



**PLANINJ**

**ANNUAL REPORT 2021**

PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY



**FORMING CIRCLES OF SUPPORT**



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## MISSION

The mission of **Planned Lifetime Assistance Network of New Jersey (PLAN|NJ)**, a nonprofit organization, is to help family members of people with disabilities answer the question: **“Who will care for my loved one when I’m gone?”**

A person with intellectual, developmental or physical disabilities, or with mental health challenges, needs a bedrock of individually-designed, person-centered support. What home environment is best? Who will visit when I cannot? How will medical costs be covered? What activities and supports are needed to thrive?

We offer exemplary care coordination, guided oversight of financial affairs, and compassionate actions to enhance quality of life. We partner with families to provide their loved ones a lifetime of assistance. Whether services are needed now or in the future, we initiate assistance whenever a family is ready and help to maintain continuity and peace of mind for all concerned.

The families and individuals we serve have personal preferences and dreams for the future as well as specific needs. We take a whole person approach when putting plans in place and provide the coordinated supports needed to enable people with disabilities to live full and more independent lives.

Once a LifePLAN is created, families can opt in to Advocacy and Home Visit Monitoring — even before a special needs trust has been funded. With this service, one of PLAN|NJ’s case managers, called a Service Coordinator, will be assigned to visit the home of the individual once a month and build a trusting relationship — this is true whether someone is in a home with 24/7 supervision or with limited support. Having eyes on the individual makes it easier to identify any areas of concern before they become more serious issues. The Service Coordinator can provide crucial feedback to family members who live out of state and may be unable to visit. The Service Coordinator can also function as an emergency contact for both the beneficiary and their family if the need arises.

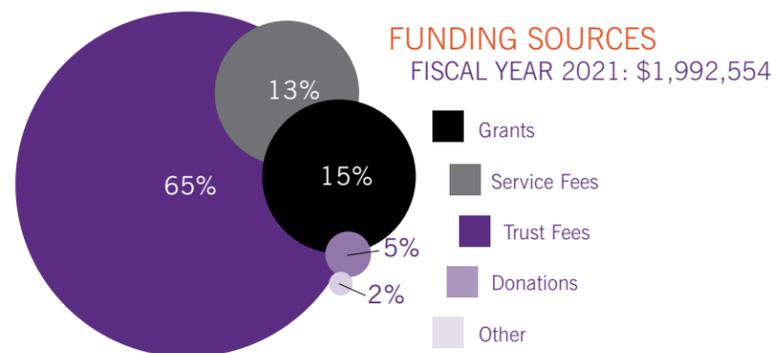
## VISION

PLAN|NJ envisions that all individuals with disabilities have the following opportunities:

- A safe and appropriate place to call home
- Financial stability and security
- Suitable and appropriate education
- A challenging and rewarding place of employment
- A fulfilling network of support
- Participation as a contributing member of the community
- The ability to have choices and personal control
- An end to loneliness and isolation
- Advocacy to protect human rights and to access benefits and services.

## VALUES

- We believe all people with disabilities have the right to experience their highest possible quality of life and to receive a lifetime of services they need and desire.
- We deliver services by forming a circle of support comprised of the person, family members and friends, social service providers, attorneys, financial advisors and trust administrators. This enables us to implement specific plans of action for each individual we serve and to maintain necessary services while enhancing quality of life, as requested.
- We value a strength-based, person-centered philosophy, compassionate and comprehensive care coordination, transparency, accountability, state-of-the-art systems, and continuous improvement.



## LETTER FROM LEADERSHIP

Dear PLAN|NJ Community,

As 2021 began, we breathed a collective sigh of relief, thinking the pandemic and social justice upheavals would subside. We now know the devastating toll these prolonged situations continue to take on our communities.

If you are a person with a disability, you bore extra social, emotional and physical burdens.

If you are a family member, you took on added concerns and complications supporting your loved one.

Professionals scrambled to identify and keep up with new ways to keep clients healthy, safe and engaged.

We are proud to say our organization has remained resilient and is preparing for better days ahead.

