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## **SPECIAL NEEDS TRUSTS**

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**Lisa L. Wilson  
William R. Hayes\*  
Julia R. Hayes  
Caroline G. Kuipers**

**HAYES & WILSON, PLLC**  
Attorneys at Law  
1235 North Loop West, Suite 907  
Houston, Texas 77008  
Telephone: 713.880.3939  
Fax: 713.880.9990  
[www.hayeswilsonlaw.com](http://www.hayeswilsonlaw.com)

*\* Board Certified in Estate Planning and Probate Law  
by the Texas Board of Legal Specialization*

## THE SPECIAL NEEDS TRUST

A family's resources can quickly be depleted when caring for an individual with a disability (the "**beneficiary**") who may have many medical needs, and for whom it may be difficult or impossible to find sufficient medical insurance. For most families it is crucial for the beneficiary to become eligible and maintain eligibility for SSI, Medicaid, Medicaid Waiver, and similar programs. These programs provide funds for basic support in addition to medical coverage, and may also provide services such as case management, therapies and support services, residential facilities, day programs, job training, and job support.

A key component of the family's estate plan will be a Special Needs Trust ("**SNT**") (also called a Supplemental Care Trust). The SNT can be set up to receive funds from any source - whether proceeds from a life insurance policy, a bequest under a Will, funds from a litigation settlement, or other sources. The SNT will contain specific provisions that allow the assets in the trust to be disregarded for determining eligibility for SSI, Medicaid, and other government programs that are based on financial need. In most circumstances, the trust will not be funded until one or both parents are deceased. The trust then receives assets from the parent or parents' estates or through life insurance policies or the beneficiary designations on employee benefits.

Typically the funds in the SNT can be spent on life enhancing goods and services, such as recreational and leisure activities, supplies and equipment for a hobby, cable TV, stereo equipment, movies, books, magazine subscriptions, dental treatment, equipment and therapies not covered by Medicaid, vacations, holiday celebrations, telephone and internet access, and more.

Choosing a trustee requires careful consideration, as all distributions to or for the benefit of the beneficiary are at the discretion of the trustee. The trustee must invest the funds in a reasonable and prudent manner based on the amount in the trust, the current and anticipated needs of the beneficiary, and the life expectancy of the beneficiary. The trustee must keep current on changing Medicaid laws in order to not inadvertently disqualify the beneficiary from the much needed support and services. It is often advisable to name a trust company as trustee to eliminate any conflict of interest in family members who may serve as trustee and also be the remainder beneficiaries of the trust. A good balance is to have a trust company serve as trustee, but to give family members access to trust accountings and trust records at any time, and to also designate a family member who has the authority to hire and fire the trustee.

A non-profit pooled trust, such as The Arc of Texas Master Pooled Trust, is also an option. With a non-profit pooled trust, the family can get the benefits of a professional trust company, but at reduced fees.

The trust document will instruct the trustee where to distribute funds once the beneficiary dies. Usually, the remaining funds are distributed to other family members.

**TYPES OF GOVERNMENT BENEFITS AVAILABLE TO AN INDIVIDUAL WITH SPECIAL NEEDS  
(NOT A COMPLETE LIST)**

**I. Welfare-Type Benefits.**

**A. Supplemental Security Income (“SSI”).** Monthly cash payments to the individual with a disability who has little or no income, and who has not worked enough to qualify for entitlement Social Security benefits. To be eligible, the individual cannot own assets with a cumulative value of more than \$2,000.00, or have monthly income over a specified amount (\$733.00 in 2015).

**B. Medicaid.** Covers the cost of medical care with specific providers (there may be some limitations on prescription drug coverage). Medicaid may also cover transportation to and from medical providers, and may reimburse for private health insurance premium payments.

**II. Entitlement Programs.**

**A. Social Security Disability Insurance (“SSDI”).** An individual with a disability can receive disability based on his or her own work record. A child who is disabled prior to age 22 can claim disability based on a parent’s work record.

**B. Retirement, Survivors, Disability Insurance (“RSDI”).** An individual with a disability can receive disability payments based on a parent’s (or sometimes grandparent’s) work record.

**C. Medicare.** Covers the cost of medical care and prescription drugs with some limitations (mostly premiums and co-pays).

**Note:** It is possible to be eligible for both entitlement programs and welfare-type benefits. Many individuals with disabilities receive both Medicare and Medicaid.

**III. Medicaid Waiver Programs.**

The Social Security Act allows states to waive some income requirements from eligibility determination for certain individuals seeking home or community-based assistance. Without this assistance, these individuals are likely to require care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded (“**ICF-MR**”). The types of service provided include residential facilities and care, life skills and vocational training, nursing, respite, and speech and language therapies. The resource limits are generally the same as SSI, but with higher income limits. There are “interest” lists (waiting lists) for most of these programs up to nine years long.

## **PRESERVING WELFARE-TYPE BENEFITS FOR THE INDIVIDUAL WITH A DISABILITY**

A trust is a device by which property, real or personal, is held by one party for the benefit of another. Typically any property held in a trust for the benefit of an individual with a disability will be counted as an available resource and will likely make the beneficiary ineligible for benefits such as SSI and Medicaid. The exceptions are below.

