People & Families

NEW JERSEY COUNCIL ON
DEVELOPMENTAL DISABILITIES

VOLUME 4, 2024

Love or Survival: The Medicaid "Marriage Penalty"

Patrice Jetter with her partner, Garry Wickham

The New Jersey Council on Developmental Disabilities

Advocate. Collaborate. Educate

njcdd.org

COMMUNITY INNOVATION PROJECTS CIP

The New Jersey Council on Developmental Disabilities' **Community Innovation Projects (CIP)** encourage new and innovative activities designed to bring about meaningful change for people with developmental disabilities and their families.

Primary Goals

The primary goals are to produce short or long-term system change and ideas that can be replicated.

FUNDING UP TO $10,000 FOR 12 MONTHS AVAILABLE ALL YEAR

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.

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/41gYuQi** and email the form to **grants@njcdd.org**

People & Families

PUBLISHER New Jersey Council on Developmental Disabilities

CHAIRPERSON Paul A. Blaustein

EXECUTIVE DIRECTOR Mercedes Witowsky

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS
Brenda Considine, Maryann Hunsberger, Jonathan Jaffe, Jason Krasnow

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

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 People & Families 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

CONTENTS

Volume 4, 2024

6

LETTER FROM THE EXECUTIVE DIRECTOR

From legislation, public policy, and systems change, storytelling is at the heart of advocacy.

cover story

7

LOVE OR SURVIVAL: THE MEDICAID “MARRIAGE PENALTY”

by Jonathan Jaffe

Patrice Jetter and Garry Wickham are in love, but if they get married, they will lose the benefits that allow them to live independently. The subject of Patrice: The Movie, a new Hulu documentary, the so called “Marriage Penalty” is one of many outdated elements of public benefits programs.

12

THE NEXT GENERATION OF ADVOCATES

by Jason Krasnow

As the first generation of New Jersey’s most visible and outspoken self-advocates reach ‘retirement age,' many have asked: “Where are the younger self-advocates who will carry on the work?”

16

THE OLMSTEAD DECISION IS 25

by Jonathan Jaffe

In the landmark case of Olmstead v. L.C., the U.S. Supreme Court ruled that it is a form of discrimination for people with disabilities to face needless institutionalization, a violation of the 1990 Americans with Disabilities Act (ADA).

21

COOPER UNIVERSITY HEALTH CARE: IMPROVING CARE FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by Maryann Hunsberger

Going to the hospital is never ‘fun,’ but Cooper University Health Care is taking steps to meet the needs of patients with I/DD to reduce stress, anxiety, and agitation.

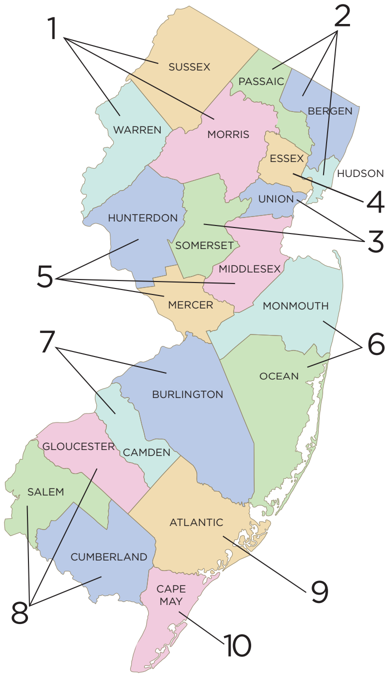
28

DR. DEBORAH SPITALNIK: CELEBRATING 41 YEARS OF SERVICE

After more than 40 years at the helm of New Jersey’s University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD), Dr. Deborah Spitalnick has retired. Her work has left an indelible mark on New Jersey’s system of supports and services for people with I/DD and their families.

26

INFORMATION ABOUT STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS



31

NJCDD COMMITTEE UPDATES

The Council’s standing committees consist of the Executive Committee, State Plan Committee, Public Policy Committee, and Grants Committee.

The Importance of Individual Advocacy

"Over and over, we see the important role of individual stories and how personal experiences can shift public perception and fuel systemic transformation."

This summer, America celebrated 25 years of the U.S. Supreme Court's Olmstead decision. That court decision changed the system of disability services. The case was brought by two women with disabilities, Lois Curtis and Elaine Wilson. The court heard their story and ruled that they had the right to live in the community, rather than an institution. The decision opened doors to deinstitutionalization and made it possible to fight for more funding for community-based services.

Kevin Nuñez, a self-advocate and member of NJCDD, was invited to a special ceremony at the White House to share his story. He spoke about his road to self-advocacy.

Patrice Jetter is a disability rights activist. Through Patrice: The Movie (which aired on Hulu), she shared her journey of overcoming systemic barriers and challenged assumptions about disabilities. She demanded dignity and inclusion not just for herself, but for all people with disabilities.

Early pioneers in the self-advocacy movement, including Bill Byrne and Barbara Coppens, are role models for the next generation. Parents' advocacy has also led to improvements in many areas, including changes at Cooper Hospital.

Over and over, we see the important role of individual stories, and how personal experiences can shift public perception and fuel systemic transformation. All of these stories and more are in this issue of People and Families.

By sharing our stories and pointing out injustice, we help make change for the better. What is YOUR story?

Sincerely,

Mercedes Witowsky

Mercedes Witowsky, Executive Director,
New Jersey Council on Developmental Disabilities

LOVE or SURVIVAL

The Medicaid "Marriage Penalty"

By Jonathan Jaffe

It seems so simple.

Patrice Jetter with her partner, Garry Wickham

Patrice Jetter and Garry Wickham are in love. They have been best friends for more than 35 years. And they are eager to get married.

But, as people with developmental disabilities who rely on the government's help to get by, their dreams of officially exchanging vows may never happen — unless there's an official act of Congress and a President's signature.

- continues

If Jetter, 60, and Wickham, 60, got married, they could lose financial support in the form of Social Security disability benefits, Medicaid and Section 8 housing vouchers.

The exchange of vows would be financially devastating for the couple, who both have cerebral palsy. It would create what members of the disability community refer to, with disdain, as “the marriage penalty.”

So unfair is the situation that it has become the focus of a new documentary on the Hulu streaming service, titled “Patrice: The Movie,” which premiered on Sept. 30 after its debut at the Toronto International Film Festival earlier in September.

