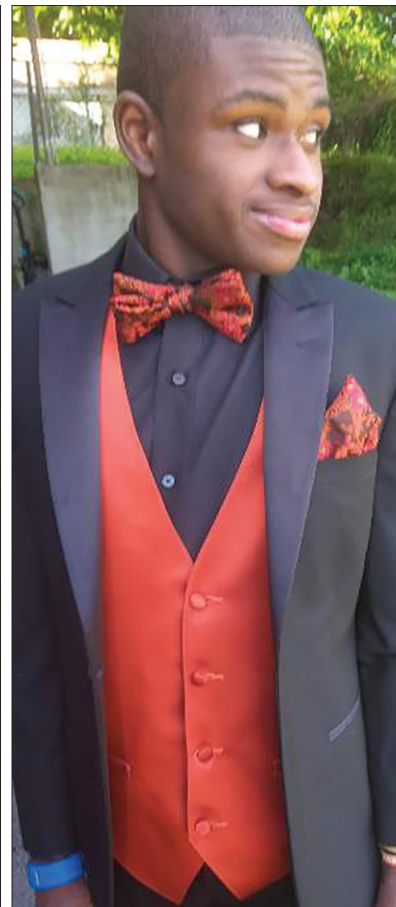




PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY

2019 ANNUAL REPORT



“Who will care for
my loved one when
I’m gone?”

PLAN/NJ MISSION & VALUES

Planned Lifetime Assistance Network of New Jersey, Inc. (PLAN/NJ) helps the families of people with disabilities in New Jersey answer the question, “Who will care for my loved one when I’m gone?”

WE BELIEVE all people with disabilities have a right to experience the highest possible quality of life and to receive the services they and their families need and desire throughout their lives.

WE DELIVER SERVICES by forming a circle of support comprised of families, 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 their quality of life.

WE VALUE a person-centered philosophy, compassionate and comprehensive care coordination, transparency, accountability, state-of-the-art systems, and continuous improvement.



“Mother and Daughter” by Tamara Kaplowitz;
see pages 12-13.

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LETTER FROM OUR PRESIDENT

The work of disability rights advocates is unrelenting and unceasing. Well over 900,000¹ individuals live with a disability in New Jersey. There is a continuing need to leverage our collective compassion and advocate for legislative action to support people with disabilities, their caregivers and service providers. Individuals with disabilities continue to evolve in their need and desire for self-determination, even as the state and federal regulations developed to protect them shift and evolve. Best practices in case management and fiduciary services must adapt to meet this reality.

I am pleased to report that Planned Lifetime Assistance Network of New Jersey, Inc. (PLAN/NJ) is a nationally recognized best practices standard-bearer in Special Needs Trust administration, monitoring and advocacy services. Nearly 1,000 people with disabilities and their families are supported by PLAN/NJ. It is our responsibility therefore to keep current with the processes and procedures that preserve their public benefits and private support, to act on their behalf, to facilitate independence, and to help them achieve their best quality of life. For long-term strength and sustainability, PLAN/NJ continues to increase capacity, contribute to the national field of disability rights and services, and scale our organization to serve many more people with disabilities.

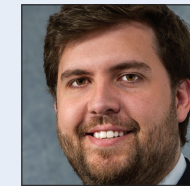
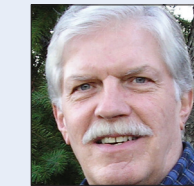
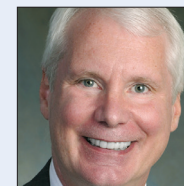
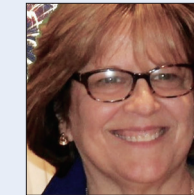
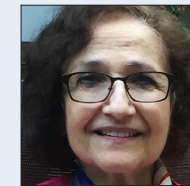
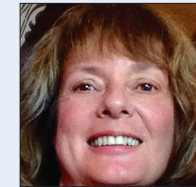
I am honored to share PLAN/NJ governance responsibilities with the remarkable members of our Board of Directors, who are nominated, vetted, and recruited for their professional expertise and passion for people with disabilities. Our board is comprised of individuals with proficiency in public policy; best practice trends in social service supports, investments and financials; pro bono fund development; medical care and disability rights. More than half our board members also have a loved one with a disability. They serve as our compassionate ballast to remind us of the very personal and human component of the work we do, thus ensuring that we always support the dignity and self-determination of the people we serve.