### **I. Self-Settled Trusts (The Beneficiary's Money).**

If a disabled individual is receiving means-tested benefits (welfare-type), and the person also receives disqualifying resources (usually through inheritance, a personal injury claim, or a lump-sum back payment of Social Security benefits), a SNT can preserve those program benefits for the individual. As long as the individual is under the age of 65 and the trust provides for reimbursement to Medicaid upon the death of beneficiary, Social Security and Medicaid will not count the assets held in trust as an available resource for purposes of SSI and Medicaid qualification. Any funds distributed from the trust will be evaluated under the income requirements of each program.

### **II. Third Party Trusts (Other People's Money).**

The family of an individual with a disability who is receiving means-tested benefits can set aside funds for the benefit of such individual in a SNT, and such funds will not be counted as a resource available to such individual for the purposes of SSI and Medicaid qualification. Typically families will set up a SNT that will be funded by testamentary bequests or by life insurance policies on the lives of the parents. The individual's basic needs will be met by the government programs, such as Social Security and Medicaid Waiver programs, and all life enriching, life enhancing goods and activities will be provided by the special needs trust. For example, if an individual with a disability is receiving Social Security, Medicare, and Medicaid, they will have their rent, utilities, and food paid for out of Social Security. The SNT can then pay for clothing, cable TV service, videos, telephone service, summer camp, tuition to take a course of interest, the cost of the beneficiary's sister (who lives in another state and has limited resources) to come visit, etc.

### **III. Non-Profit Pooled Trusts.**

A pooled trust collects the assets of many individuals for investment purposes, but maintains sub-accounts for each individual beneficiary. In Texas, The Arc of Texas Master Pooled Trust can meet the requirements of either a self-settled or a third party funded SNT. This is often a good option for those with no family member to serve as trustee, or for those with sums too small for a corporate trustee to manage.

## HOW A SPECIAL NEEDS TRUST IS USED\*

The following examples are not exclusive, but will illustrate the types of disbursements that are appropriate for a third party funded Special Needs Trust when paid directly to a provider of a good or service. The rules for first party or self-settled Special Needs Trusts are very strict and policies change and we **STRONGLY URGE TRUSTEES** to obtain current rules and policies of SSI or Medicaid prior to making any distributions.

- Health and dental treatment and equipment
- Rehabilitative speech, music, equine, massage and occupational therapy services not covered by Medicare or Medicaid
- Medical and diagnostic treatment, even though not medically necessary or lifesaving
- Alternative medical care – acupuncture, hypnosis, and relaxation therapies
- Medical insurance premiums
- Supplemental nursing care
- Supplemental dietary needs
- Entertainment, recreation, and cultural experiences
- Burial plot and pre-paid funeral expenses
- Life skills training
- Private case management
- DVD player, movies, books
- Computer, software, CD/MP3 player, audio books, iPod, iPad
- Television, and cable equipment and service
- Telephone service and answering machine
- Training and educational programs
- Camp
- Clothes
- Furniture, bedspreads, knick knacks, hobby items, frames, photos, pictures, plants
- Club or hobby memberships and magazines
- Trips and travel (any airline ticket must NOT be refundable to the traveler)
- Pet care, including supplies and vet bills

The following are items for which the trust cannot make disbursements without affecting the level of benefit under the Supplement Security Income (SSI) program. If the beneficiary is on SSI, then these items are typically paid for with the SSI funds.

Cash to the beneficiary

Food

Shelter

- Rent or Mortgage (including property insurance required by the mortgage holder)
- Real property taxes
- Heating fuel
- Natural Gas
- Garbage collection
- Electricity
- Water/Sewer

\*This list is subject to changes of interpretation by the Social Security Administration at any time. As of 2015, this is our best understanding of the acceptable disbursements allowable out of SNTs. Please contact an attorney or the Social Security Administration if you have any questions regarding a disbursement.

**OTHER ESTATE PLANNING MATTERS FOR  
THE FAMILY WITH A DISABLED MEMBER**

**I. Goals of Estate Planning for the Family Member With a Disability.**

- A.** Assure continued eligibility for government benefits (such as Medicaid)
- B.** Furnish a source of funds to provide enrichment for the individual's life
- C.** Plan for smooth transition after death of parent or primary caregiver
- D.** Identify and empower individuals who can be available to make sure family member's needs are met (guardian and trustee)

**II. Components of an Estate Plan for a Family Member With a Disability.**

**A. Will.** Used to direct property away from the family member with a disability individually, and instead into a SNT for their benefit. With no Will, Texas laws of descent and distribution will determine who gets the property.

**B. Designation of Guardian.** If you have been appointed guardian for your adult child, you can name a successor guardian.

**C. Special Needs Trust.** Allows family member to set aside a portion of their estate for the benefit of the family member with the disability in a manner that does not cause the beneficiary to be ineligible for government benefits based on financial need.

**D. Letter to Guardian and Trustee.** Provides guidelines for those who will serve as guardian and trustee after you are gone on issues such as the daily or weekly routine the family member is used to, their favorite activities, holiday traditions, complete medical history, a list of providers (past and present), and the level of independence you expect the family member to achieve.