



PLAN|NJ NEWS

THE NEWSLETTER OF PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY
FUNDED BY THE NEW JERSEY STATE BAR FOUNDATION

WINTER 2016

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**Who will care for your loved
one when you are gone?**

PLAN NOW!

RUTH: *Leading Life Independently*

Ruth is an independent woman. She lives in her own apartment, has a roommate, holds a rewarding job, goes to parties, and loves to eat at Pizza Hut. She likes to cook, keep her apartment clean, and celebrate the holidays. Ruth has also traveled extensively and is planning vacations in the Dominican Republic and Sweden next year.

A resident of South Orange, Ruth lives in an apartment complex run by a nonprofit organization that provides residential and other support services for individuals with disabilities.

“Ruth is ensured she will receive the support services she needs to live an independent life, one that is similar to those who have no disabilities, and this is imperative to her well-being,” says her PLAN/NJ service coordinator.

All people have the right to experience a good quality of life, and PLAN/NJ works to achieve this for those who live with disabilities. PLAN/NJ’s clients who receive Guardianship and Home Visit Monitoring Services have opportunities to live in community-based housing, to be employed, and to participate in recreational activities.

Ruth’s PLAN/NJ service coordinator assists Ruth with getting to medical appointments and advocates with doctors on her behalf to address important medical concerns. She often takes her shopping and to lunch. “Her favorites are Pizza Hut and Target, or we go to TGI Fridays and Macy’s for special occasions like her birthday and Christmas,” she says.

Earning a paycheck is important to Ruth’s independence, enabling her to pursue her travel interests and hobbies. She gets excited when speaking about her job. “I help patients at a nursing home with activities and morning meals,” says Ruth. “I have been to Hawaii, Lake Tahoe, and to Ocean Grove (NJ). I am glad to have the opportunity to work, travel, and visit new places.” Ruth is also



thrilled to learn things, and she recently took up knitting and computers as new hobbies.

“Independent living does not mean that our clients do everything by themselves, or that they do not need anyone,” says her service coordinator. “It means that people who live with disabilities are entitled to the same choices and control in their everyday lives that others often take for granted: things like going to school, working in jobs that are educational and interesting, and participating in activities of their own choosing. Ruth is an ordinary woman who lives her life freely,” she concludes.

PLAN/NJ is proud of Ruth and her many accomplishments, and we are proud that we can assist Ruth with a life of personal independence.

PLANNING FOR THE FUTURE: *Special Needs Trusts as Tools to Enhance Quality of Life*

By Ellen Nalven, Executive Director, Planned Lifetime Assistance Network of NJ (PLAN/NJ)

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 they 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 well-being 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) be eligible for Medicaid in order to receive the essential services and funding that will meet their unique needs over their lifespan. 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 his or her 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 permits 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 it is even more challenging to consider how to best support and protect him or her 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.specialneeds-alliance.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 21 counties in New Jersey. For more information, contact: Ellen Nalven, Executive Director
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End of the Year Thank You's!

PLAN/NJ would like to sincerely thank all the individual, corporate and foundation support we received in 2015! Your generosity helps us to continue to meet the needs of individuals and their families in New Jersey with severe and multiple disabilities.

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PLAN/NJ PRESENTS A CELEBRATION OF ABILITIES

Mark Your Calendar for Thursday, May 12, 2016

PLAN/NJ will be hosting our annual awards presentation, **A Celebration of Abilities, on Thursday, May 12, 2016, at 6 PM at the New Jersey Law Center in New Brunswick, NJ.**

This special event marks PLAN/NJ's 27 years of service to New Jersey residents with developmental, physical or psychiatric disabilities and their families, and will include jazz music and an awards presentation recognizing individuals who have made significant and long-term contributions in improving outcomes and enhancing their quality of life. PLAN/NJ will also recognize selected clients for their unique contributions to this ongoing and important multi-service effort.

Featuring an evening of cocktails, hors d'oeuvres and a keynote address by a special speaker, this event is an excellent opportunity to come together with families, social service professionals, attorneys and financial advisors who support and serve individuals with disabilities.

Mark your calendars for May 12, 2016, and be sure to look for our invitation, sponsorship opportunities and more information on guest speakers and award recipients, coming soon.

PLAN/NJ PROFESSIONAL SPONSORS DIRECTORY

Attorneys and Financial Advisors/Planners

The following professionals have interest and experience in estate planning and many other related matters for individuals with disabilities and their families, including guardianship, public benefits, and special education laws. **Inclusion on this list does not represent a recommendation or endorsement by PLAN/NJ** and the list is not inclusive of all attorneys in New Jersey who provide such legal services. Families should contact attorneys personally regarding services, fees, and to determine whether a particular attorney meets the family's needs.

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