PLAN|NJ families, staff, service providers, partner organizations, vendors and board members drew from a shared reserve of practical strength and problem-solving skills throughout the year. We formed and strengthened circles of support for people with disabilities.

We reached out, visited, consoled, consulted, encouraged, testified, advocated, partnered, educated, planned and hosted. We went to a ballgame together. Read our 2021 Highlights on pages 8-10.

We continue to be tested but our organization is holding strong, as evidenced by the impact results achieved this year. We continue to deliver on our mission to help family members of people with disabilities answer the question, "Who will care for my loved one when I am gone?"

With appreciation,

Ellen B. Nalven, M.Ed.  
Executive Director, PLAN|NJ

Peter A. Phillips, CPA  
President, PLAN|NJ



Ellen B. Nalven, M.Ed.  
Executive Director  
PLAN|NJ



Peter A. Phillips, CPA  
President  
PLAN|NJ

## OUR LOVED ONES DESERVE A PLAN

A consortium of parents of people with disabilities formed PLAN|NJ 33 years ago. Each was concerned about how their child would be protected and supported if their own health faltered and they were no longer able to care for their loved one.

Today, thanks to the vision of our founders, at least 51% of our board will always be made up of family members who have a loved one with a disability. We truly understand the necessity, as well as the complexities, of providing person-centered care.

Whether an individual lives with an intellectual, developmental or physical disability, or a mental health challenge, we can determine and coordinate services and supports to meet their needs — now and in the future.

### PLAN|NJ: A TRUSTED FRIEND AND EXPERT FOR INDIVIDUALS, SIBLINGS AND FAMILIES

We guide families as they form their initial circle of support so continued care from legal, financial and social service providers will be appropriate to their needs. And we remain involved with this individualized team to help family members navigate the changes and complexities in the legal, financial, health care, supportive housing and employment systems.

A special emphasis is placed on educating families to understand the best ways to continue supporting their loved one to receive means-tested benefits while elevating them out of poverty. We work with families to understand how to best use tools like ABLE Accounts to increase personal control of finances and preserve vital public benefits while allowing money to be saved to strengthen their safety net for basic needs.

Our top priority is to maintain a commitment to each individual's needs and the family's wishes to ensure a lifetime of support.

### PLAN|NJ: STABLE, STRONG AND GROWING TO TACKLE INCREASING DEMANDS

PLAN|NJ employs a team approach when planning for the future financial and personal care needs of individuals with disabilities.

Our staff of special needs trust administrators and social service coordination professionals work to provide for the health, happiness, safety and independent living of nearly 800 individuals with disabilities.

We help families achieve greater peace of mind. For those who request long term follow-along support, we develop a flexible plan for the future and provide practical solutions as life's inevitable changes occur. We help your loved one achieve these fundamentals:

- A suitable and appropriate home environment
- Protection of public benefits, financial assets and stability in order to maintain and supplement quality of life
- Essential medical coverage and coordination of changing healthcare needs
- Education, employment, and participation in community life
- Planning and advocacy to successfully navigate the ever-changing complexities of the health, housing and social service systems to enhance wellness and security
- Friendship, activities, safety, support and pleasures needed to thrive at home and in the community.

If you know someone who would benefit from our services, please call PLAN|NJ. We are here to help. Learn more at [www.plannj.org](http://www.plannj.org). You may also wish to review additional tools and resources at [plannj.org/tools-resources](http://plannj.org/tools-resources).



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

# 2021: FORMING CIRCLES OF SUPPORT

This year, a prevailing pandemic and ongoing social injustices continued to task us all. PLAN|NJ worked to remain flexible and evolve as needs arose. We drew from a shared reserve of practical strength and problem-solving skills throughout the year. We formed and strengthened circles of support for people with disabilities. Our efforts caused a ripple effect of change and optimism during challenging times. **More than 1,900 people benefited from PLAN|NJ's professional and educational services.**

2005 >>>>>>> 2021

## TRUST ADMINISTRATION

- Served as Trustee for **562 Private and Pooled Special Needs Trusts**, managing more than \$135 million in trust assets for deposits from \$25,000 to \$5 million
- Increased successor Private and Pooled Trust services for future administration to **317**



