

## WHY YOU NEED AN ESTATE PLAN TO PROVIDE FOR A LOVED ONE WHO IS DISABLED

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Too many people interpret the phrase “estate planning” as something required only of the wealthy. In fact, estate planning is for all of us. Estate planning is especially vital for those with loved ones who are disabled and depend (or will depend) on government benefits. This includes parents and grandparents of children with special needs and spouses and relatives of older individuals residing in nursing homes and assisted living facilities. Failure to plan comes at a very high cost for the disabled individual who may lose critically necessary public benefits if there is no estate plan.

Many individuals with disabilities are dependent on public benefits like Supplemental Security Income (“551”) and Medicaid. Those benefits are means-tested, that is, only available to individuals with very limited assets.

Unfortunately, a poorly designed plan is as disadvantageous to a disabled person as failure to plan. Because of the specialized nature of this area of law, most attorneys do not understand the complexities of special needs trusts and Medicaid eligibility. This sometimes creates problems for their clients, who are attempting to provide for a loved one with special needs.

In December of 2003, the North Dakota Supreme Court held that a developmentally disabled grandchild was ineligible for Medicaid assistance because the inheritance left to him by his grandparent went into a “support trust” rather than a “special needs trust.” The child’s parent sought to correct the problem by creating a special needs trust and transferring the assets to the new trust. The Court held that the assets were nonetheless available to the grandchild thereby rendering him ineligible for his government benefits. *Linser v. Office of Attorney General* (N.D. No. 20030184, Dec. 19, 2003).

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A “self-settled trust” is used where a person receives property or money that would otherwise disqualify him or her from government benefits. This property is placed in a special type of special needs trust that meets federal requirements. We

always look at the source of the assets to fund the trust in determining what type of trust to use—are the assets those that the person with disabilities is already entitled to, or are the assets those of another individual, who is choosing to provide for the person with disabilities. We do not mix the two, and sometimes we set up two trusts for a person with disabilities, because of the different requirements for self-settled trusts and third party trusts.

A special needs trust typically gives broad discretion over the administration of the trust to a Trustee, and the beneficiary with disabilities cannot serve as the trustee. If the beneficiary should die before the assets of the special needs trust are exhausted, the remaining trust property can be distributed to other family members or to charity. Those who have loved ones with disabilities deserve the peace of mind that comes from a good estate plan that can maximize the resources of the loved one with special needs and improve the quality of his or her life.

Adapted by Nancy P. Gibson in 2004 from an article by Jane Skelton, a Special Needs Alliance member in Bangor, Maine. See [www.specialneedsalliance.com](http://www.specialneedsalliance.com) for a listing of all Special Needs Alliance members.

# **SPECIAL NEEDS TRUSTS**

## **A TOOL FOR HELPING PERSONS WITH DISABILITIES**

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### **I. INTRODUCTION**

Special Needs Trusts, also called Supplemental Needs Trusts, are trusts designed to provide assets for the care and comfort of beneficiaries who are disabled without jeopardizing their access to programs, funds and/or medical benefits that may be available to them. The cost of care for such persons can be prohibitive and is simply out of reach for most people to afford privately. Because many government-funded programs in the United States today provide substantial benefits, and in many cases are the only available programs for persons with disabilities, access to these services is critical. However, the requirements for qualifying for these benefits often thwart the efforts of families to provide support to their loved ones with disabilities.

To qualify for government benefits, an individual must meet the definition of “disabled.” A person who is disabled, according to the Social Security Administration, is a person who is over the age of 65, blind or unable to do any substantial gainful activity due to physical or mental impairments that will result in death or will continue for not less than one year. 42 U.S.C. ~ 423(d) (1) (A). “Substantial gainful activity” is the ability to do work that produces earnings. “Physical or mental impairments” are disabilities that appear on the Social Security Administration Listing of Impairments.

Once a disability is established, the type of benefit available will depend on additional

criteria. Some programs, such as Social Security, base the benefit on the earnings of the worker prior to her disability or retirement. Some benefits are entitlements, such as Medicare, which is available to all people who have attained age 65. Other programs measure the current income and resources of the disabled person to establish eligibility. Supplemental Security Income and Medicaid are two such “means-based” programs. In order to access these benefits, the recipient must not only be aged, sick and/or unable to work, but also poor. If significant assets become available to the recipient, the benefits will be curtailed until those assets are used up. When the excess assets are gone, the recipient can reapply for the benefits.

