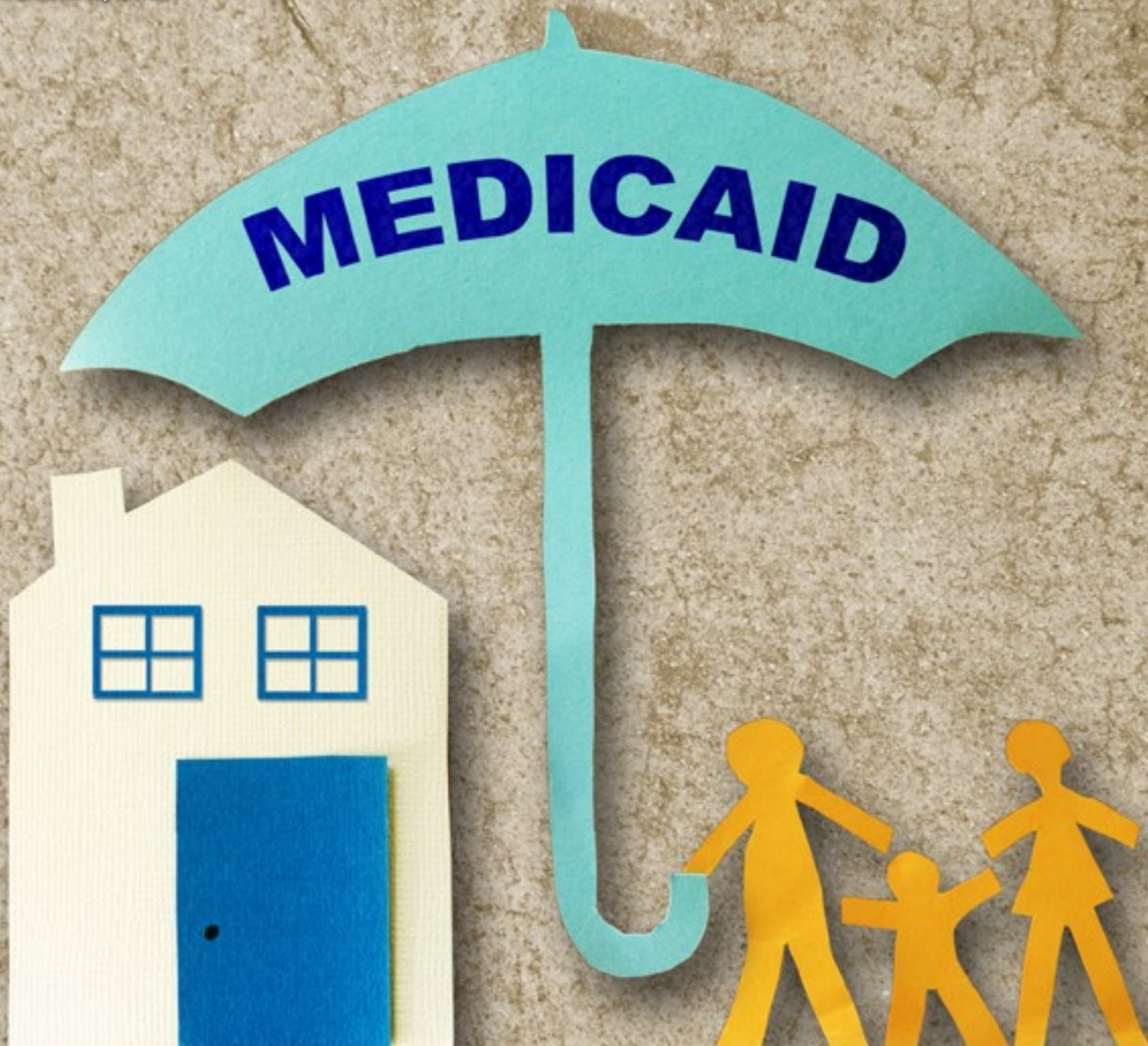


Peoples & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

MEDICAID UNWINDING

VOLUME 2, 2023



COMMUNITY INNOVATION PROJECTS CIP

The New Jersey Council on
Developmental Disabilities'

Community Innovation Projects (CIP)

encourage new and innovative activity
designed to bring about meaningful
local change.



Primary Goals




The primary goal of Council-funded activities is to produce short and/or long-term system change. Ideas that can be shared and replicated.

COMMUNITY INNOVATION PROJECTS REQUIREMENTS

- ☒ Relate to the Council's 5-Year Plan.
- ☒ Focus on advocacy, local capacity building, systems change, social change, equal access, community competence, or education of families and self-advocates.
- ☒ Create and strengthen relationships with local associations and groups.
- ☒ Position people with developmental disabilities and/or their family members as active and engaged participants who influence the work and participate directly.
- ☒ Have a plan for sharing successful practices.
- ☒ Reflect the values, preferences, languages, and cultures of the communities they engage.

FUNDING UP TO
\$10,000 FOR
12 MONTHS
IS AVAILABLE.

ACTIVITIES CAN INCLUDE

-  An innovative approach to a systemic challenge OR;
-  An activity that addresses a systemic problem that is being overlooked, OR;
-  An innovative project or pilot project related to the 5-Year plan that demonstrates a best practice.

To apply, fill out our
letter of interest found at
<https://bit.ly/2ZUVnNB>
and email the form to
grants@njcdd.org



PUBLISHER New Jersey Council on Developmental Disabilities

CHAIRPERSON Paul A. Blaustein

EXECUTIVE DIRECTOR Mercedes Witowsky

EDITOR Gary L. Brown

EDITORIAL BOARD MEMBERS

Kelly Boyd, NJ Office of Emergency Management

Mike Brill, Family Advocate

Michael Brower, Esq., Disability Rights NJ

Peg Kinsell, Statewide Parent Advocacy Network

Kevin Nuñez, NJCDD Council Member

Diane Riley, Supportive Housing Association of New Jersey

Beverly Roberts, The Arc of New Jersey

Carole Tonks, Alliance Center for Independence

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SELF-ADVOCATE MEMBERS

Todd Emmons, Andrew McGeady,
Myrta Rosa, Kevin Nuñez, Ryan Roy

**PARENT, FAMILY MEMBER,
AND GUARDIAN MEMBERS**

Sarah Aziz, Walter Fernandez,
Safiyyah Muhammad, Michael McCarthy,
Paul A. Blaustein, Margaret Kinsell, Elizabeth Dalzell,
Helen Steinberg, Kara Kushner,
Nantanee Koppstein, Annette Smith

PUBLIC MEMBER

Laura Williams

FEDERALLY-MANDATED MEMBERS

*Federally-mandated members of the Council are mandated to
serve in accordance with the federal
Developmental Disabilities Assistance and Bill of Rights Act*

Peri Nearon, Division of Disability Services
Jonathan Seifried, Division of Developmental Disabilities
Kimberly Murray, Office of Special Education Programs
Phyllis Melendez, Division of Medical Assistance
and Health Services
Karen Carroll, Division of Vocational Rehabilitation Services
Dawn Mergen, Division of Family Health Services
Joyce Jelley, The Boggs Center on
Developmental Disabilities at Rutgers University
Gwen Orlowski, Esq., Disability Rights NJ

The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

Subscriptions to *People & Families* are free and are available through the Council office or by e-mail at njcdd@njcdd.org. Please include your name and address. Articles may be reprinted without fee by permission. Expressed opinions are not necessarily those of the Council's membership. We welcome your letters and comments. Send them to Gary L. Brown, editor, NJCDD, PO Box 700, Trenton, NJ 08625-0700. Please include your name and town. Letters may be reprinted and edited for space.

New Jersey Council on Developmental Disabilities, PO Box 700, Trenton, NJ 08625-0700. TELEPHONE: 609.292.3745
TDD 609.777.3238 FAX 609.292.7114 E-MAIL njcdd@njcdd.org INTERNET www.njcdd.org

C O N T E N T S

6 LETTER FROM THE EXECUTIVE DIRECTOR

Medicaid Unwinding

Late last winter, Congress passed legislation that requires state Medicaid programs to go back to the rules that were in place before the pandemic. This process is called “Medicaid Unwinding.” Over the course of the coming year, every person who is currently receiving Medicaid benefits must be reassessed for eligibility.



7 NJCDD COMMITTEE REPORT

The Council’s standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee. Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy Committee. The Diversity Equity and Inclusion (DEI) Sub-Committee meets under the State Plan Committee and the Advocate Advisory Sub-Committee meets under the Executive Committee.

COVER STORY

12 MEDICAID UNWINDING

What Families Need to Know

Medicaid is a lifeline for many people with intellectual and developmental disabilities (I/DD). The government insurance program, financed jointly by states and the federal government, funds health care and community-based supports for millions of low-income people, including those with I/DD. In New Jersey, Medicaid eligibility is required to access vital services from the Division of Developmental Disabilities (DDD).

**MEDICAID
UNWINDING**

12

17 NJCDD SUPPORTS OUTREACH TO BLACK STUDENTS WITH DISABILITIES AND THEIR FAMILIES

LeDerick Horne describes himself in many ways. He is a poet. A professional speaker. An advocate. A bridge-builder between learners and leaders. While his career is certainly diverse, there is a common thread: Serving people with developmental disabilities within the Black community.



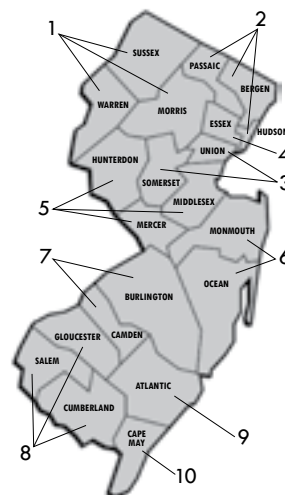
19 THE FAMILY SUPPORT ACT

30 Years of Family-Driven Decisions

Thirty years ago, a group of trailblazing parents— mostly moms—made history. Their advocacy work led to the passage of The Family Support Act and marked a turning point in disability policymaking in New Jersey. For the first time, decision-making was placed in the hands of families.