The ABC News Studios documentary highlights Patrice, a colorful person whose email address includes the term “cool crip.” She has won more than 100 Special Olympics medals in numerous categories, and is also a juggler, painter, bowler, horseback rider, figure skater and on and on.

> “The deciding factor about whether to get married should be love, not whether it affects [Patrice's] benefits...
>
> We need to organize and advocate to remove these outdated barriers so people with disabilities can enjoy the lifelong companionship and commitment that marriage offers.”
>
> - Maria Fischer, Esq.

Perhaps her most prized possession is “PTown,” a detailed model train community and miniature amusement park that she has been building in her home for 20 years. It features a large Ferris wheel.

“Patrice: The Movie” carries an important message. But it is also a love story, showing a fun couple saddled by the harsh realities of what many consider to be woefully outdated federal rules and, of course, money and politics.

Patrice has led fun “commitment ceremonies” as a quasi-justice of the peace for people with disabilities who want to be married but can’t because their federal benefits would be cut.

“I want what everyone else has,” said Patrice, a crossing guard and artist from Hamilton. “I want to get married. There is nothing better than getting to spend the rest of your life with your best friend.”

“They can stop us from getting married, they can stop us from living together, but they're never going to stop us from loving each other,” Garry said.

Tying the knot would open the flood doors to countless issues, as the couple’s finances would have to merge. Garry, of Princeton, has a trust fund to help cover his basic needs, so Patrice could lose her Medicaid benefits and her Section 8 benefits for reduced, government-subsidized rent. And, if something should happen to Garry, Patrice would end up at the back of a long line to once again secure the benefits she sacrificed to get married.

In addition, New Jerseyans with disabilities who don’t qualify for Medicaid are also excluded from state Division of Developmental Disabilities programs that provide a host of services and supports.

Marriage should not cost people with disabilities the benefits they need to live independently.

Patrice and Garry now have a strong advocate in The President's Committee for People with Intellectual Disabilities (PCPID), an advisory body that assists the President of the United States. The committee knows Patrice well; she spoke at a May 1, 2023 session about her financial challenges as a person with disabilities, sharing her desire to get married.

In its report released this fall, PCPID reported that Supplemental Security Income (SSI) has the strictest resource limits, as individual beneficiaries like Patrice and Garry can only have $2,000 in assets. The committee agreed that the $3,000 limit in assets for a married couple constitutes the marriage penalty — a 25% benefit cut.

“It’s gonna end up costing more money if you cut people and then they have to apply for more public assistance to compensate for that loss,” Patrice told The Star-Ledger.

Those who exceed the limits will be terminated from the SSI program, which has not updated its standards since 1989. “As such, it is not reflective of the current economic conditions and is not enough for individuals to pay for an emergency or save for the future,” the report said.

It is important to note Congress has introduced several proposals over the past decade to increase the asset limit to $10,000 per beneficiary. One proposal would even increase the amount to $100,000 in assets.

> **“It’s gonna end up costing more money if you cut people and then they have to apply for more public assistance to compensate for that loss.”**
>
> **- Patrice Jetter**

The PCPID concluded with an important recommendation to the President: Congress and the Social Security Administration should update statutes and regulations to eliminate the so-called “marriage penalties” by establishing “couple” limits that are twice as much as “single” limits.

The low asset threshold forces many people with disabilities to spend down their savings to qualify for services, as the cost of care can sometimes exceed their savings. This necessary but difficult

- continues

> “To me, this is a civil rights issue and a human rights issue — one that needs to be addressed soonest. True marriage equality must include people with disabilities. My hope and expectation is that Patrice will drive this important conversation forward by speaking to the need for true marriage equality in a powerfully personal way.”
>
> - Paul Aronsohn,
> New Jersey Ombudsman for people
> with intellectual/developmental disabilities
> and their families.

choice increases their risk of financial instability and homelessness in the face of emergencies such as a leaking roof or major vehicle repair.

“It should not be this way,” said Patrice, noting that these mandated income limitations make it impossible for her to save money to purchase a vehicle. “I want to be able to live in the same house as my spouse.”

Paul Aronsohn, the state’s Ombudsman for people with intellectual/developmental disabilities, agrees.

Ted Passon, the filmmaker and native of Haddon Heights, said in a press release that if you are lucky enough to find the person you want to be with, but you’re disabled and collect Social Security or Medicaid benefits, you must choose between being with your partner and your own survival.

Patrice Jetter speaks to a crowd as she accepts an award from the New Jersey Council on Developmental Disabilities.

“Not only can’t you get married, but you can’t even live with your partner,” he said. “And so the fight for true marriage equality in this country is not over.”

Maria Fischer, a Lawrenceville-based attorney who appeared in the documentary meeting with the couple, noted the film focuses on SSI and Medicaid, but people with disabilities rely on a patchwork of other benefits to support their lives.

Government programs, she notes, helps pay for housing, food, transportation and utilities, such as electric and gas. “I am the mother of a young woman with I/DD,” she added. “The deciding factor about whether to get married should be love, not whether it affects her benefits.”

While there are discussions about legislative changes at the state and federal level, Fischer said, the community must do more.

“We need to organize and advocate to remove these outdated barriers so people with disabilities can enjoy the lifelong companionship and commitment that marriage offers,” she said. P&F

Eye on Advocacy

THE NJ COUNCIL ON DEVELOPMENTAL DISABILITIES

Weekly e-newsletter

Eye on Advocacy is a NJCDD weekly e-newsletter focusing on important news and events for the I/DD community. It is 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
800-792-8858

www.njcdd.org
VISIT OUR WEBSITE

Barbara Coppens is honored with PLAN-NJ's 2024 Outstanding Advocate Award

Frank Digiovanni Photography

THE NEXT GENERATION OF SELF-ADVOCATES:

Building the Future of a Movement

By Jason Krasnow

The self-advocacy movement formed in the 1970s in response to discrimination against people with intellectual and developmental disabilities. In a time when prevailing norms encouraged silence, early self-advocates insisted that they speak up about the issues affecting them, a focus which continues today. Self-advocates often utilize the help of a support person or network for assistance with research or public speaking, but support providers follow their guidance.

Acts of self-advocacy can include speaking up about one's own food, housing, or daily schedule. More coordinated, centralized self-advocacy efforts tackle broader societal problems facing people with I/DD. Frequent goals include deinstitutionalization, benefits policy, and the language used around disability. With a new and fragmented array of issues to consider, though, many in the field say the self-advocacy model needs adaptation. New training and organizing methods, under the direction of a younger generation of self-advocates, offer a path to expanded relevance for the movement.

