

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 1,
2023

NASSAN'S VILLAGE

Changing minds, hearts and lives



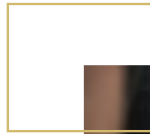
*Nassan Arbubakarr
and his mother,
Nadine Wright-Arbubakarr*

COMMUNITY INNOVATION PROJECTS CIP

The New Jersey Council on
Developmental Disabilities'

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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.

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- ☒ 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.
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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.

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Aspiring writers are often given the advice to “write what you know.” That is exactly what New Jersey native, Niya Wright did when she wrote the script for an episode of the Emmy award-winning Netflix animated children's program, *Ada Twist, Scientist*.

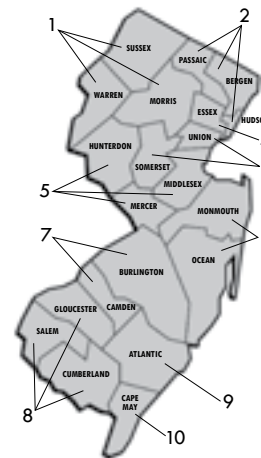
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Cultural liaisons are diverse individuals within the I/DD community who connect their own network of contacts and resources to the Council for disability-related information. A person's network can include family, friends, places of worship, college or trade school, employment or volunteer contacts, memberships or associations, and leagues or clubs. The Council has started hiring and working with cultural liaisons in Passaic and Hudson Counties.



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What Parents & Educators Need to Know

New Jersey became the nation's first state to ban corporal punishment in schools. But there is a loophole. For the 240,000 students with disabilities in New Jersey, a different set of rules apply. In an emergency, it is legal to physically restrain children with disabilities as young as preschool. It is also legal to place them alone in a locked room (often with padded walls), a practice known as *seclusion*.

20 REACHING UNDERSERVED COMMUNITIES

Similar to most trends, architecture addresses the needs and desires of the moment. Just look at all the new homes that are being built around New Jersey, as the latest and greatest appeal to demanding buyers who consistently call for the most modern conveniences, innovation and ease. That same need for quality and comfort is also in the intellectual/developmentally disabled community, where architects are steadily redefining the "group home." Many are quick to dismiss supportive living as the traditional single-family ranch in a residential neighborhood, with a shared kitchen and living space.

20 NEW LEADERSHIP FOR STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCIL

Eileen Hurley and Gabrielle Bohon have completed their terms as chair (Hurley) and vice-chair (Bohon) of the New Jersey Regional Family Support Planning Council (NJRFSPC). RSFPC members voted for new leadership. In October 2022, Dotty Blakeslee was chosen as the new chair, and Cathy Tamburello was elected vice-chair.

from the Executive Director ■

Reaching Underserved Communities

While we usher in a new year, we set our sites on new goals and initiatives that help improve the lives of people with I/DD and their families. We recently launched our new cultural liaison initiative which will help us better reach and connect with underserved communities.

Cultural liaisons will support diverse communities by linking people with I/DD and their families to valuable resources like the New Jersey Council on Developmental Disabilities and our federal partners at The Boggs Center on Developmental Disabilities and Disability Rights New Jersey, along with The Office of the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families and state offices. Cultural liaisons are individuals from diverse backgrounds within the I/DD community who use their own network of community contacts and resources such as family/friends, religious institutions/ faith-based places of worship, school/college/trade school, employment/volunteer, memberships/associations, and leagues/clubs AND connects their network to the NJCDD and other resources for information related to disability services and supports. You can read more about cultural liaisons in this issue of People & Families magazine.



This issue also examines the topic of seclusion and restraint in schools. The story provides parents and educators with valuable information about this controversial topic.

We launch a In Memoriam section of this magazine to honor individuals who have recently passed away after making significant contributions to our field. In this issue, we also showcase some new and creative supportive housing options and how they are changing the landscape in New Jersey for people with I/DD.

I welcome Dotty Blakeslee and Cathy Tamburello to their new roles as chair and vice chair of the statewide Regional Family Support Planning Council. I'd also like to acknowledge the outstanding work of Eileen Hurley and Gabrielle Bohon as outgoing chair and vice chair. Their commitment to listening and representing the voices of the whole family support community was evident throughout their tenure. They effectively raised the bar in reaching families and providing them a platform for systems change in New Jersey.

In closing, I call on families and advocates to continue to speak out and lift their collective voices to continue to encourage positive changes in the lives of people with I/DD and their families.

Warm Regards,

A handwritten signature in cursive script that reads "Mercedes Witowsky".

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. Two new subcommittees, the Diversity Equity and Inclusion (DEI) and the Advocate Advisory, were added. DEI meets under the State Plan Committee and the Advocate Advisory 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:

- The Exec Comm reviewed the Community Building Awards. All agreed the event was a great success. The honorees were amazing, and the participation most gratifying. All attendees appreciated the opportunity to meet the honorees and celebrate their accomplishments.

- The Executive Director announced that the Council's Five-Year Plan has been accepted by the federal Administration on Community Living.
- 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 will include our DD Act partners.
- The Executive Director provided an update on the statewide initiative to enact legislation providing a legal basis for Supported Decision-Making as an alternative to Guardianship in New Jersey.

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. After the draft plan was approved by the Council, it was finalized and submitted to the Administration for Community Living (ACL) last fall. 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 on September 30, 2022 of the Council's Program Performance Reports for fiscal years 2020 and 2021.

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:

- NJCDD Grants Committee has overseen the process of issuing Requests for Proposals (RFPs) consistent with the 2022-2026 Five Year Plan. Four contracts have been awarded since October 1, 2021. RFPs to fulfill Five Year Plan activities will continue to be reviewed and released.
- NJCDD Grants Committee will continue to review current contracts and any Community Innovation Projects submitted for funding.
- NJCDD Grants Committee is currently reviewing guidelines for the submission of Community Innovation Projects and anticipates final language changes will be incorporated in early 2023.

Public Policy Committee

Kara Kushnir 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 fourth meeting of the Legislative Disabilities Caucus this year was held on October 25, 2022. The session was devoted to Special Education issues, including school safety, behavioral services, and school district accountability. Co-chair and Senate Majority Leader M. Teresa Ruiz hosted the event. Speakers included Peg Kinsell and Kim Rivers of NJSPAN, both of whom are parents. Senators Conaway and Bucco and Assemblywoman Dunn and Assemblyman Greenwald also participated, as well as other legislators
- The Student Mental Health Plan as proposed by the Governor has been received with concern for the following reasons: the timeline is unrealistic, successful local school programs would be eliminated, and joint planning is not being proposed. A Summit should be convened on this issue
- Position papers and recommended action statements were developed for Housing,

Transportation and Healthcare and have been submitted to the full Council by the Public Policy Committee for approval

- Senator Joseph F. Vitale was presented with the Community Building Award for Exceptional Policymaker on September 22, 2022, for his strong advocacy for the disability community and his leadership on healthcare as 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, 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.
- 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
- 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

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.

At the Health and Wellness Subcommittee meeting on October 18, 2022, subcommittee members identified and discussed specific concerns

surrounding: System Issues, Primary Care for individuals with I/DD, Minority Access to Healthcare, and Women's Health. Dual Diagnosis of Mental Health and I/DD was designated as a core concern which will be addressed at all quarterly meetings moving forward.

Additional H&W Subcommittee activities focus on:

- Supports for individuals with I/DD through Support Coordination, MCO Care Management, CMO Care Management, transition support, and DSP Core Competencies
- Monitoring funding related to DSP nutritional training.
- Researching screening and early detection resources for the underserved populations of minority access, complex care, and behavioral concerns.
- Continued engagement in next step planning of regulations for newly passed Pediatric Network Adequacy (S3000) legislation.

