

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 2025, NO. 1

Kevin F., a student at The Phoenix Center in Nutley packs baked goods at Felina Restaurant, in Ridgewood, NJ. It is all about building independence for adulthood.

(See story on page 7)



Transition Planning

Teaching Independence, Not Reliance

CONNECTION MATTERS



<https://njcdd.org/subscribe-to-the-njcdd/>

The New Jersey Council on Developmental Disabilities is using a new electronic platform for publications, news, resources and announcements.

Please use the link or QR code on this page if you **only** receive this publication in the mail and are not signed up for NJCDD emails.

This information will not be shared with anyone and will be used to help us connect you with relevant resources, news and events in the format you prefer.

Thank you for taking the time to update your information and your continued interest in the NJCDD. We sincerely look forward to providing subscribers, like you, with improved materials that are tailored to your preferences and areas of interest.

 For more information
800 792-8858

 www.njcdd.org
VISIT OUR WEBSITE





PUBLISHER New Jersey Council on Developmental Disabilities

CHAIRPERSON Paul A. Blaustein

EXECUTIVE DIRECTOR Mercedes Witowsky

EDITORIAL BOARD MEMBERS

Kelly Boyd, NJ Office of Emergency Management

Mike Brill, Family Advocate

Peg Kinsell, SPAN Advocacy

Kevin Nuñez, NJCDD Council Member

Carole Tonks, Alliance Center for Independence

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

SELF-ADVOCATE MEMBERS

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

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

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

PUBLIC MEMBER

Laura Williams

FEDERALLY-MANDATED MEMBERS

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

Peri Nearon, Division of Disability Services

Jonathan Seifried, Division of Developmental Disabilities

Kimberly Murray, Office of Special Education Programs

Phyllis Melendez, Division of Medical Assistance
and Health Services

Charyl Yarbrough, Division of Vocational Rehabilitation Services

Kourtney Pulliam, Division of Family Health Services

Joyce Jelley, The Boggs Center on

Developmental Disabilities at Rutgers University

Gwen Orłowski, Esq., Disability Rights NJ

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

Subscriptions to *People & Families* are free and are available through the Council office or by e-mail at njcdd@njcdd.org. Please include your name and address. Articles may be reprinted without fee by permission. Expressed opinions are not necessarily those of the Council's membership. We welcome your letters and comments. Send them to 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 2025, No. 1

6

LETTER FROM THE EXECUTIVE DIRECTOR

Every person has the right to live a fulfilling, self-determined life. This vision is central to the mission of the Council and underscores the importance of individuals with disabilities having the same opportunities as their peers to grow, thrive, and contribute to society.



7

cover story TRANSITION PLANNING: TEACHING INDEPENDENCE, NOT RELIANCE

By Brenda Considine

The use of 1:1 paraprofessionals has increased dramatically in recent years to the point that in some classrooms, there are as many adults in the room as there are students. But is it not the crowded room that is the biggest problem. The danger lies in the fact that on-going 1:1 support means many students never learn the skills they need for independence as adults. There are ways to prepare.



12

A CRISIS OF OUR OWN MAKING: ADDRESSING THE SHORTAGE OF DIRECT SUPPORT PROFESSIONALS

By Jonathan Jaffe

Disability advocates offer a three-prong solution to addressing the chronic shortage of Direct Service Professionals (DSPs) in New Jersey: Pay more. Train better. Create higher standards. There are now two key initiatives underway to address the shortage of DSPs in New Jersey. One focuses on a pilot college career development program; the other has New Jersey entering a six-state pilot program.



16

NAVIGATING THE MEDICAL MAZE: MEDICAL TRANSITION FROM CHILDHOOD TO ADULTHOOD

By Jason Krasnow

Without a legal mandate for medical transition planning, parents, families, and loved ones must navigate the process using whatever resources they can. Insurance changes, social security, disability services, the transition to an adult doctor, self-advocacy skills, and issues of discrimination all come into play. Above all else, planning is key.

20

THE ARC MERCER: SUPPORTING DIRECT SUPPORT PROFESSIONALS IN MEANINGFUL WAYS

By Jonathan Jaffe

It is safe to say the DSPs have a say in virtually all facets of the operation. That is one of the reasons why The Arc Mercer is bucking the national trend through innovative efforts to recruit and retain professionals for this in-demand work. Steve Cook, the agency’s executive director and chief mastermind, said the initiatives are innovative, impactful and lasting.



26

THE NEW JERSEY DEPARTMENT OF HEALTH: A SOURCE OF SERVICES FOR CHILDREN WITH DISABILITIES

By Maryann B. Hunsberger

From Newborn Screening to Special Child Health Services Case Management, the New Jersey Department of Health offers multifaceted programs for families with children who have long-term medical and developmental disabilities, helping them navigate within and across systems of care.



20

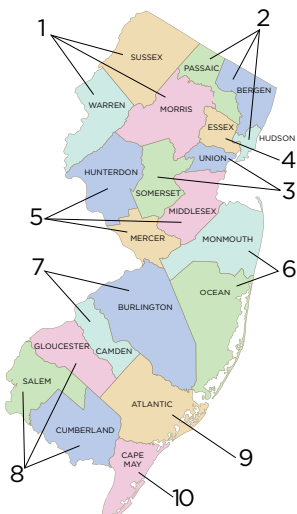
31

NJCDD COMMITTEE UPDATES

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

24

INFORMATION ABOUT STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS



from the Executive Director ■

Living a Self-Determined Life



Dear Friends,

As both the mother of a young woman with I/DD, and the Executive Director of the New Jersey Council on Developmental Disabilities (NJCDD), I believe deeply in the right for every person to live a fulfilling, self-determined life. This vision is central to the mission of the Council and underscores the importance of individuals with disabilities having the same opportunities as their peers to grow, thrive, and contribute to society.

In order to achieve this vision, three things need to happen.

1. We must make sure that people with I/DD have the supports and services they need. Direct support professionals (DSPs) play a vital role. Individuals with I/DD are empowered by DSPs to fully participate in their communities and lead lives that reflect their personal choices and goals. But in New Jersey, as in the rest of the nation, there is a painful shortage of DSPs.
2. We must ensure that people with I/DD — from a young age — have an opportunity to learn the skills they need for increased independence and self-direction. By fostering these skills, we empower people to take charge of their own services and live the life they envision.
3. We must make sure we maintain and leverage all of the supports and services that are available to people with I/DD and their families. This includes protecting supports and services from any potential budget cuts at the federal or state level.

In this issue of *People & Families*, we share stories that explore strategies and solutions to address the DSP crisis. We learn how one innovative provider maintains staff for longer periods (and recruits others!) when DSPs are truly supported in ways that matter to them. We share stories that underscore the vital importance of teaching and promoting self-direction and self-advocacy to transition aged youth so they can advocate for what they need in areas including health care, employment, and daily living. And we share a story about the rich array of services and supports offered through the New Jersey Department of Health.

Let us continue to learn, share, and advocate together so that hopes and dreams become reality.