Early self-advocacy efforts tended to focus on deinstitutionalization. According to Frank Latham, Youth Leadership Coordinator with the New Jersey Council on Developmental Disabilities, the early movement in the 1970s through the 1990s "was built around the deinstitutionalization movement, but also, they echoed the civil rights movement, for rights more broadly." People with I/DD wished to join the movement for civil rights, with the immediate goal of opposing condescension, mistreatment, and placement in institutions as a default for their lives.

More recent efforts focused on the "R" word and other derogatory language. "As far back as a decade ago, one of the pulse points for self-advocates was the use of the 'R' word," Latham says. "They galvanized around that, spoke directly to the council, and talked about how we could change the use of that word, in terms of how and why people used it, and to provide education about how people used it socially and in what context they used it."

Seasoned first-generation advocates recall the difficulties of work in a less hospitable environment and contrast their goals with the broader range of options available to a younger generation. In the words of Bill Byrne, a decorated self-advocate from Morris County, "They don't have to go through what we went through when we were thrown in institutions and forgotten about."

Self-advocate Barbara Coppens lists the changes in detail. "We advocated to get people out of the developmental centers, out into the community, to get jobs, also on getting rid of the 'R' word," she explains. But newer generations, these trailblazers say, struggle to achieve the same momentum.

"A lot of us older self-advocates are aging out, so I'm really concerned about the next generation of leaders," Byrne says. "I do a lot of Zoom meetings, and a person said to me, 'Why does this matter to me?' This is the danger part, because a lot of the younger generation today are saying 'Why does this matter to me? It isn't happening to me, that happened in the past.'"

Some of the older methods of self-advocacy still work, among them testimony to legislatures, committees, or other decision-making bodies. Erin Smithers, Director of The Arc of New Jersey's Self-Advocacy Project, says, "We make sure that we have at least one person that is testifying on the state budget."

But the absence of a single issue to rally around limits organizing, according to Latham and others. "I don't think there's a single galvanizing issue for them because many issues that were significant have been, if not resolved, mitigated in a way that

- continues

Transition planning can provide a pathway to self-advocacy for people with I/DD, and develop their experience before they enter adulthood. This can include advocacy through regular channels, and programs which support self-advocacy during the transition process. "We have a transition program within The Arc of New Jersey, called Planning for Adult Life. They do a great job of getting to schools and teaching students what comes next, what their options are," says Smithers.

With some other aspects of the transition, though, the specifics can prove difficult. Kathleen Halligan, Project Specialist at Community Options and an advisor for the Center for Advocacy Leaders, underlines the separation between school and adult services. "I think that there's always been a big separation between people that are still in school and adult services," she says. "Sometimes advocacy has been exclusive to the world of adult services. I think we can bridge that gap, but it is difficult."

Governor Chris Christie and Bill Byrne, a press conference attendee at The New Jersey State House.

has fragmented them," he says, echoing a common sentiment. Self-advocate Cortez Range suggests a solution in enterprise. "You've got to look at it as a business model," he insists. "You're going to have to start up your own thing."

While contemporary issues of interest to self-advocates tend to cover a wider space than past decades' focused campaigns, autonomy remains a common theme. "They pick the topic they would like to work on," Smithers says, listing some recent areas of concern for people with I/DD. "Lately it's been about DSP (Direct Support Professional) wages, transportation, and marriage equality, to make people with disabilities able to have as much in their savings as those without disabilities, to get married." The different committees and requirements involved across this spectrum of issues present an additional challenge and a need for further training.

Barbara Coppens is joined by Assembly Speaker Craig Coughlin following a 2023 REV UP the Vote event at the State House in Trenton.

Bill Byrne, a lifelong self-advocate.

In 2021, Community Options, a national nonprofit that works to provide housing and employment for those with disabilities, received a grant from the New Jersey Council on Developmental Disabilities to train younger New Jersey residents in self-advocacy. This grant provides funds for a leadership academy program which teaches self-advocacy techniques.

Halligan elaborates, “We developed a Leadership Academy for civic engagement. Each year we are accepting 30 individuals in the program, and it is open to everyone in New Jersey, 14 or older, that has a developmental disability. Individuals get paid to attend the sessions. We have a number of guest speakers, with a focus on public speaking, civic engagement, and creating leadership opportunities at local, state, and national levels.”

For those hesitant to engage, with the multifaceted state of self-advocacy today and the disparate methods used to accomplish different goals, the program offers a nonbinding introduction. “We also have opportunities for individuals who don’t want to attend the entire program,” Halligan adds. “Anybody is welcome to come to a session or two as a guest.” Approaches like this, which prioritize the involvement of the most possible people with I/DD through a diverse array of engagement options, promise a renewed and bright future for the self-advocacy movement. P&F

“Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.”

- Justice Ruth Bader Ginsburg

The Olmstead Decision is 25

By Jonathan Jaffe

For many advocates in the developmental disability community, the pivotal moment arrived with jubilation on June 22, 1999.

It was the day — 25 years ago — that the U.S. Supreme Court rendered a 6–3 decision that would forever change the lives of people with developmental disabilities, as well as their family, friends and caregivers.

In the landmark case of Olmstead v. L.C., the court ruled that it is discrimination for people with disabilities to face unjustified segregation, a violation of the 1990 Americans with Disabilities Act (ADA). It was the first time the Supreme Court decreed that needless institutionalization is a form of discrimination.

The Court ordered state and local governments receiving federal funds to ensure people with disabilities receive services in the most integrated setting appropriate to their needs. No longer would state-run institutions serve as the go-to solution to serve this population. Rather, the court decision swung open doors to full community inclusion, with people finally living amongst friends and family in the communities of their choosing, while getting the services they need.

The justices also called for more community support systems for people with disabilities, such as counseling, housing assistance, job training, medical care and help in managing daily tasks like shopping and cooking.

Impact

“To some, the 6–3 decision meant an end to the forced, ‘unjustified institutionalization’ of people with disabilities,” explained Paul Aronsohn, the state Ombudsman for people with intellectual and developmental disabilities. “To some, it meant that and a whole lot more. It was about dignity. It was about civil and human rights. It was about personal choice — about acknowledging that people with disabilities — like all people everywhere — should be able to choose ‘where’ and ‘how’ to live their lives.”

“Taken together, the Olmstead decision was a long-overdue affirmation by the nation’s highest court that people with disabilities matter,” he added. “What they need matters. What they want matters. What they say matters.”

