

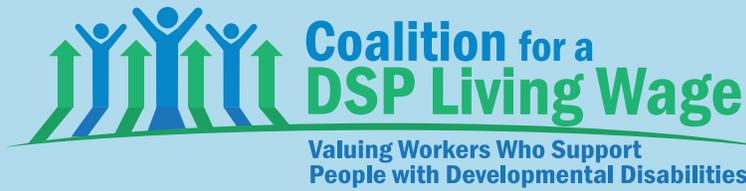
# Peoples & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SUMMER 2019



**QUANIA KENNEDY  
CHARTING  
HER OWN  
CAREER PATH**



Thanks to your outstanding  
**ADVOCACY**



## Governor Murphy Approved **\$20M** DSP Wage Increase for FY 2020 Budget

The final FY2020 budget Governor Murphy signed into law includes \$20 million in new state funding. It will generate additional federal Medicaid matching funds.

# Thank You!





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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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Photo by Rebecca Shavulsky

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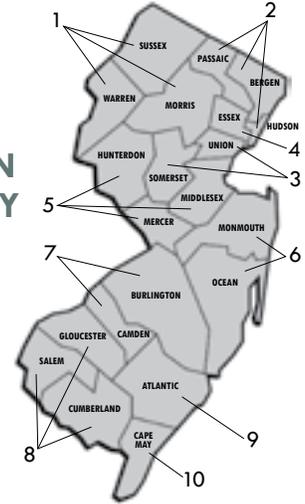
An IEP must focus on a student’s preferences, interests, needs and strengths. All students, regardless of age or disability, should be involved in the development of their own IEP. Quania Kennedy and Bobby Kopac are two examples of students who are charting their own career paths.



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from the Executive Director ■

## Advocating for Safe and Effective Special Education



I find it hard to believe that another summer has flown by in the blink of an eye. As many of you dive in to another school year, I wanted to give you some valuable information to help you and your loved ones.

So, we're dedicating this issue of *People & Families* to special education.

I also felt it was important to honor the lives of Colleen Fraser, and Joseph M. Amoroso. Colleen served as NJCDD chairperson. She was also a passenger on United Airlines Flight 93 which crashed in Shanksville, Pennsylvania on September 11, 2001.

Joseph passed away peacefully on September 5, 2019. He was the former Director of the Division of Disability Services. Both Colleen and Joseph were tire-

less advocates for people with disabilities. They will always be remembered for their drive and determination.

Advocating for the rights of students with disabilities remains at the forefront of the Council's many priorities. Above all, our students have the right to a safe and productive learning environment.

We recognize the urgency of effectively addressing school safety, particularly for students with intellectual and developmental disabilities. As a result, the Council convened a School Safety Summit. We created a forum to discuss issues and best practices related to the needs of students with disabilities.

Our goal was to explore issues and challenges while generating tangible solutions to address school safety for students with disabilities. I encourage you to read the story written about this important challenge. The Council will share more information about our collective efforts during the coming months. So, stay tuned!

Among other important items, the Summer 2019 issue of *People & Families Magazine* highlights disproportionality in special education, an issue that continues to adversely impact students of color. I'm sure you will agree that all students with disabilities regardless of sex, race, national origin or sexual orientation deserve equal access to a fulfilling educational experience devoid of externally-imposed distractions that could inhibit their growth.

I sincerely hope you enjoy this issue, and wish you a safe and productive school year.

*Mercedes Witowsky*  
*Executive Director*

*New Jersey Council on Developmental Disabilities*

# School Safety Summit

## *A Call to Action*

By Brenda Considine



*Kevin Nuñez (center) is an active NJCDD member.*

**W**hen Kevin Nuñez was a teenager, he attended his local public high school. He was fully included in everything—almost.

“I was basically treated like everyone else,” said Kevin, who now serves as a member of the New Jersey Council on Developmental Disabilities.

But there was one big exception. During drills for school emergencies, Kevin, who has cerebral palsy, was left behind.

“The school’s evacuation plan was for me to wheel myself into the ladies’ bathroom and pull into the handicapped stall—it was the only place big enough for my power wheelchair. They told me to turn around with my back to the door so if a shooter came in, the bullets would have to go through the metal door and my wheelchair before

they hit me. I was told to wait there quietly, alone in the dark. That was the plan,” he said.