Sincerely,

A handwritten signature in black ink that reads "Mercedes Witowsky". The signature is written in a cursive, flowing style.

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



Ashley (R) removes items from envelopes and sorts them by first letter, as employment specialist Elba (L) looks on. The goal is to reduce reliance on 1:1 support as students near graduation.

Transition Planning for Students with Complex Disabilities

Teaching Independence, Not Reliance

By Brenda Considine

Transition planning is a critical component of special education. This process, which begins as early as age 14, helps students with disabilities get ready for adulthood. It involves far more than academic success — it includes job skills, independent living skills, and community participation.

For students with intellectual and developmental disabilities, those skills are often taught and reinforced in very small groups — sometimes with 1:1 help. But what happens when they graduate, and enter the system of adult services where they face a world with fewer supports and far fewer staff?

The Role of Paraprofessionals in Transition Services

In school, paraprofessionals often provide essential support to students with complex disabilities. They might help with daily tasks, support behavioral needs, provide academic assistance,

help with mobility, keep a student organized and on task, and facilitate communication. Paraprofessionals can help transition-aged students access vocational training, life skills instruction, and community-based experiences (job coaching, job shadowing, mobility training).

The use of 1:1 paraprofessionals (one adult working with one student) has increased dramatically in recent years to the point that in some classrooms, there are as many adults in the room as there are students. But is it not the crowded room that is the biggest problem. The danger lies in the fact that on-going 1:1 supports are not available for most students after graduation, and students may have never learned the skills they need for independence.

“We have high expectations for students, which is good. But the challenge arises when the level of assistance to meet those expectations is too

high, and opportunities for independence are too few,” said Peg Kinsell, Director of Public Policy at SPAN Parent Advocacy and Chairperson of the NJCDD Subcommittee on Children and Youth.

“When a student becomes overly reliant on a 1:1, they never get to practice problem-solving, self-advocacy, or task completion on their own. There is also a stigma, making it harder for them to engage their peers. It can be a barrier to the natural development of friendships and relationships. Once they graduate, they may end up failing in a job or living situation, even when they have the potential to function more independently. But they have never been taught,” she concluded.

Kinsell offered an example of a student who worked in a job during high school with the assistance of a 1:1 aide. He struggled when placed in a similar job post-graduation, where he did not have a 1:1 and was expected to work more independently. The absence of the familiar support system led to frustration, behavior challenges, and ultimately, cost him his job.

The Harsh Reality of Adult Services

As students with complex disabilities transition into adulthood, they encounter a major shift in the availability of support services. While high schools often offer a wide range of services, including 1:1 paraprofessionals and specialized programs, adult services are more limited.

“There is a stark contrast between the structured, supportive environment of high school and the less supportive, less structured world of adult services,” said Jared Oberweis, Esq., an attorney at Hinkle, Prior, Fischer and Oberweis, who specializes in disability law. “While still in school, students are entitled to services in the IEP, where supports can be highly individualized and intensive. But once they graduate, they face a much more limited range of supports in adulthood.”

“Division of Developmental Disabilities (DDD) and DVRS both fund support services, but, in most cases, they cannot provide the same level of hands-on assistance that students might receive in the school system. This discrepancy can be jarring

for students who graduate from high school expecting to continue receiving the same level of individualized support,” Oberweis added.

Tom Baffuto, executive director of The Arc of New Jersey, has been in the field of disability services for more than four decades. He has urged providers of adult services to do more to prepare to meet the needs of increasingly complex graduates. He believes that interagency collaboration is key. While there is a requirement that school districts work with adult providers to ensure seamless transition, more often than not, DDD and DVRS representatives do not attend these meetings.

“There has to be better communication between schools and adult providers,” said Baffuto. “We need more data — not just about the numbers of students leaving school, but also, the nature of their needs. The adult system is not set up to provide 1:1. If students transition out of these situations without good planning, there will be

Key Skills for Independence

Make decisions independently: Students may need to solve problems on their own and make decisions regarding how to approach tasks or handle conflicts. If they are always told what to do or guided step-by-step, they may never develop these essential skills.

Advocate for their needs: Advocacy is a critical skill that students must develop to navigate the adult world. Students who are overly dependent on aides may never learn how to effectively communicate their needs or ask for accommodations in a workplace or social setting.

Manage time and tasks with less support: In a job setting, managing one’s schedule, tasks, and productivity is essential. However, students who rely on an aide for constant reminders and supervision may struggle to manage these tasks independently.



Technology can be used to help increase a student's independence.

a real dose of reality for both the providers and for the family.”

Mitigating the Risks: Preparing Students for Independence

When students with disabilities enter the adult workforce after working with a 1:1 paraprofessional, they may not be prepared to perform tasks on their own, manage their schedules, or meet the expectations of employers who are not able to provide constant supervision.

John J. Mulholland Jr., Esq., is the Executive Director of ASAH, a statewide association of roughly 120 state-approved out of district schools in New Jersey that partner with public schools to serve students whose needs cannot be met in the local district.

He believes it can be a disservice to students to rely heavily on 1:1 paraprofessionals during the transition years without carefully considering the future.

“The reality is that once a student graduates, they will not have someone by their side all day, prompting and re-directing. ASAH schools, as a whole, work hard on strategies to reduce those supports so students are ready for the world of work, higher education, or adult services,” he said.

One of those schools is The Phoenix Center in Nutley, where executive director Julie Mower sees the challenges every day. There, transition specialists work in collaboration with sending school districts and parents to gradually build independence for students who have had 1:1 support. Once plans to fade 1:1 supports are in place, transition specialists take data. As a student demonstrates the ability to work with decreased support, 1:1s are removed from student IEPs.

To make this happen, The Phoenix Center uses a range of strategies:

“Teachers are encouraged to rotate paraprofessionals in the classroom, which can help reduce dependence on a single individual for support

and provides opportunities for a student to navigate interactions with various support staff,” said Mower.

In addition, they gradually reduce the level of prompting and guidance provided by the 1:1 aid, helping students develop self-reliance and problem-solving skills.

For students in community-based instruction (CBI), the school works to increase the frequency of CBI, allowing students to navigate challenges with decreased support in the local community. Through their Work-Based-Learning programs, they introduce job shadowing and internships, which provides opportunities for students to experience real-world work environments with gradually decreasing levels of support. The school also provides volunteer and in-house work experiences.

Mower believes supporting families is critical. The Phoenix Center helps families with the process of applying to DDD, selecting a support coordinator and visiting adult programs with the student and their families to see what might be the best fit for them. She underscores the importance of good transition plans as effective tools for determining what the student needs, post-graduation.

“My advice to families is to trust in the process, communicate openly with the out-of-district school and your local school district personnel. A collaborative partnership can help ensure the student transitions as smoothly as possible to *life beyond the classroom* with the maximum amount of independence and potential possible for that individual,” she concluded.