Despite the enormous gains with Olmstead, New Jersey still needs to address accessibility issues involving people with disabilities, Aronsohn said. Specifically, he notes:

- Diversity in the workplace, especially positions at the most senior levels of government, should include people with lived disability experience, individuals as well as family members. Governmental policy decisions should also include the thoughts of these individuals.
- All government offices and committees — not just those focused on disability issues — should have meaningful representation from the disability community on their staff.
- Public meetings, including legislative hearings, should be offered in hybrid fashion, providing individuals with disabilities and family members the option to participate by video or in person.

"We need to do more to ensure that the voice of individuals and their families is heard in a meaningful way — not just on issues that directly affect them, but also in the larger policy discussions that take place in Trenton and in communities throughout the state," Aronsohn said. "Indeed, people with disabilities and their families should not just have a seat at the decision-making table; they should be driving the conversation, too. And we, in government, should do a better job listening to them."

The Road to Olmstead

The Olmstead case was prompted in part by the late Lois Curtis, who had been involuntarily shuffled from one mental institution to another in Georgia. Curtis was not yet 12 when she became a patient of Georgia Regional Hospital, where she was often kept sedated and spent her childhood in a mental health unit. Curtis spent two decades in institutions, while hoping to one day live in a group home in her own community.

"I prayed to God," she recalled in an interview for the University of Minnesota's Institute on Community Integration in 2014. "I cried at night so I prayed to God every night in my bed."

Lois Curtis, the plaintiff in Olmstead v. L.C., (center) presents President Barack Obama with a self-portrait of herself as a child that she painted. Joining them are, from left, Janet Hill and Jessica Long, from the Georgia Department of Labor, and Lee Sanders, of Briggs and Associates. The Oval Office, June 20, 2011. (Official White House Photo)

Her journey to the Supreme Court was launched in 1995, when the Atlanta Legal Aid Society filed suit against Tommy Olmstead, Georgia's commissioner of human services, demanding that the state transfer her to a group home.

"She'd say: 'Get me out of here. Would you please get me out of here?'" Sue Jamieson, her Legal Aid lawyer, recalled in an oral history. "'When am I getting out of here?'"

The Legal Aid Society convinced the federal courts that Curtis and another plaintiff, Elaine Wilson, had been denied civil rights. Georgia then appealed to the Supreme Court, saying there were insufficient funds to provide community care. The court sided with Curtis and Wilson.

Following the landmark case, Curtis was able to move to her own apartment and became an artist. She also became a public advocate for the rights of people with disabilities and on June 20, 2011,

- continues


Kevin Nuñez , a member of the NJCDD, spoke as part of a panel of guests marking the 25th Anniversary of the Olmstead Decision.

presented a painting to President Barack Obama in the Oval Office. She died in 2022 at age 55.

A Greater Voice

For the New Jersey Council on Developmental Disabilities, as well as for advocates across the nation, the Olmstead decision was the result of decades of work. In a unified voice, people raised awareness of the injustices surrounding institutions and the prejudices that residents faced each day, forced away from their loved ones and their homes.

Armed with the provisions of the ADA, which demanded people with disabilities enjoy the full rights of citizenship, the disability community was engaged and focused on change. Olmstead reflected those facts, and honors those bold enough to challenge the status quo in America.

It was also a call to eliminate the soft bigotry of low expectations placed upon people with disabilities, and work to build a society where all people can decide the direction of their own lives.

In June, 2024, the White House welcomed disability advocates from across the country, including NJCDD memeber Kevin Nuñez.

In this rare and remarkable event, a dozen developmental disability councils, as well as the National Association of Councils on Developmental Disabilities (NACDD), spoke of the importance of the court decision to countless lives.

Nuñez, 37, of Willingboro was the clear choice to represent New Jersey's disability community. Besides his past leadership role with the NJCDD, he is also involved with "Self Advocates Becoming Empowered," a regional and national self-advocacy organization. His first book, "Confessions from Disability Limbo," was published in 2021. His creation, "The Advocacy Life Podcast and Blog," a disability awareness podcast and blog, was relaunched in 2022.

In his White House remarks about the importance of Olmstead, Nuñez reminded the audience that plenty of advocacy work is still needed, such as providing more workforce training for those who work with people with disabilities and opening more career paths.

"Don't live in fear because of your disability — find your abilities," Nuñez told the audience. "Get involved with your Council on Developmental Disabilities because years ago, someone took a chance on a kid who had given up on college. Now, I sit here today in the White House. It is time for others to make a difference for the next generation."

As part of the 90-minute White House event, the participants viewed "Take Me Home," a short film about an adult with a cognitive disability living with her mother in Midland, Florida. There was also a panel discussion highlighting new federal efforts to support individuals with disabilities in leading fulfilling lives, securing employment and living independently within their communities rather than in institutional settings.

"We want everyone to understand what Olmstead is and means to us, and — because having people with disabilities living in the community is good for the WHOLE community — we want people outside of disability circles to understand that Olmstead is good for them," said Jill Jacobs, Executive Director for NACDD, who worked closely with the White House to plan the celebration, which was also broadcast virtually.

Added Erin Prangley, Policy Director, NACDD: "Lucky for us, Lois Curtis and Elaine Wilson kicked down the door that kept people with disabilities in institutions and gave people with disabilities the key to living in the community in the Supreme Court Olmstead decision."

Recent regulations from Centers for Medicare and Medicaid Services (CMS) now give people with disabilities greater say in the types of supports they need to live in the community, but only if they are aware of these new rules and organize to take advantage of them, Prangley noted.

"State Councils on Developmental Disabilities and others nationwide are still fighting today to get states to follow these new rules that help raise direct care workforce pay, increase access to services, and improve health and safety conditions for home and community-based services so community living becomes a reality for everyone." she added. P&F

> "The Olmstead decision was a long-overdue affirmation by the nation's highest court that people with disabilities matter. What they need matters. What they want matters. What they say matters."
>
> - Paul Aronsohn,
> New Jersey Ombudsman
> for people with intellectual/
> developmental disabilities
> and their families

> "Recent regulations from Centers for Medicare and Medicaid Services now give people with disabilities greater say in the types of supports they need to live in the community, but only if they are aware of these new rules and organize to take advantage of them."
>
> – Erin Prangley, Policy Director, NACDD

Kevin Nuñez, New Jersey Advocate

By Jonathan Jaffe

As a statewide disability advocate, NJCDD Member Kevin Nuñez has many opportunities to highlight the needs and concerns of people with developmental disabilities.