Diversity, Equity, and Inclusion Subcommittee

Sarah Aziz serves as chair and Annette Smith serves as co-chair for the Diversity, Equity, and Inclusion Subcommittee. The subcommittee ensures 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 NJCDD are present throughout the plan's goals and objectives.

The following are recent subcommittee activities:

- At the September 14, 2022 meeting, the subcommittee discussed the results of the work group survey that created two work groups. The first work group, Building Relationships with Elementary Schools: Sharing is Caring, will be led by subcommittee chair, Sarah Aziz. This work group will focus on creating access and awareness in schools at the Elementary School level.
- Co-Chair Annette Smith will lead the second work group, Pipeline or Lifeline: Addressing the need for culturally competent interactions as people are welcomed or introduced into the I/DD community. The goal of this work group

will be to establish a pipeline of information and access to I/DD related services for individuals and their families from diagnosis or birth, to end-of-life planning.

- NJCDD Executive Director, Mercedes Witowsky, announced that the Cultural Liaison initiative was in the final stages of launching. Cultural Liaisons will seek individuals who identify from the I/DD community utilizing their network of personal and social supports with the goal of increasing awareness of the NJCDD and its DD act partners as well as helping people effectively navigate the human services systems through their lived experience. Cultural Liaisons will be part-time, paid positions and will begin in Hudson and Passaic counties.
- The importance of culturally competent community outreach was discussed as a priority. The difference between partnering with communities to implement change versus going to communities to “tell them what you are going to do for them” was distinguished. Not understanding the difference between the two, can be received by the community as aggressive and tone deaf. The subcommittee will continue with the goal of connecting and having meaningful engagement with diverse

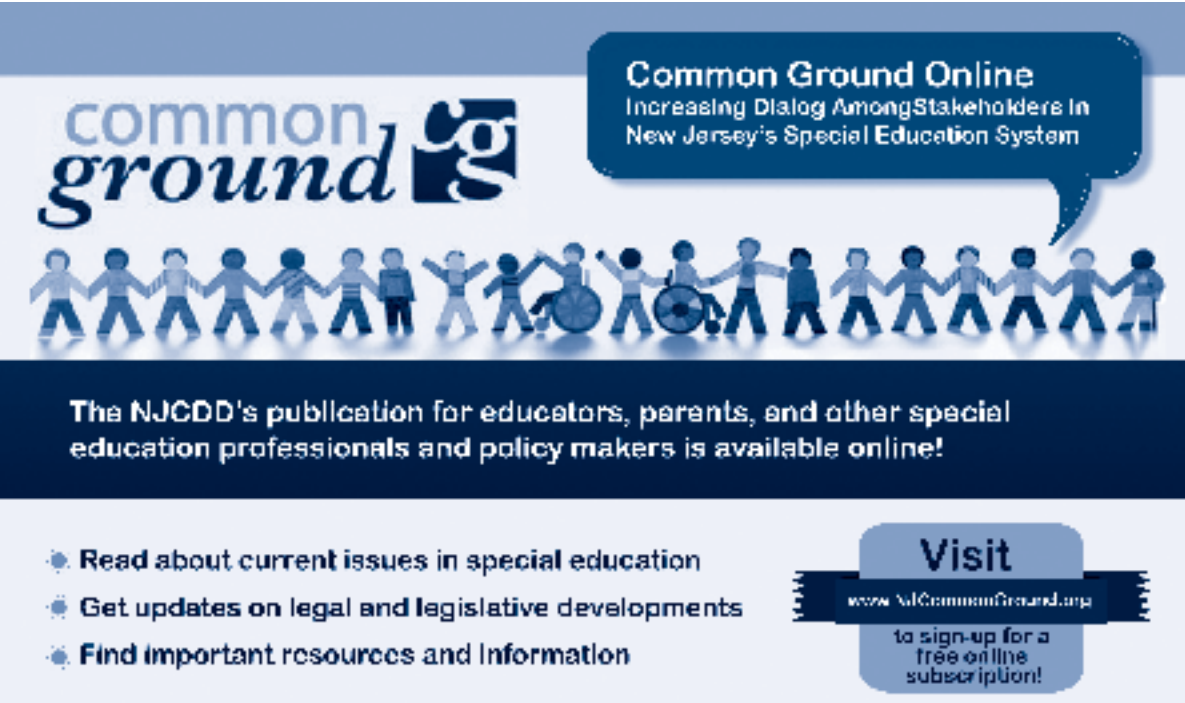
communities to ensure they have equitable access to information and resources from the NJCDD and its DD Act partners.

The subcommittee will continue to meet on a quarterly basis moving forward. The two work groups will meet monthly.

Self-Advocacy Advisory Subcommittee

The Self-Advocacy Advisory Subcommittee was established under the recently amended bylaws to ensure the voices of advocates are being heard and supported through the Council’s goals. Ryan Roy serves as chair. The subcommittee’s recent activities include:

- The group met on August 1 and November 7. The group discussed employment, transportation and housing. The group also discussed the impact that COVID 19 had on the larger disability community and on self-advocates, which included their ability to attend meetings and to engage in other community activities.
- The group also will also provide feedback to the DEI subcommittee around language to help develop plain language materials for self-advocates. **P&F**



The banner features the 'common ground' logo in a stylized font, with a large 'g' icon. Below the logo is a row of colorful stick figures holding hands, including two figures in wheelchairs. A speech bubble on the right contains the text 'Common Ground Online' and 'Increasing Dialog Among Stakeholders In New Jersey's Special Education System'. 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!'. Below this bar are three bullet points with icons: 'Read about current issues in special education', 'Get updates on legal and legislative developments', and 'Find important resources and information'. On the right side, there is a 'Visit' button with the URL 'www.njCommonGround.org' and a call to action to sign up for a free online subscription.

common ground

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New Jersey's Special Education System

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NASSAN'S VILLAGE



Changing Minds, Hearts and Lives

By Brenda Considine

Aspiring writers are often given the advice to “write what you know.” That is exactly what New Jersey native, Niya Wright did when she wrote the script for an episode of the Emmy award-winning Netflix animated children’s program, *Ada Twist, Scientist*.

In the 11-minute episode, “A Wheel with a Twist,” (Season 3) young Nassan arrives to spend the afternoon with his cousin, Ada, the show’s spunky protagonist who loves science. Initially, Ada’s friends are confused about why Nassan does not speak. Ada explains that Nassan has autism, which means that “his brain is different.” Initially, Nassan plays with Ada’s friends, but quickly retreats, covering his ears, crying, and running away when the sounds and activities get to be too much. Ada reassures her friends that Nassan just needs a “brain break.”

“He can do things we can do, he just needs us to be patient,” she tells them. And when Nassan needs to let others know what he wants, he picks up his augmentative communication device—a tablet—and points to a picture of chicken nuggets.

The story is fictional, but for Niya Wright, it is not fiction at all. It is a snapshot of her own life experience as the older sister of a brother with autism, and it is a story she wishes *she* had seen as a young girl.

“Growing up, I rarely saw the people I love on TV. I wanted to tell the stories that I wish I had seen as a kid. Because autism is so personal to me, I knew that was where I needed to start,” she said.

Wright is currently the production manager for *Ada Twist, Scientist*. In her first role as the script coordinator, the show’s executive producer, Chris Nee, and the showrunner and co-producer, Kerri Grant, invited Niya to pitch her first story for television—an episode of *Ada Twist, Scientist*. Initially, she was reluctant to bring autism to the show.

“I was not sure how it would work out, but my mom always said, ‘Closed mouths don’t get fed,’ so I went out on a limb and pitched the story idea. I am so blessed to have mentors and a team who really support me,” she said.