Kevin is not alone. Even today, many schools rely on strategies that force students to simply wait for help, although advocates agree that “sheltering in place” and waiting for help is not a comprehensive solution. It leaves students in harm’s way, can be terrifying, and may be dangerous to other students and staff. In addition, lockdown plans designed to keep children safe often ignore the needs of students with disabilities like autism, who may have adverse reactions to alarms that overwhelm senses, difficulty processing instructions, or an inability to remain still or quiet.

“This is literally a matter of life and death, but it would appear that meeting the safety needs of students with disabilities is sometimes

an afterthought,” said Mercedes Witowsky, Executive Director of the New Jersey Council on Developmental Disabilities. “This issue is both urgent and critical.”

In June, the Council convened a Summit on School Safety at The College of New Jersey in Trenton. Planned by the Council’s Subcommittee on Children and Youth, the Summit brought together a broad and diverse group of stakeholders and thought leaders. The goal for the Summit was to identify and explore issues related to school safety for students with disabilities, and to generate tangible solutions and recommendations for change.

“Our hope for this Summit was to move the needle on this issue and make sure that the needs of all students with disabilities are considered and planned for,” said Peg Kinsell, a lifelong advocate and policy leader who serves as Chairperson of the Council’s Subcommittee. “Let’s not leave anyone behind in an emergency.”

More than 70 guests from the public and private sector took part in the Summit, representing major stakeholders in New Jersey’s special education community as well as the emergency response community. Discussion was led and moderated by veteran New Jersey journalist John Mooney, founder of New Jersey Spotlight and former education reporter for the Newark Star Ledger. Carolyn Marano from NJDOE brought her department’s welcome and thanked the Council for their leadership and initiative.

“I am thrilled by the robust response and full engagement of safety experts, parents, school leaders, policy makers, and non-profits at our Summit. People are very busy, but they made time to be there and be part of the discussion,” she said.

Speakers included disability specialists from the New Jersey Office of Emergency Management,

the Office of Homeland Security, and the DAFN (Disability Access and Functional Need) Active Shooter Preparedness Group, as well as school security experts with decades of experience in law enforcement, school safety, and de-escalation.

According to guest speaker Jim Mottola, MS, CPP, CISM, the Vice President of Data, Privacy, Investigation, and Security at Porzio School Safety and Compliance Services, the issue of school safety for students with disabilities needs much more attention.

“In our work across the state with schools, we encounter many leaders who want to do the right thing, but may lack proper training, information and guidance. We are helping one district at a time, but it is clear there is a lack of resources for many schools and we are filling that void,” said Matolla.

Motolla, a former Special Agent in charge of the Newark Field Office of the United States Secret Services recently testified before the New Jersey Legislature on the issue of

school safety for children with disabilities.

Throughout the morning, guest experts shared ideas, strategies, and experience with the group. Following the presentation and discussion, guests talked in small facilitated workgroups, sharing successful practices and discussing gaps and challenges in policy and practice.

“There was a great deal of consensus,” said Kinsell. “We heard over and over again about the need for more state guidance, training, and information regarding expectations and promising practice related to emergency planning for students with disabilities,” she concluded. “People share our sense of urgency and were really eager to talk about this issue and share ideas.”

While there were many areas of consensus, one theme was particularly evident: the need for individualized planning for some students.

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***“Schools should provide a safe and inclusive environment for all students. The ADA mandate is especially pronounced when it comes to programs involving student safety.”***

—acting New Jersey US Attorney  
William E. Fitzpatrick

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Even with a good school-wide plan, participants at the Summit agreed that some students will need more. Each student's individual plan should ensure full integration, participation in practice drills, staff training, and an evaluation process to identify obstacles before they arise. The plan should delineate explicit instructions in skills needed for drills, and support services for each student during a school emergency.

“For most students with disabilities, we already have a vehicle for that kind of individualized planning we need—the IEP, IHP or the 504 plan. Safe and appropriate supports to allow a student to remain safe during a school emergency or crisis—as well as instruction and support—can and should be part of the discussion,” added Kinsell.