24 INFORMATION ABOUT FAMILY SUPPORT PLANNING COUNCILS



26 PARTNERS IN POLICYMAKING

Empowering Advocates to Make Things Happen

New Jersey Partners in Policymaking (Partners), a leadership development and advocacy education program, works to prepare a new generation of disability advocates in our state. The program is for adults over age 21 with developmental disabilities and family members of children and transition-age youth with developmental disabilities.

30 WELCOME, NEW COUNCIL MEMBERS

The Council welcomed four new members: Annette Smith, Michael McCarthy, Laura Williams and Nantanea Koppstein. Council members review the state's service systems for people with developmental disabilities and advise policy makers on the best ways to change those systems to better serve the population.

from the Executive Director ■

Medicaid Unwinding

During the pandemic, the federal government declared a public health emergency. Special rules allowed eligible people to access and keep health coverage through Medicaid. Because no one was disenrolled from the program during the pandemic, enrollment swelled to 2.25 million. 570,000 people joined the rolls from February 2020 to February 2023. Today, nearly one in four Garden State residents get their health insurance through Medicaid, also known as NJ FamilyCare.



Late last winter, Congress passed legislation that requires state Medicaid programs to go back to the rules that were in place before the pandemic. This process is called “Medicaid Unwinding.” Over the course of the coming year, every person who is currently receiving Medicaid benefits must be reassessed for eligibility.

Each month, starting in April 2023, about eight percent of the people on Medicaid will get a notice that they are required to reapply. By the end of the 12-month period ending in March 2024, everyone should have been notified and reassessed.

I cannot stress enough how important it is for Medicaid recipients to keep an eye out for these renewal packets in the mail. Ignoring the renewal packets could be costly. Advocates estimate that nearly 300,000 people are at risk of being kicked out of the program.

This year marked the 30th anniversary of the Family Support Act of 1993. The goal of the Family Support Act was to create a system that prevented the premature need for residential services. To ensure that the new system remained family-driven, the Act established ten Regional Family Support Planning Councils (RFSPCs) made up of families to advise the government on local needs. Self-Advocate and Family Advocate voices are inspiring and we are grateful for the tireless efforts advocates make to improve the service system in New Jersey.

In closing, I want to send a heartfelt welcome to four new members of our Council. Annette Smith, Michael McCarthy, Laura Williams and Nantanea Koppstein recently joined our ranks. Council members review the state’s service systems for people with developmental disabilities and advise policy makers on the best ways to change those systems to better serve the population. Members also review and award grants to spark innovative projects throughout New Jersey, as well as advocate for people with developmental disabilities and their families on an ongoing basis.

You can read more about Medicaid Unwinding, the Family Support Act and our new Council members in this issue of *People & Families Magazine*.

Warm Regards,

A handwritten signature in dark ink that reads "Mercedes Witowsky". The script is cursive and fluid.

Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities



NJCDD COMMITTEE UPDATES

The New Jersey Council on Developmental Disabilities (NJCDD) is authorized under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (The DD Act), P.L. 106-402 and New Jersey Administrative Code P.L. 1979, Chapter 103.

The purpose of the NJCDD is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of life through culturally competent programs.

Council members include NJ Governor appointed public members, representatives of state agencies and federally mandated members with a majority of members (60 percent) who are individuals with developmental disabilities or a family member of an individual with developmental disabilities.

The Council conducts four public meetings each year. The Council's Executive Committee meets throughout the year to handle matters concerning the Council when it is not possible for the full Council to meet and monitors the Council's Standing and Ad Hoc Committees.

The Council's standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee. Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy

Committee. The Diversity Equity and Inclusion (DEI) Sub-Committee meets under the State Plan Committee and the Advocate Advisory Sub-Committee meets under the Executive Committee. The following is a snapshot of some of the committee highlights.

Executive Committee

Paul Blaustein serves as chair of the NJCDD Executive Committee. The Committee acts on behalf of the full Council in all matters when it is not possible for the full Council to meet. The Executive Committee is responsible to assure that ongoing policies and procedures are in place and implemented consistently with Council bylaws as well as federal and state mandates, including oversight of the Council's budget and monitoring the Council's committees.

The following are recent Executive Committee activities:

- Nominations for one-year terms as Council Vice-Chairperson and Executive Committee Member-at-Large were solicited during the May 11 Council meeting.
- The Council retreat was held on May 10, 2023. It focused on Diversity, Equity and Inclusion, as well as cultural competence and linguistic responsiveness. The objective was to enable the Council to better engage with all New Jersey residents with developmental disabilities, and their families and caregivers.

- The Executive Director provided an update on the national initiative to enact legislation providing a legal basis for Supported Decision-Making as an alternative to Guardianship. Outreach has been done to engage with other organizations in NJ to assure inclusion of all available knowledge, experiences and perspectives. We appreciate the leadership role of Disability Rights NJ in this important initiative.
- The Executive Director provided an update on the federal grant that will include NJCDD as a participant in years 2-5 of the national Bridging Aging and Disability Services project. The project includes our DD Act partners. NJCDD is bringing together all stakeholders to this effort.
- NJCDD continues to monitor the State's plan to create behavioral crisis stabilization beds for 8-12 individuals on the grounds of the New Lisbon Developmental Center. The first two individuals have arrived. The Council's primary concern is the lack of suitable services available in the community for individuals after treatment at the new facility.

State Plan Committee

Helen Steinberg is chair of the NJCDD State Plan Committee. The role of the State Plan Committee is to manage federal requirements related to the development and implementation of the Council's Five-Year Plan.

- The Planning Committee worked on the 2022-2026 Five-Year Plan for a year and a half, gathering information from public comments, focus groups and in-depth conversations with the Ad Hoc Committee on Equal Access to DD Services. ACL notified the Council on September 30, 2022 that the 2022-2026 Five-Year Plan was approved for full implementation.
- The plan contains three broad goals in the areas of advocacy, capacity-building and system change. The plan can be found at: <https://njcdd.org/njcdd-5-year-planning-2022-2026/>
- The Administration for Community Living (ACL) issued approval of the Council's Program Performance Reports for fiscal year 2022.

Grants Committee

Kevin Nuñez is chair of the NJCDD Grants Committee. The role of the Grants Committee is to oversee the development of funding announcements that align with the Council's Five-Year Plan goals, objectives and activities. The Grants Committee reads all responses to funding announcements and makes recommendations to the full Council for funding and continued funding aligned with the Council's Five-year Plan and based on grantee performance. The following are recent committee activities:

The Grants Committee continues to review the four current grants awarded in Year 1 and 2 of the NJCDD Five-Year Plan. Year 2 contracts were awarded to two of the current grantees (Community Options and LeDerick Horne Speaks) and an extension was granted for one of the expiring contracts with SPAN. The Year 2 contract with The Arc of NJ was also processed.

The Grants Committee continues to make direct systems change to improve the lives of our vulnerable constituency by awarding contracts that meet the goals and objectives of our Five-Year Plan. For a listing of current grants, please visit the NJCDD website.

Public Policy Committee

Nantanee Koppstein is chair of the NJCDD Public Policy Committee. Andrew McGeady is the NJCDD vice-chair of the Public Policy Committee. The role of the Public Policy Committee is to review legislation and public policy materials made available by Council staff and other sources. After discussing these materials, the Public Policy Committee recommends positions and follow-up actions.

- The second meeting of the Legislative Disabilities Caucus this year was held on April 21, 2023. The session was devoted to affordable community housing issues, including developing infrastructure, providing support services, and assessing federal, state, and municipal responsibilities. Co-chair Senator Anthony Bucco Jr. hosted the event. Speakers were Staci Berger of the Community and Housing Development Network of NJ and Tom Toronto of Bergen County's United Way. Senator Brandon Umba also participated in the discussion, as well as other legislators

- The FY 2024 State Budget, as proposed by the Governor has been received with a mostly positive response by the disability community with some notable concerns: there needs to be an increase in DSP wage rates to ensure staff retention for essential services and full funding for special education is still lacking
- Legislation to provide safety plans for students with disabilities in active emergency situations came closer to reality with the passage of A1174 in March 2023 in the Assembly Education Committee. This legislation was developed after the Summit on School Safety was sponsored by NJCDD in 2019
- NJCDD, ABCD, and the MCO Users Group met with Senator Joseph F. Vitale's staff on early intervention and Managed Care Organization issues in March 2023. Senator Vitale is the Chair of the Senate Health, Human Services and Senior Services Committee.

Subcommittee on Children and Youth

Peg Kinsell is chair of the NJCDD Subcommittee on Children and Youth. The NJCDD Subcommittee on Children and Youth (C&Y), comprised of more than a dozen parents, advocates, community leaders, state leaders, educators and Council members. It focuses on issues that affect those under the age of 21 and their families. The subcommittee is addressing:

- Support/advocacy needs of children and their families through COVID.
- Compensatory education.
- Access to Family Support Services Through the Department of Children and Families, Children's System of Care.
- Seclusion and restraint racial, ethnic and gender disparities which affect access and outcomes in special education.
- School safety.
- Helping to ensure positive outcomes and high expectations for students with I/DD
- Ensuring that youth with disabilities are included in the States plans to address the needs of youth who have Adverse Childhood Experiences (ACEs).
- School based mental health services.
- Students on home-bound instruction and those send home pending psychiatric review.

Subcommittee on Health and Wellness

Elizabeth Dalzell is the chair of the Health and Wellness Subcommittee. The Health and Wellness Subcommittee advises the Council on health and wellness matters that impact individuals with I/DD and their families, advises the Council on health and wellness legislation and policies impacting individuals with I/DD, and conducts activities that align with, and fulfill the goals and objectives of, the Council's state plan.

The most recent subcommittee meeting was held on April 18, 2023. Subcommittee members were joined by members of the CHOP Government Affairs Team for an information exchange session regarding recent healthcare legislation. In addition, members were updated on past projects and received a brief overview of the NJ budget.