Government benefits for persons who are disabled include cash payments and health care. Supplemental Security Income and Social Security Disability Income provide cash for these individuals. For many people, this is the only cash that they receive. They are too sick, too weak, or too old to access any other forms of cash. The major government health care programs are Medicare and Medicaid. Medicare provides coverage for acute care, such as hospitalization, and some rehabilitation, but it does not cover the cost of prescriptions or the cost of long term custodial care. Medicare recipients may also have access to private health insurance, which often pays for prescriptions and doctor visits. However, most health insurance policies will not cover long term custodial care. Long term care insurance will pay for custodial care, but it is not available for someone who is already disabled. Medicaid is the only government program in the United States that provides for long term skilled nursing care for persons with disabilities other than the Veterans Administration. Medicaid pays for prescriptions, therapy, and doctor visits as well as custodial care.

Families who are planning for a family member who is disabled know how critical these benefits are. In the past, families would either intentionally disinherit the loved one or attempt to create oral trusts or other arrangements with surviving family members. These methods often had heart breaking and cruel results or were ineffective or fraudulent. On the other hand, many families could not bring themselves to disinherit their loved one. As a result, the beneficiary who is disabled would receive a share of the estate outright, and lose his or her government benefits

until the inheritance was used up. Planning with Special Needs Trusts can solve this dilemma.

Some disabilities are the result of someone else's negligence. In these cases, the person with disabilities may recover money damages. However, the injured person may require lifetime assistance at enormous cost, which may be well beyond the amount of the recovery. Treatment of the injury necessitates government-provided benefits. Therefore, even though a recovery may

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provide substantial assets, the recovery can put these benefits at risk. Planning with Special Needs Trusts can solve this dilemma.

## **II. HOW GOVERNMENT BENEFITS SYSTEMS WORK**

### **A. The Basics**

Planning for beneficiaries who are disabled requires a basic understanding of how government benefits systems work. These programs together disperse benefits to millions of people in the United States every month. Yet, most people, as well as lawyers, do not have a grasp of the features and the distinctions among them. The names of the programs are very similar, which makes it more confusing. While access to the means-based programs requires special planning, it is important to know how other programs interrelate and in some cases complement the means-based programs. To help in that understanding, attached are two simple charts to illustrate and compare three programs provided through Social Security and Medicare and Medicaid.

### **B. Means-Based Programs**

The Supplemental Security Income (SSD) system provides the rationale at the federal

level for Medicaid, even though the benefits under the two systems are quite distinct. 551 provides minimal cash payments each month that are designated to provide for food, clothing or shelter. Briefly, in order to maintain eligibility for SSJ, a recipient cannot receive unearned income from any source in excess of \$552.00 per month. Income, according to the SSJ rules, is anything that “comes in” to the recipient in any month. At the end of the month, income that is not used up converts to a resource. Thus, a resource is accumulated income. An 551 recipient may not own resources that are available to be spent on food, clothing, or shelter in excess of \$2000.00. Income and resources are measured independently.

Some income and some resources are exempt from the eligibility calculations. Non-countable income includes other means-based payments such as food stamps, medical care and services, income tax refunds, loans, and any item that if retained would not be a countable resource. Exempt resources include the personal residence of the recipient, regardless of value; one vehicle, if it is needed to provide transportation; household contents such as computers,

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electronics, physical training equipment, hot tubs and ordinary furnishings for living; life insurance with a face value of less than \$1500.00 and irrevocable burial plans. Thus a person who owns a \$ 500,000 house, a \$ 60,000 specially-outfitted van, whose life is insured by a \$2 million term life insurance policy, and who has limited income, could qualify for SSI.

But why is this significant? The government-provided cash benefit under SSJ is paltry. The amount of the SSI benefit is so small that maintaining SSI eligibility hardly seems to be a worthy goal. The prize that makes the quest worth pursuing is Medicaid. For many disabled individuals, SSI provides the gateway to the substantial medical benefits of Medicaid. As the charts demonstrate, no other government benefit provides long term medical care, including the cost of prescriptions. In most states, including New Mexico, eligibility for SSI categorically results in Medicaid eligibility. Therefore, observing the qualification criteria for 581 will enable a beneficiary to receive medical care that she may not be able to obtain from any other source.

### **III. REQUIREMENTS OF SPECIAL NEEDS TRUSTS**

A properly drafted Special Needs Trust will preserve assets for the benefit of a person who is disabled so that she can obtain government benefits, and have additional comforts, enjoyment, education, entertainment and medical care not otherwise provided by the government programs. A Special Needs Trust must be written and its terms express. The trust document will be reviewed by the Social Security Administration and Medicaid. All distributions of income and/or principal must be in the discretion of the trustee. The beneficiary cannot be entitled to receive income or principal. The Trustee should be prohibited from making any distribution that would jeopardize the recipient's benefits. The Special Needs Trust can delineate those items or categories for which distributions are proper. Distributions for support, food, clothing or shelter would affect SSJ eligibility. The trust document can describe in detail permissible distributions, such as recreation, travel, entertainment, medical care not otherwise provided such as hearing aids, glasses or personal companions and aids.

