditors of the person with the disability. As long as the trust is set up properly, it is completely separate from your estate, having a separate entity and its own tax number.

Whether to choose a revocable or irrevocable trust can depend on the age of the parents. For younger parents, the answer may be a revocable trust. For older parents, the irrevocable trust may be the only option. Your attorney, in consultation with your financial planner, is probably the best resource in making this determination. It is important, however, to create a current letter of intent, which will help your trustee interpret the “legalese” of either the revocable or irrevocable trust, in light of your hopes and desires for the future of the person with the disability.

## Trustee: The Manager of Resources

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It is one thing to leave resources to a trust, and it is quite another to manage them in a way to last the lifetime of the person with the disability. Every trust must have a trustee, someone who will manage the trust’s assets. As most special needs trusts are

established to provide supplementary assistance, they generally are quite small by bank standards. Ideally, it would be nice to have a local bank manage the trust resources, while taking a personal interest in the person with the disability; sadly, very few banks are willing to manage cash assets under \$150,000 to \$200,000 or become as involved in the person’s life as you would wish.

In the case of a living trust where there are sufficient funds and relatives, the family usually nominates future or successor trustees to manage the trust after the parents die or go into a nursing home. Families may even nominate a group of people to serve as joint trustees—several relatives, perhaps—who administer the trust together. An advocacy or disability organization also should be listed as the last successor trustee because it is possible that the human successor trustees will die before the person with the disability. In the event that the human successor trustees are unable to serve, the advocacy or disability organization may take on the responsibility, or be able to recommend someone in their group who could do so. Of course, discussing this with the disability or advocacy group to obtain consent first, before listing the organization as a future trustee, is a good idea.

## Financial Planning: Funding a Special Needs Trust

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As families undergo estate planning for their loved ones, they tend to think of it as a legal issue only. However, a lawyer can only establish the trust. Someone has to find the funds to put into the trust and make sure there are sufficient funds to last the lifetime of the person with the disability. That is where a financial planner comes in.

Financial planners sometimes have the reputation of trying to sell investments and insurance through high-pressure techniques. And while the financial planner may very well use various financial products to fund the trust, the more reputable ones realize that most families have limited resources. Therefore, the planner’s primary job is to help the family see what resources are available and then re-allocate them, so that the future funding of the trust will be realistic.

As with attorneys, there are very few financial planners who have any experience with planning for the future of a person with disabilities. Most are trained to look at the overall family estate and provide as many dollars as possible, while looking out for potential problems. When they realize that there is a person with a disability involved, they may assume that the person will need extra help, and direct more dollars to the person with a disability, without understanding the consequences this might have in terms of the person’s government benefits.

An experienced financial planner will examine your letter of intent and run a detailed financial analysis based on the

## Resources to Fund a Special Needs Trust

- 1) Standard government benefits.** These can form the foundation for the future.
- 2) Savings.** No matter how you look at it, the family will have to save for the future. The government benefit programs have never provided enough for even poverty-level existence. A regular savings program is essential to meet the person with the disability's supplementary needs in the future.
- 3) Family assistance.** Family members may want to provide residential care, supervision and supplemental assistance down the road.
- 4) Parents' estate.** Parents may leave a portion or all of their estate to the trust.
- 5) Inheritances.** Relatives or friends who have expressed an interest in providing for the person with the disability should be given instructions and assistance on how to leave a gift to the trust.
- 6) Property.** Some families want their loved one to live in the same house. The house can be placed in the trust and managed by a local nonprofit agency for the benefit of the person.
- 7) Investments.** Certificates of deposit, IRAs, KEOGHs, etc. can be directed to the trust.
- 8) Military benefits.** Some families have elected a survivor benefit option (SBO), so the person with the disability will always have some income and medical care. They still may want a special needs trust to manage the other resources, which will supplement the military benefits.
- 9) Insurance.** For the average family, life insurance may be the only way they can leave a large lump sum for the future by making small monthly payments. It also is one of the few guaranteed methods of funding a trust. While the above items may fizzle out as people change their minds or the economy falters, a paid-up life insurance policy in an irrevocable trust will guarantee future funds.
- 10) Other resources.** Many families have resources unique to them. The financial planner will help you determine which ones are appropriate for funding the trust.

future costs of supplementary items and advocacy. The planner then will look at the many different resources available to fund the trust, now and in the future.

Most families are surprised to learn that they do in fact have a variety of resources within their reach that can be directed to the special needs trust, including:

As families examine ways to fund the trust, they need to keep in mind something very important: Do not forget the other brothers and sisters. Sometimes families assume that, while they must pay for the services of a bank trustee and a guardian/advocate, relatives who take on these responsibilities should do so for free, because that is what families do. While the siblings may be pillars of love and understanding when it comes to their brother or sister

with a disability, they probably have seen a great deal of your time and energy spent in the disability arena. They should not be left out at the end.

With proper legal and financial planning, a family can guarantee that the person with the disability will enjoy a comfortable lifestyle after the parents are gone.

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