

Planning for the Future: Special Needs Trusts as Tools to Enhance Quality of Life

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The future is always a concern for families of individuals with disabilities. How will they provide a good life for their children even after they're gone? Good financial planning is a crucial part of a well-designed 'whole person' approach to providing for their adequate care, comfort, enjoyment and engagement in life. Many parents are aware that they must maintain crucial public benefits and services for their children throughout their lifetime, and wonder how they can still hope to enrich their children's lives while meeting Medicaid criteria. Special Needs Trusts are one answer to this dilemma.

Needs, Public Benefits and Special Needs Trust Quality of Life Enhancements

To begin, it helps to accept the fact that public benefits are truly essential to the health and wellbeing of many individuals with significant disabilities. Here is how it works: Medicaid-supported medical benefits and services, as well as Social Security cash benefits, HUD housing vouchers and food stamps are available to people with disabilities who meet the "means" criteria. The NJ Division of Developmental Disabilities (DDD) requires that individuals with intellectual and developmental disabilities (ID/DD) have Medicaid in order to receive the essential services and funding that will meet their unique needs over their lifespan. [*Editor's note:* There may be a small number of exceptions to the Medicaid requirement for DDD services, and The Arc of New Jersey may be able to provide helpful information to families, in some situations.] DDD provides eligible individuals with a variety of appropriate choices in independent and supportive living, employment, day programs, skill-building programs, as well as personal and medical supports.

The laws that govern Supplemental Security Income (SSI) and Medicaid do in fact maintain that these essential services are still preserved and available to an individual with an ID/DD when the family establishes a Special Needs Trust, and when the funds from the Special Needs Trust are used to improve the quality of life for their loved one. This is good news for families.

Special Needs Trusts are financial accounts that enable family funds to be set aside to supplement these essential benefits and services. Life enhancing financial distributions from a Special Needs Trust might, for example, be used to fund additional or non-covered therapies, medical and dental services, adaptive equipment, wheelchairs, hearing aids, and case management services, as well as to pay for cell phone and internet services, electronic equipment, furniture, and personal travel.

Types of Trusts: What's Right for Your Family?

Each Special Needs Trust is governed by a Trust document that guides the use of its funds while meeting specific Social Security Administration and Medicaid rules. There are primarily two types of Special Needs Trusts: **Third Party Trusts and Self-Settled Trusts**. Choosing which

trust may be the most appropriate for a particular beneficiary or for a family, depends on the origin of its funding.

Parents wishing to leave personal assets such as savings, investments, insurance policies or retirement plans to their loved one with a disability can set up a **Third Party Special Needs Trust** (also known as a Supplemental Benefits Trust). Rather than leave these assets directly to their child and risk a possible loss of public benefits for the individual or exposure to financial exploitation, a transfer of assets to a Third Party Trust will not only protect the eligibility for public benefits, but also offer a means to ensure that these funds will be used in accordance with their wishes.

The other type of special needs trust is known as a Self-Settled Trust. A person with a disability who has personal savings or who becomes the recipient of a monetary payout (such as a settlement from a lawsuit), can establish a Self-Settled Special Needs Trust. There are similarities in the basic concepts of using these funds to supplement public benefits rather than supplant them. Avoiding distributions that would be considered income to the beneficiary is also of primary importance since income and assets are the crucial determination of eligibility for public benefits.

Differences between Third Party and Self-Settled Trusts. A Special Needs Trust funded with money that has been left directly to an individual beneficiary is actually less advantageous than a pre-planned Third Party Trust. Third Party Special Needs Trusts offer more flexibility to the trustee in the use of the funds than Self-Settled Trusts. *Self-Settled Special Needs Trusts also require a payback to Medicaid after the death of the beneficiary, if that beneficiary was a recipient of Medicaid benefits throughout his/her lifetime.* Third Party Special Needs Trusts do not. Self-Settled Special Needs Trusts often require Court intervention to be established. A trustee is appointed to administer the trust and make discretionary distributions on behalf of that beneficiary. If the beneficiary was allowed to control the Special Needs Trust, the money in the Trust would then be considered accessible assets to the individual and not be exempted for eligibility purposes.

A **Pooled Special Needs Trust** is especially helpful when an individual or their family has smaller amounts of funds with which to establish a Special Needs Trust. Pooled Trusts are administered by non-profit agencies. Sub-accounts in a Pooled Trust may be either Third Party Trusts or Self-Settled Trusts. The PLAN/NJ Community Trust, for example, has a Master Trust that defines its use and how it meets the criteria to exempt these funds from being considered a resource or asset by the Social Security Administration and Medicaid.

Participating in Pooled Trusts offers many advantages to its participants. The Pooled Trust Master Document and Joinder Agreements can be provided to the family and to their attorney at no cost. It saves the family the expense of having an attorney write a trust document. It also enables funds to be invested at reduced costs since new funds are combined within the larger existing pool of assets. A Pooled Trust allows for a beneficiary to establish his or her own sub-account whereas only a parent, grandparent, legal guardian or the court may establish a Self-

Settled stand-alone (non-pooled) trust. For some families, participating in a Pooled Trust is the best solution to enhancing care while maintaining public benefits.

The law governing Pooled Trusts permit the non-profit agency to retain a percentage of the remainder in the sub-account after the beneficiary's death for charitable purposes, to benefit individuals with disabilities. There are instances, however, when a Pooled Trust sub-account may not be the best option. For example, families wishing to name remainder beneficiaries in their Third Party trusts may opt to use a non-pooled stand-alone trust where all the remaining assets are distributed according to the families' direction.

It may be helpful to review a real-life scenario to imagine what is best for an individual with disabilities. Let's look at the example of Sarah, a young woman with Cerebral Palsy who lives with her mother in her family home. Sarah's father died two years ago, and then, sadly, Sarah's mother became ill and passed away as well. After the mortgage on the family home is paid off, Sarah will inherit \$25,000. A local supportive housing provider can support her in a supervised apartment if she remains eligible for Medicaid. Sarah is DDD eligible, but she would lose her Medicaid funding since the parents' assets were left directly to her. Had Sarah's parents planned in advance to have their assets directed to a Third Party pooled Special Needs Trust sub-account, Sarah's Medicaid would have remained intact and the funding for the supervised apartment would have been available without interruption. A Self-Settled Special Needs Trust can still be established – so that Sarah can be eligible for Medicaid -- but an attorney and the courts will need to be involved, adding additional cost to an already relatively small amount of assets. Furthermore, the related funds will now be subject to a Medicaid payback, as mentioned above.

It is never easy to care for a loved one with a disability, and even more challenging to consider how to best support and protect them when a parent is gone. These trust options were established to make complex financial decisions easier for families. Families are advised to write a comprehensive Life Plan that considers all aspects of the individual's social, emotional, health and financial needs. More information is available on financial and life planning from the National PLAN Alliance at www.nationalplanalliance.org, the Special Needs Alliance at www.specialneedsalliance.org, or from the Planned Lifetime Assistance Network of NJ (PLAN/NJ) at www.plannj.org.

Planned Lifetime Assistance Network of NJ (PLAN/NJ) is a non-profit social service agency established to provide a broad spectrum of support services to individuals with disabilities and/or mental health challenges. Our mission is to help families answer the question “**Who will care for my loved one when I'm gone?**” Services include case management, home visit monitoring and advocacy, legal guardianship, special needs trust administration, and Social Security representative payee. Established over 25 years ago, PLAN/NJ currently provides services to more than 620 clients throughout all twenty-one counties in New Jersey. For more information, contact:

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