H&W also continues to focus on:

- Minority Access to Healthcare
- Medicaid Unwinding
- The continuation and expansion of Telehealth services
- Comprehensive Healthcare
- Dual Diagnosis of Mental Health and I/DD
- NJ S3000 Legislation implementation

Diversity, Equity, and Inclusion Subcommittee

The Diversity, Equity, and Inclusion (DEI) Subcommittee was established within the bylaws of the Council and in alignment with the goals of the 2022-2026 Five-Year State Plan. The important work of ensuring that there is diverse representation within the Council and its members, equity in practices, policies, messaging, communication and interactions with people, awareness of environmental impact on family and communities served, as well as openness and accessibility to information and all services provided by the Council are present throughout the planned goals and objectives.

Sarah Aziz is the chair and Annette Smith is co-chair for the DEI subcommittee. The DEI subcommittee is comprised of NJCDD Council members, members of the I/DD community and their family members, advocates/self-advocates, and state agency representatives.

The following are recent subcommittee activities:

- Subcommittee members welcomed new member Jessica (Jessi) Lax, from Disability Rights New Jersey (DRNJ) and briefly reflected on previous meetings and discussions that led to the creation of the subcommittees two work groups as well as the current focus for the subcommittee moving forward.
- Subcommittee co-chair, Annette Smith shared Work Group 2's most recent data collection tool, created by member Nelly Schoeman. Some of the information captured about the larger hospital systems in Union County was discussed as not having enough support in place to help families navigate through the services they provide and not having accessible language on their websites.
- Two recommendations were proposed by the committee:
 - Investigate if hospitals would consider using a universal name, and having a universal position in which an intern or paid staff would serve as a patient navigator with experience or knowledge in accessing services for individuals and families in the I/DD community.
 - Discuss with hospitals and community providers if they have a language access plan (LAP) and how to access information about it.
- A greater conversation led to members sharing the possibility of partnerships including local community colleges, the Boggs Center, and grantees being partners who could assist interested hospitals and providers interested in creating these positions and receiving training.
- The subcommittee will continue to meet on a quarterly basis moving forward. The two work groups will meet on a monthly basis with the dates to-be-determined by group members.

Self-Advocacy Advisory Subcommittee

Ryan Roy serves as chairperson of the Self-Advocacy Advisory Subcommittee. It is comprised of all of the self-advocate members of the Council. As well as self-advocates from the community. The subcommittee:

- Serves as a voice for New Jerseyans with I/DD by promoting self-advocate participation and peer advocacy that advances independence and inclusion.
- Advises the Council regarding self-advocate needs including ensuring full participation in all meetings.
- Advises the Council regarding policies, programs and any other areas affecting self-advocates in New Jersey.
- Conducts activities that align with the goals and objectives of the Council's state plan.
- Reviews materials and other Council produced information to evaluate and make recommendations regarding plain language approaches.
- Responds to additional requests made by the Council or in conjunction with other committees.

The group met on May 10, 2023 and discussed ways to expand the role of self-advocates and how to increase membership for the group. The group voted to hold meetings the night before the Council meetings. The group still plans to have a virtual option for those advocates who would like to attend remotely.

The group continues to look for ways to get greater participation from both self-advocate members of the Council and well as independent self-advocates who are not on the Council. **P&F**

In Memoriam

Countless advocates, individuals, family members and professionals continue to make meaningful contributions to the lives people with I/DD in New Jersey. This segment pays tribute to those who have made meaningful contributions and have recently passed away.

Gary Rubin

Gary Rubin passed away on June 29, 2023. He was a Council member for many years. He also worked part-time as a security guard.

He moved out of his parent's home when he was 15 years old. Rubin lived in a few different congregate care settings including the Woods School, E.R. Johnstone Training & Research Center, and North Princeton Developmental Center.

Living in these large congregate settings motivated him to become an advocate. His advocacy began in New Jersey but reached more broadly in his national role as a board member with Self Advocates Becoming Empowered (SABE).

If you are aware of the recent passing of someone who has made significant contributions to the New Jersey I/DD community please email a brief description to gary.brown@njcdd.org.



Disability
in Focus

The New Jersey Council
on Developmental Disabilities

Presenting
Facts

Sharing
Views

Starting
Conversations

Visit the NJCDD's Blog, **Disability in Focus** to get the latest news and views from around the state and across the country about our developmental disabilities communities. Join the conversation by sharing your own views on topics we discuss.

We Can't Wait to Hear From You!
Visit us at www.njcdd.org

MEDICAID UNWINDING

WHAT FAMILIES NEED TO KNOW

By Brenda Considine

Medicaid is a lifeline for many people with intellectual and developmental disabilities (I/DD). The government insurance program, financed jointly by states and the federal government, funds health care and community-based supports for millions of low-income people, including those with I/DD. In New Jersey, Medicaid eligibility is required to access vital services from the Division of Developmental Disabilities (DDD).

Under Medicaid, DDD provides extensive services to over 24,000 people with I/DD. DDD administers two Medicaid waiver programs, the Supports Program (SP) and Community Care Program (CCP). Through these programs, individuals with I/DD can receive home- and community-based services based on their assessed needs and individualized budget.

Unwinding

During the pandemic, the federal government declared a public health emergency. Special rules allowed eligible people to access and keep health coverage through Medicaid. Because no one was disenrolled from the program during the pandemic, enrollment swelled to 2.25 million. 570,000 people joined the rolls from February 2020 to February 2023. Today, nearly one in four Garden State residents get their health insurance through Medicaid, also known as NJ FamilyCare.

Late last winter, Congress passed legislation that requires state Medicaid programs to go back to the rules that were in place before the pandemic. This process is called “Medicaid Unwinding.” Over the course of the coming year, every person who is currently receiving Medicaid benefits will need to be reassessed for eligibility. Each month, starting in April 2023, 1/12 (about eight percent) of the people on Medicaid will get a notice that they are required to renew their Medicaid. By the end of the 12-month period ending in March 2024, everyone will have been notified and reassessed.

State Efforts Underway

At the March public meeting of the New Jersey Council on Developmental Disabilities, Jennifer Langer Jacobs, Assistant Commissioner of the Department of Human Services in the Division of Medical Assistance and Health Services, provided an overview of state efforts to notify Medicaid recipients of the process and make sure they respond. She leads New Jersey’s Medicaid program

It’s All the Same Thing

The following terms may be used to describe the process:

- Medicaid Unwinding
- Medicaid Redetermination
- Medicaid Restart
- Medicaid Renewal
- Medicaid Reassessment

and the Children’s Health Insurance Program, which together are known as NJ FamilyCare.

Her office developed and oversees the process for redetermination, guided by the North Star Principles to ensure that people experience personalized, seamless, proactive, transparent, compassionate, and consistent services. Her office has developed special teams, training programs, toolkits, posters, workshops, and other outreach activities.

In April, DHS began the process of mailing out redetermination notices. The state and county boards of social services are working closely with the managed care organizations that provide the coverage to supply contact information and send out Medicaid renewal reminders. The five NJ FamilyCare Health Plans (Aetna, Amerigroup, Horizon NJ Health, United, and WellCare) will send postcards at the beginning of each month to the 1/12th of members who will get their renewals that month. They will follow up later in the month by phone, email, and text message, when possible.

Beware of Scams

- NJ FamilyCare will never charge or ask for money from members to enroll or re-enroll.
- Do not share banking or credit card information with anyone that calls you, claiming to represent NJ FamilyCare, the Department of Human Services, the Division of Medical Assistance and Health Services, or your NJ FamilyCare Health Plan.

Human Services officials say they cannot stress enough how important it is for Medicaid recipients to keep an eye out for these renewal packets in the mail.

“Please make sure you open your mail,” Langer Jacobs urged members of the council and its public guests. “Don’t put this notice in a pile on your kitchen table or ignore it. Open it and take action,” she said.

Failure to do so could be costly. Advocates estimate that nearly 300,000 people are at risk of being removed from the program.

Everyone will get a mailing from NJ FamilyCare (Medicaid) telling them that they need to reapply. Many people will receive an invitation to do their renewal online, a new feature since the pandemic. Every person enrolled in a Medicaid program will be reviewed to see if they still qualify for coverage. They will be asked to provide or confirm information, including proof of income and family size. People who do not respond to NJ FamilyCare/Medicaid mail will lose their coverage.

According to Beverly Roberts, Director of Mainstreaming Medical Care at The Arc of New Jersey, families need to know if their family member with I/DD is receiving Supplemental Security Income (SSI) or if it is a different type of Social Security benefit.

“If their loved one with I/DD receives SSI, then Medicaid unwinding does not apply to them. Families should also be aware that Social Security is mailing redetermination letters for continuation of SSI or SSDI benefits. Although this is different from Medicaid unwinding, it is very important to respond promptly to all requests for information from Social Security or NJ FamilyCare/Medicaid,” Roberts said.

Who Is Eligible

To be “Medicaid Eligible” means that an individual has applied for and been enrolled in Medicaid and continues to meet the income and financial resources criteria for Medicaid.

- Children up to age 19 when their household income is less than 355% of the federal poverty level, (\$8,875 per month or \$106,500 a year for a family of four).
- Adults aged 19 to 64 years when they earn no more than 138% of the federal poverty level (\$1,677 a month and \$20,124 a year for a single person, and \$2,268 a month and \$27,216 per year for a couple).
- Pregnant women when they earn 205% of the poverty level (\$5,125 per month and \$61,500 a year for a family of four).
- Undocumented immigrant children are eligible for coverage in New Jersey under a new policy that took effect this year.
- Many individuals with I/DD are permitted to have a maximum of \$2,000 in resources.

Advocacy Efforts to Prevent Disenrollment

Across the state, advocacy groups, including The Arc of New Jersey, the New Jersey Council on Developmental Disabilities, and the Regional Family Support Planning Councils have been hosting events and webinars to raise awareness of the process and help people with I/DD and their families learn about how to protect vital Medicaid benefits.

