# 2015 ANNUAL REPORT



Planned Lifetime Assistance Network of New Jersey







Who Will Care For My Loved One When I'm Gone?

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#### A MESSAGE FROM THE PRESIDENT



Regina Tegeler, President

This year, my family and I experienced many joys: for example, we joined our newly married daughter and her husband on several vacation trips. There were challenges, too; I experienced a serious illness, which impacted us in unforeseen ways. Upon my recovery I have realized that PLAN/NJ provides added security. They were available if needed to help provide reliable care and attention for our son to continue living his busy, happy life as an individual who has disabilities.

We took great comfort in knowing that we can rely on PLAN/NJ's advocacy and support for our son in the future, should that need arise. They are truly the extra eyes and ears I need to help sustain my son's vitality of life. PLAN/NJ is a crucial voice for our family in advocating for his current needs, and because of the LifePLAN we have put in place, I am confident they will look out for him in the future.

If you have a relative who is living with a disability, PLAN/NJ can help you provide them with the life they deserve. Our non-profit, social service organization offers

practical solutions for families today, and lessens their fear and anxiety when planning for the future. We were established by the ARC of New Jersey over 25 years ago to serve all 21 counties in New Jersey. Since that time, our organization of social service professionals and family members dedicated to supporting individuals with disabilities has grown tremendously. For the past several years we have seen a huge increase in the number of families contacting PLAN/NJ for all of our services. Currently, PLAN/NJ provides services for more than 800 clients, and the number of requests grows every year.

This 2015 Annual Report describes our services, recent successes, and plans for the future. You'll learn more about the bedrock of comprehensive support we offer for families and individuals: Case Management, Life Planning and Family Support, Legal Guardianship and Financial Administration. You may wish to spend time reading about the values-based pillars of our client-centered service model, and enjoy reading the case studies described in our Spotlights on Home Visit Monitoring and Trust Administration. Please take note of the institutional supporters and individual donors listed here; they help ensure PLAN/NJ's continued impact on the health and well-being of all the citizens of New Jersey.

Above all, I want to thank you for your support.

Sincerely,

Regina Tegeler



#### **MISSION:**

#### WHO WILL CARE FOR MY LOVED ONE WHEN I'M GONE?

An individual with a physical, developmental or mental health disability needs a bedrock of carefully-designed support. For the family members, there are daily questions to answer. How will his medical costs be covered? What home environment is best? What activities and care does she need to thrive?

With PLAN/NJ's help, not only has my sister Mary's life been enriched and her well-being protected, but so has mine. Thank you for all your support!

Barbara S.,family member

Perhaps the most difficult questions arise when considering how a loved one will still be supported even after parents or other immediate family are gone. It's a challenging question, but the answer is embedded in our name: Planned Lifetime Assistance Network of New Jersey, Inc. (PLAN/NJ). PLAN/NJ ensures that all necessary supports are available to individuals with various developmental disabilities and mental health challenges including autism, cerebral palsy, intellectual disabilities, traumatic brain injury and severe mental illness, enabling them to live full and more independent lives.

PLAN/NJ is a non-profit organization comprised of qualified staff and volunteers who provide exemplary care coordination, guided oversight of financial affairs, and compassionate actions that enhance quality of life. We partner with families to provide a lifetime of assistance for people with differing abilities. Whether loved ones need these services now or in the future, we put this assistance in place whenever a family is ready, helping to maintain continuity and peace of mind for all concerned.

Imagining a time when they could no longer be their loved ones' primary advocates, a consortium of New Jersey families formed PLAN/NJ over 25 years ago to address the concerns they shared for the quality of their loved ones' future support. Today,

PLAN/NJ helps family members prepare for the years ahead and provides the legal, financial and independent living supports that their loved ones need and deserve. Family members always play a vital role in developing the programs and services implemented for their loved one by PLAN/NJ. At least 51% of our Board of Directors consists of relatives of people with disabilities or mental illness. We understand how important it is to you that we help your loved one thrive. Our strong beginnings and ongoing commitment ensure that PLAN/NJ keeps clients and their families at the center of all we do.

