

# Creating a Special Needs Trust

If something were to happen to you today, who would be there to protect the needs of your loved ones — especially those with special needs? A SPECIAL NEEDS TRUST can help ensure they will have the resources necessary to live fulfilling lives.

According to “The National Survey of Children with Special Health Care Needs,” conducted in 2009-2010, 15.1% of U.S. children under the age of 18 (over 11 million children) have special health care needs.<sup>1</sup> This study found that 23% of households with children include at least one child with a special health care need.<sup>2</sup> In the past 25 years, the definition of “special needs” has broadened, making financial and estate planning vital for the care givers of these children. An update from a survey conducted in 2011-12 resulted in the number of children with special health care needs increasing to 14.6 million.<sup>3</sup> Think of all your current and probable future special needs-related expenses -- special residential homes, employment assistance and other costs. And while it may be tough to meet these obligations now, imagine the implications once you’re gone.

## There is Some Help from Uncle Sam ...

Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Medicaid<sup>4</sup> are three sources of government benefits available to eligible disabled individuals. SSDI is a non-needs-based benefit that is available to all taxpayers who have earned sufficient credits, based on their taxable income. SSI and Medicaid are both “needs” and “income-based” programs; they are available to those who are disabled or blind and have limited financial resources. One of the most important benefits of SSI is that it automatically makes a recipient eligible, and in some states, qualified, for Medicaid. For those not receiving SSI, Medicaid eligibility is determined by state law. SSI may also entitle an individual to other benefits and services, such as food stamps and payment of Medicare premiums, depending on the state of residence. Medicaid provides comprehensive coverage for medical care, physical therapists, occupational therapists, medical equipment, recreational and social programs, rehabilitative and custodial services.

## ... But Not Without Conditions

The government puts a major condition on the receipt of SSI and Medicaid benefits. The programs offer support to a dependent with special needs only if the total value of their assets falls below a certain threshold; for most states, this threshold is \$2,000. Therefore, if the value of all assets exceeds \$2,000, the government can reduce or eliminate support.<sup>5</sup> The policy rationale is that SSI and Medicaid are meant for

### Ask the Right Questions

When carefully structured by an estate planning or guardianship law attorney, a Special Needs Trust could ensure your financial resources are able to provide a lifetime of quality care for your loved one. When creating a Special Needs Trust, ask yourself the following key questions:

- What are the goals and objectives for my loved one, now and in the future, when I am no longer here to care for that person?
- What is the average cost of my loved one’s supplemental needs above and beyond government benefits?
- What level of support must I provide for other family members?
- Who is the designated trustee(s)?
- What funding vehicles should I use for my trust?

those who have limited financial resources. If a dependent with special needs is found to have “excessive” income or assets, the government will not assist until the assets are “spent down” below the threshold.

The limit applies only to those assets in the dependent’s name. This may seem like an easy standard to maintain, especially when the dependent is not working. However, often dependents with special needs may inadvertently lose or have their benefits decreased after receiving large gifts, inheriting property, receiving death benefits from a life insurance policy or a retirement plan, or being a class beneficiary under the will of a parent, sibling, grandparent, aunt or uncle. These well-meaning gifts from caregivers and/or loved ones may increase the value of the dependent’s assets beyond the \$2,000 threshold, thus jeopardizing receipt of governmental benefits.

However, there is an estate planning tool that can help maintain government benefits. By indirectly providing care and/or assets to loved ones with special needs, the caregiver can supplement the government aid that may be available while improving the quality of life for the person with special needs.

## Supplementing Federal Support

Supplementing federal and state support is why many people turn to a Special Needs Trust. This estate-planning tool can offer an affordable way to help meet the ongoing needs of a person with a disability — or to provide a substantial gift — without jeopardizing eligibility for government benefits. More importantly, if something happens to you, a Special Needs Trust can help provide financial security for your loved one’s continued care.