In our persistent efforts to expand and improve our services, this year we measured the outcomes of our 2015-18 PLAN/NJ Strategic Plan, and from these results developed goals and objectives for 2019-21. Please read more about our impact and accomplishments in this PLAN/NJ 2019 Annual Report.

Sincerely,

*Samantha J. Herrick, Ph.D., CRC, NCC, ACS
President, PLAN/NJ Board of Directors*

¹Erickson, W. Lee, C., & von Schrader, S. (2016). *2015 Disability Status Report: New Jersey*. Ithaca, NY: Cornell University Yang Tan Institute on Employment and Disability (YTI).



(left to right, top to bottom)

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2019-20 BOARD OF DIRECTORS



YOUR
LOVED ONE
DESERVES
A PLAN

A family that includes a loved one with disabilities often has more questions than answers about how to support and maintain their health, happiness, and independent living now and in the future. They do know their loved one needs and deserves consistent, well-planned support. Arrangements for their safety and protection must be individualized and comprehensive, whether their disabilities are physical, developmental, involving an aspect of mental health, or a combination of several. At **PLAN/NJ**, we stand firmly with you to ensure that responses to your loved one's support needs continue without interruption. We are a trusted friend and expert for individuals, siblings and families; we navigate the changes and complexities in the legal, financial, health care, supportive housing and employment systems. Our organization is stable, strong and growing to meet increasing demands. We will help you maintain your loved one's safety, coordinated care, public benefits and financial stability, now and after you're gone.

PLAN/NJ recommends a team approach to planning for the financial and personal care of individuals with disabilities. Our care coordination services provide the safety and sense of security all people deserve. Specific services include Special Needs Trust Administration, Legal Guardianship, Home Visit Monitoring, Advocacy, Life Planning Consultation, and Representative Payee for Social Security Benefits. We help families achieve greater peace of mind as we work to achieve these fundamentals:

- A suitable home environment
- Education, employment, and participation in community life
- Essential medical coverage
- Financial stability
- Practical solutions and enduring support as life's inevitable changes occur
- Friendship, activities and pleasures needed to thrive.

We provide a lifetime of support to people with physical, developmental or mental health challenges, or traumatic brain injury. Our top priority is to maintain a focused commitment to your loved one's needs and your family's wishes. Our qualified **PLAN/NJ** staff can begin these lifelong services today and continue them after you're no longer able to be your loved one's primary advocate:

- Coordinate ongoing health care needs as they change over time
- Plan for the future regarding supportive housing, health, and wellness
- Guide your family to protect financial assets that can then be used to supplement the quality of your loved one's care
- Advocate within the complexities of the health and social service systems
- Keep them safe, supported and thriving at home and in the community.

Learn more at www.plannj.org

PLAN/NJ stands firm with families of people with disabilities aged 3 to 89. More than 3,740 people benefitted from our professional services and educational outreach this year. We deliver advocacy services and work with families and professional partners to execute comprehensive life plans. We foster greater community engagement; protect people from abuse, neglect and exploitation; and help identify their needs. We put vital supports in place, always guiding them toward available resources and striving to achieve next-level excellence. As we grow in capacity, we will be able to provide lifetime supports to even more people with disabilities.

HIGHLIGHTS:

- Provided 701 people with fiduciary support, life planning for independent living, guardianship, and care coordination
- Raised \$51,000+ from individuals and professional sponsors through **PLAN/NJ**'s 30th Anniversary: A Celebration of Abilities event and 30@30 fundraising, nearly triple the amount raised at the last event
- Supported people with significant disabilities who are in need with nearly 600 hours of guardianship, home visit monitoring and advocacy services at no cost
- Offered 500+ hours of in-depth technical assistance to 239 families who do not yet use **PLAN/NJ**, guiding them with legal, estate and independent living planning to address future support needs
- Distributed two newsletters to 2,000+ people in state and national disability rights communities
- Held 28 life planning seminars and exhibits for 1,566 people with disabilities, family members, professionals in human services, schools and community organizations. Since 2006, we have educated 20,700+ people about our life planning and care coordination services through 300+ such events
- Replaced two vehicles for safer, more fuel-efficient transportation
- Upgraded to a best-in-class, cloud-based client file storage system so critical records are secured in perpetuity
- Participated in trainings and conferences sponsored by National PLAN Alliance, Stetson University College of Law, University of Texas, Boggs Center UAP, Autism New Jersey, Arc of New Jersey, Community Health Law Project, and the New Jersey State Bar Association Elder Law Section
- Served on the 2019 National PLAN Alliance Annual Conference Committee to promote best practices. **PLAN/NJ** will host the 2020 National PLAN Alliance Annual Conference in Morristown
- Co-chaired the National Pooled Trust Standards Committee, which establishes best practices for fiduciary and care coordination for individuals with disabilities and their families