The Two Most Important Things to Know

1. Make sure NJ FamilyCare/Medicaid has your correct contact information, especially if you have moved in the last three years. Contact them at 1-800-701-0710 (TTY: 711).
2. Watch for mail from the State of New Jersey, NJ Family Care, Medicaid or your county. To avoid a gap in coverage, open it and **REPLY IMMEDIATELY**.

Some people will lose benefits because they now make too much money or have employer-sponsored health insurance. Many others will remain *eligible* but lose coverage simply because they did not get the information in the mail, moved, or did not respond to mailings in a timely fashion.

When this happens, county and state officials are prepared to restore people's enrollment quickly—some within a few days—if people have been terminated in error. People may also request a hearing to challenge a termination.

While some people with I/DD could be disenrolled in error, Roberts urges families to be alert, but not “overly anxious” about Medicaid Unwinding.

“We anticipate that the overwhelming majority of people with I/DD will not have this problem,” she said. “If Medicaid is terminated, then DDD services are halted! If Medicaid mails a termination notice, the letter must also provide information on requesting a Medicaid fair hearing. Families are advised to submit a request for a fair hearing promptly if a Medicaid termination letter is received,” she said.

Paul Prior, Esq., a partner at Hinkle Prior & Fischer, Attorneys at Law, has dedicated his career to disability law. He is concerned about the Medicaid Unwinding process.

“My own brother has autism and receives services through a Medicaid Waiver program,” said Prior. “I am watching the mailbox closely for this notice.”

In addition to watching out for his brother's renewal information, Prior and his colleagues are advising the firm's clients to do the same and get ready for the renewal process.

Everyone will get a mailing from NJ FamilyCare (Medicaid) telling them that they need to reapply. ... Every person enrolled in a Medicaid program will be reviewed to see if they still qualify for coverage.

“Parents should contact the Medicaid Help Desk proactively to be sure Medicaid has up-to-date information such as address, phone numbers, and emails,” says Maria Fischer, Esq., also a partner with the firm. Maria's daughter is on the autism spectrum and also receives services through a Medicaid Waiver. Families should gather relevant documents to demonstrate continued eligibility, including bank records, proof of income, proof of payments, and other financial records,” she stated.

Prior and Fischer, as well as their colleagues at the firm, are offering free workshops and other information to families who are concerned about the process. “We want families to know how to prepare for renewal, how to appeal a denial, and how to use financial tools, such as ABLE accounts, to maintain eligibility, if needed,” said Fischer.

“Anytime the government has such a massive undertaking, there will be errors. There will be people with disabilities who are eligible but disenrolled. We want to minimize any disruption or interruption in services,” says Prior. **P&F**

RESOURCES

- <https://nj.gov/humanservices/dmahs/staycoverednj/>
- <https://www.arcnj.org/programs/mainstreaming-medical-care/medicaid-unwinding.html>
- 1-800-701-0710 (TTY 771)
- Medicaid Help Desk: DDD.medielihelpdesk@dhs.nj.gov
- Ombudsman for I/DD: 1-609-084-7764
- Disability Rights NJ 1-800-922-7233

Eye ^{on} Advocacy

THE NJ COUNCIL ON DEVELOPMENTAL DISABILITIES

Weekly e-newsletter

Eye on Advocacy, a new NJCDD weekly e-newsletter focusing on important news and events for the I/DD community. It will be published every Tuesday and replaces the monthly Advocacy in Action e-newsletter. We welcome news items and encourage your feedback about this new publication. Please send potential news items and your feedback to njcdd@njcdd.org.

UPCOMING EVENTS ADVOCACY IN ACTION DISABILITY NEWS

 **The NJ Council on
Developmental Disabilities**
Advocate • Collaborate • Educate njcdd.org

 **SUBSCRIBE**



For more information
609-292-3745



www.njcdd.org
VISIT OUR WEBSITE



NJCDD SUPPORTS OUTREACH TO BLACK STUDENTS WITH DISABILITIES AND THEIR FAMILIES

By Jonathan Jaffe

LeDerick Horne describes himself in many ways. He is a poet. A professional speaker. An advocate. A bridge-builder between learners and leaders.

While his career is certainly diverse, there is a common thread: Serving people with developmental disabilities within the Black community.

The Franklin Township resident's latest work involves a project through the NJCDD, in which he is working with Black youth with disabilities to ensure their voices are being heard. His hands-on, face-to-face project has taken him to Piscataway and, very soon, to East Orange.

Horne is paving the way for a statewide "Black I/DD Consortium," involving the NJCDD, school districts and local advocates. The two-year pilot program, funded with a \$248,676 grant through the Council, is designed to increase access to information and services to strengthen the outcomes of Black residents with disabilities. The pilot project is set to end December 31.

"We are committed to increasing access to information and services for Black New Jersey residents with intellectual/developmental disabilities and their families," explained Horne, 45. "We want to further engage Black communities."

Horne is ideally suited for such work. A 1996 graduate of Franklin High School, he faced many challenges as an individual with disabilities in the Black community. He was classified with a disability when he was nine years old, placed in a self-contained special education classroom and deemed "neurologically impaired."

This future professional speaker struggled with math, spelling and reading, noting his disability makes him highly distracted. During his junior year of high school, Horne said, he had an



emotional breakdown. He realized his life could go in two very different directions: Accomplishing little or becoming determined to graduate from college and build a career.

"I never saw anyone in my special ed classes in high school who then went on to college," Horne said. "But I started talking about the possibility with my IEP team. It was suggested that I go to Middlesex County College where there are supports for students with disabilities."

He flourished on the Edison campus and then transferred to a four-year school, New Jersey City University, which also provided the supports he needed to earn his undergraduate degree. There, in Jersey City, he learned how to write poetry.

"So much of my poetry centered on me wrestling as a Black man and as a person with disabilities," he said. "And I began sharing with young people what my experience had been."

With a degree in math, and a minor in fine arts for painting, Horne was hired by the state Department of Education, Office of Special Education, to conduct student leadership conferences, leading to his present-day career.

Horne is undertaking the NJCDD contract with his mentor, Bill Davis of Piscataway. Davis describes himself as a semi-retired educator, teaching African-American courses at the college level. He brings tremendous perspective, a young man witnessing the 1967 riots in Plainfield, graduating college with a degree in Africana studies and serving as a specialist at the Boggs Center on Development Disabilities in Piscataway.

“There’s way too many Black children in special education in our schools,” Davis said. “Black boys are the largest group; not because of cognitive issues, but because of behavior.

“Through this program, we hope to create a model to help schools and communities better serve their students,” Davis added. “We also want students, families and school staff to have more healthy engagements with students with special education. Hopefully, it can be a program replicated around the state.”

Davis said the pilot program intentionally targets school districts with large populations of Black students. It is not difficult to decide where to go, as he said New Jersey is one of the most segregated states in the nation.

“Just by zip code, we can deduce where Blacks live,” he said. “And it is an important part of our outreach. There is a high correlation between Black students in special education and incarceration. We hope to reduce this school to prison pipeline.” To undertake this pilot, Horne and Davis have three main priorities:

- To gather information, interviewing the NJCDD members, staff and partners, as well as Black families and advocates. The objective is to learn what information needs to be shared with the Black community about services, activities and supports available for people with I/DD.
- Launch outreach to Black students with disabilities. The initial focus was the Piscataway school district, in which Horne, Davis and others now regularly work with Black students



LeDerick Horne serves people with developmental disabilities within the Black community

with disabilities. Workshops are scheduled to discuss self-advocacy and highlight notable Black people with disabilities who are making a difference in the world. About 35 students and others from the school district are involved. The project is now expanding to East Orange, Horne said.

- Create a “NJ Black I/DD Consortium,” meeting quarterly with an estimated 25 individuals representing various areas/demographics of the state. Participants discuss issues facing Black students with disabilities

and their families, identifying ways in which to create better outcomes and better access to services.

The consortium has also launched an in-person support network to assist Black applicants to apply for PerformCare, which partners with the New Jersey Children’s System of Care (CSOC) to help people up to age 21 with I/DD, behavioral health or substance use issues. Starting with just one phone call, PerformCare makes the connections that parents or guardians need to help their children.

“Through PerformCare, people are eligible for financial support, funded through the state, for respite, therapies and other support for children,” Horne said. “We are learning that many Black families can’t get through the application process. PerformCare will provide phone support, but not someone to sit with you to go through the application. We’ve hired a navigator to help them through an application that is over 20 pages long; it feels like you need a master’s degree just to apply.”

Twelve students have been assisted through the initial cohort, he noted.

“It’s all about creating a better environment for Black students in special education to succeed, working with parents, teachers and administrators,” Davis said. “It’s the largest group in special education; we need to make sure they are supported in a positive way. **P&F**

THE FAMILY SUPPORT ACT: 30 YEARS OF FAMILY-DRIVEN DECISIONS

By Brenda Considine

Thirty years ago, a group of trailblazing parents—mostly moms—made history. Their advocacy work led to the passage of The Family Support Act and marked a turning point in disability policymaking in New Jersey. For the first time, decision-making was placed in the hands of families.

A statewide family support policy must acknowledge that families themselves are able to define their own needs and select their own services: family supports must be chosen by families, controlled by families, and monitored by families.

—The Family Support Act of 1993

The goal of the Family Support Act was to create a system that delivered “whatever it takes” to prevent the premature need for residential services. To ensure that the new system remained family-driven, the Act established ten Regional Family Support Planning Councils (RFSPCs) made up of families to advise the government on local needs.

A lot has changed since the Family Support Act was passed, but today, the RFSPCs continue to provide a venue for family members of people with intellectual and/or developmental disabilities (I/DD) to exchange knowledge and information about family support services, and to talk directly with state decision-makers about unmet needs.

“For thirty years, families have been advocating for a more user-friendly, person-centered

system—one that fits the needs they identify,” said Kyoko Coco, Statewide Coordinator of the Regional Family Support Planning Councils at the New Jersey Council on Developmental Disabilities (NJCDD).