An Authentic, Intentional, and Important Character

While people with autism are increasingly showing up in Hollywood productions, they are usually cast as bright, quirky, funny, verbal... and White. It is rare for them to be non-speaking, and even more rare for them to be Black.

“A Black character was very intentional,” said Niya. In the show, Nassan is Ada’s cousin. Nassan’s mom, “Auntie Nadine,” is Ada’s aunt. They are part of the family.

“Growing up, I NEVER saw that. I have never seen a tall, non-verbal Black character with autism. To my knowledge, it has not been done before so it is new territory for kid’s content,” she said.

In a 2021 interview with Mary Ellen Holden for the Geena Davis Institute on Gender in Media, *Ada Twist, Scientist* executive producer, Chris Nee underscored the vital importance of representation in media:

“Kids like the power of seeing themselves. However, it is also extremely powerful when you do **not** see yourself onscreen. It is the negative impact that resonates. I grew up not seeing myself in kids’ content, which affected me and started a narrative in my brain. It’s tough to create your personal path against what you see. But, as content creators, there is a unique impact on what we do. And the more we bring in voices that don’t have uniformity, the greater the chance that we will talk to and empower someone who does not feel seen.”

ADA TWIST, SCIENTIST

Ada Twist, Scientist is an educational animated series written for a young audience centered around science, technology, math, and engineering. The show features eight-year-old scientist Ada Twist, a Black female character, and her two best friends. The program is produced by Higher Ground productions, which was formed in 2018 by Michelle and Barack Obama, to lift up diverse voices in the entertainment industry.

Based on a children’s book by the same name, the series is now in its third season. It received a 2022 Annie Award for Best Animated Television/Broadcast Production for Preschool Children, and recently won an Emmy Award for Outstanding Preschool Animation Series.



Auntie Nadine and Nassan in Ada Twist, Scientist

Nassan's character is as true to life as an animated character can be because it is based on Nassan himself, and his expression of autism. He stims, flaps, has a "melt down," shows food preferences, and chirps with joy when he is happy. The show's producers were also intentional in casting Justice Killebrew, a nonverbal Black teen actor on the autism spectrum, for the voice of Nassan.

Niya is proud of the show and the messages it teaches.

"I was raised with love by a village of family and teachers—I wanted to honor my community and create stories that make people feel seen," she concluded.

And it already has. On a social media page, one fan, Tom Bruno, the father of two, writes:

"Sometimes kids' TV shows don't realize how powerful they can be. My brother Danny is autistic to the point he can barely speak. He has ticks and makes sounds, and as a kid growing up, I never knew how to explain it to people. I was lucky enough to make friends who understood the things I couldn't explain.

We just happened to have this show on [Ada Twist, Scientist], and there was an entire episode about a boy who is just like my big brother. I heard the characters on the show explain what was happening in a way I never could articulate, even as a 35-year-old. Not going to lie, I found it beautiful. 'He can do things we can do, he just needs us to be patient.' So thank you, whoever wrote that show. That meant a lot to me. I'm sure Danny appreciates it."

Nassan

Back in New Jersey, Niya's brother, 18-year-old Nassan Arbubakarr, is the real life inspiration for the Netflix character. He lives in East Orange with his mother Nadine Wright-Arbubakarr. Standing at six feet six inches, and weighing 340 pounds, Nassan is not going to be ignored by anyone. In fact,

he is the reason not only for the Netflix episode, but for local action, outreach, support, and awareness efforts.

Nadine describes Nassan as her "man child," adding that "he is like a two-year old. Nassan will always be with me. I know he will need someone with him 24/7," she said.

The mother of four children and two step children, Nadine admits that raising Nassan took "an emotional toll" on her, but believes that she is now "living her purpose." A former bank manager, Nadine was putting in more than 60 hours a week before she left her career in order to be home with Nassan. In search of work that offered

more flexible hours, she went back to school to get her degree so she could start teaching, but quickly realized she could be doing more outside the classroom.

“Back when he was diagnosed, I did not know what autism was—my community certainly did not have any resources. I believe that every child, no matter the zip code, should get services,” she said. “I did not want to be part of a problem. I wanted to be part of a solution.”

With that inspiration, and her background in business and marketing, Nadine launched Nassan’s Place in 2012 when her son was just eight years old.

“When I started, I had no idea what I was doing,” she laughs.

Helping Others in Underserved Communities

Nadine has a gentle force about her: a confident, unrelenting determination rooted in compassion and purpose. She created Nassan’s Place to address the lack of accessible and affordable educational and recreational programs and other resources she needed for her own son, in and around her underserved, inner-city community. Since that time, the organization has helped

“When a family lives with autism, many things happen.”

—Nadine Wright-Arbubakarr

more than 6,000 families through affordable after-school care, Saturday programs, summer camp, basketball camp, and more. Nassan’s Place has hosted nearly 300 workshops, sensory-friendly movies, outings, and events, and helps with special education advocacy. With the help of Congressman Donald Payne, Jr., they were recently awarded a \$750,000 grant to plan a new state-of-the-art facility. The mayor of the City of Newark gave the organization a building, which meant a great deal to Nadine.

In the decade since Nassan’s Place was founded, Nadine has witnessed tremendous needs in her community.

“This is bigger than I thought,” she admits. “We cannot judge what people need. Most urban,

INCREASING DISABILITY PRESENCE IN CHILDREN’S PROGRAMMING

There is growing interest in the entertainment industry in telling stories about people with disabilities. RespectAbility is a diverse, disability-led nonprofit, that partners with studios, production companies, writers’ rooms, and news organizations to create equitable and accessible opportunities to increase the number of people with lived disability experience throughout the overall storytelling process. These initiatives, including the award-winning RespectAbility Entertainment Lab, increase diverse and authentic representation of disabled people on screen. The program’s alumni are now working at studios including DreamWorks Animation, Netflix, Nickelodeon, Paramount Pictures,

Sony Pictures Entertainment, and The Walt Disney Company, as well as in writers’ rooms.

RespectAbility recently announced a new Children’s Content Lab for Disabled TV Creators. The new lab provides education and training for disabled writers, animators, and creative executives interested in preschool and children’s television. Supported by Netflix’s Fund for Creative Equity, the Children’s Content Lab offers workshops, trainings, panel conversations, and networking events. Each Fellow works with a mentor and takes part in a talent showcase with table reads of each writer’s project performed by disabled actors. The Lab also includes a week of career development training with industry experts.

inner-city parents are just not educated about the system,” she stated.

Nadine’s approach to service delivery is simple and straightforward. Her goal is for Nassan’s Place to provide services that her own family needed, and to do so in ways that *she herself* would want them delivered.

“When my phone rings in the middle of the night, I pick it up, because that is what I would have wanted for me,” she said.

In addition to the core services, Nassan’s Place provides other assistance too—help with housing, food, and access to care for mental illness. Nadine gets requests from many families dealing with food insecurity and homelessness, which she notes is made even harder with a child with autism.

“Foodbanks don’t always do the trick when you have a child who will only eat certain foods, or certain brands of certain foods,” she said.

According to Nadine, 75 to 80 percent of the families served by Nassan’s Place are single “autism moms,” many of whom have lost jobs due to their caregiving responsibilities. She offers “Pamper Me” days for moms, and hosts a “Women’s Empowerment Luncheon.”

“Many of these moms have what it takes to be an entrepreneur, but they are so defeated. We try to lift them,” she said. “And when Nassan’s Place needs extra help, I pay them to step in. Who better?” she asserts.

“We have an emergency fund for families in need. It is hard to go to social services—they have waiting lists and rules for eligibility that can take a long time,” she stated.