## GUARDIANSHIP

- Served as Guardian for **39 individuals**, promoting self-determination and supported decision-making with choice, dignity and respect



## LIFE PLANNING

- Wrote **31 new LifePLANS**, describing individual preferences and needs, and the people and resources necessary to maintain a good life
- Secured **299 LifePLANS** on file, for future social and/or Guardianship services



## ADVOCACY AND CARE COORDINATION

- Visited **51 people** each month in their homes, connecting with them and assessing their well-being
- Provided time-limited advocacy for **45 people**, resolving concerns with service providers and governmental agencies



## PRO BONO FAMILY SUPPORT SERVICES

- Protected **47 people** with Guardianship, Advocacy and/or Home Visit Monitoring
- Managed public benefits for **41 people** with Representative Payee for Social Security services
- Guided **291 families** with life planning consultations
- Delivered nearly **1,400 hours of service** at no cost to the individual or family
- Aligned with the Family Support Organizations of Essex and Passaic Counties to **expand access** to advocacy and other services in their communities



## EDUCATION & OUTREACH

- Delivered **27 educational webinars** for nearly **1,000 families and stakeholders**
- Reached **2,000+ people** via the PLAN|NJ News newsletter twice during the year
- Improved and added more life planning tools available at [plannj.org](http://plannj.org)



## LEADERSHIP

- Co-chair, 2021 Virtual National PLAN Alliance Annual Conference
- Host and Chair, 2022 National PLAN Alliance Annual Conference in Morristown, NJ
- Co-chair, the National Pooled Trust Standards Committee

## KEY PARTNERSHIPS

- Alliance for the Betterment of Citizens with Disabilities
- Centers for Independent Living (CILs)
- Elder Law Section of the Bar of New Jersey
- Family Support Organization of Essex County
- Family Support Organization of Passaic County
- National Alliance for Mental Illness
- National PLAN Alliance
- New Jersey Chapter of the National Academy of Elder Law Attorneys
- New Jersey Council on Developmental Disabilities