Family-Driven from the Start

The Family Support Act is a study in grassroots organizing. A small group of dedicated advocates organized the Family Support Coalition of New Jersey to address the needs of families caring for a child with disabilities living at home. Committed from the start to building a coordinated statewide system of family support—not programs—the coalition studied model legislation from other states, learned about best practices, and developed a list of principles to guide the effort.

With strong support from the NJCDD, the coalition organized public hearings. Hundreds of families not only told their stories, they showed their stories, bringing their sons and daughters with them to hearings, meetings, and rallies.

Organizers launched a petition drive, collecting more than 14,200 signatures. Page by page, the petitions were collected by The Arc of New Jersey, which played a major role in organizing and promoting the campaign. In the spring of 1992, more than 1,000 families converged on Trenton, demanding a statewide system of family support and a seat at the table. With reporters and camera crews on hand, advocates presented a foot-high stack of

petitions to lawmakers. A year later, Governor Jim Florio signed the Family Support Act, mandating a “coordinated system of ongoing public and private support services.” Families were then invited to draft the regulatory language to implement the Act—another first in disability policy-making.

The Family Support Act recognized that families are the major providers of support, care, training, and other services for their family member with I/DD living at home. The Act promised that the statewide system would include, but not be limited to, the following services:

- After-school care; cash subsidies; communication and interpreter services; counseling services; crisis intervention; daycare; equipment and supplies; estate and transition planning; home and vehicle modification; home health services; homemaker assistance; housing assistance; medical and dental care (not otherwise covered); parent education and training; personal assistance services; recreation services; respite care for families; self-advocacy training; service coordination; specialized diagnosis and evaluation; specialized nutrition and clothing; therapeutic or nursing services; transportation; voucher services; and *other services as identified by the family.*

A Shift in the System

At the time the Family Support Act was signed, the Division of Developmental Disabilities (DDD) was solely responsible for providing services and support to families of children with I/DD as well as adult services. As such, they managed family support for those under age 21. The RFSPCs worked with DDD leaders on in-home supports for younger children that were designed to delay interest in residential placement.

In 2013, the responsibility for serving children with I/DD and their families shifted from the Department of Human Services to the Department of Children and Families (DCF). Their Division of Children's System of Care (CSOC) serves children and adolescents with emotional and behavioral healthcare challenges and their families, as well as children with I/DD and their families. Like DDD, CSOC has

committed to providing these services based on the needs of the child and family in a family-centered, community-based environment. According to the CSOC website, the following services are offered throughout New Jersey, although individual regions may have different options:

- In-home respite
- Self-directed respite
- After-school activities
- Weekend recreational activities
- A short-term placement in a licensed setting
- Camp
- Assistive technology devices

CSOC's Developmental Disability Family Support services are intended to help support uncompensated caregivers for individuals who are eligible for developmental disability services and living in their own homes. The RFSPCs assist the CSOC in allocating funding for these services by making recommendations based on input they receive from families.

Regional Councils: Empowering and Energizing Families

The Family Support Act established ten Regional Family Support Planning Councils. Their mission is “to empower and energize families to advocate for a lasting family-centered support system and community living for people with I/DD.

The main role of the RFSPCs is to be the voice of fellow families in their regions. They meet regularly to collect data, monitor and evaluate the system, work with other advocacy groups, and make recommendations to the State of New Jersey. They inform policymakers and advocate with local officials and state legislators about the needs of those who support a family member with I/DD.

One of the most important roles is the strong collaboration with the Division of Developmental Disabilities (DDD) and the Division of Children's System of Care (CSOC) on how to better serve individuals and their families.

The RFSPCs are organized geographically around counties or groups of counties. They meet on a regular basis, usually once a month, with meetings open to the public.

PROGRESS

VOL. 35 NO. 2

SPRING - 1992

A publication of The Arc of New Jersey and its 20 local county chapters

NEW JERSEY DEVELOPMENTAL DISABILITIES COMMUNITY LAUNCHES INITIATIVE FOR FAMILY SUPPORT

For the past six months The Arc of New Jersey has worked with other statewide developmental disability organizations to form a coalition, one of whose initiatives is to help families make known the serious lack of support services in New Jersey for families who have a member with a disability living at home. The New Jersey Developmental Disabilities Community, as the coalition is called, began the campaign to "Support Family Support" by collecting over 14,000 signatures on a petition calling for a legislated family support policy.

The next step was organizing six public hearings on family support across the state during the month of March. The hearings gave families the opportunity to tell their story to members of the Legislature, the Governor's Office, the NJ Developmental Disabilities Council, the NJ Department of Human Services and the NJ Family Support Coalition. Over three hundred families responded by submitting testimony in person, in writing or on videotape.

The family support initiative gained the support of Governor Jim Florio as he proclaimed May 4, 1992 "Family Support Awareness Day". On that day nearly 1,000 people gathered in front of



Senate President Donald DiFrancesco and Assemblywoman Maureen Ogden accepting the petitions containing 14,000 signatures supporting family support from Sandi Jackson, President of the New Jersey Family Support Coalition

Photo By E. Ozem

the State House in Trenton to rally for family support. Amidst the cries "Support Family Support", it was announced that Assemblywoman Maureen Ogden (R-21) had introduced the "Family Support Act of 1992" in the Assembly (A-1355) on April 30 and that Senate President Donald DiFrancesco was planning to introduce a companion bill in the Senate (S-757) on May 7.

The bills state that families are the major service providers to people with developmental disabilities, and that services and supports must be provided to families in order to allow them to continue caring for a family member with a disability at home. The program proposed in the bill would coordinate services according to a family's needs, and strengthen and promote families who care for a person with a disability at home. Many of the services the state already provides are formally named as

(Continued on Page 4)

Family Support Act of 1992

PRIME SPONSORS

Assembly

Maureen Ogden (R-21)

Nicholas Felice (R-40)

Senate

Senate President Donald

DiFrancesco (R-22)

Peter Inverso (R-14)

CO-SPONSORS

Assembly

Richard Bagger (R-22)

Mel Cottrell (R-30)

Marion Cecce (R-34)

John Gibson (R-1)

Rose Heck (R-38)

Monroe Lustbader (R-21)

Joe Roberts (D-5)

Virginia Weber (R-4)

Barbara Wright (R-14)

Senate

James Caflero (R-1)

John Ewing (R-15)

IN THIS ISSUE....

Celebrate the Volunteer.....	page 2
The Arc of NJ Convention.....	page 3
Around the State.....	page 5
The Arc of NJ Programs.....	page 6
Government Update.....	page 7

Annette Smith: Region 4

Lifelong Newark resident, Annette Smith, joined Regional Family Support Planning Council #4 (Essex County) 27 years ago, when her daughter Tiffany was just 12 years old. Since that time, she has been helping to shape family support services and public policy. Smith was recently appointed by the Governor to serve as a member of the NJCDD.

Smith believes that connecting with other parents is a vital component of her work on the RFSPC.

"We are not looking for pity. Our kids are not a piece of broken furniture, we are not trying to fix them. We want them to have the best life possible," she stated.

As a member of Council 4, Smith said she learned how to ask questions and keep lines of communication open. She also learned to speak up about systemic barriers that affected her family and others.

“When Tiffany was a baby and in Early Intervention, I took a bus to support meetings in Livingston. As an African-American woman living in Newark, my experience was different. There were many programs in those communities that I could not access because I did not have a vehicle and because Tiffany used a wheel chair. Just by being there and asking questions, I opened people’s eyes. They simply did not have the experience, so they did not see the problem. The more I spoke, the more they understood the barriers. Eventually, the programs changed. More families in Newark could actually use them because the necessary supports were there,” Smith recalled.

While her work with the RFSPC has evolved over the years, she said there is still an emphasis on doing “whatever it takes” to support families. Her Council takes a lifespan approach to advocacy and does frequent outreach events to help reach more families and engage more diverse communities.

“Especially in minority communities, we find that some cultures don’t ask for help—they rely only on family. We are engaging other people to help us reach these families better,” said Smith.

“We help families understand the system and get benefits that might be hard to secure. It seems like some services and programs are well kept secrets.”

An Opportunity to Shape the Future

The 1993 legislation emphasized that family support services need to be, among other things, “accessible, flexible, and culturally sensitive.”

Today, Coco sees efforts around diversity, equity, and inclusion (DEI) as a major part of the work ahead. Outreach and public relations activities at the state and regional levels are focused on making sure that leadership and engagement in Council work better reflect the communities they serve. NJCDD has hired cultural liaisons to help build bridges to underserved and underrepresented communities. The hope is that the liaisons can help introduce new families to the RFSPC and form collaborations to reach a more diverse group of families.

Coco described a recent initiative of Council #2 (Hudson). In collaboration with DDD leaders, they synthesized more than 250 pages of regulatory language into a 20-page user-friendly “Quick Guide” to DDD services, which was then translated into Spanish.

“Region 2 found that there were Asian families in their area who needed help, and for whom language was a major barrier,” noted Coco. “Families did not fully understand the system or scope of DDD services, so they were not even applying. To better meet the needs of families in the region, they asked NJCDD for help translating the Quick Guide into Korean,” recalled Coco.

Coco believes that “representation matters.”

“When people see someone who looks like them talking about issues—especially developmental disabilities—that some cultures do not talk about, it opens doors. We need every voice included,” she stated.

As Coco looks ahead to the future, she is hopeful that more families will get involved and remain involved.

“The Regional Councils have a 30-year history of having on-going and regular access to the state’s top decision-makers at DDD and now, at CSOC. Families get to have difficult but honest conversations with state leaders in ways that change services and systems,” she said. “What we really need now are new voices, new members, and new parent leaders.”

Smith agrees.

“My hope is that we can still find better ways to connect with families,” said Smith. “We are still finding people we have never seen, especially when we meet them for the first time and they are older parents.”