2019:
REACHING
FOR
NEXT-LEVEL
EXCELLENCE

(continued)



- Improved **PLAN/NJ** policies and trust administration procedures
- Reviewed the 2015-2018 Strategic Plan and measurable outcomes to substantiate and grow support from institutional and individual supporters
- Developed new Growth & Sustainability, Quality Assurance, and Governance objectives for 2019-2021.

FIDUCIARY SUPPORT: TRUSTEE AND REPRESENTATIVE PAYEE

- Served as Trustee for 516 Special Needs Trusts
- Managed \$104.6 million in trust assets for deposits from \$25,000 to \$4 million
- Acted as Representative Payee for 38 individuals receiving Social Security benefits, providing assistance to budget, pay bills and maintain financial solvency.

LIFE PLANNING FOR INDEPENDENT LIVING

- Held 253 LifePLANS for individuals' future care, including 19 newly written plans.

GUARDIANSHIP

- Served 32 people as Legal Guardian, making monthly visits, providing surrogate decision-making and promoting choice with self-determination, dignity and respect
- Ensured optimal quality of life in health, housing, education, employment, recreation and community living.

CARE COORDINATION: HOME VISITS, MONITORING AND ADVOCACY

- Visited 41 people at home each month to assess living arrangements; monitor employment; review day centers; and ensure proper engagement with physicians, state and federal agencies, and other service providers. Advocated for 27 people to resolve concerns and address needs
- Provided advocacy, case management and family support services to 122 people in partnership with the New Jersey Division of Child Protection and Permanency.

For 30+ years, PLAN/NJ has guided families and their loved ones with compassionate, confidential and uninterrupted fiduciary and care coordination. As we grow, we will sustain our commitment to person-centered planning, and strive for excellence in all areas of service.

PLAN/NJ has helped hundreds of families structure well-designed plans for their loved ones. We tailor all fiduciary, care coordination and life planning consultation services to fit the distinct needs of each individual we serve, and to accommodate their family members' wishes. When important life decisions are pending—such as where they should live or how medical care will be provided—we offer professional expertise, individualized attention, and compassionate support. Our key service areas include future life planning and family support, care coordination, special needs trust administration, representative payee for Social Security benefits, and pro bono services for people in need.

FUTURE LIFE PLANNING AND FAMILY SUPPORT

PLAN/NJ works closely with families to design a LifePLAN that addresses all aspects of life. This LifePLAN defines roles and responsibilities for independent living and identifies necessary legal and financial supports. During collaborative development, several questions are answered to ensure uninterrupted support, such as:

- Where will their loved one live, and with whom?
- Who will consider and adhere to their preferences when making future life decisions?
- How will they continue to receive and enjoy quality care and life satisfaction at home, school, work, and in their day program?
- Will a Trustee and/or Representative Payee be needed to manage their financial responsibilities?
- What do we need to put in place to ensure they remain financially comfortable?
- Who will make sure that they receive good healthcare? Who will talk with medical professionals if they cannot?
- What else do they need to feel happy and secure?
- Who will do for them the many additional things that we do now?
- Who will arrange for them to practice their religious faith, observe their birthday, celebrate holidays, arrange for social/recreational activities, and ensure they thrive?
- Who will make sure the family's funeral traditions and wishes are carried out?

We keep each person's needs and preferences at the forefront as we implement the plan according to the family's wishes.

CARE COORDINATION

PLAN/NJ promises families that qualified staff will maintain consistent, quality contact with their loved ones. We function as the eyes and ears of distant relatives, making regular home and day program visits and communicating after each visit. Experienced service coordinators monitor those whose family members cannot make regular visits or who have no living relatives. We are the



DELIVERING LIFELONG SUPPORT THROUGH PERSON-CENTERED SERVICES

(continued)



first to respond when crises or emergencies occur. We offer unwavering care coordination, crucial social engagement and customized personal support in these areas:

Social Engagement

- Encourage relationships with neighbors, family and friends
- Accompany them to recreational activities and shopping
- Celebrate birthdays, holidays and other special occasions.