Dr. Josie Badger is the co-director at the RAISE Center, a nationwide organization funded by the Rehabilitation Services Administration (RSA) to provide support to students with disabilities through the transition from school to adult life. Growing up with a rare form of muscular dystrophy, Badger needed a lot of support, including 24/7 nursing care. As she entered high school, she and her parents recognized that the

need for assistance would likely continue, but the ways in which that assistance was delivered needed to change.

Badger is quick to emphasize that independence does NOT mean the student gets no supports, but rather, that supports are more self-directed, more invisible.

“It is possible to have 1:1 support and still be more independent,” stated Badger.

She suggests that IEP teams consider life *after* the IEP disappears.

“There are so many students now with 1:1 para. If they are encouraged to do too much for the student, and to anticipate their needs, the student will not have a good transition. Even a job coach will fade out eventually so youth need to be able to state what they need help with. *Before* 1:1 paraprofessional services are put in the IEP, there should be discussions about the expectations for the student’s level of independence, and then, training and guidance for the para that reflects those expectations,” said Badger.

Badger believes that long range planning is vital.

“Will the student gradually go down a sequential path toward independence, learning new skills along the way, or will they reach the end of the school services in the IEP and fall off a cliff?”

Badger emphasizes the importance of teaching self-direction as part of the transition planning process.

- **Gradual Shift of Responsibility:** The IEP should reflect a gradual change in the ways in which supports are delivered, where aides provide support at first, but this support decreases over time. This helps students gradually take on more responsibility for their own actions and tasks or for asking for the help they need.
- **Fostering Self-Advocacy and Self Direction:** The IEP should explicitly teach students to advocate for themselves in academic, work,



“It is possible to have 1:1 support and still be more independent.”

—Dr. Josie Badger

Dr. Josie Badger (seated) with her husband Mike (l), son Ray and foster son (r) whose adoption is pending.

and social situations. This includes teaching students how to communicate their needs, ask for help when necessary, and seek accommodations when needed in various environments.

- **Teach and Reinforce Self-Regulation Skills:** Self-regulation refers to the ability to manage emotions, behaviors, and reactions to situations. By learning these skills, students can better control their reactions, stay focused, and handle challenges without needing constant help from job coaches or staff.
- **Job Shadowing and Internships with Increasing Independence:** IEP teams need to plan for the student to have the opportunity to participate in work experiences where they gradually take on more responsibilities and work with less supervision.
- **Life Skills Training:** Time management, money management, meal preparation, and problem-solving skills should be integrated into the curriculum to ensure that students are prepared for the demands of adult life.

- **Collaboration with Adult Service Providers:** Schools should collaborate with adult service agencies early in the transition process to ensure that students are prepared for the level of support they will receive after graduation. By working with these agencies, families and students can better understand the types of support they can expect and plan accordingly.
- **Technology for Independence:** Some people with disabilities struggle with staying focused, managing tasks, and knowing when to take breaks or ask for help. Technology, cellphones, smart devices, timers, and apps can provide the support they need to perform tasks without relying too much on a job coach or staff member.

“Transition is about preparing young people for the future. There is a lot that educators and families can do, just by recognizing that the world of adult services is different than the world of school-based services. By promoting self-direction, gradually reducing supports, and providing opportunities for independent work and life skills development, students with disabilities can lead more independent lives,” concluded Badger. **P&F**

“A Crisis of Our Own Making”

Addressing the Shortage of Direct Support Staff

By Jonathan Jaffe

Disability advocates offer a three-prong solution to addressing the chronic shortage of Direct Service Professionals (DSPs) in New Jersey:

Pay more. Train better. Create higher standards.

For years, these solutions have been discussed and debated. Yet, many social service agencies in the state still struggle to recruit, train and retain DSPs, in an era when the Baby Boomer generation is entering the golden years and will soon require the care that DSPs provide, 24-7, 365 days a year.

DSPs are critical in assisting people with disabilities. They also play an important role in ensuring they are valued, participating members of their communities. In spite of these facts,

wages for DSPs remain comparatively low. Their work schedule often includes nights, weekends and holidays. The intensive, often grueling, job requires cooking, shopping, tracking of prescriptions, toileting, attending medical appointments and on and on. These factors have led to a shortage of DSPs for both in-home and group home care.

The ongoing concerns are not lost on state leaders and decisionmakers. The shortage of DSPs is commonly noted in the annual report of the state’s Ombudsman for Individuals with Intellectual and Developmental Disabilities and Their Families. The ombudsman, Paul Aronsohn, said that without the appropriate number of trained direct care staff, abuse and neglect happens.

Direct support professionals are the backbone of community-based living for people with I/DD.



“Yet the state continues to allow many direct care staff to be paid low wages, to receive minimal training, and to work with minimal supports — a questionable approach that seems to lead inevitably to high job turnover rates, high job vacancy rates, and continued abuse and neglect,” Aronsohn said.

“We have discussed this serious, persistent challenge in every annual report, and while there have been important steps taken to increase some salaries and to revisit some training requirements, much more needs to be done,” he added. “In fact, many within the disability community believe that the workforce crisis has never been worse — that the shortage of qualified, trained direct care staff is putting unprecedented strains on our system of care.”

He calls it a “crisis of our own making,” noting some provider agencies already receive “a lot” of taxpayer money but choose not to spend it on direct care staff salaries or training. And the state allows them to do so.

Working for Solutions in New Jersey

There are now two key initiatives underway to address the shortage of DSPs in New Jersey.

One focuses on a pilot college career development program, and the other has New Jersey entering a six-state pilot program.

The Establishment of the Direct Support Professionals Career Development Program (DSPCDP)

The New Jersey Association of Community Providers in Ewing, in partnership with the Office of the Secretary of Higher Education (OSHE), has entered into an agreement with the New Jersey Community College Consortium for Workforce and Economic Development to recruit and train more DSPs.

For the fifth consecutive year, ANCOR has conducted a survey to measure the impact of this workforce crisis on both providers and the people they support. The results of the 2024 survey are a sobering revelation of a system of care in peril. Key findings from the State of America’s Direct Support Workforce Crisis 2024 include:

- 90% experienced moderate or severe staffing challenges in the past year.
- 69% reported turning away new referrals.
- 39% were discontinuing programs/services.
- 64% intended to delay the launch of new programs.
- 34% were considering further cuts to programs if recruitment and retention challenges failed to subside.
- 45% were experiencing more frequent reportable incidents.
- 57% of case managers struggled to connect people with services.
- 57% reported delivering services in areas where few or no other options exist.

Access the full report here:



<https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2024/>

For high school students 18 and over, there are internships and training that provides first-hand experience working with individuals with disabilities. Students shadow experienced DSPs in services and support. The high schoolers receive stipends for their work, and perhaps even high school credits, depending on the school district.

The program also caters to workers who are looking to change their career, as well as DSPs who want to learn other aspects of the job. The



Many adults with I/DD could not live independently without support from direct support professionals.

program is available at both Bergen Community College and Rowan College of South Jersey. Eligible DSPs can attend these colleges tuition-free through Community College Opportunity Grants based on household income.