Nadine says respite care is one of the most requested services, and often, it is emergency respite. “We don’t get to pick and choose when our kids have a meltdown. When you need help, you cannot wait,” she notes.

“When a family lives with autism, something happens. There is a stigma associated with it, so we try to offer events for the whole family. We celebrate birthdays together, since many of our kids do not get invited to birthday parties. We get our kids and families out into the community to make sure they know they are part of the community. And we always include siblings,” she said.



Nassan pictured with his sister, Niya and his mother, Nadine

Hollywood Comes to New Jersey

Nadine is “beyond proud” of her daughter, Niya.

This fall, Nassan’s Place hosted a private screening of the *Ada Twist, Scientist* episode featuring Niya’s script about her brother. The event, hosted at City Plex 12 in Newark, featured a meet-and-greet with Nassan himself, along with Niya Wright, the writer, and actor Justice Killebrew, who provided the voice talent for Nassan in the episode.

Niya credits Nadine for helping her become the woman she is today.

“My mom has been selfless in the way she has used her journey to give hope and support to families in need. My mom is a superhero without a cape, and she has taught me the importance of sharing information in order to help others.”

“With autism, the whole family is affected,” Niya concluded. “I am so honored to share Nassan’s story. I hope it inspires others to ask more questions and be more kind.” **P&F**

Cultural Liaisons

Supporting Diverse Individuals in the Community

By Maryann B. Hunsberger

The Council has started hiring and working with cultural liaisons in Passaic and Hudson Counties. Cultural liaisons are diverse individuals within the I/DD community who connect their own network of contacts and resources to the Council for disability-related information. A person's network can include family, friends, places of worship, college or trade school, employment or volunteer contacts, memberships or associations, and leagues or clubs.

The goal of having cultural liaisons is to increase the capacity of people with I/DD by identifying and tackling barriers to becoming fully engaged in their communities. Cultural liaisons will support diverse individuals and families by sharing information and linking them to resources and services. For instance, a cultural liaison might be able to reach others through speaking the same language as people in a diverse community or by belonging to a diverse religious community.

Cultural liaisons report to the Council's diversity, equity and inclusion consultant, Jade Pollock.

She stressed that cultural liaisons should be people with lived experience in the I/DD community. "They can guide others going through similar experiences by connecting them with agencies, needed services and supports. Once connected,



Jade Pollock, Diversity, Equity and Inclusion Consultant at her home in Somerdale, NJ

people with I/DD and/or their families will gain information and new resources to assist now and in the future."

Pollock, who is biracial, emphasized the importance of liaisons coming from diverse backgrounds. "The goal is always for inclusivity. Diverse communities need representation so we can reach these communities with equal access to information and resources."

Pollock lives in Somerdale and has two sons, ages 8 and 13, with disabilities. She graduated from Temple University and American Public University. She explained how a cultural liaison can work within a community. "Let's say I am part of a community college group in my town that meets to swim, and I'm also an active member of my church. As a cultural liaison, I will reach out to people in those groups to see if they want to learn information about the Council, DDD and other state resources. I will determine if those groups are open to learning ways to participate, gain information and having a presentation."

In addition, liaisons can help the Council gain knowledge of positive as well as negative experiences in the community. "When people realize a community of people needs something, our instinct is often to help. Sometimes that community just needs

assistance in finding their voice and connecting with one another to make change. It doesn't have to be someone else or an organization coming in and doing the work for them. It draws a line between advocacy and self-advocacy. There will always be a need for advocacy, but it's also important for those who can and want to advocate for themselves to do so. Cultural brokering allows for diverse communities to do that. It's a building block, a starting place. It helps build community."

The Council is partnering with the Supportive Housing Association of New Jersey (SHA), who will offer assistance to the liaisons. SHA has created a toolkit to show municipalities how to better serve people in the I/DD community who live within the municipality they serve. SHA will provide training to the liaisons through their leadership academy and self-advocacy initiatives.

SHA will administer the toolkit and teach liaisons to reach out to municipalities and to use the toolkit with them. Some municipalities have already used the toolkit, which goes through a series of questions to see which areas can be improved for inclusion. The toolkit has 14 sections, including such topics as physical environment and accommodations, cultural and recreational opportunities, and civic engagement and participation.

The Council and SHA feel this work is necessary because many people with I/DD and their families aren't accessing services and resources. "For some reason, we are missing pockets of people. It could be a mix of everything--language, culture, community—that are all barriers. We're trying to combat these. Some of it could be just lack of representation. We're trying to figure out why and identify diverse people who can empower people in their communities. The goal is that this really helps the people we are having such a hard time reaching. We can then share what works with other partners and agencies. These toolkits, used in a diverse community, will work toward the Council's goal of diversity, equity and inclusion."

Although liaisons are starting in only two counties, eventually more counties will be included. "We want to take our time and invest in this and learn. Hopefully what we learn will give us insight into what we can do better. Sometimes



Jade Pollock, Diversity, Equity and Inclusion Consultant at her home in Somerdale, NJ with her husband, Jonathan Williams and their son Caiden Pollock-Williams, bottom right, and Jade's son and Jonathan's stepson, Kai Pollock-Waites, bottom left.

we put timelines to accomplish things and we rush. We don't want to do that. This is so important that we want to commit to doing this well. We will start out small and hopefully get good feedback and results and grow. There should be a give and take with both sides of the community listening and learning together. It's a great place of understanding."

According to Pollock, one important part of working with cultural liaisons is learning to change the way things are worded. "Words are powerful. We can unintentionally alienate people who we are trying to engage. We want to make sure that the supports and access to information are there for everyone in a culturally competent way, using words that are inclusive. I'm hoping that through cultural liaisons, people with more diverse backgrounds can tell us what is equitable, fair and appropriate."

A limited number of part-time cultural liaison positions are available at this time. The Council will compensate candidates at \$22.00 an hour, plus reimbursement for authorized travel at the State of New Jersey approved mileage rate, currently \$.47 cents per mile. **P&F**

Community Building Awards

The 2022 Community Building Awards were held on September 22 at the Estate at Farrington Lake. The New Jersey Council on Developmental Disabilities established the awards program to encourage more inclusive communities while showing appreciation for exceptional commitment and advocacy. Congratulations to the awardees:

Elizabeth Boggs Family Member Advocate Award	Melanie Ayers
Colleen Fraser Self-Advocate Award	Bill Byrne
Exceptional Policymaker Award	Senator Joseph F. Vitale
The Daniel J. Keating Leadership Award	Diane D'Orazio
Distinguished DD Systems Change Award	The Collaborative for Citizens Directed Supports New Jersey
Fellowship Inclusive Education Award	Tracy Rand
Access Above & Beyond Award	Ava Loveland
Multi-Media Award	Gene Myers
Lifetime Achievement Advocacy Award	Diana Autin





REDEFINING SUPPORTIVE HOUSING

By Jonathan Jaffe

Similar to most trends, architecture addresses the needs and desires of the moment.

Just look at all the new homes that are being built around New Jersey, as the latest and greatest appeal to demanding buyers who consistently call for the most modern conveniences, innovation and ease.

That same need for quality and comfort is also in the intellectual/developmentally disabled community, where architects are steadily redefining the “group home.” Many are quick to dismiss supportive living as the traditional single-family ranch in a residential neighborhood, with a shared kitchen and living space.

As leaders of the Supportive Housing Association of NJ (SHA) note, there is no longer a cookie-cutter definition of design for group homes accommodating people with I/DD. In fact, the association sponsors an award program each year that honors remarkable design, as architects and builders find new ways to redefine the way in which people of all abilities live.