Learn more about the services we offer our clients and families at www.plannj.org





# FROM ACTION TO IMPACT: PLAN/NJ'S ACCOMPLISHMENTS IN 2015

The cornerstone of a life well lived is a safe, secure and independent lifestyle. PLAN/NJ supports New Jersey's families with loved ones who live with a variety of developmental, physical or mental health challenges. We offer Life Planning for Independent Living, Guardianship, Home-Visit Monitoring and Advocacy Services, as well as Private and Pooled Trust Administration.



#### INCREASING ACCESS TO QUALITY SERVICES

In 2015, PLAN/NJ increased support to New Jersey's families, adding 199 new clients -- an increase of 32% over 2014 -- for a total of 820 individuals served. Of our clients served, 455 have received Life Planning, Trust Administration, Guardianship, Home Visit Monitoring, Advocacy and/or Representative Payee Services this year. We additionally served 365 Department of Child and Family Services (DCF) clients with short-term monitoring, advocacy and family support services.



Guiding families through the design of a LifePLAN - a comprehensive future plan - for a relative with a disability or mental illness is a signature service of this agency. We have more than doubled the number of LifePLANs written since 2014, resulting in a total of 28 families who have provided for their loved one's social service support needs this year. PLAN/NJ sets the standard for best practices in lifetime support coordination to loved ones with disabilities.

Throughout the years, I have helped my developmentally challenged son in many ways.

I always assure him that everything will be fine and that his needs and wants will be taken care of, and I can say that with confidence, because my son and I have utilized the services of PLAN/NI.

I feel comfortable, relieved and secure knowing someone trustworthy will always be there for Matthew - even when I can't be.

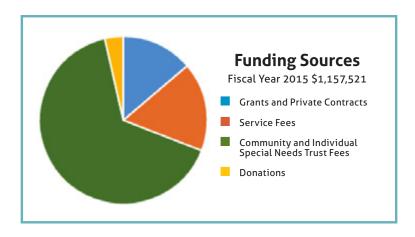
- Audrey W., parent

#### ENSURING FINANCIAL STABILITY FOR CLIENTS AND AGENCY

Many individuals' families have entrusted us with the responsibility to ensure that the funds they have set aside for their support are used solely to improve their loved one's care and quality of life. PLAN/NJ serves as Trustee for Special Needs Trusts with small and large principal values, with minimum deposits as low as \$25,000 and several accounts in excess of \$1 million. In total, we manage \$64,269,160 in assets for 361 individuals with significant disabilities. The number of private Trust Administration clients grew by 15% to 221 private trusts administered in 2015.

PLAN/NJ also holds a pooled Special Needs Trust, the PLAN/NJ Community Trust. We served 160 clients as participants in The Community Trust, representing a 6% increase in Pooled Trust sub-accounts since last year.

We also serve as Representative Payee for 42 individuals receiving Social Security benefits, helping with budgeting, bill-paying, and other day-to-day financial management needs. This service protects people from potential financial exploitation, ensuring that clients' financial needs are met, and that their income and expenses are properly managed.

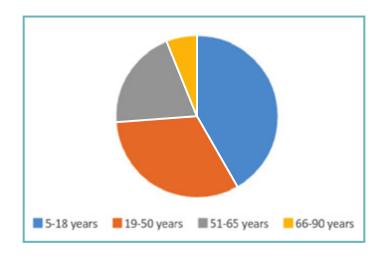


#### INCREASING EDUCATION AND OUTREACH EFFORTS

Ongoing outreach is vital to improved outcomes for people with disabilities. Our goal is to help more people understand the legal, estate and independent living planning needs of people with disabilities. We aim to ensure that people's preferences are honored, that personal relationships are maintained, and that required services are identified and put in place. This year, PLAN/NJ held Life Planning Education Sessions via twenty-eight seminars and exhibits, reaching 1,698 family members, clients, partners, and human service and related agency staff.

#### SUPPORT THROUGHOUT THE LIFESPAN

PLAN/NJ provides services to individuals within a broad age span, from age 5 to age 90.