The individual who is disabled must be the sole beneficiary of the trust during his or her lifetime. However, the Special Needs Trust can provide compensation for caregivers and pay for the cost of travel for a caregiver to accompany the individual with disabilities, even if the caregiver is a family member.

A Special Needs Trust must be irrevocable. However, some disabilities that are caused by accidents or mental conditions that may be improved with medication may improve or end. Therefore, a Special Needs Trust can provide for discretionary distributions of income or principal as long as the beneficiary is not receiving government benefits. Careful drafting can

provide flexibility within the trust documents to allow for changed circumstances. The terms of the trust should always allow the trustee to reform the trust to protect eligibility for benefits.

#### A. Third Party Trusts

A third party-settled trust is a trust funded with assets provided by a person other than the beneficiary. This can be done either in a living (or “inter-vivos”) trust or a testamentary trust, which is established in a will. A third party-settled Special Needs Trust can provide that the remaining trust assets be distributed to the chosen remainder beneficiaries of the grantor at the death of the beneficiary, and thus be preserved for future beneficiaries.

#### B. Self-Settled Trusts

In 1993, Congress provided in 42 U.S.C. § 1396p that a person could not attain Medicaid eligibility by transferring her own assets to an inter vivos trust, even if the trust was irrevocable and the Medicaid applicant had no further control over the assets, unless the transfer took place more than 5 years before the Medicaid application. A transfer to the trustee within the 5 year period results in the assets being attributed to the applicant for the period of time that it takes to use up those assets to pay for the care of the applicant. This “penalty period” can put the applicant in the worst possible situation, i.e., not having the assets to pay for care, but being penalized as if the applicant has the assets, and therefore being unable to obtain Medicaid. Transferring one’s own assets to a trust as a planning method 5 years in advance of need is only feasible when the disability can be planned for, such as with a Parkinson’s patient or an Alzheimer’s patient. For persons with disabling conditions, this is not an option. Even if a court establishes a special needs trust, the assets are attributed to the person who is disabled. However, under 42 U.S.C. § 1396p (d)(4), two types of safe harbor trusts have been created that can relieve this dilemma for Medicaid eligibility. Transfers of the assets of the disabled person to these statutory self-settled trusts are exempt from the penalty period.

The first type of trust is provided for in 42 U.S.C. § 1396p (d)(4)(A) and is commonly

called a “d4A” trust. Because the d4A trust is funded with the beneficiary’s own assets, the statute requires that at the death of the beneficiary or termination of the trust, the remaining

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assets in the trust must be used initially to reimburse any state government that provided Medicaid to the beneficiary during her lifetime. Therefore, this trust can also be called a “payback trust.” In addition to the payback requirement, the d4A trust must be irrevocable; it can be created only by a parent, grandparent, court or guardian; and the beneficiary who is disabled must be younger than 65. Further funds cannot be put into the trust after age 65. Anyone other than the person with disabilities can be the trustee of the trust. The trust can provide that after the beneficiary’s death, once Medicaid is reimbursed, the remaining balance of the trust fund can be distributed to the intended beneficiaries of the person who is disabled.

The second type of safe harbor for a self-settled trust is found in 42 U.S.C. § 1396p (d)(4)(C). In this case, if the person who is disabled transfers her own funds to a non-profit 501(c)(3) organization as trustee, which manages the funds as part of a pooled trust for persons with disabilities, the transfer is exempt from penalty. In this case, the trust must be irrevocable; it can be created by the beneficiary as well as by a parent, grandparent, court or guardian; and the beneficiary maybe any age. At the death of the beneficiary, the non-profit organization may retain a portion of the trust fund. However, Medicaid must be reimbursed from the remaining funds before the trust can be dispersed to other remainder beneficiaries.

### C. The Trustee

Trustees of Special Needs Trusts have the same duties as trustees of other trusts. These duties include the duty of loyalty, the duty of care of a prudent person, the duty to observe the terms of the trust agreement, and the duty not to waste or squander the trust assets. However, trustees of a Special Needs Trust have added responsibilities.