“People are quick to have an antiquated vision when they think of supportive housing,” said Diane Riley, executive director, SHA, based in South Orange. “But what some architects have done over the last few years has been astounding. Meanwhile, families are creating their own models of supportive housing, rather than waiting for someone else to create it. It has all created a tremendous new and exciting trend for people with intellectual and developmental disabilities.” Below are examples of some recent award-winning projects, showcasing how they are changing the landscape in New Jersey for people with I/DD.

Weinberg Commons in Cherry Hill

This is an innovative, community-based housing model, in response to designers tasked with finding a way to build affordable housing for adults with autism and similar intellectual developmental disabilities in close proximity to a support network of family, friends, and support services.

The project, through the Jewish Federation of Southern New Jersey (JFed), created an integrated, multigenerational development of housing and support services for special needs adults just down the street from the main campus. The 18-acre site consists of the existing Annex Classroom Building, two 80-unit affordable housing residential buildings, a standalone community building, and onsite amenities. Each residential building is home to 16 special needs residents and 64 seniors ages 55 and over.

To maximize the number of special needs units, something different needed to be developed. The architects with Kitchen & Associates of Collingswood (now Thriven Design) recommended building a group home underneath traditional senior housing. A concept was born by stacking modules which could be carved into either one- or two-bedroom senior units or four-bedroom special needs “cottage” units.

Each cottage is a standalone entity with private front and rear entrances, shared living spaces, communal cooking, covered porches, and support spaces plus four 1-bedroom apartments explicitly designed for autistic and other adults with I/DD.

There is extra consideration for sound transmission between internal spaces and the external environment, clear transitions between public to

private spaces with availability to retreat quickly into a secure environment, visual access into spaces prior to entering, convectional cooking and extra counter space, sinks, etc. for teaching and group meal preparation.

Residents with I/DD have access to a Fitness and Arts center, computer lab, culinary training, a community garden, and onsite laundry facilities. Each resident has the opportunity to take advantage of the support services, and programs offered by Jfed's agencies, currently serving more than 50,000 people living in the surrounding area. There's even day and evening trips.

Weinberg Commons opened in October 2019.

Village at Harmony Garden In Glassboro

This community, also designed by Kitchen & Associates, focuses on affordable housing to people with I/DD in Gloucester County. Residents live independently, yet are near supportive services to help achieve daily living success. The prime location near Rowan Boulevard provides access to local shops, services, and attractions.

The design features 65 one-story cottage units containing 57 one-bedroom and 8 two-bedroom units. Seventeen units are set aside for people with disabilities, providing mixed living.

All apartments have the rent supported by Glassboro Housing Authority project-based vouchers, helping those in the community in need at all levels access this new housing.

Village at Harmony Garden, replacing unsightly public housing, also features a clubhouse that includes a community room, fitness room, and supportive services center. There is also garden for residents to grow their own vegetables, as well as a gazebo. It opened in the fall of 2022.

The Pinnacle in Fort Lee

Innovative supportive housing can also be in a luxury high-rise, evident in The Pinnacle in Fort Lee, opening in July 2020. The Class-A complex offers affordable supported independent apartments and DDD-licensed group homes in one of the densest urban locations in New Jersey.

More than 50% of The Pinnacle's 143 units are affordable units, indistinguishable from the market-rate units in the same building, on Main Street.

Residents are living along the waterfront across from Rockefeller Park, overlooking the George Washington Bridge and sweeping views of the NYC skyline. It is also near eateries, restaurants and nightlife, as well as public transportation via rail, bus and ferry.

Designed by Kitchen & Associates, it is cat-friendly luxury housing that even features like a sauna, steam room and gym.

One key consideration in the design of high-rise structures is to take advantage of 'stacking efficiencies' wherever possible. Steve Schoch, the project architect, began the design work on The Pinnacle with this in mind.

He recognized that by stacking the four DDD group home units in the same plan location on four sequential floors, the building would be both efficient, and these unique units would also be dispersed vertically—so that no one floor would be dominated by the group homes, and result in isolation of the residents.

"The best kind of supportive housing is the kind you don't really notice—it looks just like a place that anybody would want to live," Schoch said. "That's what community-based living options are all about, and with the right personal support programming there are now many options that weren't available before – it's not a one-size-fits-all solution.

While the central hub of supportive services remained on the sixth floor, each group home has internal staffing and is functionally independent from the others - which meant that proximity to those centralized services was not a critical parameter. The floor plan of the large 4-bedroom unit was then transitioned on the floors above to achieve two, two-bedroom apartments within the same overall footprint.

The northwest corner of the floor plate was selected for the DDD group homes to reduce glare while allowing for natural light and views, and also to reduce outside traffic noise.

Funded in part with Low Income Housing Tax Credits from a special reserve for "mixed income" projects, The Pinnacle's inclusionary program offers 66 market rate apartments, 45 affordable apartments, 16 individual supportive apartments for adults with Autism, and 16 group home residents sharing the four, four-bedroom units that DDD licenses.

“Supportive housing is truly the wave of the future for people with I/DD,” said Krystal Odell, CEO of PennReach, a non-profit dedicated to affordable housing, serving as the supportive service provider for The Pinnacle. “It offers inclusive housing with neighbors in the building without disabilities, layering the unique service supports needed to be independent. It adds another independent opportunity to the more traditional group home offering, truly proving that one size does not fit all.”

“The Pinnacle has offered one of those opportunities in Bergen County,” she added, noting residents can take advantage of the building gym, walk into town and visit their neighbors.

“The subset of special needs apartments give added support to the residents, while living an active life in the community,” Odell said. “This model offers great opportunities for service providers to provide flexible custom options for our consumers. We are all on a learning curve to offer the most inclusive options within supportive house and moving toward the future of this housing in the world of I/DD services.”

Some parents are also taking it upon themselves to secure innovative living opportunities for their adult children. Karen Fluharty of Montvale, founder of the non-profit “Parents With A Plan,” said the organization has secured parcel of land in Red Bank and is planning to appear before the local zoning board for approval of a three-story apartment building for people with autism.

Fluharty, a single mother, says she wants to make sure her 20-year-old son, Ryan, has an ideal place to live independently, but with resources. She looked as far as the west coast of the United States and Tel Aviv to find the right place, but found limited opportunities for her son in New Jersey.

“The model for Ryan was in Phoenix,” she said. “Not here. Why do parents have to choose between geography and a good program?”

Red Bank is the ideal location for a neuro-inclusive apartment building, she said, as it is easily walkable, near where he can work, recreate, volunteer and walk. The proposal calls for a supportive setting with staff who are professionals at working with people with autism.

The ground floor of the 32-unit complex is to feature a 24/7 security desk, a teaching kitchen,

educational spaces, a community room and health and wellness services. Each one-bedroom apartment would be designed for people with autism, including stoves with motion sensors, floor drains in the bathrooms and low-voltage lighting.

She said the building would be constructed by a limited liability corporation, with tenants using DDD funds and other supports to pay rent, staffing and amenity fees. The hope is to break ground by the end of this year.

“This is the way that parents can create the safe, nurturing environments that our children need when we are no longer here,” Fluharty said.

There is another trend in supportive housing that is occurring in California and other states. It is known as “accessory dwelling units,” (ADU) in which a small house or trailer can be constructed on a single-family lot for use by a person with disabilities.

According to the American Planning Association, ADUs increase housing affordability (both for homeowners and tenants), create a wider range of housing options within the community, enable people with disabilities to stay near family as they age, and facilitate better use of the existing housing fabric in established neighborhoods.