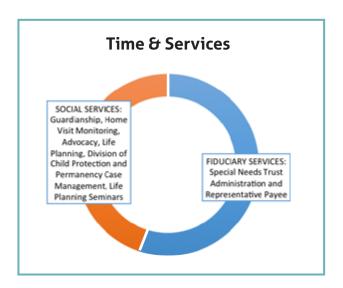
#### STRATEGIC PLANNING 2015-18

In 2015, PLAN/NJ completed a rigorous strategic planning process involving all members of the board and staff. This has resulted in an even stronger strategic commitment to ensuring success in the areas of Growth and Sustainability, Quality Assurance, and Effective Governance, with measureable outcomes articulated. Our goal was to ensure PLAN/NJ's capacity to serve its clients in the long-term. Participants reviewed and set new standards, systems, staffing, operations, infrastructure, facilities, business development and guidance benchmarks to ensure that we continuously improve on its ability to provide New Jersey with access to high quality fiduciary, guardianship and social services for all. We strive to set a standard of success for other states to reference. In the coming months and years, PLAN/NJ will:

- Grow and sustain New Jersey's access to high-quality independent living
- Assure quality in all areas of service
- Effectively govern PLAN/NJ for future growth and achievement

For more information, contact Ellen Nalven, Executive Director.







## PROGRAMS AND SERVICES: SUPPORTING INDIVIDUALS SO THEY CAN THRIVE

PLAN/NJ offers vital family service options to all individuals with disabilities and to their families. Our high-quality, individualized support model ensures that individuals with one or more disabilities have access to a continuum of quality services and resources. Our goal is to support each person's optimal health and well-being over the course of a lifetime. This year the number of individuals we support in all service areas has expanded by 32%, requiring evermore diligent and individualized attention to support their needs.



#### **CORE SERVICE OPTIONS**

## Life Planning and Family Support:

- We guide families through the design of a comprehensive future plan a LifePLAN for a relative with a disability or mental illness
- We consult with siblings and other caregivers to improve their capacity to advocate for their loved one

### Case Management / Home Visit Monitoring:

- We visit clients at home, in person; we transport them to doctor visits and shopping
- We help negotiate the disability and mental health service systems
- We assist and advocate for access to emergency and planned housing, education, food, medical, financial and other supports from federal, state and local agencies such as the Social Security Administration, Medicaid, Division of Developmental Disabilities, Division of Mental Health Services and Housing Authorities
- We assist individuals in life transitions, such as a move from a family home to supportive housing, or following the loss of a parent
- We advocate for the quality short- and long-term support of each client
- We provide referrals to legal, financial and social service resources
- We organize private home health care, nursing home placements, and hospice care as appropriate
- We maintain the safety and well-being of individuals during natural hazards, such as Hurricane Sandy
- We advocate for greater understanding of clients' needs with hospital and social services staff
- We provide Spanish-speaking services
- We also provide case management services for clients of the Dept. of Children and Families' Division of Children Protection & Permanency

# Legal Guardianship:

- We serve as Legal Guardian, responsible for surrogate decision-making while promoting choice and self-determination, dignity and respect
- We provide all aspects of Case Management services as described above, including a minimum of one monthly in-home visit
- We ensure quality of life in all areas including health, housing, education, employment, recreation and community living

## **Special Needs Trust Administration:**

- We serve as trustee of Third-Party and Self-Settled private, stand-alone Special Needs Trusts
- We operate a pooled Special Needs Trust, the PLAN/NJ Community Trust, serving as Trustee of Third-Party and Self-Settled sub-accounts
- We serve in a fiduciary role for clients, providing oversight and monitoring of client funds in order to help them maintain their Medicaid and other public benefits
- We help apply for public benefits and other social services
- We help develop budgets and spending plans
- We monitor and assist with paying bills
- We ensure that car registration and insurance are current, and assist with and monitor health insurance claims and disbursements as needed
- We provide financial accounting and reporting to public benefits agencies, courts, and legal representatives as required
- We provide referrals to attorneys or financial planners when needed

# Representative Payee for Social Security Benefits:

- We serve as Representative Payee for Social Security Benefits, assisting with eligibility/benefits issues, ensuring that personal needs and financial obligations are met, and preventing homelessness
- We monitor and assist with paying bills and help develop a budget
- We provide reports, accountings and redetermination reviews as required by the Social Security Administration



# Spotlight On Special Needs Trust Administration: Enhancing Quality of Life Through Financial Planning

Good financial planning is a crucial part of a well-designed 'whole person' approach to providing for a loved one's adequate care, comfort, enjoyment and engagement in life.