Case Management/Home Visit Monitoring/Advocacy

- Travel to visit people at home, attend medical and other appointments and advocate on their behalf
- Promote healthy life decisions by developing person-center support
- Advocate for appropriate services related to housing, employment, day programs, medical, financial, legal and other providers
- Negotiate the disability and mental health service systems
- Coordinate advocacy efforts for families and represent family concerns
- Assist with applications for public benefits and other social services
- Organize private, nursing home and/or hospice care
- Maintain contact during life transitions.

Personal Support and Emergency Response

- Establish necessary supports while encouraging independence
- Confirm financial obligations are met and personal needs addressed
- Increase personal contact when health or other crises occur
- Act as “first responder” when the need for assistance arises
- Protect safety and well-being during natural disasters.

FIDUCIARY SUPPORT

We follow a ‘whole person’ approach to the careful administration of Special Needs Trusts and in our role as Representative Payee. We act to ensure your loved one is never without the care, comfort, enjoyment and engagement in life that is their right. We monitor the necessary and lifelong public entitlements for which they are eligible, and we protect any additional funds to further support their needs and maintain the quality of life they deserve.

Special Needs Trust Administration

PLAN/NJ serves as trustee of Third Party and Self-Settled private, stand-alone Special Needs Trusts (SNTs). We also operate a Community Trust that pools funds for third party and self-settled sub-accounts. We will work with families, attorneys and other professionals to determine and administer the most suitable type of trust for your loved one’s needs. Our Trust Administration department will:

- Oversee and monitor funds to improve quality of life and to maintain Medicaid and other public benefits

- Communicate directly with trust beneficiaries and their representatives
- Advocate for personal needs and hire professionals to assist
- Develop budgets and spending plans
- Pay bills according to trust document and government benefit rules
- Assist with applications and maintenance of public benefits and other social services
- Monitor health insurance claims and disbursements
- Produce financial accounting and reports as required by public benefits agencies, courts and legal representatives
- Guide families to review a directory of attorneys and financial planners as needed
- Offer Spanish-speaking services.

Representative Payee for Social Security Benefits

When an individual needs assistance with budgeting and bill paying, we manage their Social Security and other income to ensure financial solvency and protect them from potential financial exploitation. As Representative Payee, PLAN/NJ will:

- Communicate with them, monitor expenses and pay bills
- Ensure that basic requirements are met for food, clothing and shelter
- Submit required government agency reports
- Assist with budgeting and other regular financial management.

Legal Guardianship

The need for a legal guardian is determined by due process in courts of law. As Legal Guardian, PLAN/NJ will:

- Promote choice, self-determination, dignity and respect
- Visit them at home once per month, at minimum, and provide ongoing case management
- Ensure quality of life in health, housing, education, employment, recreation, community living and other areas
- Take responsibility for surrogate decision-making
- Protect them from fraud or undue influence
- Protect personal property.

We prioritize supported decision-making to help ensure individuals have the necessary supports while respecting their wishes and preferences. We assist when family members are unable to serve in this capacity.

PRO BONO SERVICES: PROMOTING INDEPENDENT LIVING FOR PEOPLE IN NEED WHO LIVE WITH SIGNIFICANT DISABILITIES

We are grateful to those individuals and foundations whose contributions offset the cost of services for a group of people with limited means who are in need of lifelong support. We aim to extend these services for more people with disabilities in the years to come.

“WHO WILL CARE FOR MY LOVED ONE
WHEN I’M GONE?”

FAMILY STORIES: CELEBRATING ABILITIES



PLAN/NJ's person-centered services support people with disabilities and their families to maintain the meaningful life, purpose and passion they determine will best help them thrive.

TAMARA KAPLOWITZ

Tamara discovered her interest in visual arts alongside her mother, Ursula, who was a potter with a studio in the basement. Tami worked with her for many years as she was growing up. Through Ursula's encouragement, Tami learned to manipulate clay into fanciful animal sculptures.