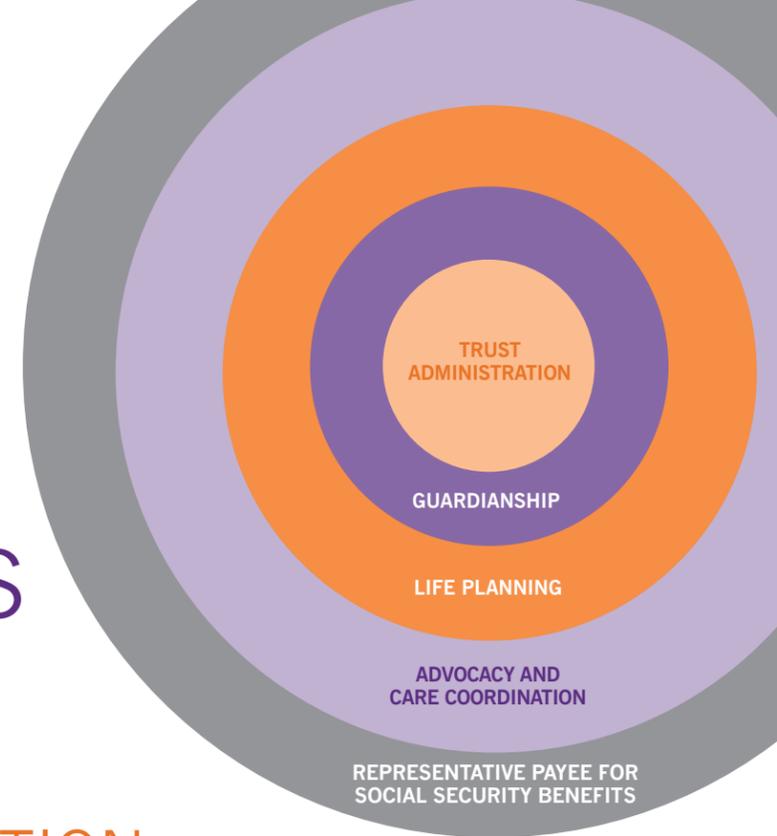




#### ADDITIONAL HIGHLIGHTS

- To increase access to services, we reached out to more families through the Family Support Organization of Essex County (FSOEC) and expanded the initiative into Passaic County
- Informed clients living independently about the COVID-19 vaccine and accompanied them to appointments if desired
- Ensured government stimulus payments to our clients were properly documented and expended as desired by recipients
- Collaborated with national Pooled Trust Administrators to identify and promote best practices in all service areas
- Advocated with families for legislation to provide extended school years for eligible special education students disadvantaged by the pandemic
- Provided testimony to state legislators leading to new language promoting self-determination under guardianship in proposed changes to New Jersey Guardianship laws
- Hosted more than 500 family members, partners and friends for a Family Night Out at the Somerset Patriots, with members of the PLAN|NJ family singing the national anthem, throwing the first pitch and cheering on the team
- Reimagined PLAN|NJ's *Celebration of Abilities* as a fundraising dinner and awards ceremony in a larger venue with indoor/outdoor social-distancing protocols for 2022.

## OUR CIRCLE OF KEY SERVICES



### TRUST ADMINISTRATION

At PLAN|NJ, we emphasize personal life planning along with financial strategies for people with disabilities in order to be inclusive of the whole person's goals and preferences. PLAN|NJ serves in a fiduciary role as Trustee, providing oversight and monitoring of either individual Special Needs Trusts or sub-accounts in our pooled trust, the PLAN|NJ Community Trust. We invest, monitor and distribute funds to improve quality of life and supplement public benefits. We offer families a combination of financial support and social services uniquely developed to meet our mission to serve people with disabilities. In keeping with our mission to serve people with disabilities, we have developed expertise in the area of Trust Administration and extensive experience as Trustee, making PLAN|NJ exceptionally well-suited to serve families in these roles.

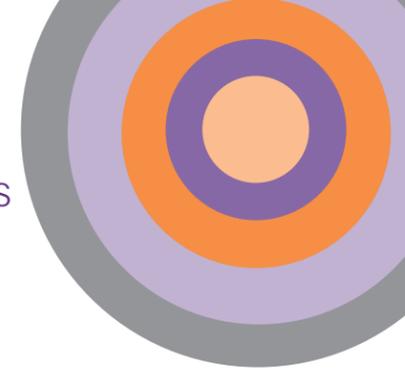




## GUARDIANSHIP

When an individual has been declared incapacitated by the Court and family members are unable to serve as Legal Guardian, PLAN|NJ can serve in this capacity. As Legal Guardian, we prioritize supported, surrogate decision-making on individuals' behalf and promote choice, self-determination, dignity, and respect. We visit the individuals we support under guardianship a minimum of once monthly to assess living arrangements, monitor employment, review their day centers, and ensure proper engagement with physicians, state and federal agencies, and other service providers.

We advocate to resolve concerns, address needs and serve as an emergency contact. We seek to actively promote quality of life for the individual in all areas of life including health, housing, education, employment, recreation and community living. We keep the individual at the center of our efforts, manage their personal property and protect them from fraud or undue influence.



## LIFE PLANNING

Our compassionate, whole-person approach to addressing all aspects of a person's life creates a circle of support for individuals and their families. A LifePLAN document holds this information on behalf of the individual and helps those in the circle of support to act according to the wishes of both the person and the family. The LifePLAN defines roles and responsibilities for supporting individuals' choice and independent living, identifies necessary legal and financial protections, as well as ideal living/work arrangements, community engagement, healthcare, and everything else the individual needs to feel happy and secure. **For a list of Initial Life Planning forms, visit [www.plannj.org](http://www.plannj.org).**

## ADVOCACY AND CARE COORDINATION

PLAN|NJ maintains consistent contact to ensure individuals with differing abilities are protected and able to thrive. Experienced service coordinators make regular home and day program monitoring visits, acting as the eyes and ears of family members who cannot regularly do so. We provide support for many aspects of daily living and are the first to respond when crises or emergencies occur. We help arrange for quality social engagement; celebrate birthdays; assist with shopping for essential items; oversee the quality and safety of living arrangements, employment and day centers; advocate for the necessary level of physician and other provider engagement; identify client concerns and ensure their preferences are honored; and coordinate other services as needed.