But very little compares to the enormous opportunity he experienced on June 18. He found himself in the White House, surrounded by some of the most experienced disability advocates, policy makers and federal government leaders, talking about the importance of the 25th anniversary of the Olmstead court decision.

As staff members of the Biden Administration took notes, Nuñez shared his thoughts about the importance of the U.S. Supreme Court decision in 1999 and how the principles of Olmstead have drastically changed the lives of countless people and their loved ones.

Nuñez is proud to have spent more than 15 years at the forefront of New Jersey's disability self-advocacy movement as an advocacy leader, author and podcaster. His first book, Confessions from Disability Limbo, was published in 2021.

Nuñez, who graduated from Bridgewater-Raritan High School in 2006, joined the NJCDD in September 2016, focused on advocacy work for himself, his twin brother with disabilities, Abner, and the population as a whole. Because of Olmstead, the brothers have been able to live at home, with modifications, with their father in Willingboro.

"Kevin's participation in the White House's panel discussion was an affirmation of his impact as a thought leader, and underscores the NJCDD's ongoing dedication to ensuring that people with developmental disabilities in New Jersey and across the nation have the necessary support and opportunities to thrive," said NJCDD Executive Director Mercedes Witowsky.

Nuñez said he received the White House invitation about 10 days before the event, prompting a flurry of preparation. "It came on as this fast and wonderful experience to be part of the bigger picture," he said. "So often, America sees people with disabilities as a footnote when it comes to politics and public policy. So, to be at that table was thrilling for me."

Kevin Nuñez, a member of the NJCDD, at an event in Washington, D.C.

A self-described loudmouth who prompted good-natured laughs at the White House event when he declared that all the "cool kids" have cerebral palsy, Nuñez has parlayed his outgoing personality into important roles with the NJCDD.

What started with a nine-week leadership program with NJCDD's Partners in Policymaking has led to a life dedicated to activism — a world Nuñez didn't know existed. In a society that dedicates few resources toward creating opportunities for people with disabilities once they graduate high school, his work with the Council has changed his life, he said.

Although Olmstead has led to better lives for millions of Americans with disabilities, Nuñez reminded White House attendees that there is a lot of work to be done in areas such as providing more training for those who work with people with disabilities and opening career paths for Americans with disabilities. P&F

Improving Health Care for People with Intellectual and Developmental Disabilities

By Maryann Hunsberger

Health care quality and access for people with intellectual and developmental disabilities (I/DD) are a priority for the Council. Cooper University Health Care (Cooper), with several locations in South Jersey, is making impressive progress in this area.

Cooper has started the Cooper Intellectual and Developmental Disabilities Patient, Family, and Caregiver Support Program, which is taking steps to meet the needs of patients with I/DD to reduce stress, anxiety and agitation so these patients can receive the medical care they need, and their families can feel more comfortable in a hospital setting. The Cooper Program has five pillars, as follows:

1. Specialized Care-Coordination Team:

Cooper has a specially-trained nurse navigator who knows the best practices and protocols and is dedicated to the screening and anticipation of care of patients with I/DD. The nurse navigator helps to coordinate a care team comprising office and clinical staff, case managers, guardians, caregivers, support staff and transportation services.

Depending on the patient and family needs, the team does the following:

- Identifies special needs in advance of the patient's visit;
- Creates an individualized care plan for each patient;
- Offers developmentally appropriate explanations about the patient's condition and what to expect during the visit;

In the pediatric sensory room, a patient uses a fidget toy to control the Vecta Mobile Sensory Station

- Provides sensory spaces and items that promote a soothing environment;
- Supports parents and caregivers so that they can rest and recoup.

- continues

2. Education for All Team Members:

Cooper began specialized training and education for all nurses, critical care technologists and other team members so they know the best practices and protocols for caring for patients with I/DD.

Erin Shipley, CEN, MSN, RN, Cooper's Vice President of Consumer Experience, said, "We have a whole I/DD team with front line physicians, physician leaders and advanced practice nurses. We have a core curriculum created for physicians, nurses, residents, advanced practice providers and even our security guards. We're trying to find the preferred way that we can customize care for patients based on their diagnosis."

Franziska Jovin, MD, Chief Experience Officer at Cooper University Health Care, said, "Not only do we educate our clinical staff, but also all of our leaders. They need to understand the complexity of care to influence the decisions they make. We have done presentations for the senior vice president, vice president and administrative council."

The team also teaches outside of Cooper. Shipley said, "We have a nursing education team that helps teach clinical outcomes for continuing education. We want to make sure it's not just coming to a class, but that we do hands-on teaching at the bedside and in the offices. We recently held a conference that was designed specifically for nurses and caregivers of individuals with intellectual

The Council's Health and Wellness Subcommittee

Although the Cooper Project is not a part of the Subcommittee, this project fits neatly with its mission. The functions of the Committee are as follows:

(1) Advise the Council on health and wellness matters that impact individuals with I/DD and their families.

(2) Be composed of self-advocates and family advocates as well as state partners.

(3) Advise the Council on health and wellness related legislation and policies impacting individuals with I/DD.

(4) Utilizing the Council's State Plan, conduct activities that align and fulfill the goals and objectives of the State Plan with consent of the Public Policy Committee.

(5) Respond to other responsibilities as requested by the Council or in conjunction with other Committees.

Elizabeth C. Dalzell, a Council member and chair of the NJCDD Subcommittee on Health and Wellness, is the parent of a 30-year-old daughter, Liesl, with multiple disabilities. She also serves on Cooper Hospital's Patient Family Advisory Council. The Haddonfield resident said, "As a parent, this makes a huge difference. At Cooper, the medical staff has a better understanding of who this population is, and that these individuals deserve to be treated with dignity and respect, especially in a medical setting."

and developmental disabilities. We are showing caregivers the tools and resources and encouraging their use during patient visits. They are part of the team."

3. Electronic Medical Record Enhancements:

An I/DD infrastructure has been created within Cooper's electronic medical records system to allow clinicians to document patients' specific needs for better coordination of care, bridging the gap between parents, guardians, caregivers and specially-trained hospital care teams.

Dalzell said, "If a patient has I/DD, a summary of their needs is easily accessible to all the providers. It has the most important things the medical team needs to know, such as if someone is nonverbal; if someone has diabetes; what bothers them, such as loud noises or sensory overload; if they need liquid medicine vs. pills; if they have a history of seizures; who the decision maker or legal guardian is. Once a patient is part of the program, the I/DD team calls them a few days ahead of time to ask if they need a private waiting room or if they want to wait in their car."