Her father, Ken, teaches art at The College of New Jersey. He was always drawing at home, even at the dining room table. Her sister, Kimberly, also drew, as did her brother, Daniel. Daniel majored in guitar; Kimberly received a degree in art from Moore College of Art in Philadelphia.

Today, Tami draws whenever the mood strikes her and fills her walls with framed pictures of her colored-marker works. She loves drawing, is mostly self-taught and usually depicts biographical images of her family, friends and events in her life. She makes prints of her colorful drawings and gives copies to friends, teachers, and others as gifts on their birthdays. She also puts her works on Facebook and on a website made especially for her at www.creations-by-Tami.com.



"Friends Playing Ball"
by Tamara Kaplowitz.

According to her father Ken, "Her talent and style of work has been appreciated by all who see it. It helps Tami to feel confident about herself. The warmth and originality seen in the work is an emotional expression of who she has become and is her means of connection between herself and the world."

Tami's mother died 10 years ago; her father is now 78 years old and her siblings live in other states. **PLAN/NJ** was contacted to become Tami's future guardian and financial adviser based on its reputation and the advice of the family's special needs lawyer.

BRANDON SMITH

Brandon Smith, 20, attends Howell High School with a 1:1 aide in the Autism Program. At 21, he will transition into an adult program, which the family hopes will have a music component. He performed Beethoven's "Moonlight Sonata" at **PLAN/NJ's 30th Anniversary: A Celebration of Abilities**, and received a **PLAN/NJ** Life Planning Partner Award.

Brandon discovered his love and talent for playing piano at only five years old when he played a piano game that required him to repeat the notes he heard by hitting the correct keys.

"He won the game with 100% accuracy, and we learned this was called perfect pitch. We immediately arranged for a piano and never looked back. On the day we brought it home, he sat down and played Mozart by heart because for years he had listened to the Baby Mozart DVDs," explained his mother, Amy.

Brandon began reading music in fourth grade and continues with the same music teacher to this day. Above all other genres of music, Brandon's favorite style is classical. He loves Mozart, Beethoven, Chopin and many more. In addition, he loves to play any music that is meaningful to him. He practices well in advance of any concert, and loves to simply sit down and play any music that he hears.



"Girl Holding Dog" by
Tamara Kaplowitz.



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



PLAN/NJ's 30th Anniversary: A Celebration of Abilities opened our hearts and surpassed our Board of Directors' fundraising goals. The sold-out event, held at the New Jersey Law Center in New Brunswick, raised more than \$51,000 to support more people who have disabilities with **PLAN/NJ's** person-centered services.

PLAN/NJ's Board of Directors hosted tables named for our core values and services.

"This moving event brought together New Jersey's disability rights community and reflected why we are so passionate about what we do at **PLAN/NJ**," said Ellen Nalven, Executive Director. "We are grateful to everyone who attended and helped make the event so meaningful."

For more photos and information, visit plannj.org/a-celebration-of-abilities-2018

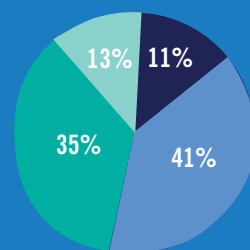


PLAN/NJ@30: A CELEBRATION



PLAN/NJ IN NUMBERS

Client Ages

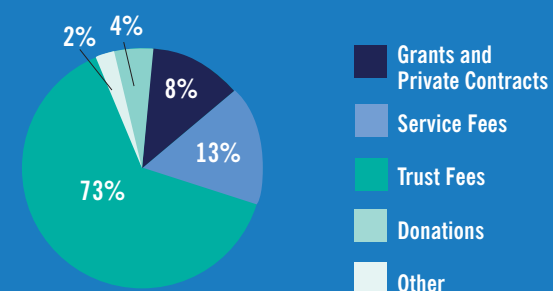


- 3-18 years
- 19-50 years
- 51-65 years
- 66-90 years

Celebrating more than
30 years of service to people
with disabilities and their families