For Walter Kalman, who has a 21-year-old son with disabilities, an ADU would be the ideal solution. But his hometown, South Plainfield, does not allow more than one home on a single lot. Kalman, a consultant who helps families transition into supportive housing as part of long-range planning, said there is a bill in the state Legislature that would allow ADUs, but there are many roadblocks for universal support.

“New Jersey is all about home rule,” he said, noting that he knows of only Maplewood and Princeton that allows such a unique housing arrangement.

“It is an ideal living situation,” Kalman said. “A family member can live independently with financial support from the DDD and his or her family. But without a state law, it means that 565 municipalities now decide independently to allow such an arrangement. We need to do better and families need to plan earlier—when their children are still children—to identify the best alternatives for supportive housing.” **P&F**

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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

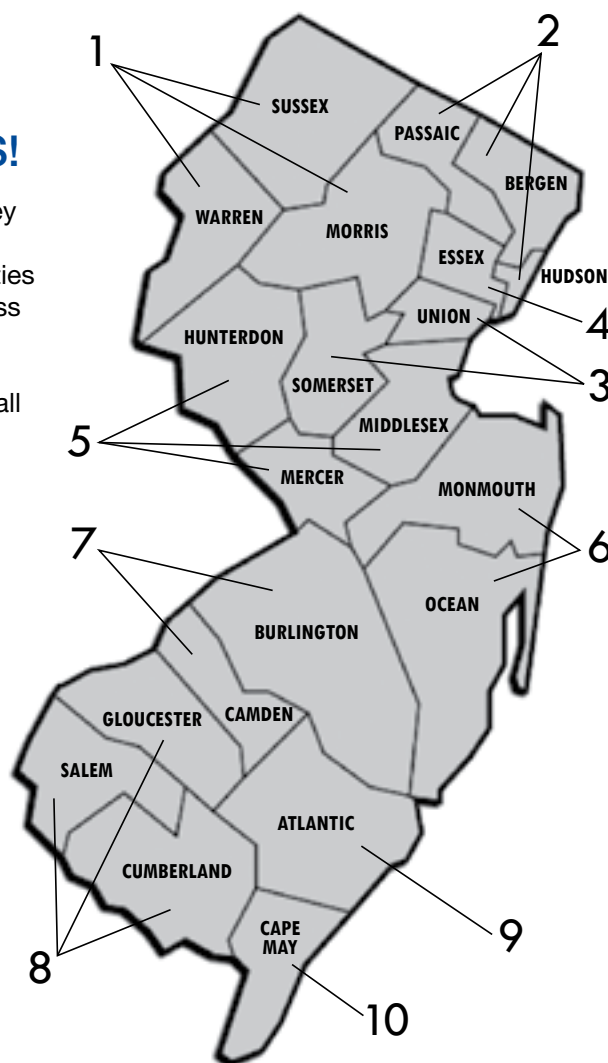
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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.

SECLUSION AND RESTRAINT IN SCHOOLS



What Parents & Educators Need to Know

By Brenda Considine

Inmates in America's prisons are protected from corporal punishment, but in nineteen states, teachers and principals are allowed to strike a child—using a paddle, an open hand, or even a ruler—to punish them.

In 1977, the US Supreme Court ruled that corporal punishment in public schools is constitutional (*Ingraham v. Wright*) leaving it up to each state to make its own rules. They found that the "Cruel and Unusual Punishments Clause" of the Eighth Amendment does not apply because it was intended to protect criminals, not school children. They asserted that the openness of public schools, along with their supervision by the community, afforded significant safeguards against these kinds of abuses.

But do they really?

Seclusion and Restraint In Special Education

One hundred ten years before the *Ingrahm* decision, in 1867, New Jersey became the nation's

first state to ban corporal punishment in schools. But there is a loophole. For the 240,000 students with disabilities in New Jersey, a different set of rules apply. In an emergency, it is legal to physically restrain children with disabilities as young as preschool. It is also legal to place them alone in a locked room (often with padded walls), a practice known as *seclusion*.

For years, there have been efforts in Washington, DC to regulate the use of seclusion and restraint in America's public schools, but those have stalled. Only six states have banned the use of these procedures.

In 2018, New Jersey Governor Chris Christie signed a law describing how restraint and seclusion techniques could be used with students with disabilities in school settings. Before that legislation, New Jersey was one of only a few states that lacked any formal policy around restraint and seclusion. The legislation, which was opposed by parent advocacy groups who had hoped for a ban, had the support of many in the education establishment.

Emergencies and Imminent Danger

In a document released in 2015, the US Department of Education wrote:

“restraint or seclusion ... should not be implemented except in situations where a child’s behavior poses imminent danger of serious physical harm to self or others and not as a routine strategy implemented to address instructional problems or inappropriate behavior (e.g., disrespect, noncompliance, insubordination, out-of-seat), as a means of coercion or retaliation, or as a convenience.”

Emergency situations and moments of imminent danger, by their very nature, should be rare occurrences. Many educators and advocates recognize that seclusion or restraint may be necessary to keep students and staff safe, such as when a student’s behavior places them or others in immediate physical danger (consider a child darting out in front of traffic...) But data show that the use of these procedures is not rare. In fact, in some school settings, they are used frequently and repeatedly.

According to a 2019 report issued by the Government Accountability Office (GAO), a fact-based, non-partisan information-gathering arm of Congress, 78 percent of New Jersey school districts reported zero incidents of restraint or seclusion. Advocates believe this number is low; even the GAO admits that the use of these procedures is underreported.

Although data are limited, it is estimated that New Jersey public schools placed more than 1,100 students in seclusion rooms between 2011 and 2017. Ninety-one percent of these students had physical or emotional disabilities. Forty-four percent of students in seclusion were Black, even though Black students make up fifteen percent of the school-age population.

There are scores of media reports of schools that violate the law by placing children in seclusion rooms for minor behavior challenges, like refusing assignments or taking off their shoes in class. Students have been strapped into a chair or had weights attached to their bodies simply to reduce their classroom activity. There are also reports of escalation that resulted in physical and emotional harm to the students. The GAO report found that students subject to seclusion and restraint have suffered physical injuries, along

with psychological, social, and emotional harm. The GAO concluded, “these techniques can be dangerous because they may involve physical struggling, pressure on the chest, or other interruptions in breathing...even if no physical injury is sustained ... individuals can be severely traumatized during restraint.”

Keeping Children Safe When They Are Dangerous to Themselves and Others

The US Department of Education has stated that there “continues to be no evidence that using restraint or seclusion is effective in reducing the occurrence of the problem behaviors that frequently precipitate the use of such techniques.”

Under IDEA, students have the right to a Free, Appropriate Public Education (FAPE), so they must not be allowed to endlessly repeat harmful behaviors, or endlessly experience restrictive practices. Advocates and educators agree that “emergencies” must be examined so that learning can take place, and the frequency of the crisis behavior is decreased.

The repeated use of restrictive “emergency” techniques—or even a request from the child’s school program to use them—might suggest that the student’s programming may not be effective. In addition, repeated and extended use of seclusion can have a cumulative effect of denying the student instructional time and related services. Students are not learning if they are being held alone in a room.

In an emergency, however, brief physical intervention may be needed to prevent a student (or people around the student) from immediate physical danger. After the emergency, parents, guardians, and educators should ask(*):

- What happened before the situation started?
- How did the situation progress to an emergency?
- What was the unacceptable risk of harm to the child or others?
- How could this risk have been avoided without using restrictive practices?
- How could teachers or staff have avoided, de-escalated or diffused the situation?
- Is a risk to property used as an excuse for an emergency response?