Upon graduating from community college, future DSPs can then transfer to a New Jersey public four-year college or university and receive additional funding for tuition through another state program called the “Garden State Guarantee.”

Valerie Sellars, CEO of the New Jersey Association of Community Providers, said the program has been in place for three years. Nearly 50 students have become DSPs, attracted to the \$5,000 stipend, college credits at no cost and the specialized training.

“Although we are in ‘Year Three,’ this program is still in its infancy,” she said. “I want to see this really grow. DSPs should be pursuing a college

education and talking to their providers about career pathways so they know they can advance through their organizations.”

Sellers noted the state still needs to address the wage structure for DSPs, as those starting out earn less than \$20 an hour, despite the enormous responsibility and erratic hours. “There remains a lack of recognition of how challenging this job is,” she said. “All of a sudden, new DSPs are working with people with behavioral issues, have a risk of being harmed and didn’t see themselves changing diapers.”

“I have so much respect for the people who work in this community; they absolutely care about the people they are serving,” she added.

Focusing on recruitment issues, the National Alliance for Direct Support Professionals (NADSP) provides professional development opportunities along with initiatives to recognize and acknowledge hard-working DSPs. For

example, the NADSP “E-Badge Academy” awards DSPs electronic badges to demonstrate their knowledge, skills and values, as well as certifications and ongoing training to keep these human service providers in the industry.

New Jersey Joins Direct Care Workforce Technical Assistance Project

Through a six-state initiative, New Jersey is creating the “Direct Care Workforce Technical Assistance Center.” The new program is designed to help the state improve its recruitment, training and retention of DSPs. New Jersey will collaborate with the other states facing similar challenges to share best practices and strategies to address the workforce shortage.

The six selected states receive up to 250 hours of individualized technical assistance, have a coach, and access to subject matter experts to support them in addressing the DSP shortage.

New Jersey is conducting a formal needs assessment and strategic planning process; resources and expertise are being used to address the ongoing shortage. The team includes the state Department of Human Services, the Office of the Secretary of Higher Education and the state Department of Labor and Workforce Development.

Each team includes representatives from the state’s Medicaid, aging, disability, and workforce development agencies, in addition to other stakeholders. The state teams design solutions through reforms in policy, practice, programming, payment and performance.

The program, through the Administration for Community Living, an operating division of the U.S. Department of Health and Human Services, has its first cohort running through December 31, 2024. The other five participating states are Alaska, Colorado, Delaware, Indiana and New Mexico.

“NJCDD applauds the Administration for Community Living’s technical assistance to improve the recruitment, retention, training, and professional development of the direct care workforce across our county,” said Mercedes Witowsky, Executive Director of the NJCDD.

“NJCDD is delighted to play a role in New Jersey’s approach to improve workforce training and career development to address our state’s workforce crisis in order for people with developmental disabilities to have access to quality supports and services,” she added.

Following the Money

The state ombudsman said wages remain a key factor for recruitment. He is calling for a requirement that all provider agencies for people with disabilities publicly report their revenues and spend a specific percentage of those revenues on direct care staff — similar to the requirement for New Jersey nursing home providers and aligned with the federal Centers for Medicare and Medicaid Services (CMS).

“We should consider a requirement that all direct care staff — Direct Support Professionals, Self-Directed Employees, and Private Duty Nurses — be paid at least a living wage, one indexed annually to account for increases in the cost of living,” Aronsohn said.

Also, to sustain the workforce, New Jersey should consider a requirement that agencies that provide supports in state-licensed residences maintain minimum direct care staff-to-resident ratios — similar to the requirement for New Jersey nursing home providers — to ensure appropriate staffing levels, he noted.

“Simply stated, without urgently needed reform — without higher salaries, higher standards, more training, and better work conditions — the abuse and neglect will continue,” Aronsohn said. **P&F**

NAVIGATING THE MEDICAL MAZE

Medical Transition from Childhood to Adulthood

By Jason Krasnow

Healthcare is confusing, even more so during the transition from child to adult care. For people with intellectual and developmental disabilities, the healthcare system can present additional challenges. Besides the typical challenges faced by people with any disability, they may also struggle to understand medical instructions or communicate with their healthcare providers. Without a legal mandate for medical transition planning, as there is for transition planning when a student leaves school, parents, families, and loved ones must navigate the process using whatever resources they can. Insurance changes, Social Security, disability services, the transition to an adult doctor, self-advocacy skills, and issues of discrimination all come into play. Above all else, planning is key.

First, insurance. When a child reaches the age of majority, 18 in most parts of the United States, it can trigger a change in their insurance status if covered by a government-subsidized insurance program. Under current law, though, a child covered through the parent's work-based insurance can keep it until they reach age 26. During this period, a person with a disability can have both private health insurance and Medicaid at the same time.

Nicole Pratt, Parent Advocate with SPAN Parent Advocacy Network, Family and Professional Development Director, and Project Director for Leaders Empowered as Advocates with Dignity (LEAD), explains this policy's importance.

"If it's private insurance, what they have to remember is that if they turn 18, if that person is also eligible for SSI Medicaid, they have a choice. They can put in an application for that service, and

simultaneously, they can keep the child on private insurance until they're 24. They can keep the child on the private insurance for medical care and use the private insurance for medications, which are often expensive, or they can keep the person on a Medicaid HMO if they feel that will be more cost effective for the prescriptions as well," she said.

This arrangement causes no negative impacts on the person's private health insurance; it pays first, and Medicaid serves as a payer of last resort for what insurance leaves uncovered. It leaves the person's access to their doctors through their private health insurance intact. Medicaid can also cover health services often left out, such as some medical supplies and personal care assistance.

Even in a situation where a person does not need Medicaid, Medicaid eligibility can impact the availability of other services. The New Jersey Division of Developmental Disabilities (DDD) requires individuals to maintain Medicaid eligibility to receive services, as some of the funding for their programs comes from the federal government. One of the most common pathways to this eligibility is an application for Supplemental Security Income (SSI). In New Jersey, a person deemed eligible for SSI automatically receives Medicaid coverage, and with it, eligibility for DDD services.

There is a single major exception to these rules, explains Connor Griffin, Director of Health Care Advocacy with The Arc of NJ.

"Normally, Medicaid is required for DDD, but there is a smaller subset of individuals that will sometimes become eligible for Social Security

benefits before the age of 18, because the parent either retired, became disabled, or passed away. When a child is receiving that benefit, it usually means their income is too high to qualify for Medicaid or SSI. The individual should apply through a DDD waiver process, and then they can get Medicaid at 21. The Arc of New Jersey has a Medicaid problem form on their website, which can be submitted to the DDD to make sure the individual is able to be processed through the waiver unit,” Griffin stated.

Some young adults can remain on their parents’ private group health insurance after the age of 26, in addition to retaining Medicaid coverage, if they meet certain qualifications under New Jersey law. This requires that their disability prevent them from sustaining employment, and that they remain mostly dependent on their parent for support. Insurers require the person to provide proof of incapacity before the date when their coverage would otherwise end. Parents should contact their health insurance administrator a few months be-

fore their child turns 26 to leave time in case they need more documents.