## REPRESENTATIVE PAYEE FOR SOCIAL SECURITY BENEFITS

We serve as Representative Payee for Social Security benefits for individuals already in our care. We manage public benefits and other income to ensure their basic needs are met, assist with budgeting and bill paying and provide protection from potential financial exploitation.

Learn more about all our services at [www.plannj.org](http://www.plannj.org)

### PROMOTING INDEPENDENT LIVING FOR PEOPLE WITH DISABILITIES

**PLAN|NJ serves people with significant disabilities regardless of their ability to pay. Guardianship, Home Visit Monitoring, Representative Payee, Life Planning and other advocacy and care coordination services are available for individuals in need. We are expanding outreach with key partners including the Family Support Organizations of Essex and Passaic Counties. Costs of these pro bono services are partially offset by individual and foundation contributions. Please join our efforts by making a donation at [www.plannj.org/donate](http://www.plannj.org/donate).**



## FOCUS ON FOUNDATION PARTNERS

The New Jersey State Bar Foundation provides education to the New Jersey public to enhance awareness of the legal profession and legal system. Their support to PLAN|NJ has taken the form of a co-sponsored effort to communicate the need for legal and estate planning to people with disabilities, family members and the professionals who serve them. These efforts intend to better equip individuals with disabilities and their families to address the challenges they face when planning for the future.

Presentations are given at the invitation of partner groups including Centers for Independent Living, Intensive Family Support Services, family support organizations, residential provider agencies, schools, and others. In nearly two decades we have provided educational seminars to more than 10,000 people. This continuity has made a profound impact and a significant difference in the lives of people with disabilities by helping them better understand the laws that affect them every day. The New Jersey State Bar Foundation's vision is to promote access to the justice system, ensure fairness in its administration, and monitor the independence and integrity of the judicial branch. Their commitment to diversity and inclusion in the legal community informs and inspires those serving people with disabilities. We are grateful for their contributions.



Pictured enjoying the ballgame are, L-R: Ellen NaIVEN, PLAN|NJ Executive Director; Joseph Spann; Chelsea Palermo, singer, and her mother, Cindy Palermo.

### PLAN|NJ HOSTS FAMILY NIGHT OUT FOR PEOPLE WITH DISABILITIES AND FAMILIES

More than 500 family members, partners and friends celebrated with PLAN|NJ at its Family Night Out at the Somerset Patriots Ballgame. PLAN|NJ hosted the event after a year of isolation and challenge due to the pandemic. Chelsea Palermo sang the National Anthem, while Joseph Spann threw out the first pitch; both are members of the PLAN|NJ family. Many community leaders came onto the field to show their support for people with disabilities. A portion of the proceeds from the evening's 50/50 Raffle will directly benefit the beneficiaries and families served by PLAN|NJ. Read more and see a gallery of photos at [plannj.org](http://plannj.org).

FRANK DIGIOVANNI

## ONE FAMILY'S STORY

PLAN|NJ works with the family of **Olivia Rae Vargas** to provide life planning, fiduciary and social services so that she may live to her full potential and enjoy life to the fullest.

What began as equine therapy grew into a love for horses, and with great determination, Olivia began to ride and compete. Despite her health challenges she was able to train, qualify and attend youth nationals, and in 2019 she became a US National Champion at the Arabian Horse Association Youth Nationals in the "Arabian & Half Arabian Hunt Seat Equitation Not to Jump Walk Trot 10 and Under" competition in Oklahoma City, OK.

We will recognize Olivia with a Life Planning Partner Award at the 2022 PLAN|NJ Celebration of Abilities. Learn more about this special event at <https://plannj.org/2022-celebration-of-abilities>



Olivia Rae Vargas is pictured above at age 12 with her horse and below with recent national awards. Read more about Olivia in the Fall 2020 PLAN|NJ News at [planni.org/news-publications](http://planni.org/news-publications).