Summit participants also agreed on the need for continued discussion and dialogue, looking to explore promising practices, and identify practices and policies in other states.

## A Legal Mandate

The obligation to keep students with disabilities safe is not only a moral one: it is also a legal mandate.

Fifteen years ago, in the wake of the 9/11 attacks, President George W. Bush signed Executive Order 13347, Individuals with Disabilities in Emergency Preparedness. It adds to existing legislation policy to ensure that the safety and security of individuals with disabilities are appropriately supported, and requires public entities to consider the unique needs of individuals with disabilities in their emergency preparedness planning.

The Americans with Disabilities Act (ADA) provides “a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities,” including emergency response. In 2004, a Maryland Circuit Court confirmed that the ADA requires places of public accommodation to consider the needs of people with disabilities in developing emergency evacuation plans after a woman with mobility impairments brought suit against a national

discount store. She became trapped in the store during an emergency evacuation and was required to exit into an area below ground level, where she could not leave because the elevators were shut down and all the exits had stairs. She received no assistance or guidance from the store or mall personnel.

In New Jersey, a public school district violated the ADA when its emergency planning was found to have failed to meet the needs of a high school student with mobility disabilities. The student was unable to evacuate the building when a fire alarm shut down the school elevators. He was left alone in the building and was never evacuated. A settlement agreement required the district to enforce an emergency evacuation policy that ensures equal participation and the safety of students with mobility disabilities. In a public statement about the decision, acting New Jersey US Attorney William E. Fitzpatrick wrote, “Schools should provide a safe and inclusive environment for all students. The ADA mandate is especially pronounced when it comes to programs involving student safety.”

New Jersey schools are required to have drills on a regular schedule, and are required to have a school safety and security plan. While state guidance on school safety addresses 91 specific elements of planning, only one touches on the needs of students with disabilities, requiring schools simply “to accommodate students with disabilities.” There is no further guidance or information.

“The Summit was a first step. Our goal for the Summit was to start the dialogue and get key stakeholders together to talk about this issue,” concluded Witowsky. “The next step is policy action. The issue is urgent and cannot wait.”

As *People & Families Magazine* goes to press, the NJCDD is finalizing a report on the Summit and will be issuing recommendations to state leaders to help bring about change.

“We need to take action now so that there is never another child left behind in a school emergency. The stakes are simply too high and the potential consequences too great,” she concluded. **P&F**

# The Changing Landscape of Disproportionality in Special Education

By Brenda Considine

*“A child miseducated is a child lost.”*

*—John F. Kennedy*

**W**hat does it mean when a greater proportion of students of color are suspended from school than their white peers? What are the implications when data shows an unexpectedly low percentage of Asian children identified as having intellectual disabilities? And what does it mean when there is a greater proportion of black males identified as ‘emotionally disturbed’ than the statistics would predict?

These questions lie at the intersection of race and special education, and bring advocates, policy makers, educators, and parents to the issue of “disproportionality.”

*dis`pro`por`tion`al`i`ty - “an over representation in special education services, or under representation of a particular racial or ethnic group in special or gifted education relative to the presence of this group in the overall student population.”*

—The National Association for Bilingual Education



*Over identification of minority students can contribute to racial separation.*

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When data shows the number of students from any racial or ethnic group is statistically higher (over representation) or lower (under representation) than predicted, they are considered disproportionate. Disproportionality shows up in special education data in the number of children identified as being eligible for services; the number of children classified with particular types of disabilities; the number of children placed in different educational settings; and the number of children subject to disciplinary actions.

In their 2007 report, *Truth in Labeling: Disproportionality in Special Education*, the National Education Association laid out the argument for why disproportionality matters. The core issue is the fact that students will not get the services they need because they have been either overlooked for services or labeled in a way that changes expectations and outcomes.

Among the other major concerns include:

- Labeling a student tends to remain throughout their school career.
- Lower expectations can lead to diminished academic and limited post-secondary opportunities.
- Students identified as disabled have a greater risk of dropping out.
- Students identified as disabled are often stigmatized, contributing to social emotional challenges.
- Over identification of students from minority populations can contribute to racial separation, because they are more likely to be placed in separate classes.
- Students who are not disabled are treated as if they are.