“People don’t think they can make a difference, or that their voice matters. It does! We want to hear what you need,” she concluded. **P&F**

RESOURCES

**Statewide Family Support
Coordinator, Kyoko Coco**

Kyoko.Coco@njcdd.org, 609-341-3112

Now Available
for download <https://bit.ly/3lZJ5lg>

AN ENHANCED **FAMILY CRISIS SUPPORT HANDBOOK**

A Behavioral Health Wellness Toolkit

Promoting voice and choice for
New Jerseyans of all ages with
intellectual and developmental
disabilities, and all stakeholders
who support them.



Available in English and Spanish

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

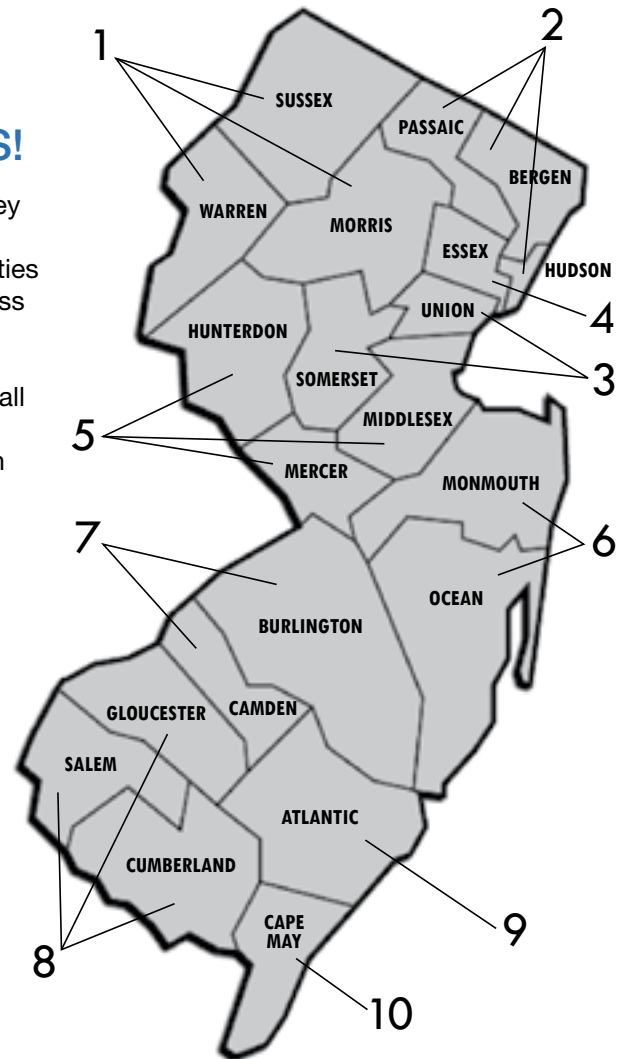
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

A number of regional councils were established in New Jersey by the Family Support Act of 1993 (see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and other forms of assistance that promote self determination, independence, productivity, and integration and inclusion in all aspects of community life.

The councils work in partnership with the state's Division of Developmental Disabilities and Children's System of Care to advise on policy decisions that affect people with developmental disabilities. Councils sponsor events where individuals and their families can learn about the services available in the area, as well as host public forums to solicit feedback from the community. In addition, councils regularly distribute literature with important information for people with developmental disabilities and their families.

Family members of people with developmental disabilities can volunteer to serve on their regional planning council. Council members assist and advise the Division of Developmental Disabilities and Children's System of Care as to how resources can best meet the needs of families and individuals living in their region.

Councils meet regularly—usually once a month; each Council may have up to 11 members. Council members are volunteers but will be reimbursed for reasonable transportation, child care, and other costs related to serving on the council.



For more information, Call the Statewide Family Support Coordinator Kyoko Coco at 609-341-3112 or email her at kyoko.coco@njcdd.org

Or visit our website at www.njcdd.org and follow the link to Family Support & Facebook page at www.facebook.com/NJFSPC.

THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with developmental disabilities.

Visit the NJ Council on Developmental Disabilities' web site at: www.njcdd.org, click on the link for Family Support, and the number corresponding to the Regional Family Support Planning Council in your area.

1 SUSSEX, WARREN, MORRIS

RFSPC #1

e-mail: RFSPC1@gmail.com

Chair: Margaret Hefferle

Meets the third Tuesday
of each month

Wegmans Market Cafe
34 Sylvan Way
Hanover, NJ 07054

7:00 p.m. - 8:30 p.m.

2 BERGEN, HUDSON, PASSAIC

RFSPC#2

e-mail: RFSPC2@gmail.com

Co-Chairs: Dorothy Blakeslee, Fel Lim

Meets the third Monday
of each month
Secaucus, NJ 07094

6:30 p.m. - 8:00 p.m.

3 SOMERSET, UNION

RFSPC#3

e-mail: RFSPC3@gmail.com

Chair: John Brewer

Meets the third Tuesday
of each month

7:00 p.m. - 8:00 p.m.

4 ESSEX

RFSPC#4

e-mail: RFSPC4.Essex@gmail.com

Chair: Yolanda Smith

Meets the first Wednesday
of each month

7:00 p.m. - 8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5

e-mail: RFSPC5@gmail.com

Chair: Paul Blaustein

Meeting times and dates TBD

6 MONMOUTH, OCEAN

RFSPC #6

PO Box 76

Lakewood, NJ 08701

e-mail: RFSPC6@gmail.com

Chair: Mike Brill

Meets the second Thursday
of each month

6:00 p.m. - 7:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7

e-mail: RFSPC7@gmail.com

**Co-Chairs: Laura Kelly,
Jenn Arey**

Meets the second Thursday
of the month

Odd months: 7:00 p.m. - 8:30 p.m.

Even months: 12:00p.m.-1:30p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8

e-mail: RFSPC8@gmail.com

**Co-Chairs: Amy Kiger,
Elena Gardner**

Meets second Thursday
of each month

7:00 p.m. - 8:00 p.m.

9 ATLANTIC

RFSPC #9

e-mail: RFSPC9@yahoo.com

Chair: Mary Ann Philippi

Meeting times and dates TBD

10 CAPE MAY

RFSPC #10

PO Box 199

South Dennis, NJ 08245

e-mail: RFSPC10@yahoo.com

Chair: Anne Borger

Meets the third Thursday
of the month except January,
April, July, August, and December

6:30 p.m. - 8:00 p.m.

All meetings (except RFSPC#1) are held virtually.
If you are interested in attending, please contact
a chair to request a meeting link.

PARTNERS IN POLICYMAKING

Empowering Advocates to Make Things Happen

By Maryann B. Hunsberger

New Jersey Partners in Policymaking (Partners), a leadership development and advocacy education program, works to prepare a new generation of disability advocates in our state. The program is for adults over age 21 with developmental disabilities and family members of children and transition-age youth with developmental disabilities. Partners takes place through a collaboration between the New Jersey Council on Developmental Disabilities, the Boggs Center on Developmental Disabilities, and Disability Rights New Jersey.

The Council began the Partners program in 1996 with Jane Dunham of the Council as the coordinator. In 2016, the Council entered into an agreement with the Boggs Center to continue the Partners program with Colleen McLaughlin, associate director of the Boggs Center taking the lead. The latest Partners class graduated on April 22 2023, at the Hyatt New Brunswick with 22 graduates.

McLaughlin spoke with enthusiasm about the Partners alumnae she has worked with this past five years. “We’ve seen past graduates start employment programs at their places of employment. We have a number of graduates who have gone on to be members of school boards to focus on change in public education. A number of graduates have invested in advocacy around the direct support professional (DSP) workforce. Some have given public testimony before their legislators. Others have been on statewide committees. The emphasis in Partners isn’t just to advocate for

yourself or your family, but to advocate for the greater good for people at the state and national level.”

Some changes have been made to Partners since the pandemic. Instead of in-person legislative mock testimony, this is done virtually now. McLaughlin said this convenience allows more legislators to attend. Each participant has to invite their own legislator now, and Partners invites others. The panels focus on supports for children and families, inclusive education, healthcare disparity and adult supports and services, including transition and employment.

“While each topic is broad, each participant brings their own story and perspective so the legislators can get real life information to see how things work for people with disabilities and their families in the state. We emphasize people telling their stories and their advocacy visions.”

McLaughlin said Partners allows people to “feel like they aren’t alone in this adventure. This year’s participants are all like-minded. They are all invested in community inclusion. They are up against so many battles, and they come and find their people. They all said they gained by learning from each other.”

Leidy Infante

One Partners participant was Leidy Infante, whom McLaughlin described as passionate about inclusion. She has a 15-year-old nonverbal son, Daniel Reyes, with autism spectrum disorder.

Infante learned about Partners from a friend who attended.

Daniel is Infante's only child. She lives with him in Passaic along with her husband and mother. She earned an associate's degree in early childhood education at Patterson Community College, where she works as a teaching assistant with young children at the college's Child Development Center daycare. "I have to continue my education so I can eventually teach preschool. My son is my inspiration every day to continue."

Infante had some prior experience with advocacy. In 2011, she contacted SPAN Parent Advocacy Network and obtained information about resources, training and workshops for parents of children with disabilities. She participated in their Parent-to-Parent program, talking to parents needing support. She also joined the monthly Passaic Special Needs Support Group meetings in her community in Passaic and met many parents in need of support. In 2013, she participated as a parent team member at her son's school, supporting parents of children with disabilities.

Daniel attends a school for students with disabilities. She advocates for his needs at school and for more in-home therapy to teach him independent living skills, such as brushing his teeth, tying his shoes, doing laundry and making sandwiches. She's also advocating for a successful transition to adult life. "One reason I attended Partners was because I wanted to learn to advocate better for him."

Infante said the most important thing she learned about at Partners was inclusivity. "We learned about including children in every activity. They can try to do everything and find things they can do. We learned about the achievements of people with disabilities. It was amazing to see how much people with disabilities can do. It opened my mind and heart and changed my life. My goal now is for my son to learn job skills through the Division of Vocational Rehabilitation Services (DVRS) and eventually be employed."