Specifically designed to provide funds to supplement necessities (food, shelter and clothing), a Special Needs Trust may help pay for additional items such as medical therapy or procedures not covered by SSI or Medicaid, including:

- Cable/Satellite/Internet
- Computer/Printer/Scanner
- Education
- Recreation
- Television/Media
- Transportation
- Travel
- Travel guardians
- Vacations
- Cell phones/Electronics

## Special Needs Trust: How it Works

An irrevocable trust is created for the dependent’s benefit. It includes specific terms that supplement the dependent’s government benefits. There are three types of special needs trusts:

1. Third-Party Trust
2. Qualified Self-Funded Trust [or First-Party Trust]
3. Qualified Pooled Trust

The qualified pooled trust is typically created and administered by a non-profit organization for the benefit of many dependents with special needs. A qualified self-funded trust is created by the dependent, typically with funds awarded from a lawsuit. Our focus will be on the most common form of special needs trusts. This is the third-party trust, which can be created by anyone, for the benefit of a dependent with special needs. Typically, the caregiver(s) is the grantor of the trust, a separate person is named trustee, and the dependent with special needs is the beneficiary (can also be one of several beneficiaries). The trust has specific provisions which allow the trustee to use assets for the dependent’s benefit. The trustee can use these assets during the caregiver’s life or after their death.

The trustee uses assets to purchase special supplies and/or medicine, pay education fees, pay rent, arrange and pay for vacations, etc. The trustee essentially pays for those items not covered by SSI or Medicaid. The key is not to give the money directly to the dependent, but to make payments on the dependent's behalf. If the asset is not in the dependent's possession, it is not counted and therefore not included in the \$2,000 threshold. By paying for those needs not covered by SSI or Medicaid, the trust maintains the dependent's federal and/or state assistance. This is what is meant by supplementing the government benefits. The government pays for the necessities, but the trust pays for everything else by making payments on behalf of the beneficiary. The trust can be created during the grantor's life (Inter-vivos Trust) or at his or her death (Testamentary Trust).

**Testamentary Trust.** For anyone looking to create a bequest to a beneficiary with special needs upon his/her death — a testamentary Special Needs Trust may be most suitable. Established through a will (or a revocable living trust) and implemented upon the grantor's death, a Special Needs Trust is created based on the terms and conditions specified in the will (or revocable living trust). The trust receives all assets allocated to it from the deceased's estate. This option offers a secure way to lock in a lump sum for your dependent's continued care.

**Inter-vivos (Living) Trust.** In certain situations, an inter-vivos, Special Needs Trust may be more appropriate. With this trust, the trustee can access the liquid funds to help pay special medical or supplemental expenses while the grantor is still living. Your attorney will help you determine how much you can borrow without affecting a loved one's eligibility for government assistance.

### **Providing Gifts Through a Trust**

Both a testamentary and living trust can offer a viable way for friends, grandparents or other relatives to make a substantial gift to a loved one with special needs to help supplement their care without jeopardizing federal and/or state assistance. Friends and relatives can either contribute to a caregiver's existing special needs trust or create a new trust that addresses the immediate and future special needs of the dependent.

## **Funding a Special Needs Trust**

The funding vehicle you select for your Special Needs Trust can have a dramatic impact on the amount of resources available for your loved one. Investments or other financial resources can be one vehicle that potentially multiplies the value of the trust-fund over the years. At the same time, today's fluctuating market and evolving tax laws could lessen the value of these savings.

Permanent life insurance is another funding source that can provide death proceeds as well as other significant short- and long-term advantages. These include the opportunity to accumulate cash value for the future, on a tax-deferred basis, and the ability to access cash value through withdrawals and loans to help meet more immediate expenses over the years.<sup>6</sup> In addition, one can "leverage" the premium payments, since the death proceeds of the policy are often greater than the premium costs over time.

If life insurance is used, the policy will typically insure the life of the grantor/caregiver, with the trust as owner and beneficiary of the policy. The trustee will either purchase a new policy or an existing policy will be transferred to the trust.<sup>7</sup> This ownership arrangement prevents the beneficiary having special needs from having direct control or management over the funds, which could otherwise put him or her at risk of losing government benefits.

The face amount of the life insurance policy should be at least equal to, if not more than, the estimated amount necessary to meet your dependent's needs over his or her lifetime. Your understanding of your loved one's diagnosis, prognosis, functional skill level, earning potential and abilities will assist in determining the

appropriate amount of life insurance that will be required. The life insurance policy can insure the life of either one or two individuals. A single life policy pays a death benefit after the individual insured's death, and a survivorship policy pays the death benefit after both insureds – typically the parents – have died.<sup>8</sup>

The premium payments begin to create cash value for the trust, which may be accessed by the trustee through loans during the insured's lifetime.<sup>9</sup> You may want to name other children or relatives as successor beneficiaries of the trust to receive remaining funds in the event your loved one with special needs dies before the trust principal is depleted. You may also consider naming a qualified charity as the successor beneficiary of the remaining trust assets.