"The responsibility of being trustee for a person with a mental health challenge is far more difficult than I had imagined.
PLAN/NJ guides me about my nephew's needs and the resources available to him."

Aunt of PLAN/NJ client

Social Security, Medicaid and the New Jersey Division of Developmental Disabilities (DDD), among other state and federal agencies, provide essential services and funding to protect the health and well-being of many individuals with significant disabilities. This support is available to people who meet the disability definitions and "means" criteria. Special Needs Trusts are financial accounts that enable family funds to be set aside to supplement essential public benefits and services, allowable when the funds from the Special Needs Trust are used to improve the quality of life for their loved one.

PLAN/NJ administers both private, free-standing Special Needs Trusts and also a pooled Special Needs Trust, The PLAN/NJ Community Trust. Our Director of Trust Services works with families, attorneys, and other professionals to determine which type of trust is most appropriate, then aides them in setting up the trust. She and her staff interact directly with the beneficiaries and/or their legal representatives of the trusts we manage. If a loved one is living with significant disabilities, establishing the trust early on will ensure peace of mind for families as they consider how to manage their assets on behalf of their family member, now and in the future.

The following are examples of how some individuals benefit from PLAN/NJ's Special Needs Trust Administration services.

# John's Story

John's parents have provided support and assistance to John all his life. John has autism and has limited ability to verbally express his desires and needs. Knowing that he would need the assistance of the New Jersey Division of Developmental Disabilities to provide him a group home and around-theclock staffing to live a full life, his parents planned for his future support by establishing a Third Party Special Needs Trust. Because he has no siblings to administer the Trust in the future, his parents arranged for PLAN/NJ to be the Trustee and to provide Home Visit Monitoring Services. A PLAN/NJ Service Coordinator visits John monthly and works with the group home staff to help determine John's needs. The Trust funds have enriched his life by paying for a computer



tablet to help John communicate and also play games. The Trust pays for supervised vacations to the Bahamas and to Disney World, furniture, clothing, haircuts and movie tickets. PLAN/NJ ensures that John's life is enhanced by the use of these funds and oversees his well-being with visits from a Service Coordinator.

# Diane's Story

Diane lived in a home left to her by her family after they passed away. When she needed to sell her home and move to assisted living, she knew that the funds remaining after her mortgage was paid off would cause her to lose her Medicaid benefits. In order to retain her benefits while still having the benefit of the proceeds of the sale of her home, she established her own sub-account in the PLAN/NJ Community Trust. Based on the budget prepared for her monthly expenses, Diane's Trust Assistant provides her with a credit card for her to purchase specific items. When she has a need to purchase an item that exceeds her credit limit, Diane contacts her Trust Assistant, who assists by making the purchase on line and shipping it to her. This empowers Diane with personal independence, enabling purchases like haircuts, movie tickets, cab rides and drug store items, while remaining within the Medicaid rules of allowable uses of the Special Needs Trust.

# Spotlight On Case Management Services: Promoting Vitality Through Home Visit Monitoring

Home Visit Monitoring is a unique and vital service offered by PLAN/NJ. Our experienced service coordinators go to the client's homes and provide practical assistance with housing, personal, medical or financial concerns. PLAN/NJ provides Home Visit Monitoring Services for clients who have no living relatives or whose families cannot make regular visits. We are the eyes and ears of distant relatives, keeping them updated after each visit, attending meetings to represent family concerns, and making extra visits when health or other crises arise. Service Coordinators:

- Visit clients regularly to make certain all of their medical, employment, social, legal and financial needs are met
- · Support clients in making healthy decisions for themselves
- Act as advocates, making sure that our clients' preferences are taken into account by service providers
- Monitor living arrangements, employment, day center, physicians, and other providers to identify concerns and ensure good delivery of services
- Attend planning meetings to assist in developing individualized, person-centered support plans