PHOTOS USED WITH PERMISSION FROM THE VARGAS FAMILY.

## SPOTLIGHT ON KEY STAFF



**NANCY DILLIPLANE, DIRECTOR OF TRUST SERVICES** “As someone who has had family members with disabilities, I can relate to the challenges and worries that families encounter personally and within social services systems. When families tell me they’re glad we exist, I feel great pleasure and pride.”



**JASON MILLER, DIRECTOR OF SOCIAL SERVICES** “Parents choose us because we get to know each individual and build a personal relationship. Clients see immediate improvement in the quality of their lives, and we help them get through crises in positive ways.”



**KERRY LEE, DIRECTOR OF OPERATIONS** “Working alongside professionals who share a strong culture of service and compassion makes me incredibly proud to have a supporting role in our success. To touch somebody’s life in a meaningful and lasting way is our goal each and every day.”



**ROBERTA LEE, OFFICE MANAGER** “It is so gratifying to me to answer questions and resolve problems to the satisfaction of our clients. As the parent of a child with a disability, this interaction is helpful to me, too. I feel as if I am a part of the family.”



**NICOLA NERO, SENIOR SERVICE COORDINATOR** “To be given the opportunity to help improve the quality of a person’s life by providing support services and resources is an immeasurable reward.”



**MELANIE MIQUEL, SOCIAL SERVICES MANAGER** “When families call us for the first time, they are often feeling overwhelmed by the idea of planning for the future care of their loved one. It is rewarding to be a part of the team who will compassionately support these families and their loved ones through the years to come.”



**SHANTE EDELEN, SENIOR TRUST COORDINATOR** “It gives me pleasure to be able to help and advocate for our clients in any way possible. It makes me happy to be able to fulfill the clients’ needs and wants and keep them happy with the services we provide. When they call and thank me for our services it is very rewarding.”



**ELLEN NALVEN, EXECUTIVE DIRECTOR** “I am gratified daily by the opportunity to provide practical solutions to complex challenges, and peace of mind to people and families as they strive to enjoy life to the fullest.”



## YOU CAN MAKE A DIFFERENCE

One in four adults in the U.S. has some type of disability or lives with a challenging combination of several. Many face complex medical, financial and everyday living decisions and may be vulnerable to isolation, exploitation and substandard care. PLAN|NJ provides professional fiduciary and advocacy services and solutions to nearly 800 people with disabilities each year and offers education and consultation to thousands more — and the need is growing. We guide families in the process of life planning, ideas on how to optimize employment as well as public benefits and options for trusteeship, guardianship, advocacy and care coordination.

As a 501(c)(3) nonprofit organization, we rely on **YOUR TAX-DEDUCTIBLE DONATIONS, GIFTS AND ENDOWMENTS** to:

- offset costs to serve people with significant disabilities
- promote independent living
- provide services at no cost for those in need
- strengthen our organizational stability.

**YOUR GENEROSITY** helps more families attain peace of mind, now and in the future. Your contribution to PLAN|NJ helps more families answer the question, “Who will care for my loved one when I’m gone?”

Kindly visit [www.plannj.org/donate](http://www.plannj.org/donate) to support PLAN|NJ. **THANK YOU!**

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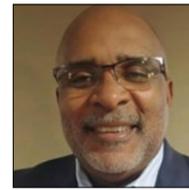
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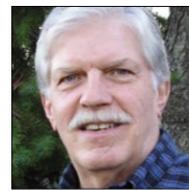
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# Lifetime Advocacy for People with Differing Abilities

PLAN|NJ serves families impacted by disability throughout New Jersey. If you or someone you know may be in need of our services, we encourage you to contact us today.



## Planned Lifetime Assistance Network of New Jersey

P.O. Box 547  
Somerville, NJ  
08876-0547  
(908) 575-8300  
Fax: (908) 927-9010  
[info@plannj.org](mailto:info@plannj.org)  
[www.plannj.org](http://www.plannj.org)