She also learned about networking, using the media and connecting with other parents. She has plans to use her newfound knowledge. "Sometimes we are afraid to speak up, but I feel more able to advocate now. I will volunteer at



Leidy and her son Daniel at South Jersey Deaf and Hard of Hearing Coalition in Hammonton NJ.

the POAC Autism Services Walkathon in Clifton this year and also at the 2023 Special Olympics New Jersey. I also want to advocate to improve the workforce for people with intellectual disabilities in my community this year. This is part of my Partners advocacy plan. My son having a disability opened my eyes to the need for support. It's my passion now to advocate for all people with disabilities."

Octavio Cuenca Maldonado and Luisa Chastel Messner

Two people with disabilities who attended Partners this year are Octavio Cuenca Maldonado and Luisa Chastel Messner, who are roommates in Hammonton. Both are deaf. "Octavio is extremely outspoken. He's very invested in advocating for more American Sign Language (ASL) across the board. He wants people who are not deaf to learn ASL. Luisa's interests are similar, but she just wasn't as vocal about it as Octavio. He was

more out front, while Luisa was more behind the scenes,” said McLaughlin.

Maldonado and Messner are both part of the South Jersey Deaf and Hard-of-Hearing Coalition (SJDHHC), where they work to improve accessibility for the deaf and hard-of-hearing community. Their supervisor shared information about Partners with them. “We realized that being part of this program would benefit us in becoming better advocates and leaders in our deaf, hard-of-hearing and developmental disabilities community,” said Maldonado

Messner had no previous experience advocating for either herself or others, but Maldonado advocated for himself in school when they hired unqualified ASL translators.

Messner said she learned about decision making from a different perspective at Partners. “Before, I never thought that people with disabilities could make decisions for themselves or have a say in making things better for everyone. Often, parents or caretakers make decisions for them without realizing that they are intellectually capable of doing it themselves.”

Maldonado said the most important thing he learned about was the collaboration between school districts and the Division of Vocational Rehabilitation Services (DVRS). “DVRS should go into schools and help any student with disabilities early on with applying for colleges and planning for their careers.”

At Partners, Maldonado met many parents of children with disabilities who were frustrated with the lack of resources and support for healthcare, education and accessibility. He gained a greater understanding of the need for accessibility and accommodation in all areas of life. Messner said that by sharing her own experiences and skills, she was able to help parents of nonverbal children find new ways of communicating and connecting with their children through sign language.

Messner said she enjoyed the brainstorming board that was set up at Partners. “It was a helpful tool for generating ideas and solutions to various issues facing the disability community. The board was a collaborative space where participants could share their thoughts and perspectives on different topics, and it helped to facilitate discussions and



Luisa Chastel Messner and Octavio Maldonado PIP graduates, work at South Jersey Deaf and Hard of Hearing Coalition in Hammonton NJ.

encourage creativity.”

Throughout the program, both participants learned how to better advocate for families and help them navigate systems. They said this empowered them. Maldonado shared that the program helped him to better understand the legislative process and terminology, which will allow him to effectively advocate for the programs and policies that will benefit the deaf and hard-of-hearing community. “I feel that I gained valuable skills and knowledge that I can use to make a positive difference in the world and create change at a systemic level.”

He also said that what he learned at Partners will provide him with mental health advocacy skills. He spoke about the many traumatic experiences within the deaf and hard-of-hearing community, such as being ignored, abused or experiencing language deprivation in childhood. “Without the proper resources and support, these

experiences can have a lasting impact on an individual's mental health. Many individuals in our community face higher rates of suicide, addiction, and depression. Advocating for mental health resources and support for the deaf and hard-of-hearing community can ensure that people have access to the help they need to heal and thrive."

Messner said Partners empowered her as an advocate by providing her with knowledge and understanding of different disabilities, which she can use to advocate for a wider range of people. She is particularly passionate about advocating for the rights of deaf students in education. "I have become more confident in my ability to advocate for myself and others, which is a valuable skill to have."

Both participants are committed to using the skills and knowledge gained from Partners to advocate for the deaf community. They plan to make a positive impact in their respective areas of focus. Maldonado will use the skills and knowledge gained from Partners to continue advocating for better resources and access for the deaf community. He intends to partner with different organizations to amplify his voice and work toward his advocacy goals.

Messner plans to advocate for the needs of deaf students at Individualized Education Plan (IEP) meetings to ensure they have access to the education they need. She will use the knowledge gained from Partners to do so effectively. She encourages other young people to attend Partners in Policymaking and get involved in leadership and advocacy. "Partners provides a valuable platform for deaf advocates to gain knowledge, skills, and confidence in advocating for their rights and the rights of others."

Maldonado said, "It has been an incredible experience. We have learned so much, met amazing people, and gained valuable skills that we can use to make a positive difference in the world. We are grateful for the opportunity to be part of Partners in Policymaking and can't wait to see what the future holds."

McLaughlin stressed that each session of Partners helps to empower the participants to build their toolkit of strategies for advocacy needs. "The sessions are validating to them. People often tell them things aren't possible. We empower them to say, "Let's see how we can make it happen. **P&F**



The banner features the 'common ground' logo in a stylized font, with a blue speech bubble containing the text 'Common Ground Online' and 'Increasing Dialog Among Stakeholders in New Jersey's Special Education System'. Below the logo is a row of blue stick figures holding hands, including two figures in wheelchairs. A dark blue bar at the bottom contains the text 'The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!'. On the left, a list of three bullet points describes the website's offerings. On the right, a blue box with a black ribbon contains the word 'Visit', the website URL, and a call to action for a free online subscription.

common ground

Common Ground Online
Increasing Dialog Among Stakeholders in
New Jersey's Special Education System

The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!

- Read about current issues in special education
- Get updates on legal and legislative developments
- Find important resources and information

Visit
www.NJCommonGround.org
to sign-up for a
free online
subscription!

WELCOME, NEW COUNCIL MEMBERS

By Maryann B. Hunsberger

The Council welcomed four new members: Annette Smith, Michael McCarthy, Laura Williams and Nantanee Koppstein. Council members review the state's service systems for people with developmental disabilities and advise policy makers on the best ways to change those systems to better serve the population. Members also review and award grants to spark innovative projects throughout New Jersey, as well as advocate for people with developmental disabilities and their families on an ongoing basis.

Annette Smith

Annette Smith is a parent advocate. Her youngest daughter Tiffany, who will be 40 in July, gave Smith her first experience in working with someone with a disability. "Tiffany developed differently from my older daughter, Alicia. At a year old she still wasn't turning over, crawling or walking. We saw a developmental specialist who diagnosed her with cerebral palsy. I heard a laundry list of things that could go wrong with her. Since about five years ago, she has a tracheostomy and a feeding tube. But, she's doing well. She's still at home. I have great support staff, including her sister."

When Tiffany was 10, Smith heard about the Regional Family Support Planning Councils and began attending her local council's meetings. She eventually served as the chair and the co-chair of council #4 and is still an active member. Smith was a member of the New Jersey Minorities with Disabilities Coalition. She also served on DDD's Urban Outreach Program to explore ways to reach urban families with information about the Division of Developmental Disabilities.

The Newark resident started her activity with the Council by attending Project Take Charge, a two-weekend advocacy training program. She then attended Partners in Policymaking (Partners), an eight-weekend advocacy training program. "I liked

► *Annette Smith, new Council member*



how the programs were almost a respite for the parent who went. You didn't feel guilty because you were learning how to help your child."

She found it moving to hear people's life stories at Partners. "I learned so much from these individuals. We met once a month, and each time was a different experience. We had such a good time getting close to each other. One woman was placed in a developmental center as a teen. She lived there for years. She told us what her life was like and how she was mistreated there. When the movement to take people out of the developmental centers took hold, she worked with a group of people to get out of the institution and then became her own advocate.

"When we graduated, each person made a speech. It remained in my head for so long. It made me really understand person-first language because I saw the person first, not the disability. I

learned to not assume that they needed our help. It was a great experience.”

One of the first things that initially moved Smith to learn about the disability movement was the cost of medications that Tiffany needed. “I got laid off from work and no longer could afford to buy them. Tiffany had to go on Medicaid. She would have been cut off if I made a dollar too much, so I couldn’t go back to work. I couldn’t find out how to access programs for working parents to get Medicaid for their children. I used that time to learn about the disability movement, how to get supports and services and how to help other families to do the same. Once Tiffany turned 18, I was able to work without it holding her back from receiving supports and services.”

Although Smith never expected to work in the disability field, she found a full-time job as the coordinator of the Out-N-About Program at Family Resource Network. “It was a respite program where staff would take individuals into the community. We went to farms and movies and cultural events.”

She now works at Neighbours, Inc., an agency that helps individuals and families to receive the supports and services they need. As a community navigator, Smith assists individuals and families in locating these supports and services. She walks them through Medicaid issues, staffing issues and finding additional resources.

Smith serves as the Vice-Chair of the Council’s Diversity, Equity and Inclusion (DEI) Subcommittee. When the subcommittee presented information about the results of a survey, she learned that the highest percentage of people receiving services—about 80 percent—were in the white community. The next highest was the African American community at 7 percent. “The subcommittee’s primary goal is to increase information and access to services in diverse communities. People don’t know which services are available or how to access them. The subcommittee has talked about hospitals and doctors and how if you don’t know the language, you don’t find the connections. If someone has autism or cerebral palsy, they need a navigator to lead them in the right direction. We want to connect people to medical systems that have different language lines. We want to help families access what they need.”

Laura Williams

Laura Williams was appointed to the Council by Governor Murphy as its Public Member. Williams is the executive director of The Arc, Ocean County Chapter. She’s the mother of a 15-year-old son, Chris, who is dually diagnosed with a developmental disability and a mental health diagnosis. “We adopted him at 15 months old from foster care. We immediately recognized the developmental delays and he’s been getting services as long as we’ve had him. He is in a specialized private school for kids with disabilities. He benefits from the Children’s System of Care and will need lifelong supports. It’s a challenge to access the right supports and services for anyone.”