A Parent's Vital Role

If a child with disabilities has challenging behavior, a parent or guardian has the right to ask questions about the child's behavioral support program. They may want to ask(*):

- *What training has staff received in positive behavior support and trauma informed practices?*
- *Are staff trained in techniques of prevention, de-escalation, and redirection in the face of a challenging situation?*
- *Has staff been involved in a professionally-conducted functional behavioral assessment (FBA)?*
- *Has restraint or seclusion ever been used or considered for my child?*
- *Are adequate numbers of trained staff always on duty?*
- *Is medical oversight of restrictive practices adequate and readily available?*
- *Has staff tried all proposed restrictive interventions on themselves first?*
- *Does staff fully understand the laws, regulations, and ethics that govern their actions?*
- *Is staff fully aware of both the general and specific physical and psychological risks to your child if they resort to the use of restraint or seclusion?*
- *Is staff fully aware of the legal risks to themselves if they resort to the use of restraint or seclusion?*

If a child with disabilities has experienced seclusion or restraint (even once) parents may want to take action by asking for an IEP meeting to review the student's IEP and behavior support plan. During that meeting, parents should request that the school conduct or obtain a Functional Behavioral Assessment (FBA) or a new and/or independent evaluation of the student.

It is a good idea for parents to review their child's records—including the contents of the IEP, discipline records, health records and incident reports (these may be kept in the school's main office or the nurse's office), the contents of any behavior or treatment plan, and any "incident reports" in the child's files. Parents should also keep careful records (photos and dated notes) of

NEW JERSEY LAW: SECLUSION AND RESTRAINTS

"Physical restraint" means: *"the use of a personal restriction that immobilizes or reduces the ability of a student to move all or a portion of his or her body."*

The law says that physical restraint is used only in an emergency where the student is exhibiting behavior that places the student or others in immediate physical danger.

- Students may only be restrained in the prone position if the student's primary care physician authorizes the use of this restraint technique.
- Staff members who are involved must receive training in safe techniques for physical restraint.
- The parent or guardian must be immediately notified, and a full written report must be provided to them within 48 hours of the incident.
- The restraint must be carefully and continuously visually-monitored to ensure that it is used in accordance with established procedures.
- The restraint must be documented in writing in sufficient detail to enable the staff to use this information to develop or improve the behavior intervention plan at the next IEP meeting.

"Seclusion technique" means *"the involuntary confinement of a student alone in a room or area from which the student is physically prevented from leaving, but does not include a timeout."*

Seclusion techniques may be used only in an emergency in which the student is exhibiting behavior that places the student or others in immediate physical danger.

- The seclusion must be carefully and continuously visually-monitored to ensure that it is used in accordance with established procedures in order to protect the safety of the child and others.
- The seclusion must be documented in writing in sufficient detail to enable the staff to use this information to develop or improve the behavior intervention plan at the next individualized education plan meeting.
- No parental notification is required for seclusion.

anything the child says or does that is of concern. It can be helpful to consult with professionals outside of the school, such as a child's physician, psychologist, or other healthcare provider

Protections for Vulnerable Students: Going on The Record

The most critical step a parent can take to protect their child is a proactive one. One concrete strategy is to provide a form of written notice. By making their preferences known in writing, parents can make it clear that they oppose any activity that will physically limit the child's movement at school.

Such notification is especially vital if the child has any pre-existing medical conditions such as breathing issues, asthma, heart conditions; neurological or orthopedic issues, such as pins or plates in bones, seizures, or narcolepsy; or a history of trauma. Any one of these conditions could contraindicate the use of seclusion or restraint. It can be helpful to get a supporting letter from the child's physician, psychologist or other health care provider.

Parents can write a stand-alone letter, or include their preferences in the "Parental Concerns" section of the IEP.

Some parents who have taken this step have reported that the placement or school district threatened to stop serving their child, or prohibited the child from returning to school unless the parent or guardian consents to the use of restraints and/or seclusion.

School districts are required to continue providing a free and appropriate public education

(FAPE) to a child even if a parent refuses to sign documents to allow the use of restraints or seclusion. It is important for parents faced with this situation to get information from a knowledgeable source. The child may have a legal right to stay in their school or program under their IEP.

(*) Suggested questions in this article are adapted from the NJCDD Booklet, *What Parents Should Know About the Use of Restraints and Seclusion*: <https://njcdd.org/wp-content/uploads/2016/08/restraintbooklet.pdf>

A NOTE ON ABUSE or NEGLECT

If you have reason to believe that school practices constitute abuse, please contact:

NJ Department of Children and Family
609-777-NJ ABUSE
<https://www.nj.gov/dcf/reporting/how/>

DCF- Institutional Abuse
609-888-7440

**CMS, Regional Office, Region 2,
Survey and Certification**
Operations, Associate Regional Administrator
215-861-4287
ROPHIDSC@cms.hhs.gov

Disability Rights New Jersey
(800) 922-7233 in NJ only
www.drnj.org

Education Law Center
(973) 624-1815
www.edlawcenter.org

RESOURCES

New Jersey Department of Education, Office of Special Education Policy and Procedure—
Guidance on the use of restraint and seclusion of students with disabilities:
<https://www.nj.gov/education/specialed/home/docs/071018Restraint.pdf>

Restraint and Seclusion: Resource Document, US DOE (2012)
<https://www2.ed.gov/policy/seclusion/restraints-and-seclusion-resources.pdf>

A Day In Our Shoes Resource:
<https://adayinourshoes.com/seclusion-restraint/>

GAO Report on Seclusion and Restraint in K-12 Education:
<https://www.gao.gov/assets/gao-19-551r.pdf>



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.

James J. Florio

James J. Florio passed away peacefully on September 25, 2022, surrounded by his family. He served as the Governor of New Jersey from 1990–1994 and served in the U.S. House of Representatives from 1975-1990. He also served in the NJ Assembly from 1969-1975. Governor Florio signed the Family Support Act into law on March 29, 1993. It made the Division of Developmental Disabilities responsible for creating a system of family support that is flexible, strengthens and supports families at home, and empowers families to meet their loved one's needs.

Carol Dougherty

Carol Lee Dougherty passed away on Saturday, May 28, 2022. For 40 years Carol was an advocate and leader in the field of independent living services for people with developmental disabilities. She spent her life helping individuals with developmental disabilities live their lives with independence, dignity and grace. She was a leader in this field with most of her career spent as the Executive Director of Partnerships for People, an organization she ran for 28 years until they were acquired by a multi-state organization.

Margaret M Morrison

Margaret M Morrison passed away on August 20, 2022. Margo was the original chair of Regional Family Support Planning Council #7 (Burlington/Camden Counties). She was instrumental in being the first Council to start a Family Resource Fair in conjunction with Council #8 (Gloucester, Salem and Cumberland Counties). Margo was also a member of The Arc Burlington County, located in Burlington City. She was an advocate for many years who was well-known in South Jersey.

Conrad Edwin Dudziec

The Man Behind Katie's House—Conrad Edwin Dudziec age 80 of Hampton Twp., NJ passed away peacefully surrounded by his loving family Friday morning October 7, 2022.

A loving husband, father, grandfather, sibling and friend to many, Conrad was a member of the Knights of Columbus as well as an active volunteer with Healing the Children for the over 27 years. He served as a host parent for 63 children from developing countries. In addition, Conrad was also a volunteer with Katie's House for over 16 years until his battle with Bile duct cancer started.

If you 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.



NEW LEADERSHIP FOR STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCIL

By Maryann B. Hunsberger



Dotty Blakeslee,
*new chair for Regional Family Support Planning Councils,
with her daughter, Maddy.*



Cathy Tamburello,
*new vice-chair for Regional Family Support Planning Councils,
with her son, Michael enjoying a walk.*

Eileen Hurley and Gabrielle Bohon have completed their terms as chair (Hurley) and vice-chair (Bohon) of the New Jersey Regional Family Support Planning Council (NJRFSPC).