Lauren Agoratus, State Coordinator with Family Voices NJ, emphasizes that this represents a great benefit for those who qualify.

“It’s huge,” she says. “There are different rules for both private and public insurance so, with private insurance, if you have a developmental disability, you are at an advantage, because beyond the Affordable Care Act, which goes to 26, people with developmental disabilities can be covered regardless of age as long as their family member is employed.”

The range of providers a person with disabilities can see changes during the transition too. Most pediatricians stop seeing patients when they turn 21 or 22. Finding a suitable doctor who treats adults, before the switch, can make the process much easier. This search can run into difficulties, since doctors’ availability and their comfort with patients who have I/DD can vary.



Teens and young adults need to learn how to communicate effectively with medical professionals providing care.



Learning how to share information with health care providers at an early age is an important skill.

Some medical facilities offer specialized supports for people with disabilities, but these programs tend to end at adulthood. Certain facilities, like the Children’s Hospital of Philadelphia, offer specific transition services to those already seeing their providers. Advocates agree that in any case, those familiar with the person’s needs, like previous medical providers, often provide the best guidance.

“Ask your pediatrician, ask your children’s hospital, whoever you’re seeing, who is good with adults,” Agoratus suggests.

Self-advocacy represents another key aspect of a successful medical transition. Many young people receive full control over their own healthcare at 18, and those who remain under guardianship or another legal instrument still benefit from the ability to understand their treatment. Doctors do not always teach these skills as the transition period approaches; most young people with a developmental disability do not receive complete preparation for the change.

Time alone with the doctor, instruction on managing and understanding their medical care, and a discussion with their pediatrician about the

change all prepare a person for adult care. Parents can advocate for these steps, or provide the training they can if the doctor remains unable. Lauren Agoratus, with Family Voices NJ, says, “I think that you have to start out early with self-advocacy.”

Discrimination, while an unpleasant topic, can play a central role in choosing medical providers for people with a disability, and those with I/DD are no exception. Two key areas to consider are the person’s first language and their disability status itself. Those with limited English proficiency may face a particular challenge, especially if their family members also speak another language as their first. Pratt, the Parent Advocate with SPAN, says, “It affects it greatly, one, because doctors or parents don’t know they can request a professional translator.” She adds, “Two, parents could lose out on services their child needs and on understanding the care their child would need.”

A person’s disability itself can create problems with discrimination. Those searching for a new provider must consider how the provider or office staff reacts to learning that their potential patient has a disability. While the realities can be

discouraging, attention to the provider's attitude and perceptions can make a difference.

Agoratus lists a few examples to highlight the importance of caution. "I have heard really disheartening stories," she says. "I have heard the parent of teenagers with developmental disabilities told, 'Why do you want to get braces for that person?' I have heard a boy with a long-term terminal illness, likely to die in his late 20s, told 'We're not going to give him physical and occupational therapy, he's going to die anyway.' I have heard of the mom of a toddler with Down Syndrome, with pneumonia, who a doctor asked, 'Should we give her antibiotics or not?'"

With that extreme, but sadly real, example in mind, the importance of planning, preparation, and education only grows. Parents, families, and those with disabilities must often provide advisory services for themselves, piecing together information about insurance and doctor selection from the available sources. In these conditions, Pratt suggests an active approach to parents. She says, "I think they have to educate themselves as much as possible. As we educate ourselves around the



(L-R) Nicole Pratt and Diana Autin at a recent open house event celebrating the work of SPAN Parent Advocacy. Pratt's work at SPAN Parent Advocacy Network includes health care advocacy.

education system, we have to educate ourselves around the healthcare system."

Starting the education and research process early, and making a conscious effort to engage with the available options, provides the best chance of success. **P&F**

Get updates on policy, legal, and legislative developments



Increasing dialogue among stakeholders in NJ's Special Education System



The Arc Mercer

Supporting Direct Support Professionals in Meaningful Ways

By Jonathan Jaffe

On any given day, you will see meetings taking place in the conference room of The Arc Mercer in Ewing, New Jersey. The center table is surrounded by serious-looking people reviewing spreadsheets, bar graphs, and other important information that detail the performance of a \$42 million operation that runs 24 residential properties.

While such a meeting would seem commonplace among executives of an operation with 550 employees, there is a significant distinction; among those surrounding the table are front line service workers, known as Direct Service Professionals (DSPs.)

That is because The Arc Mercer wants to ensure its hourly employees — the 350 people who handle the intensive day-to-day support needs of people with developmental disabilities — have a seat at the table, literally and figuratively.

The DSPs take part in nearly every area of organizational management from employee disciplinary meetings, to new programs and work groups. They have the opportunity to share their opinions on anything from proposals to offer pet insurance (which the payroll company plans to use), to changes in email policies, possible pay advances, and upcoming company-wide events.

It is safe to say the DSPs have a say in virtually all facets of the operation. That is just one of

the strategies that has helped The Arc Mercer in bucking negative national trends in recruitment and retainment of DSPs. Steve Cook, the agency's executive director and chief mastermind, says innovations like these are impactful and lasting.

How? Just look at the retention numbers. According to a 2024 survey conducted by ANCOR, a national organization committed to strengthening the ability of community providers to support people with I/DD, the national annual turnover of DSPs at an average agency is approximately 46% — nearly half leave each year. In New Jersey, that figure is around 36%. And at The Arc Mercer? Only 6% of DSPs leave each year.

There are employees like Tarweh Witherspoon of Trenton, who has served as a DSP with the organization for 25 years. He now supports seven men with developmental disabilities who live together at a group home in Trenton.

Witherspoon also serves on the agency's Disciplinary Committee and is pleased to share the many ways in which The Arc Mercer keeps the DSPs engaged and happy.

He notes the personal birthday greetings from Cook, the annual salary raises every January, the quarterly performance bonuses, and up to \$1,200 each year for meeting strategic planning goals.



At The Arc Mercer, discussions about organizational issues include direct support professionals. Clockwise (L-R) Claudia Nance (Direct Support Professional), Kathy Rhead (Assistant Executive Director), Michael Toland (Director of Quality Assurance), Colleen Petermann (Chief Human Resource Officer), Amy Toma (Employee Relations Manager), Steve Cook (Executive Director), Mary White (Director of Janitorial Services), Jean Miller (Chief Operations Officer), Tom Crane (Chief Administrative Officer), Dority Bernard (Direct Support Professional).

Furthermore, there are opportunities for promotion, a “team impact” award, and a generous and unique 401(k) plan which reflects how the agency creates satisfying lifelong careers, rather than hourly, ‘here-today, gone-tomorrow’ jobs.

None of these initiatives compare to the real secret in the sauce — a secret which leads to the more than 100 pre-vetted job applications now sitting on Cook’s desk from community members who are eager to be hired as DSPs in 2025.