## Whole Life or Universal Life: Permanent Solutions

There are a wide variety of life insurance policies to choose from, but a permanent whole life or universal life policy may provide the greatest advantages for funding a Special Needs Trust. Both provide death benefit protection<sup>10</sup> and allow tax-deferred cash value accumulation under current tax laws.

## Selecting Trustees

The trustee(s) you select will be responsible for administering the policy proceeds and other trust assets after your death. It is generally wise to choose at least one individual who is quite familiar with your dependent's needs to serve as trustee or co-trustee.

The trustee(s) will oversee the management of funds in the Special Needs Trust prior to and after your death. You can appoint an individual trustee or joint trustees, also referred to as co-trustees. Trustees can be individuals and/or an institution, such as a bank or trust company. Because of the array and diversity of skills and experience necessary for the Special Needs Trust, co-trustees are often selected. The grantor can name an individual trustee who knows the family and dependent with special needs and an institutional trustee for their technical, accounting, and legal expertise.

Ideally, the trustee will have the following skills:

- Understands public assistance and benefits
- Conforms to all statutory fiduciary requirements
- Has sound investment management skills and resources
- Uses discretion in the best interest of the dependent beneficiary
- Understands the implications of taxes regarding an individual with special needs
- Keeps detailed and accurate books and records
- Coordinates and monitors needed services such as care managers and nursing that the disabled beneficiary receives
- Knows your dependent and is familiar with their present and future needs

## Other Considerations

### Appointing Guardians

Guardianship<sup>11</sup> is another pressing issue for people currently caring for individuals with special needs. Often siblings, aunts or uncles, or the child's grandparents are the first choice to act as guardian should the caregiver die or become incapacitated. Guardianship, however, requires a substantial amount of consideration as it is a major commitment and familial ties alone is often not enough to guarantee the dependent will be cared for properly.

Unfortunately, guardianship practices vary by state, and there is no unifying federal guideline on which to rely. Also, depending on state guidelines, guardianship may result in an adult with special needs losing any right — even limited — to self-determination in medical care, housing choices, etc. That is why a lawyer specializing in special needs planning should always be consulted and retained to draft any binding documents for a loved one with special needs.

## Letter of Intent

A Letter of Intent, written by the caregiver/guardian of an individual with special needs, provides instructions to a trustee/guardian about the type and level of care to be provided, including specific instructions regarding health care, education and living arrangements. The letter serves as a set of “soft instructions” outlining the dependent’s likes, dislikes, habits, strengths, weaknesses, or goals so the trustee or guardian has a better idea of the dependent’s needs and caregiver’s desires. While not a legal document, Letters of Intent should be witnessed and notarized.

## Conclusion

If you provide care for a person with special needs or wish to create a substantial gift, a Special Needs Trust can be of tremendous help. If carefully drafted, it can be an important estate planning document that may not affect your loved one’s eligibility for federal and/or state assistance.<sup>12</sup> And when funded with life insurance, a Special Needs Trust can provide an affordable solution that may multiply the value of your savings and resources over the years. It is an opportunity to ensure the care you give now will last a lifetime.

To learn more about the use and benefits of life insurance funding a Special Needs Trust, contact your New York Life agent.

## Endnotes

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<sup>1</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration. See <http://childhealthdata.org/browse/survey?s=1> (last reviewed 1/18/2013).

<sup>2</sup> *Ibid.*

<sup>3</sup> Annie Casey Foundation, Kids Count Data Center Project (National Survey of Children with Special Health Care Needs) – Updated August 2013.

<sup>4</sup> Known as Medi-Cal in State of California.

<sup>5</sup> Check the Social Security Website: [www.ssa.gov](http://www.ssa.gov) for more detailed information on SSI and Social Security Disability insurance, as well as a more complete definition of “disability” for Social Security purposes.

<sup>6</sup> Loans and withdrawals reduce any available policy cash values. In addition, loans against a policy accrue interest at the current rate and decrease the death benefit.

<sup>7</sup> *Ibid.*

<sup>8</sup> A Survivorship Purchase Option Rider (SPO) on a survivorship policy can allow the surviving spouse to purchase more insurance after the death of the first to die, usually for up to three months. (Note: This will increase the required premium payments.) The availability and / or terms of this rider may vary by state.

<sup>9</sup> Note 6, *supra*.

<sup>10</sup> Provided premium requirements are met.

<sup>11</sup> Check with state laws to ensure that guardianship is applicable.

<sup>12</sup> Consult with local tax and legal advisors to check if state benefits may be affected.

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