*Minority students with disabilities in New Jersey are overrepresented in restrictive settings and subject to suspension and expulsion at higher rates.*

Data also shows a correlation between special education for black students—especially boys—and higher rates of incarceration, both as juveniles and adults.

## Identifying and Measuring Disproportionality

Beginning in 1997, The Individuals with Disabilities in Education Act (IDEA) has required monitoring for racial disparities. Data collection—and the determination of whether districts had disparities broad enough to merit intervention—was left up to the states. The US Department of Education (USDOE) published data provided by the states, but because data was not collected uniformly, it was hard to compare state to state.

During the 2015-16 school year (the last year for which federal data is available) 423 school districts in the country documented “significant disproportionality.” At that level, the USDOE requires funding set-asides to remediate inequity.

Data showed disability identification rates were higher for black students (1.4 times) or

Native American students, (1.7), and lower for white students (0.9) and Asian students (0.5), with Hispanic students about as likely to be identified as the rest of the population.

The federal government monitors states on three performance indicators related to the disproportionate representation of minority students in special education:

1. Percent of districts with disproportionate representation of racial and ethnic groups in special education and related services resulting from inappropriate identification.
2. Percent of districts with disproportionate representation of racial and ethnic groups in specific disability categories resulting from inappropriate identification.
3. Percent of districts with disproportionate representation of racial and ethnic groups subject to disciplinary actions.

Reported disparities were assumed to be the result of implicit institutional bias, but the data has, for years, shown wide and questionable variability. During the 2015-16 school year, for example, more than 20 states documented no disproportionality at all. That same year, 19 percent of the 423 districts nationwide identified were in a single state, New York, and represented only around 11 percent of that state's school districts. The tiny state of Rhode Island had the greatest percentage of districts identified, with more than half of its 61 districts producing data showing disproportionality. New Jersey, with 643 districts, produced data showing 3 percent of local districts with disproportionality.

The fact that states are allowed to define and report disproportionality by their own rules makes national data comparison a challenge. In 2013, the Government Accountability Office (GAO), a non-partisan agency researching issues for Congress, studied the issue of disproportionality and determined the state's flexibility in data collection makes it harder for the USDOE to provide oversight. The report states: "Education's oversight of racial and ethnic

groups' overrepresentation in special education is hampered by the flexibility states have to define significant disproportionality."

### New Jersey's Data

Mirroring national data, minority students in New Jersey are overrepresented in certain categories. In both the categories of "emotionally disturbed" and "intellectually disabled," 31 percent of the students classified in New Jersey are black, yet they account for only 18.3 percent of all students.

Minority students with disabilities in New Jersey are also overrepresented in restrictive settings and are subject to suspension and expulsion at higher rates and for longer periods of time. In 2017, of students with disabilities removed from school for 10 days or more, nearly 43 percent were black and 25 percent were Hispanic. More than half of all in school suspensions for 10 days or more were for black students.

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*Effective school-wide positive behavior supports can help neutralize systemic bias.*



Inconsistent or inaccurate data hurts districts too. It can result in significant inequities in school districts' responsibilities for addressing the issue of disproportionality. There are significant fiscal ramifications for districts, too. Prior to 2016, districts were required under IDEA to set aside 15 percent of their federal special education funding on a small set of remedies for disproportionality. For the 423 districts identified during 2015-16, that amounted to over \$211 million.

## Equity in IDEA Regulations

In December of 2016—the final month of President Obama's second term—the USDOE responded to the problem by issuing new regulations. The "Equity in IDEA" regulations required states to use a standard approach in determining whether significant disproportionality based on race or ethnicity is occurring. Using the same methodology was intended to help states report data in ways that promoted more accurate comparisons within and across states.

The new rule did not restrict the mandated funding set-aside to a limited set of strategies, as it had before. The change allowed districts to use funds more flexibly, to address systemic issues that may impact identification, placement, and discipline decisions.