- Accompany clients to medical appointments and advocate on their behalf with medical personnel, and attend emergency meetings at hospitals or other health care facilities as needed
- Visit clients in the hospital
- Take on shopping trips, celebrate birthdays and arrange outings and recreational activities
- Are available to help with important life decisions, if necessary, such as what medical procedures might be necessary and appropriate

For 27 years, PLAN/NJ has provided Home Visit Monitoring Services for those who require support to live to the best of their ability and safely in their own community. In certain instances, we have been able to prevent homelessness, assisting clients to maintain their lives and continue relationships with neighbors, family and friends.

# carlos' Story

A haircut, a cup of coffee and a breakfast sandwich — these are little things that most people take for granted. But for Carlos, these small amenities mean the world, making his life work in just the way he prefers.

PLAN/NJ advocated for Carlos to move from a hospital to a home that is better suited for his needs, where he can live with appropriate supports and participate in the community. At his new home, Carlos enjoys the freedom to take walks, go on trips, and participate in group activities. He is thriving and is well-liked by his peers and staff.



A Service Coordinator visits him several times a month to provide the necessary advocacy for Carlos, making sure he continues to receive comprehensive medical care coordination and that his living arrangements remain a safe and comfortable place for him to live. We provide him assurance that his individualized needs are met, that his preferences are observed and that he feels protected. Oversight and having someone to call in an emergency is essential to Carlos' sense of safety and security. He is able to go on outings with his Service Coordinator to buy necessary things, get a haircut, have his nails trimmed or follow his morning breakfast routine of getting a cup of coffee and a breakfast sandwich. Carlos' continued happiness comes from the achievements of his daily life that provide him with the small pleasures we all enjoy.

# Suzanne's Story

Suzanne LOVES a parade. For years, she has been designing and sewing her own costumes and participating in parades throughout the state. Suzanne prefers to "participate in the parade" rather than watch it go by; this is a metaphor for her life as well as for many who live with disabilities. She has a "doer" philosophy. And whether they are supporting her in going to school, living in her own condominium or using her creative flair to engage in her hobbies, her family has always encouraged and assisted her with whatever she wished to participate in.

Several years ago, Suzanne's parents contacted PLAN/NJ to ensure a safe and appropriate home for Suzanne, as well as financial security. In her LifePLAN, PLAN/NJ documented all that Suzanne does to participate in the community and enjoy her life, making provisions for her to continue living in her own home and ensuring that food shopping, medical appointments and hobbies will continue.

Today, Suzanne has a PLAN/NJ Service Coordinator as an emergency contact to call for help, should she ever have the need. We also began visiting Suzanne in her home each month when her elderly parents became ill, and we continue since their passing to help her maintain her home and certain tasks. This continuity of relationship has ensured that Suzanne continues to engage with her favorite activities and people as she chooses. PLAN/NJ has fully implemented Suzanne's LifePLAN so that she will continue to develop and grow.

# FURTHERING IMPACT THROUGH EDUCATIONAL SEMINARS AND OUTREACH

PLAN/NJ reaches into communities throughout New Jersey, offering seminars and events, and distributing educational information and Life Planning Workbooks. We target family members and individuals with disabilities and/or mental illness (clients or otherwise), as well as the human service and related agency communities and other professionals who serve them. The goal is to increase their understanding of the needs of people with disabilities and of related PLAN/NJ services.

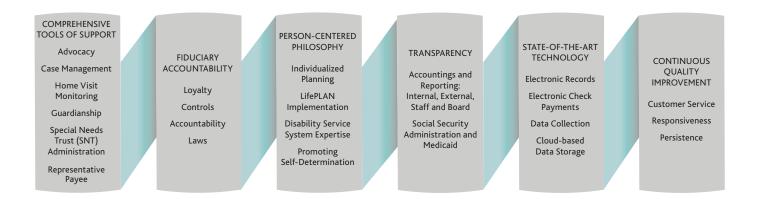
### **Seminar Topics:**

- The need for legal, estate and independent living planning for the future care of people with developmental or psychiatric disabilities
- How Special Needs Trusts (SNT) improve quality of life while preserving access to essential public benefits
- The importance of educating Trustees of SNTs about their fiduciary obligations as well as the Medicaid and Social Security rules that govern these trusts
- Guardianship and legal protections that are alternatives to Guardianship: Powers of Attorney, Representative Payee, Trustee for Special Needs Trusts, and Psychiatric Advanced Directives
- · How guardians may use person-centered practices to promote self-determination
- Legal rights to medical, residential, education and employment services for individuals with disabilities