"The I/DD team is notified on a daily basis by email of patients having health care encounters in the Cooper system. If a patient is admitted, they dispatch a team to the bedside to support the patient with I/DD."

4. Sensory Support for Patients:

The hospital experience can be stressful for anyone, and particularly so for patients with sensory sensitivities. Shipley said, "Sensory overload may lead to stress, agitation and, ultimately, behavioral challenges."

Cooper has built multisensory rooms across the hospital campus, currently located in the pediatric emergency department and the radiology department in the hospital, and in the pediatrics office in the Sheridan Pavilion. These multisensory rooms are therapeutic spaces with special lighting, soft and textured surfaces, white noise generators and fidget toys. Additional tools such as noise canceling headphones and weighted blankets are available. These features help calm and focus patients so they can better interact with the care team.

Cooper has also deployed mobile sensory units with equipment and tools that can be taken to multiple locations, such as office exam rooms, patient rooms or testing areas to help patients during potentially overwhelming or overstimulating experiences.

"The mobile units facilitate a better doctor-patient interaction. The special rooms and carts can help patients with more acute sensory needs avoid further stress, anxiety and agitation so they can access their medical care and their family can feel more comfortable," said Dr. Jovin.

- continues

Council Awards Grant to Improve Behavioral Healthcare

NJCDD awarded a contract to Woods Services in the amount of $225,000.00 for a period of 18 months, beginning April 1, 2024. Woods Services, on behalf of Woods System of Care (WSOC), serving as lead agency for this project, will build capacity and promote systems change by designing and disseminating training and tools that enable providers throughout NJ to provide better care to individuals dually diagnosed with I/DD and mental health conditions, while also empowering families with knowledge and resources so that they can better navigate the system.

A mobile team will soon partner with organizations in South Jersey to see patients in their homes, in day programs or in group homes. “We have already done work in the community. We have done vaccinations for Bancroft residents to save them a trip to the doctor’s office. Seeing patients in their own environment is less stressful, and it reduces the need for transportation. At the beginning of 2025, we plan to launch our mobile team with experienced physicians and support staff.”

5. Establishing a Patient Family Advisory Council

Cooper has recruited a Patient Family Advisory Council comprising family members, guardians and caregivers of patients with I/DD. The Advisory Council provides feedback on the services and care provided at Cooper, allowing them to learn which aspects of the program are most helpful and where adjustments should be made.

Dr. Jovin said, “At Cooper, we are committed to providing patients with I/DD with the same advanced care we provide to each of our patients. We’re confident these strategies will successfully create better patient experiences and outcomes and reduce the level of stress on patients and their families.” **P&F**

Hospital experiences are not easy for anyone, but can be especially stressful and difficult for people with developmental disabilities.


The Forman Family (l-r) Elijah Cohen, Donna Forman, Sydney Forman, Karly Forman-Cohen, and Rick Foreman.

Donna Forman: Using Her Voice in a Positive Way

by Maryann Hunsberger

Donna Forman of Cherry Hill, a member of the Cooper Foundation Board of Trustees for several years, is the parent of a daughter, Sydney, 27, who has a developmental disability. Forman was a speech language pathologist until her daughter was born. "Now my mission is to be Sydney's advocate."

Her daughter had difficulty transitioning from pediatric care at the Children's Hospital of Philadelphia to adult care at Cooper. "I felt we weren't being respected by some of the staff when Sydney was in the hospital. Many doctors didn't understand the nature of her specific needs." Forman contacted the CEO of Cooper, asking him to improve the hospital's method of dealing with people with I/DD.

Cooper's CEO, Anthony Mazzarelli, MD, responded and put her in touch with Franziska Jovin, MD. "Dr. Jovin always tried to make the experience good for the I/DD population at other hospitals before she came to Cooper. This was almost her calling," said Forman. "She listened and brainstormed with us to make things better. Cooper is a great hospital, so I wanted Cooper to be better with this specific population. They needed a better protocol, better training and better understanding. Dr. Jovin put together the Patient Family Advisory Council. I pulled in parents who are strong advocates, including Elizabeth Dalzell."

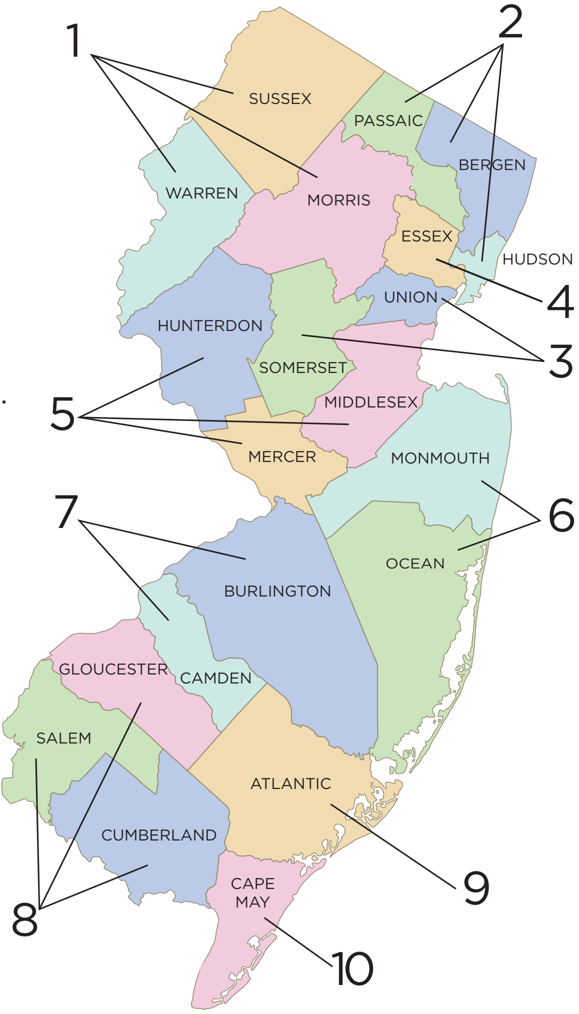
Forman recounted how Sydney went in for a CAT scan recently. She typically is frightened by the experience. "They brought a sensory cart to the room where she was having the scan. It was night and day from her last experience because we all worked together as a team. They are optimizing the time they have with each patient."