A trustee of a Special Needs Trust must develop a working knowledge of the government benefits for which the beneficiary is qualified, because the trustee must understand which distributions are appropriate and which are not. This can mean not making certain distributions, such as cash to an 5Sf beneficiary, as well as making other distributions, such as purchasing plane tickets. A Special Needs Trust trustee must know the long term care plan for the beneficiary, her life expectancy, and what activities are possible or are reasonable to expect. A trustee of a Special Needs Trust should be creative in anticipating activities or items that will enhance the beneficiary's life. For example, a beneficiary who is totally physically disabled, and who requires 24 hour care in a nursing home, but who is not totally mentally disabled, might

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enjoy a trip to the zoo or to a play. The cost of such a trip may include the cost of a personal companion. A Special Needs Trust trustee must understand which distributions would jeopardize the

benefits being received. For example, an 581 beneficiary receives cash payments that are deemed to be for the recipient's food, clothing, and shelter. The receipt of any additional cash, or any item that would be "in-kind support and maintenance," will reduce the 5Sf benefits. Therefore, the trustee should not pay the beneficiary's rent or buy a coat for the beneficiary, because those are in kind payments for shelter and clothing. Under some circumstances, it is in the beneficiaries best interests for distributions to be made that will reduce 551, but this must be done with careful consideration and in accordance with the terms of the trust.

The 881 program requires periodic reporting for all 881 recipients. Eligibility will be denied if the reports are not complete. The existence of the Special Needs Trust must be reported. Additionally, if the beneficiary changes address, gets married, obtains more resources or more income, or improves in medical condition, these changes must be reported. The report is

due within 10 days of the month in which the change occurred.

The trustee must respond promptly to any notices received from the Social Security Administration or from Medicaid. If notice is given of a change in benefits that is detrimental to the beneficiary, the beneficiary has 60 days in which to file a written notice of an appeal in order to keep the benefits in place during the appeal process. The trustee cannot ignore or postpone dealing with the government agency.

As with many types of trusts, a co-trustee of Special Needs Trusts may be advisable. If the trust holds significant assets, a corporate trustee may be beneficial for long term investment expertise. However, an appropriate family member can be a co-trustee in order for the day-to-day needs of the beneficiary to be monitored. Trustees of Special Needs Trusts often need ongoing legal representation. To the extent possible, the trustee should stay abreast of changes in the law. I recommend an annual review meeting with the trustee and counsel.

## **VI. CONCLUSION**

In the United States today, a severe disability brings with it economic peril. A person who suffers from a severe disability must deal with both the critical medical treatment required and the possible loss of economic self-sufficiency. Medical care may be extraordinarily expensive and ongoing. Many disabilities necessitate special housing, transportation and

education. While many private charities provide worthwhile services, the cost of caring for persons with serious disabilities is borne primarily by the government. However, maintaining eligibility for government programs often contradicts the efforts of family members to provide support and care for their loved ones.

Special Needs Trusts provide the mechanism for sheltering resources to benefit family members who are disabled so that these contradictory efforts can be harmonized. A wellmanaged support system, using Special Needs Trusts, can maximize the use of governmentprovided services while supporting the family's care and enhancing the comfort and enjoyment of life for the beneficiary who is disabled.

## THREE SOCIAL SECURITY PROGRAMS

SSI	SS	SSDI
Supplemental <u>Security Income</u>	<u>Social Security</u>	<u>Social Security Disability Income</u>
Disability	Retirement	Disability
Cash + Medicaid	Cash	Cash + Medicare (After two years)
No work history	Work history	Work history
Income cap (\$564/month in 2004)	Income cap (\$11,640/year in 2004, if under age 65)	Income cap (\$810/month in 2004)
Earned & unearned income	Earned income	Earned income
Resource cap (\$2,000.00)	No resource cap	No resource cap
Minimum cash benefit	Insurance	Insurance
Food, clothing, shelter	Unrestricted	Unrestricted
State supplements	Uniform in all states	Uniform in all states
US citizens only	All workers	All workers
May also have SSDI	May not have SSI or SSDI	May also have SSI
No dependent coverage	Covers dependents	Covers dependents

	<b>MEDICAID</b>	<b>MEDICARE</b>
<b>PROGRAM:</b>	Health Care	Health Insurance
<b>ADMINISTERED BY:</b>	States	Federal
<b>ELIGIBILITY:</b>	Must qualify	Entitlement
<b>QUALIFICATIONS:</b>	Financial <u>&amp;</u> Disability	Age <u>or</u> Disability
<b>COVERS:</b>	Skilled nursing care; Intermediate nursing care; Long term care; Prescriptions	Hospitalization; 100 days maximum rehabilitation; No prescriptions
<b>CONTRIBUTION:</b>	Reimbursement required	Premiums and co-pay
<b>ESTATE RECOVERY:</b>	Yes	No