Five years ago, when Cook began recruiting extensively in the Liberian community, Cook and others held meetings with dozens of employees of Liberian descent, learning their wants and desires in the workplace.

They had candid conversations about what the DSPs needed to be more comfortable at work so that leadership could gain a better understanding. There was plenty for The Arc Mercer to learn about how to become an even better employer for this West African community.

“We learned that the staff needs longer leave time, in which they can return to Liberia for two or three months and know their specific job will be here when they return,” Cook said. “We learned about immigration concerns as well as the need for these employees to get waivers for a requirement that they provide three years of Driver Abstract information, which is extremely difficult with a foreign driver’s license.”

The Liberian flag now flies proudly in “Diversity Hall,” a lobby in the agency’s Ewing offices that celebrates the heritage of employees with flags and displays from 11 other nations that represent the majority of DSPs employed there. The agency holds regular flag-raising events to celebrate all the nations, as well as cultural events to spread knowledge and understanding among this melting pot of employees.

The Arc Mercer is now working on ways the agency — one of about 600 chapters across the U.S. — can amend the national bylaws to allow for development of programs in Liberia. It would

be a landmark achievement in the 74 years of The Arc Mercer.

Cook has hopes to visit Liberia soon, and is already on his way toward building similar relationships with community members from Sierra Leone, Nigeria and Haiti, as the need for DSPs in New Jersey continues.

“The Arc has even come to the Liberian churches and visited with us,” said Witherspoon, who earned the nickname “The Dean of the Liberian Community.” “Steve has built trust in my community. They know there are good jobs here and that they will be taken care of. They know The Arc will pay it forward.”

Leaders of the Liberian churches have also visited The Arc Mercer’s headquarters and are fully

engaged in the recruitment process, Cook said, noting he has heard that clergy even praise The Arc Mercer from the pulpit for the career opportunities available.

Taking it even a step further, within Diversity Hall, The Arc Mercer established an office that is solely focused on serving people from Liberia and further easing their transition to the United States. It is an important resource, as DSPs working in Mercer County are busy people, often driving an hour from Philadelphia, Bucks County, Pa. or northern New Jersey to serve people with I/DD in this 24-7 operation.

For the last eight years, Claudia Nance of Hamilton has served as a DSP “floater,” going to whatever residential location needs her services. She said



At The Arc Mercer, direct support professionals are engaged in nearly all aspects of the organization. Leadership makes sure they know they are deeply valued. The staff turnover rate there is less than 6%, outpacing state and national averages by a long shot. (L-R) Dority Bernard (Direct Support Professional), Steve Cook (Executive Director), Tarweh Witherspoon (Direct Support Professional), Claudia Nance (Direct Support Professional).



Arc Mercer direct support professionals enjoy a day at the beach with program participants.

she joined The Arc Mercer “with an open heart” and an eagerness to help those in need.

She said the employees are the greatest ambassadors of The Arc Mercer, and regularly speak in their own communities about the benefits available. “We talk of how they take care of the employees,” Nance said. “We talk about how the employees have a voice, how we are well paid, and how we interact with dignity.”

To underscore how the DSPs are responding to the arrangement — much to the surprise of management — they voted to discontinue their labor union that had historically handled their negotiations. DSP floaters now earn \$18.25 an hour full-time, along with health benefits, bonuses and a 401(k) with a 5% contribution and a 6% match on top.

Shift managers earn \$45,760, while group home manager trainees bring in \$50,000 annually and within three months can move up, either to a se-

nior group home manager overseeing two homes at \$76,200, or a behavioral group home manager responsible for one behavioral home at \$80,000. Both totals factor in a performance bonus.

The Arc Mercer also runs an employee relief fund, with revenue dedicated by the board and generated from cash back rebates on the agency’s credit card, as well as voluntary payroll deductions and donations. The money is used to help employees pay for home repairs, medical bills, funeral expenses, temporary shelter and other emergencies that can quickly drain savings.

“When I lived in Liberia, I worked in a hospital,” said Dority Bernard of Hamilton, a DSP for three years who supports adults with I/DD at the Avalon apartment complex in Princeton. “So, when I came to work here, it was like I was coming home. And they make me feel so special here. They value me. They appreciate me. And that is why I always go the extra mile.” **P&F**

Statewide Regional Family Support Planning Councils

Wanted

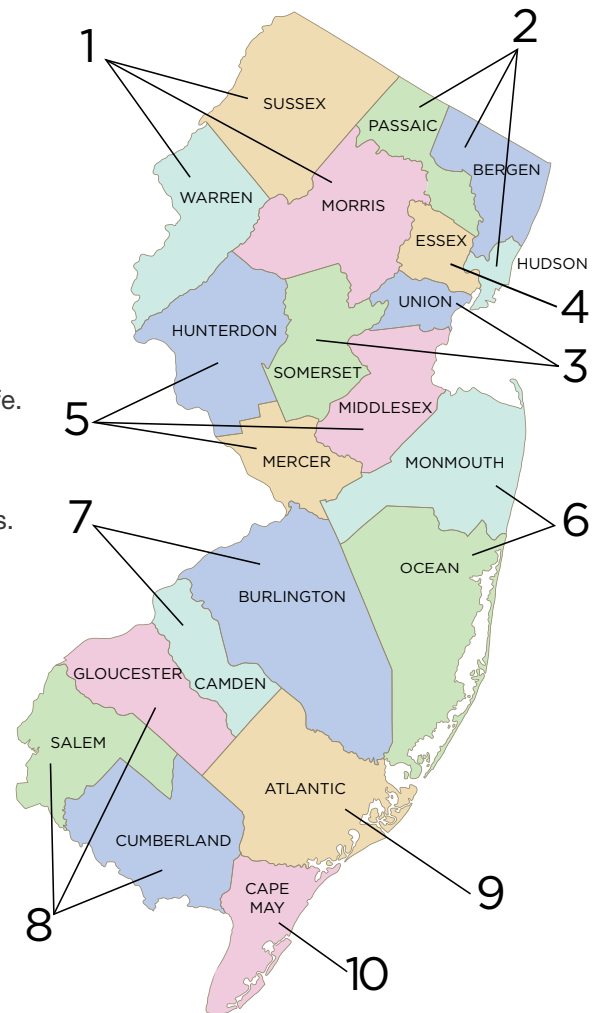
New Jersey's Regional Family Support Planning Councils are looking for new members!

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 soliciting 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 are 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.



A Source of Services for Children with Disabilities

By Maryann B. Hunsberger

The New Jersey Department of Health's Family Centered Care Services are an untapped resource for many families. The multifaceted program assists families experiencing complex, long-term medical and developmental disabilities by helping them navigate within and across systems of care. It promotes access to care through early identification, referral to community-based, culturally competent services and follow-up for children and youth who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions, and who require health and related services that are beyond what is required by most children.

Newborn Screening and Registries: An Early Referral Source

The role of the New Jersey Department of Health (DOH) begins at birth. For nearly ten years, New Jersey law has required babies to be screened for disorders that can cause serious health problems within 48 hours of birth. If there is concern, the delivering hospital or the child's physician generally informs the parents that their child may need services and then makes a referral.