Williams has a dual bachelor’s degree from Muhlenberg College in psychology and elementary education. After graduating, she worked in a group home at Morris Arc. She then worked at Community Access Unlimited. “It changed the trajectory of my career. I got my MBA from Rutgers and tried to marry the business side to the social services side. I’ve been working with people with developmental disabilities my whole professional career. I was in the field 15 years before we adopted Chris. My professional and personal lives intertwine.”

She was appointed by Governor Phil Murphy as the chair of the governor’s DDD Fee for Service Committee in 2018 and served until 2021.



► Laura Williams, new Council member

The Point Pleasant resident has worked in her position at The Arc since 2004. She said finding and retaining the workforce to support individuals with disabilities is the greatest challenge they are facing. “Ten years ago, we were looking at expanding. Since COVID-19, we are just trying to put the best supports in place for those people we are currently supporting. We are actively working to resume all of our pre-COVID-19 supports and services at the level we formerly did. It’s been a struggle. Our respite and other services need expansion.”

Williams feels that Governor Phil Murphy has done a great job of raising salaries of support workers to address the minimum wage increases in New Jersey. She also said the 2024 fiscal year budget is positive for people with disabilities. “I’m hoping this will go a long way to help these challenges, because we need to provide adequate services. Even if people are eligible for supports, it’s hard to find staff to provide services. People can’t get enough hours and it’s a challenge.”

As both an advocate and a family member, Williams feels she brings an interesting viewpoint to the Council. “I think I can bring a perspective that not too many people have. I can look at situations from both sides. I know how to work collaboratively. I was exposed to the Council since Ethan Ellis was there and I’m well aware of the impact they have. Any opportunity to work with the Council to provide supports and services is so important.”

As a Council member, Williams is most interested in the Children’s System of Care for children with intellectual and developmental disabilities (IDD). She wants to maximize supports and services for children as early as possible to minimize the need for out-of-home placements and extreme services. “If we invest in providing support for young children, we can give them tools to minimize the negative impact disability has on their lives. It’s why the Early Intervention System is so important. Our Children’s System of Care needs to be more robust. Investing in young children is advantageous down the road. Maybe they’ll never need residential service. Maybe they’ll be more work ready. The investment in children will have a great impact. It’s an area with opportunity here in New Jersey. I want to learn more about this area and have a positive impact.”

► Michael McCarthy, new Council member



Michael J. McCarthy

Michael J. McCarthy is a parent advocate who lives in Dumont with his wife, Marlene, and his 22-year-old son, William. He also has a 26-year-old son, Michael, Jr., who has autism.

McCarthy attended St. John’s University School of Insurance and worked as a chartered property casualty underwriter (CPCU) in insurance and risk management. For the first 18 years of his adult life, he helped manage a general insurance agency that his dad founded in 1956. He has always worked evenings as a theatrical stage hand and is a member of International Alliance of Theatrical Stage Employees (IATSE.). He has been a fulltime longshoreman since 2001 in Port Elizabeth. He’s a member of the International Longshoreman’s Association. “I love what I do now.”

He served as a special assistant to two different New Jersey Senate presidents, Carmen Orechio and John Russo. He ran for State Assembly twice. His father was a secretary of the New Jersey Senate in the 1980s and 1990s. In 2009, McCarthy attended events for legislation mandating therapy for autistic children. Governor

Jon Corzine signed the law and gave Michael, then 12 years old, a pen. “Once he hit adolescence, he became a recipient of the same therapy.”

When Michael graduated from school, the County Executive asked McCarthy to serve on the Bergen County Special Services Board of Education because of his activity in both his son’s school and in politics. He has held the position since then.

Michael had been diagnosed with ADHD and speech dyspraxia at 2 years old. “He started therapies right away. He began special education school at age 3. He’s mostly nonverbal. At age 8, he got an autism diagnosis.”

Michael left home at age 19 to live in a Children’s System of Care group home. Because of the lack of group homes in North Jersey, he lived two-and-one-half hours away in South Jersey. His family visited him every Sunday. “When he hit adolescence, he started having constant temper tantrums. He accidentally fractured his mom’s collarbone and gave me two concussions. Five minutes later, he’d be watching cartoons and giggling. He was 6’3” and 230 lbs. at the time. It was hard on William when his brother was at home and having crises. When William was 15, that’s when Michael had to leave to live in the group home.”

A few weeks after turning 21, Michael was transferred to a DDD group home 30 minutes from home. Michael is now 26 years old and is the youngest in his group home of six residents. He had no day program for two years because of COVID-19.

McCarthy serves on the Council’s Policy Committee. He will educate policymakers and advocate for oversight of group homes and other residential facilities. “Short staffing is a crisis. It’s about 50 percent better since COVID-19 ended. It’s one direct support professional (DSP) to two residents in adult group homes, unlike the one-to-one ratio in group homes for under 21 years old. Managers have to fill in themselves.

He still advocates for his son. “Michael needs structure, but the staff turnover is horrendous because of the low pay and the stress. He can’t feed himself, give himself medication or bathe himself. He needs a one-to-one DSP. Things are done hand-over-hand for him.”

McCarthy states that more supports are needed when children with developmental disabilities transition from the New Jersey Department of Children and Families (DCF) to DDD at age 21. “Thank God I have a terrific family and the high school had a good program to support families. But, the transition can be very stressful to a family. More family support is needed. The hardest part is the parents not understanding the process. I was in the system and even we had a tough time with it. Not as tough as other parents, but we still had issues.”

Despite everything, Michael is doing well. “He hasn’t had a temper tantrum in over a year. He has anxiety, but he’s happy.”

Nantanee Koppstein

Nantanee Koppstein was appointed to serve on the Council in June 2022. She serves on the DEI Subcommittee, the Executive Committee, and became the chair of the Public Policy Committee in March.

As a Council member, her goal is to advocate for New Jersey residents with IDD in collaboration



► Nantanee Koppstein at her home in West Windsor, NJ

with other Council members and staff. “I do this so New Jerseyans with IDD can live a meaningful and productive life in the community in accordance with each individual’s goals and objectives. My guiding principle is to consider the impact of the decision, such as a change in policy, with a 360-degree view on every member of our IDD community. Our work is not just about individuals, but about all people with IDD and their families in our state.”

On the DEI Subcommittee, Koppstein serves on a workgroup called Pipeline or Lifeline, chaired by Annette Smith. “The charge of our subcommittee is to address the need for culturally competent interactions as families of newly-diagnosed individuals with IDD navigate through the healthcare maze. One objective of the DEI subcommittee is to find best practices by hospitals, specialty care centers, pediatricians and other healthcare providers in Union County when they interact with families of newly-diagnosed children. Too often, families of children with IDD face barriers. Those families from diverse language and cultural backgrounds face compounded challenges.”

On the Public Policy Committee, Koppstein deals with education, employment and direct support professionals’ (DSP) salaries. “It’s a wide range of issues. The committee has many able members who bring forward expertise on the issues. We rely on individual members to work together and bring our community forward.”

Before serving on the Council, the West Windsor Township resident volunteered to put together recreational programs for teens and adults with disabilities for her township’s recreation department, starting in 2008. The programs continue to this day.

She has been a board member of the New Jersey Association of People Supporting Employment First (NJ APSE) since 2012. She served on the New Jersey State Independent Living Council (NJ SILC) from 2012 until 2022. She was a member of the State Rehabilitation Council from 2016 until 2022. She participated in the first summit of the Developmental Disability Advocacy Network (DDAN) in 2017 and has served on the DDAN employment workgroup since then.

Having earned her graduate degrees in economics, Koppstein’s career had been in banking and finance. She says the principle of economics—how to allocate scarce resources for social optimality—applies to the disability field. “That’s basically my guiding principle. We must consider the impacts of any decision on all members of our community. We must strive to do our best for all, given limited resources while being subject to multiple constraints.”

Koppstein’s introduction to the disability community was having her daughter, Monica, 35, who has IDD. “Monica has led the way for me. After having Monica, I realized that a lot more effort had to be made in order to obtain the services she needed. I served on the Parent’s Advisory Committee for Special Education of our local school during Monica’s middle school and high school years. I had to teach Monica how to learn to advocate for herself.”

In 2008, Monica was selected by the Council to represent New Jersey at the 2008 Self-Advocates Becoming Empowered (SABE) conference in Indianapolis. “I didn’t know much about the Council then. I thought I’d see how it went. It was her lucky break. She got to know other advocates. She got to work with Frank Latham of the Council’s Staff for Young Leadership Project. She participated in the Council’s advocacy programs for many years. This was my entry into the Council. It turned out to be a terrific opportunity for both of us.”

Monica now works full time at a large retail store. “It didn’t happen easily. She needed support and still does after so many years. By nature, she doesn’t advocate for herself because of having communication issues. The skills she learned from Frank and other self-advocates have really made this possible. I consider Monica my fulltime job. It’s a lot of work, but it’s worth the effort.”

Before the pandemic, Koppstein was invited to give a speech at a Partners graduation ceremony. “Being there made me realize that disability rights are civil rights.”

Monica still lives at home. “We considered her living elsewhere until the pandemic changed our plans. I focus on one thing at a time for her and I teach her to advocate for herself to this day.” **P&F**

PEOPLEFIRST NEW JERSEY

www.njcdd.org/peoplefirstnj

People First of New Jersey is a statewide organization comprised of youth and adults with intellectual and developmental disabilities that promotes choice and control for its members. Join chapters around the state.



CALLING ALL ADVOCATES

For People First New Jersey to grow and thrive, we're calling on advocates from all over New Jersey to join!

- Make positive changes in the community
- Speak your mind
- Take action
- All people with disabilities are welcome



Leadership • Self-advocacy • Professionalism



☎ 609-292-3453
✉ frank.latham@njcdd.org
🌐 njcdd.org/peoplefirstnj



LeDerick Horne is a poet, a professional speaker, and an advocate.