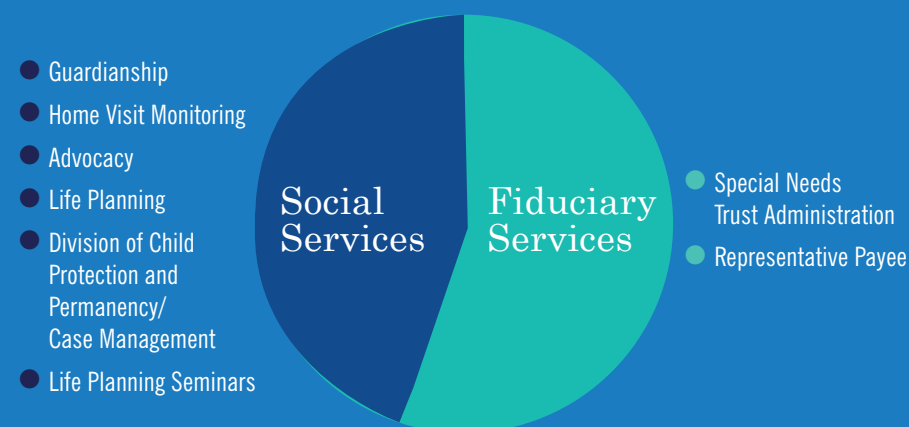
Funding Sources

Fiscal Year 2019: \$1,869,322



- Grants and Private Contracts
- Service Fees
- Trust Fees
- Donations
- Other

Time & Services



Reached **1,566** parents, siblings, potential clients, partners, human service and related agency staff with 28 educational seminars and exhibits

Drove **70,000** miles to visit clients — like driving the length of New Jersey 411+ times.



A MESSAGE FROM OUR EXECUTIVE DIRECTOR

Dear **PLAN/NJ** Supporter,

When **PLAN/NJ** began more than 30 years ago, the founders — many of whom were parents of people with disabilities — identified the need for their loved ones to receive individualized lifelong support. From the start, **PLAN/NJ** was conceived of as an organization with the ability to assist the whole person, and today, we support nearly 1,000 people who have varying resources and highly individual needs, interests, hopes and dreams.

PLAN/NJ's task is to reduce the fear and uncertainty the future might hold for the people we serve and their families. Support may involve legal advocacy, financial management, personal advocacy and/or care coordination. A critical need is to maintain the public benefits to which they are entitled. This is incredibly complex and difficult for families, especially siblings who assume the care of their family member.

Our person-centered services ensure uninterrupted support; self-determination; access to independent living; and protection from neglect, abuse and homelessness. We offer people an improved quality of life, and help them stay connected to their communities and in jobs, doing volunteer work and other meaningful activities.

This year, **PLAN/NJ's** Board of Directors established new goals and objectives to take us forward with momentum while maintaining stability and a determination to reach a new level of excellence. 20% of adults living in New Jersey have a disability, and thus we continue to ask ourselves: How do we meet more people's needs, especially those with significant disabilities? How do we help more families chart a life course for their loved one so they will be cared for, now and in the future? How do we help more families answer the question, "Who will care for my loved one when I am gone?"

The much-used adage 'It takes a village' is true. The village at **PLAN/NJ** is composed of caring staff, a dedicated board of directors, and many advocates, professionals and supporters. We never forget why our collective work in disability rights is so necessary, and why **PLAN/NJ's** contributions are so unique.

I want to extend sincere gratitude to our private foundation partners and the New Jersey State Bar Foundation, along with our many donors, collaborators and community partners, whose vision and support make **PLAN/NJ's** work possible. I also want to acknowledge the dedication of **PLAN/NJ's** staff and board, both past and present.

With appreciation,

Ellen B. Nalven

Ellen B. Nalven, M.Ed.
Executive Director, **PLAN/NJ**

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

(17)

INVOLVED!

GET

More people are living with at least one disability; many live with a combination of several. All can face complex medical, living and financial decisions and can find it quite challenging to plan and prepare for these aspects of their lives. This may leave them vulnerable to isolation, exploitation and substandard care.

Every day, **PLAN/NJ** provides solutions to a diversity of challenges. We offer life planning consultations, ways to optimize public benefits and private assets, and comprehensive care coordination options which deliver direct services and advocacy. **We serve nearly 1,000 people with disabilities and their families, and the need is great to serve many more.**

As a 501(c)(3) nonprofit organization, **PLAN/NJ** relies upon YOUR support to meet the growing demand for our services. Won't you join our efforts?

Your tax-deductible donations will help us to serve people with disabilities and their families, now and in the future. You may choose to help **PLAN/NJ** offset costs for people with significant disabilities who live on a low income and are in need of comprehensive support services. You may wish to contribute to our **General Operating Fund** or to the **Endowment Campaign** to help us build organizational strength and stability.