"We are one of the few states that have the birth defects registry and autism registry," said Kourtney Pulliam, MPH, a program manager for DOH's Family Centered Care Services. "We understand the complex needs of those children."

New Jersey operates two registries: a Birth Defects Registry and an Autism Registry. The Autism Registry has at least 40,000 children on it statewide. Once

a child is diagnosed, the provider makes the referral to the registry. A letter is mailed to the family letting them know about the registry, and one of the case managers contacts them. Parents have the option to have their child remain anonymous on the registry or have their name shown on the registry.

"The family decides if they want our services," Pulliam emphasized.

Early Intervention Services

Every state is required by Federal Law to have a system to identify and serve infants and toddlers who have or are at risk for developmental delays. In New Jersey, that system is provided through the New Jersey Department of Health. Contracted agencies serve as the Early Intervention Program providers (EIPs) and arrange for early intervention practitioners to address the needs of eligible

Disability- and Healthcare-Related Programs under the Department of Health

- Newborn Screening and Genetics Services
- Birth Defects Registry
- Autism Registry
- Early Intervention
- Specialized Pediatric Services Program
- Special Child Health Services

children and their families. Following the evaluation and assessment, an Individualized Family Service Plan (IFSP) is developed to describe the services that are needed by the child and family and how they will be implemented.

There are 5 services provided at public expense (no cost to families): evaluation and assessment, development and review of an IFSP, service coordination, procedural safeguards, and Child Find activities.

For services themselves, there may be a fee. A family's cost participation (co-pay) is determined by household income and size and is on a sliding fee scale. Services might include physical, occupational, and speech therapy; assistive technology; audiology; counseling; health services; nursing; nutrition; psychology and social work services; special instruction; transportation; and vision services.

Early Intervention services are typically provided in a natural setting, such as the child's home or daycare. Children may be eligible for EI if they are three years old or younger and have a developmental delay. Children with a diagnosed condition that has a high probability of resulting in developmental delay may also be eligible. When a child turns three, the NJ Department of Education takes over the child's special education needs.

Specialized Pediatric Services Program

The Specialized Pediatric Services Program evaluates and treats children's conditions including autism, attention deficit hyperactivity disorder (ADHD), speech/language delay or disorder, hearing or auditory delay diagnoses, visual impairment, behavioral disorders, developmental delays and disorders, intellectual disabilities, learning disabilities, psychiatric disorders and other neurological impairments. They also provide diagnostic assessments for plastic surgery, orthodontics, dentistry, otolaryngology, cardiology, neurology, gastroenterology, ophthalmology and genetics. They take almost all insurances.

Special Child Health Services

- **Statewide, with offices in all 21 counties**
- **No income tests**
- **No cost to parents**
- **Legal citizenship not required**

“We have a lot of families with multiple diagnoses, so at some of the centers, we have a one-stop shopping model with various specialists in the same place. The tertiary care centers provide for various needs for children with multiple medical issues. If a family has no insurance, there is a charity care option and on-site staff who help families get enrolled into New Jersey FamilyCare (which insures low-income people in New Jersey),” said Pulliam.

The Program is comprised of eight Child Evaluation Centers, four Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorders Centers, five Cleft Lip Cleft Palate Craniofacial Centers, and three Pediatric Tertiary Care Centers. (Tertiary care involves complex procedures and treatments for patients with specialized needs.) These centers diagnose and treat specific disorders and disabilities, and serve as resources of pediatric specialty and sub-specialty care for children with special health care needs.

Special Child Health Services

Special Child Health Services operates under the Division of Family Health Services within the Department of Health. They provide resource and referral services for families of children with special needs through county-based offices. Any child with special health care needs or at risk of developmental delay, from birth through age 21, is eligible.

Case managers — all of whom are either pediatric nurses or social workers — help families with referrals to medical specialists, linkages to community resources and agencies, insurance and educational difficulties. They work with children, parents,

physicians and specialists to evaluate a child's strengths and needs. Special Child Health Services provides services for long term medical conditions, such as diabetes, autism, hearing loss, physical disabilities, birth defects, developmental disabilities or delays and traumatic brain injuries.

According to Pulliam, the number one priority of case managers is to make sure that families are supported and have everything they need to care for their child.

"The population we serve is unique and special to us. Sometimes we help families to find specialized formula and will go through different formulas to find the right one. The case management team

might help find the formula, or the medical staff at one of our centers will identify a vendor covered by their insurance to get the formula. If a child is on a feeding tube and changes insurance, our staff will find a new vendor who can provide the medical equipment the family needs," Pulliam said.

Pulliam notes that children with complex needs that change all the time can get help through these centers.

"One of our centers had a 3-year-old boy with a rare obstruction of the small bowel, resulting in multiple surgeries. It was a really complex case with adverse feeding behaviors and feeding problems. The family had to be trained to use and

Paulina Vargas: Learning to Navigate the System with Help from Special Child Health Services

By Maryann B. Hunsberger

For the past two summers, 7-year-old Brielle Vargas has attended a therapeutic summer day camp. For a month, she relaxes and enjoys herself while receiving therapeutic services. Her mother, Paulina Vargas, learned about the grant-funded program through Special Child Health Services, which she learned about after Brielle left Early Intervention at age 3.

"She gets occupational therapy, physical therapy and speech there. We wouldn't be able to afford this without the grant that we learned about from Special Child Health Services," said Vargas. "I'm so glad the Early Intervention case manager told me about it when Brielle was so young."

Vargas finds the information provided by Nell Carmen, her case manager at Special Child Health Services, to be invaluable.

"The most important thing she told me has been about summer

camp... Because of camp, Brielle can use the bathroom, ride a scooter, put a jacket on, wipe herself, pull her pants up and down, and she is learning to write her name... when I see where she was before camp and where she is now, the progress is amazing," said Vargas.

Carmen has also helped Vargas advocate for inclusive education, and provided referrals.

"I told Nell I was interested in having Brielle included at school and she gave me a referral for SPAN advocacy, where a family resource specialist told me my rights about inclusion. After pushing for two years, Brielle is now included in school. She's doing great in school. She has Assistive Technology and also knows some words and some signs. Without Nell's support, I wouldn't have become empowered to do that," Vargas noted.

Carmen also introduced Vargas to PerformCare, the contracted

system administrator for the State of New Jersey's Department of Children and Families, Children's System of Care, which supplied respite to the family.

Vargas has nothing but praise for the support she has received.

"Special Child Health Services walks the extra mile to support families who are having challenges with the system at any level. They helped me apply for Supplemental Security Income (SSI), explained the Catastrophic Illness in Children Relief Fund, referred me to Children's Hospital of Philadelphia (CHOP) when Brielle had Lyme Disease, and provided advice and a listening ear so many times," she stated.

"It's very important for families to learn about these services so they can receive the proper support that they need. They know so many resources to help you navigate the system."