At these events, PLAN/NJ distributes forms and sample legal documents to guide families in understanding legal and financial protections, and in how to plan for resources and supports for all areas of life including housing, medical, employment, recreation and other quality-of-life concerns.

#### VALUES-BASED SERVICE MODEL

PLAN/NJ strives to be the standard-bearing agency offering fiduciary, guardian and coordinator of support services for families in New Jersey whose loved ones have specific needs. Our goals and activities are under regular review by our staff and Board of Directors, and we seek to continuously improve in all areas. We build upon best practices from the field, staying abreast of evolving research and national trends, and consider our own program assessment results, data analytics, lessons learned, and partner and funder feedback. Our clients' needs remain at the center of every decision.



#### A MESSAGE FROM THE EXECUTIVE DIRECTOR



Ellen Nalven, Executive Director

Every member of a family deserves to lead a safe, secure, engaged and vibrant life. When a loved one has a disability, high-quality and sustainable solutions are needed. To enhance their loved one's lives, PLAN/NJ offers families an array of programs that provide a continuum of independent living, legal and financial supports and services. Our agency helps individuals with disabilities thrive.

At PLAN/NJ we employ person-centered, values-based, best practice approaches in all aspects of our work. We work together to ensure access for our clients to the following opportunities:

- · A safe and appropriate place to call home
- · Financial stability and security
- Suitable and appropriate educational offerings
- · A challenging and rewarding place of employment
- A community that welcomes varied contributions and levels of participation
- The ability to have choices and personal control
- An end to loneliness and isolation
- An advocate assigned to protect them from abuse and neglect
- A fulfilling network of support

This year was important for PLAN/NJ's institutional growth and development. We have been working hard to meet the needs of our expanding client roster by reviewing and improving upon our best practices in client support. We've reinforced our infrastructures to meet the growing demand for specialized services for individuals with developmental, physical and mental health disabilities in New Jersey. We undertook a strategic planning process this year that will ensure our increased capacity for service into 2018 and beyond.

Our staff meets and exceeds the benchmarks set by our Board of Directors that continue to stabilize, strengthen and grow our Planning, Fiduciary, Guardianship and Independent Living support services. I am proud to say that PLAN/NJ can exceed your expectations too, providing exceptional support for your loved one.

Call me to discuss your family member's needs at (800) 704-PLAN. For more information or to make a donation, visit www.plannj.org.

Sincerely,

Ellen B. Nalven

Eller B. Nalven

#### **GET INVOLVED!**

PLAN/NJ relies upon a dedicated network of donors, volunteers and staff. Each day, we work toward our mission to help New Jersey families answer the question, "Who will care for my loved one when I am gone?" You can help PLAN/NJ continue to serve individuals living with developmental and mental health disabilities.

As a 501(c)(3) nonprofit corporation, we accept tax-deductible donations. Every donation to PLAN/NJ ensures that families will continue to be served, now and in the future. Individual donations may support a variety of areas, including our Scholarship Program, which enables individuals with no other source of funding to receive Guardianship, Home Visit Monitoring and/or Representative Payee Services. Establishing an endowment supports and supplements the organization's operational income, building financial strength and organizational stability.

Thousands of families in New Jersey have a loved one with a disability. What's the easiest way to help them? The more people who know about our services, the more families we are able to assist, so tell your friends and family about us. Help spread the word about PLAN/NJ's trusted legal, estate, and independent living planning supports and services. Help ensure that PLAN/NJ is here for all of our loved ones, long into the future, by making an electronic donation at <a href="https://www.plannj.org/contact\_us">www.plannj.org/contact\_us</a>.



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