They each served four years, coming into their positions in 2018. COVID-19 hit less than two years into their roles. This meant more work for them. “They had a lot to do,” said Kyoko

Coco, the Council’s family support coordinator. “They had to do things related to COVID-19 in addition to the regular position. They wanted to make sure that flexibility was available. Parents weren’t permitted to be paid to provide Division of Developmental Disabilities (DDD)-funded services. Then, staff couldn’t come to work because of COVID-19, so parents were doing everything.

The state quickly but temporarily lifted the restriction for parents, spouses, or guardians to be paid. Many want this restriction to be permanently removed, even after the public health emergency ends. Eileen and Gabrielle relayed their request to the DDD and discussed it numerous times at the Advisory Council meetings. Eventually, the Department of Human Services agreed to do so.”

During their terms, they collaborated with both DDD and the New Jersey Department of Children and Families (DCF), Children’s System of Care (CSOC) to create a shortened eligibility application for DDD services when children hit 18. Previously, when children receiving services from the CSOC reached adulthood, families had to prove again that their children have disabilities. “Gabrielle said it was too cumbersome to go through the process when they were already receiving services through CSOC, so that’s how the concept of short application was born.” They also became Charting the LifeCourse (CtLC) certified ambassadors. CtLC is a framework for helping individuals and families of all abilities and ages develop a vision for a high quality of life.

They hosted education days to keep parents informed. “The one on caregiver succession planning was very popular. Parents want to know what will happen when they die, so they invited panelists to start the conversation. Parents were told to bring any family members or others who were willing to step up.”

With Hurley’s educational background in public relations and Bohon’s educational background in law, “they were good at knowing the rules and how to use them in the right way.”

When they came into the positions, Bohon’s daughter was transitioning to adult life and Hurley had an adult son. “They covered a wide range of needs in their own experience, but always listened to people whose experience may be different from theirs. I admired their commitment to really listen and represent the voice of the whole community. They wanted to deliver the voices of families in a most effective way. They made a good team.”

They also co-chaired both DDD’s Family Advisory Council for four years and CSOC’s Collaboration Committee.

At the end of their terms, RSFPC members voted for new leadership. In October 2022, Dotty Blakeslee was chosen as the new chair, and Cathy Tamburello was elected vice-chair.



Dotty Blakeslee

The New Chair

Dotty Blakeslee, of Wyckoff, is the mother of Maddy, 31. She was a securities analyst who served as a financial advisor for state and local government and is currently a consultant for Government Strategy Group. She serves on the DDD Money Follows the Person (MFP) Direct Support Professional Competency and Capacity Building Steering Committee, on the DDD Family Provider Committee and on the DDD Family Advisory Council. She also serves on a number of other boards that are not DDD related, including the boards of Bergen Commu-

nity College and the NJ Housing and Finance Agency.

“Cathy Tamburello and I will work closely to assure we don’t duplicate efforts. She is a wonderful representative. Our plan for our term is to emphasize our families. They do such a great job of sharing information. Our outgoing chair and vice-chair were a good team. They each focused on their experience and area of interest. It’s a model Cathy and I will continue.”

Blakeslee said that since COVID-19, changes have taken place. “Council members are now using online forums. Even our hybrid meetings are mostly attended by Zoom. We are also trying to figure out if it makes sense to continue our regional education days or if it’s better to support the individual councils’ education days. We’re waiting for input. At our last statewide meeting, the morning seminar was healthcare for your child. Three families shared their experiences and Bev Roberts from The Arc of New Jersey spoke about Medicaid and various topics.”

Blakeslee wants to make clear that advocacy can be done two ways. “There’s family to family. Every time we share and reach out to an individual, it’s advocacy. But, on a larger level, advocacy takes place. We are coordinating efforts with the larger community, including DDD, DCF, other state agencies, service agencies, families and the people with disabilities.”

The NJRFSPC Health and Safety Committee was formed after a member’s child died in a group home. “That’s not to say that all group homes are bad. They aren’t. My daughter lives in a lovely one. But, when something disastrous happens, it’s a sign that something isn’t right and improvements must be made. I personally think we need to continue to push the health and safety white paper.”

The NJRFSPC gives out the white paper to families. The PDF (portable document file) is on the Council site, so it’s publicly available. “It’s important because it has a clear plan of action. We need to reach out with the white paper to agencies and other state departments and legislators. We’re trying to meet with anyone with a vested interest of improving the lives of people

with disabilities. It’s a basis for discussion to open up a line of communication to see what we can do together.”

Blakeslee said this is just one part of what they need to do. “We care about a very broad range of issues. I feel the need to make sure that all regions have the ability to weigh in on our mutual agenda. It’s important to reach out as broadly as possible.”



Cathy Tamburello

The New Vice-Chair

Cathy Tamburello of Verona has a 37-year-old son who lives in a group home. A retired school administrator, she ran Bergen County Special Services’ New Bridges Program for students with autism. She now has an advocacy consulting business, advocating for families of children who have IEPs (individualized education plans).

She is a board member for Youth Consultative Services (YCS), the agency that runs her son’s group home.

Tamburello is a CtLC certified ambassador. Since completing the training, she now integrates the use of the CtLC tool into her work and her volunteer positions. “It’s very helpful. It’s important for families to articulate their priorities for their child with disabilities. The tool provides a good road map to do that. When families can clearly articulate their priorities, they can build a strong IEP.”

Tamburello said she and Blakeslee are working on plans for the coming year. “We have two committees—the Family Advisory Council and the DCF Collaboration Committee. I spearhead the DCF Collaboration Committee. My priority is to collaborate with the division to strengthen understanding of their services and to help people access these services more easily. You can use the CtLC tool to help people articulate and reach those goals. What’s great about the committees is they provide a chance to elevate family voices. This way, the agencies providing services can hear that feedback and take it into consideration as they move forward.”

Growing the membership of the council, especially for younger families, is a priority for Tamburello. “We have some younger families, but they are busy raising their children. The council helps families who need direction and support. But, the bigger picture is important—advocating at a systemic level to make meaningful change. To do that successfully, we need to hear from the families dealing with these challenges on a daily basis. The pandemic was restricting in outreach. Now we want to expand the types of outreach we do. The personal touch, reaching out to people and strength in numbers through joint advocacy can make a difference.”

She stresses the need to increase awareness of the advocacy issues that the council has taken on and how they have made a difference. Toward that end, the NJRFSPC has started an Instagram account at <https://www.instagram.com/njrfspc/>.

“We care about a very broad range of issues. I feel the need to make sure that all regions have the ability to weigh in on our mutual agenda. It’s important to reach out as broadly as possible.”

—Dotty Blakeslee

They plan to have the local councils create their own Instagram accounts.

Tamburello said the Health and Safety Subcommittee has done tremendous work on the healthcare of individuals with I/DD, including publishing a white paper to focus on health issues and ways to recognize them in individuals with I/DD. “A priority is to get that out to agencies to help them better care for the individuals under their auspices and to expand that work so that agencies are accountable.”

The Regional Family Support Planning Council #4, Essex, Tamburello’s local council, regularly co-hosts “Family forums” with the Family Support Organization of Essex County. They were done by Zoom during the pandemic. Tamburello said they unexpectedly found they could reach more people that way. “People didn’t need to get a sitter and drive. They could just log on and listen, even if they were multitasking. We plan to continue using a hybrid way of doing things. It’s such a relief to do virtual appointments. We’re not 100 percent back to prepandemic, but we’ve opened up more. Giving new people this option can help get more people.” **P&F**

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Auntie Nadine and Nassan in *Ada Twist, Scientist*