Forman had previously been treated for cancer at Cooper. Her experience was positive, so she got involved in fundraising and they asked her to serve on the board. "They saved my life and I wanted to help. I was beyond grateful for the care I got. My board position gave me the opportunity to use my voice in a positive way. When made aware, the hospital was so grateful that we helped them open their eyes to the problems. They did everything they could to make it better. Dr. Jovin and her team are passionate about making treatment better for people with I/DD. People just aren't aware of things until someone tells them things." P&F

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, 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 the Family Support & Facebook page at www.facebook.com/NJFSPC.

The Family Support Act of 1993

This act 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.

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

7:00 p.m.–8:30 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

Meets the second Monday of each month

6:30 p.m.–8:30 p.m.

6 MONMOUTH, OCEAN

RFSPC #6
e-mail: RFSPC6@gmail.com
Chair: Mike Brill

Meets the second Thursday of each month

6:30 p.m.–7:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
e-mail: RFSPC7@gmail.com
Chair: Laura Kelly

Meets the second Thursday of the month

Odd months: 1:00 p.m.–2:30 p.m.

Even months: 7:00 p.m.–8:30 p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
e-mail: RFSPC8@gmail.com
Chair: Amy Kiger

Meets the second Thursday of each month

7:00 p.m.–8:00 p.m.

9 ATLANTIC

RFSPC #9
e-mail: RFSPC9.atlantic@gmail.com
Chair: Susan Coll-Guedes

Meets the fourth Tuesday of every even month

6:30 p.m.–7:30 p.m.

10 CAPE MAY

RFSPC #10
e-mail: RFSPC10CM@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 regional meetings are held virtually, except hybrid meetings at RFSPC #1. If you are interested in attending any meeting, please email the specific RFSPC to request a meeting link.

Celebrating 41 Years of Service

Deborah M. Spitalnik, PhD, Director of The Boggs Center, Retires

Deborah M. Spitalnik, PhD, founding Executive Director of The Boggs Center on Disability and Human Development, New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service, has retired after 41 years of service. In addition to her leadership at The Boggs Center, she was also Director of New Jersey's Leadership Education in Neurodevelopmental and Related Disabilities Program, (NJLEND), and Professor of Pediatrics and Family Medicine and Community Health at Rutgers Robert Wood Johnson Medical School.

> "Dr. Spitalnik has helped to guide our state through an incredibly dynamic time in the field of disabilities, and has done so with wisdom, grace, and compassion."
>
> Mercedes Witowsky,
> Executive Director, NJCDD

Dr. Spitalnik's career focused on developing inclusive communities by addressing the intersection between people and public policy. She promoted the health and well-being of people with disabilities through her research and teaching, educated innumerable medical students as Course Director for the Center's flagship Seminar on Family-Centered Care and Developmental Disabilities, developed model integrated primary care for adults and training for family medicine residents, and provided extensive consultation and information to people with disabilities, families, policymakers, state agencies, and service providers.

Her leadership, accomplishments and vision reached far beyond New Jersey. She co-authored two editions of the diagnostic manual in Intellectual Disability, and served as a member and chair of the President's Committee for People with Intellectual Disabilities. She was past president of the Association of University Centers on Disability (AUCD). She also served as chair of the Council on Quality and Leadership (CQL), and chair of New Jersey's Medical Assistance Advisory Council. In addition, she has been recognized by scores of organizations for her work: The AUCD Lifetime Achievement and George S. Jesien Distinguished Achievement Awards, the Rutgers Clement A. Price Human Dignity Award, the American Association on Intellectual and Developmental Disabilities (AAIDD) Dybwad Humanitarian Award, the New Jersey Council on Developmental Disabilities Lifetime Achievement Advocacy Award, the Verice M. Mason Community Service Leader Award of the Edward J. Ill Excellence in Medicine Awards, the Humanitarian Award of The Arc of Union County, the Elizabeth Boggs Citizenship Award, and the Community Health Law Project's Ann Klein Distinguished Advocate in Developmental Disabilities Award.

This fall, The Boggs Center honored Dr. Spitalnik with a retirement reception, at which she was presented a joint resolution on behalf of all members of the state legislature and a proclamation from New Jersey Governor Phil Murphy. In her remarks, she reflected on the importance of the work being done in the community of disabilities and the vital need for collaboration.

Dr. Spitalnik's contributions were recognized by the state legislature and through a proclamation from Governor Phil Murphy.

“The disability rights movement, family advocacy and self-advocacy teaches us lessons of democracy: everyone is valued, everyone belongs, that we are connected one to another, and that we must work together to weave the fabric of community,” she said.

“New Jersey is fortunate to have had Dr. Spitalnik at the helm for more than four decades. She has helped to guide our state through an incredibly dynamic time in the field of disabilities, and has done so with wisdom, grace and compassion,” said Mercedes Witowsky, Executive Director, NJCDD. P&F

“The disability rights movement, family advocacy and self-advocacy teach us lessons of democracy: everyone is valued, everyone belongs, that we are connected one to another, and that we must work together to weave the fabric of community.”

- Deborah M. Spitalnik, PhD

PEOPLE
FIRST
NEW JERSEY

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

People First of New Jersey supports individuals with intellectual disabilities to **speak for themselves, help each other**, and **make their voices heard.**

SPEAK OUT
BE HEARD

njcdd.org/peoplefirstnj

609-292-3745
P.O. Box 700
Trenton , NJ 08625

facebook.com/peoplefirstnj

facebook

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 family members of individuals 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 Council in 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 of the Council's committees. Recently, the Committee:

- Welcomed two new self-advocate members to the Executive Committee, Todd Emmons

– continues

> *The Legislative Public Policy Committee with staff from Assembly Majority Leader Lou Greenwald to promote DVRS involvement through an appointed commission.*

(Vice-chair) and Myrta Rosa (Member at Large).
- Set agenda for the next Council meeting and Lunch and Learn.
- Reviewed NJCDD's role in three National Communities' of Practice.
- Discussed updates from the Governor's Office of Appointments.

Executive Committee's 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. It serves as a voice for New Jerseyans with I/DD by promoting self-advocate participation and peer advocacy that advances independence and inclusion. On an on-going basis, the Subcommittee advises the Council regarding self-advocate needs to ensure 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; and responds to additional requests made by the Council or in conjunction with others. Recently, the Subcommittee:

- Discussed scams that target people with disabilities.
- Discussed training on the new voting machines/voting process for people with I/DD
- Discussed the need for people with disabilities to take an active apart in the upcoming national election and to be informed about disability policies.