To make a donation, kindly visit our website at plannj.org/donate

Your support to PLAN/NJ helps more families answer the question, "Who will care for my loved one when I'm gone?"

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The Investors Foundation
The Karma Foundation
The New Jersey State Bar Foundation
The Fred C. Rummel Foundation
The Arnold A. Schwartz Foundation

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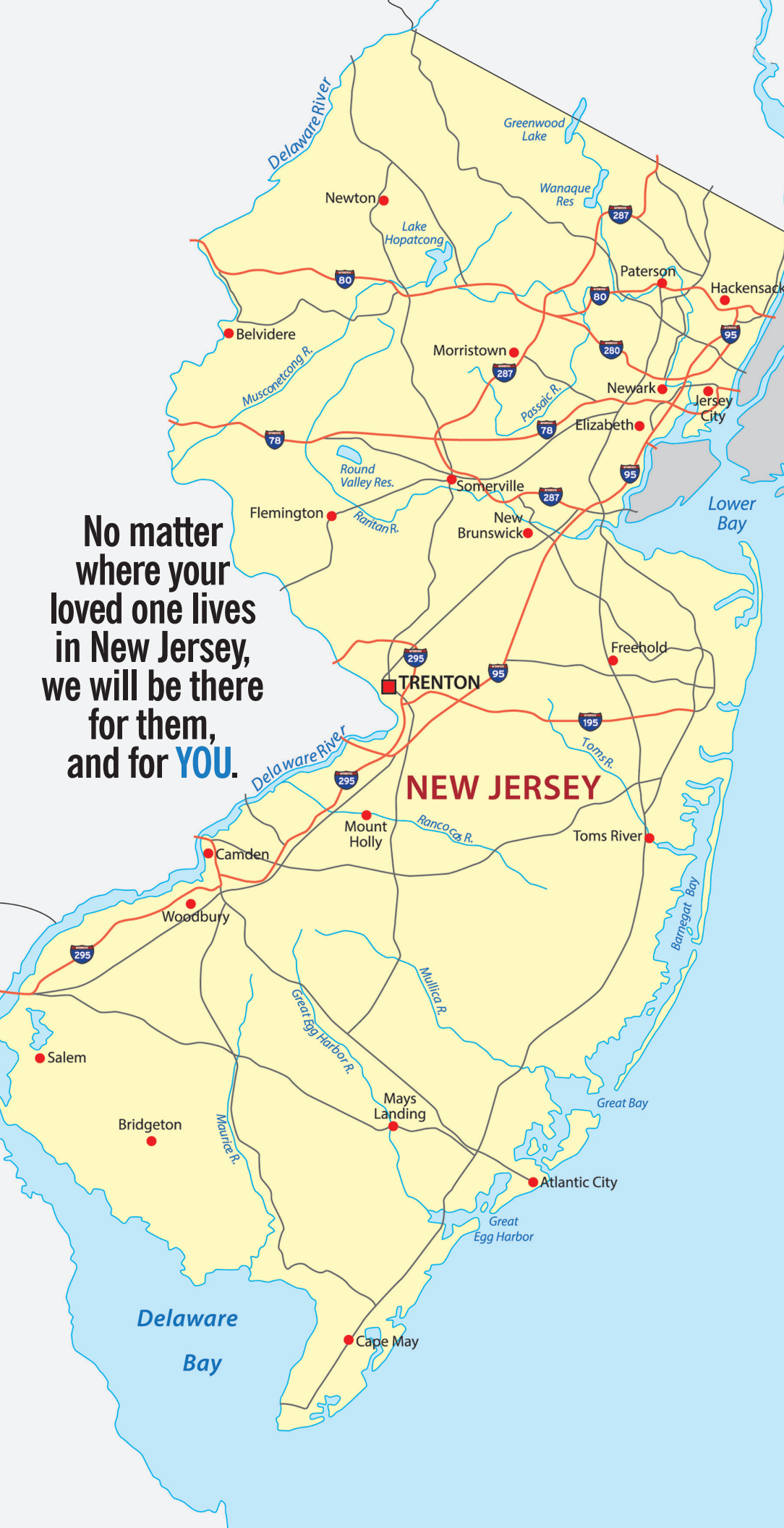
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