Families can access a wide range of support services from the New Jersey Department of Health.

properly clean equipment and how to reduce the need for going to the emergency room. We support the families in all these capacities,” she said.

Not all the progress made at the center is medical.

“We had a child with autism who was minimally verbal. The parents noticed the change in the quality of life one of our clinics brought to their child. He learned to dip foods in ketchup from watching the other kids there,” Pulliam noted.

Special Child Health Services keeps a list of special needs dentists in the state so they can be a resource of referrals to specialty dentists. “It’s challenging to find a provider who takes your insurance and provides care to the special needs population. Often times, there is a long wait list. There is a great program in South Jersey called Special Smiles. It’s dental care that serves NJ Medicaid families. For some families, the wait time for special needs dentistry was three years. Now, it’s six weeks for those going through this organization.”

Margaret Hefferle, RN, BSN, is a case manager at Special Child Health Services, where she helps families with issues such as referrals to medical specialists, linkages to community resources and agencies, assistance with insurance, school and the Individualized Education Program (IEP) process. She also provides information about guardianship and other legal alternatives, ABLE accounts, and special needs trusts.

In her role, she sometimes partners with SPAN Advocacy when families need additional educational advocacy. “We help parents read and interpret their child’s evaluation reports. SPAN is about teaching parents to be their own advocates and we can provide some tools to help with that as well,” said Hefferle.

Each county-based case management unit has a host site, such as at a hospital or a county health department. Goryeb Children’s Hospital in Morris County, where Hefferle works, has about 1,300 children in medical case management.

“We ensure families have private insurance or Medicaid if they qualify. We make sure they have a primary care provider. We let people know how to apply for eligibility and obtain services with PerformCare. We keep lists of local agencies that provide Applied Behavior Analysis (ABA) services, since ABA is now covered by most insurance companies for individuals with autism. Our services are confidential, free of charge and voluntary,” she stated.

Special Child Health Services case managers also work with families seeking services with the Department of Children and Families’ Children’s System of Care through PerformCare (serving children) and through the Department of Human Services’ Division of Developmental Disabilities, or DDD (serving those 21 and older).

“We can be particularly helpful with the transition to adult life process, whether that means college, the world of work or if they need substantial supports in their adult life. There are

many things that families must learn about to make their children as independent as possible, yet make sure they are eligible for the services that they may need,” said Hefferle.

For teens, the focus of services is independence, self-advocacy, and community connections for a smooth transition to adult life. As the child approaches 21, the age at which they will no longer be eligible for special education or Special Child Health Services, case managers help families identify a support coordination agency in the adult service system (DDD) to help them navigate in the future.

Kourtney Pulliam, MPH, the program manager at DOH’s Family Centered Care Services, explained, “Parents call Special Child Health Services for resources and support, asking how they can pay medical bills and more. We even reach out at different milestones to let parents know we are here. We don’t force ourselves on families. But we are always an available resource.” **P&F**

The graphic features the title "Eye on Advocacy" in a large, black, handwritten-style font. The word "on" is smaller and in a teal color, with a teal arrow pointing from it to the word "Advocacy". Below the title, "weekly e-newsletter" is written in a smaller, orange, handwritten-style font. To the left of the title is a teal megaphone icon. Below the title is a QR code. To the right is a smartphone displaying a social media post for "NJCDD PUBLIC MEETING HYBRID". The phone screen shows a teal background with a photo of a person holding a phone, and text including "PUBLIC MEETING HYBRID" and "NJCDD ADVOCATE COLLABORATE EDUCATE". Below the phone are social media icons for Instagram, Facebook, and Twitter, and a notification that says "Liked by State of NJ and 2 others".

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.

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

For more information
800-792-8858

www.njcdd.org
VISIT OUR WEBSITE



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:

- Set the agenda for the next Council meeting and Lunch and Learn.
- Began planning the agenda for the May Council Retreat.

The Legislative Public Policy Committee engaged in advocacy and education efforts with staff from Assembly Majority Leader Lou Greenwald's office to promote DVRS involvement through an appointed commission.

- Reviewed NJCDD's role in three National Communities of Practice.
- Reviewed 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:

- Supported 20 advocate members from the Council and public to attend the meeting in person or remotely, marking the best turn-out to date.
- Discussed the need to close institutions.
- Discussed concerns that the new administration in Washington D.C. could make changes that would jeopardize Social Security benefits.
- Discussed strategies to make sure benefits are maintained.

- Discussed the importance of self-advocates taking part in The Arc national conference.
- Discussed supported decision-making and the recent court decision in favor of one of its members.

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:

- Promoted advocacy and education efforts with Assembly Majority Leader Lou Greenwald, Senate Health, Human Services and Senior Citizens Committee Chair Joseph Vitale, Senators M. Teresa Ruiz and Anthony Bucco, and Assemblywoman Aura Dunn to promote priority I/DD and disability issues such as healthcare, access to services, school bus and student safety, and group home abuse and neglect.
- Testified on the proposed FY 2025-2026 budget for the Department of Human Services with emphasis on Home and Community Based Services (HCBS) and the necessity to raise Medicaid rates for services.
- Met with DHS Commissioner Sarah Adelman and other DHS officials on bills proposed by Senator Vitale to prevent abuse and neglect in group homes, and provided input from families and stakeholders.
- The Legislative Disability Caucus has scheduled four quarterly meetings in 2025. Expected topics are the dilemma of "Service Deserts" within NJ, expanding affordable housing and non-traditional alternatives,

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.

racial, ethnic and disability disparities in service systems, and the vital role of Medicaid in the lives of recipients.

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. Recently,

- 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 focused on improving underserved communities' access to health-care, 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 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, and summer camp services.
- Seclusion/restraint/suspension and expulsion, including racial, ethnic, and gender disparity. Also discussed issues around the provision of special education for youth in the justice system.
- School transportation safety, the roles of the IEP, and the need for more statewide training and education.
- School-based mental health services, and how the lack of them is leading to an increase in students placed on home instruction.
- Effects of the elimination of the Federal DOE on special education services and the impact of block grants on New Jersey.
- Advocacy efforts around Medicaid for children.

State Plan Committee

Helen Steinberg is the chairperson of the State Plan Committee. The committee is responsible

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.

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:

- The Administration for Community Living accepted NJCDD's 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 (DEI)

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. The Subcommittee will:

- Propose adding healthcare provider interaction education to the 5-Year Plan.
- Propose collaborating with the Ombudsman's office to analyze complaint data for input into the new 5-Year Plan.
- Invite Rowan University representatives to present their integrated service model at a statewide meeting.
- Continue to collect data from various community resources to better understand the role household member identification plays in I/DD access to services and resources, specifically individuals and families from diverse backgrounds.

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 the status of Community Innovation Projects (current, new and letters of interest).
- Discussed the remaining key activities of the 5-Year Plan **P&F**



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





Direct support professionals at The Arc Mercer are bucking national trends with longevity and low rates of turnover. (See story on page 20)