Legislative Public Policy Committee

Nantanee Koppstein is the chair of the NJCDD Public Policy Committee. Andrew McGeady is the vice-chair of the NJCDD Public Policy Committee. The Committee reviews legislation and public policy issues. Recently the committee:

- Engaged in advocacy and education efforts with staff from Assembly Majority Leader Lou Greenwald to promote DVRS involvement through an appointed commission.
- Reviewed and discussed legislation proposed by Senator Anthony Bucco to improve dental practices for people with disabilities, and steps to increase the participation of underserved communities in policymaking.
- Referred two bills to the Children and Youth Subcommittee, one addressing the expansion of Early Intervention Services to children through age 5; the other addressing referrals from school districts for private mental health services.
- Held a fall Legislative Disability Caucus hosted by Senator M. Teresa Ruiz. The caucus focused on "Ensuring ALL Children in New Jersey are Fully Included & Treated Equally." The meeting began with a brief discussion of dwarfism and other rare conditions, then delved into the racial, ethnic and disability disparities in the use of seclusion, restraint, suspension, and expulsion in schools. The Caucus discussed systemic and preventative alternatives to exclusionary discipline.

The NJCDD Subcommittee on Health and Wellness met with Coordinators of Cooper University Hospital's Cooper Intellectual and Developmental Disabilities Patient, Family, and Caregiver Support Program.

Legislative and Public Policy Committee's Subcommittee on Health and Wellness

Elizabeth Dalzell is the chair of the Subcommittee on Health and Wellness. Operating under the Legislative Public Policy Committee, this Subcommittee advises the Council on health and wellness matters that impact individuals with I/DD and their families as well as health and wellness legislation and policies impacting individuals with I/DD. It conducts activities that align with, and fulfill the goals and objectives of, the Council's state plan.

- Coordinators of the Cooper University Hospital's, Cooper Intellectual and Developmental Disabilities Patient, Family, and Caregiver Support Program met with the Subcommittee to share their efforts to improve the patient experience for individuals with I/DD by creating a safe and supportive environment tailored to their needs. The Subcommittee will explore ways to expand the program to other medical facilities throughout the state.
- The Subcommittee will continue to focus on improving underserved communities' access to healthcare, improving the supports and services available for individuals that are dually diagnosed with mental health and I/DD, and improving oral health care options individuals with I/DD.
- Special Smiles NJ will present at the next meeting on the dental services they provide to patients with I/DD.

Legislative and Public Policy Committee's Subcommittee on Children and Youth

Peg Kinsell is the chair of the Subcommittee on Children and Youth, which is comprised of more than a dozen parents, advocates, community leaders, state leaders, educators, and Council members. Operating under the Legislative and Public Policy Committee, this subcommittee focuses on issues that affect those under the age of 21 and their families. Recently, the Subcommittee discussed and addressed:

- Access to Family Support Services through the Children's System of Care.
- Seclusion/restraint/suspension and expulsion, including racial, ethnic, and gender disparity.
- School safety drills and emergency planning.
- School transportation safety.
- School-based mental health services.
- Services for youth 18–21.

State Plan Committee

Helen Steinberg is the chairperson of the State Plan Committee. The committee is responsible for gathering information and data for planning, reviewing progress through the completion of the 5-year state plan, advising on unmet needs, and making recommendations to NJCDD around policy and funding priorities.

The Council is on target to meet goals and objectives in the current State Plan.

Recently:

- continues

The State Plan Committee's Subcommittee on DEI discussed the need for provider information and training around the needs of a diverse array of family situations.

- The Administration for Community Living accepted state plan amendments as well as the Fiscal Year 2025 Work Plan that commenced on October 1, 2024.
- The Council remains on target to meet goals and objectives in the current State Plan.
- State Plan development for the next State Plan will begin in 2025 and is due in August of 2026.

State Plan Committee's Subcommittee on Diversity, Equity, and Inclusion

Sarah Aziz is the chair and Annette Smith is co-chair for the DEI Subcommittee. The Subcommittee, operating under the State Plan Committee, is comprised of NJCDD Council members, members of the I/DD community and their family members, advocates/self-advocates, and state agency representatives. Established within the bylaws of the Council and in alignment with the goals of the 2022–2026 Five-Year State Plan, the DEI subcommittee works to ensure that there is diverse representation within the Council and its members. It reviews 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 throughout the planned goals and objectives. Recently, the Subcommittee:

- Discussed the impact of caregiving on the mental and physical health of family members.
- Discussed the need for individuals and families to have access to support services, and to ensure that providers offer support services as an option.
- Discussed the need for provider information and training around the needs of a diverse array of family situations (single parent households, blended families, multigenerational households, same-sex partnerships.)
- Discussed the need for information for families about the impact of employment on Medicaid benefits and the responsibility of the State to ensure individuals understand their Medicaid eligibility.
- Discussed the need for a qualified resource center to provide quality responses to life-changing decisions as well as the need for clear and accessible information.

Grants Committee

Kevin Nuñez serves as chair of the NJCDD Grants Committee. The Committee oversees the development of funding announcements that align with the Council's Five-Year Plan goals, objectives, and activities. The Committee reads all responses to funding announcements and makes recommendations to the Executive Committee for funding and continued funding aligned with the Council's Five-year Plan, based on grantee performance. Recently, the Committee:

- Reviewed all funded projects and discussed the progress and status of each.
- Reviewed status of Memorandums of Understanding.
- Reviewed status of Community Innovation Projects (current, new and letters of interest).
- Reviewed the grantee status report update provided by the Boggs Center in the completed contract: Building Capacity to Improve Adult Health Care for Patients with I/DD.

An enhanced FAMILY SUPPORT CRISIS Handbook

Un manual MEJORADO DE APOYO PARA LAS FAMILIAS E momentos de crisis

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.

Caja de herramientas para el bienestar y la salud conductual

Fomentar que la gente de Nueva Jersey de todas las edades que padezca discapacidades del desarrollo e intelectuales, al igual que todas las partes interesadas que provee apoyo puedan dar su opinión y hacer una elección.

NJCDD
NEW JERSEY COUNCIL ON
DEVELOPMENTAL DISABILITIES

Pre-Sort Standard
U.S. POSTAGE
PAID
TRENTON, NJ
PERMIT NO. 21

Barbara Coppens receiving PLAN-NJ's 2024 Outstanding Advocate Award