Critiques of the disproportionality reporting rules in IDEA (and of the Equity in IDEA regulations) range from the scientific to the political. Over the life of IDEA, some evidence has accumulated suggesting that the disproportionality data fails to account for other important student characteristics including language disparities, family income, family education, family achievement, and reliance on medication. All of which are known to impact learning and the likelihood of identification for special education.

Studies have shown when these comorbid factors are taken into account, racial and ethnic minority students are less likely—not more likely—to be identified for special education than white students. If this is the case, the implications for groups of underrepresented students are equally disturbing.

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*“It is critical to ensure that overrepresentation is not the result of misidentification, including both over- and under-identification, which can interfere with a school’s ability to provide children with the appropriate educational services required by law. It is equally important to ensure that all children who are suspected of having a disability are evaluated and, as appropriate, receive needed special education and related services in the most appropriate setting and with the most appropriate discipline strategies employed.”*

—US Department of Education

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Political arguments have remained relatively consistent. Conservatives argue that educational decisions, including considerations of disproportionality, should be made by states. The proposed rules have also come under fire over suggestions about quotas and fear they might create a system in which districts restrict access to special education in order to avoid the financial penalties.

With the new regulation set to go into effect during the 2018-19 school year, the Trump administration announced that the USDOE was putting the Equity in IDEA regulations on hold for two years. Months later, the U.S. District Court for the District of Columbia ruled the delay of the regulations was illegal and required the regulations to immediately go into effect. In May of 2019, the USDOE appealed the District Court's decision, squashing the regulation's implementation delay. That same month, the USDOE announced states should now comply with the original regulations, and the department would be going ahead with implementation.

## Next Steps

Most states and school districts report having already expended significant time and resources on 2016 Equity in IDEA regulations implementation planning. In the wake of the administrative confusion, districts must now adopt the methods and metrics of the original regulation immediately. Applying the new standards this fall, with the start during the 2019-20 school year will be a test of those preparations.

The USDOE can still appeal the regulation and may also create rules of its own, and has signaled recently that a new proposal might be coming as early as next winter. Until then, districts must comply with the rules.

## Addressing Disproportionality

While the policy debate about data collection continues in committee hearings and the courts, educators are left with the question – what can be done to address the ways in which race and ethnicity might influence decisions made about a student as they relate to special education?

In 2017, researchers at the Public Consulting Group (PCG), a Boston-based firm that helps health, education, and human services organizations make improvements to their performance and processes, issued a paper outlining a multi-step process to help reduce disproportionality in New Jersey. They underscore that disproportionality is a complex phenomenon influenced by many factors, and is not intentional. They write, "...school teams, though well-intentioned in their desire to provide supports for struggling students, may defer to their professional judgment or cultural assumptions in the referral and evaluation process of, in particular, culturally and linguistically diverse students."

They note that even when a district receives a citation of disproportionality under IDEA, it does not mean that there is intentional discrimination, noting that the root causes of a district's disproportionality "...may be that underlying personal beliefs, or organizational practices and policies, have unintentionally created an environment in which inequity develops."

To address this, PCG researchers suggest that schools make more assertive use of the Intervention and Referral Services (I&RS), a process which is outside of special education. I&RS is an interdisciplinary team of professionals in each school who plan coordinated services and systems to address a range of student learning, behavior, social, and health problems in general education. The goal is to see measurable student improvement in the identified targeted areas.

PCG's report further suggests districts begin by focusing on increased cultural sensitivity, in which teachers and school leaders are trained to be aware of racial and cultural biases in instruction and assessment, as well as understanding cultural differences in behavior. Schools must take intentional steps to ensure culturally appropriate instruction and assessment. In addition, professional development opportunities must be designed to help educators create lesson plans that reflect the cultural, linguistic, and racial diversity of the communities they serve.

They also suggest strengthening home school communication, and working to engage families from all backgrounds in meetings and school events.

And finally, they recommend effective school-wide positive behavior supports, including evidence-based and data-based decision-making, which can help neutralize systemic bias. **P&F**

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## Students with Disabilities

# Forging Their Own Paths

By Jeremy Einbinder

**Editor's Note:** *People & Families Magazine* welcomes Jeremy Einbinder as a new contributing writer. Jeremy is a graduate of Rowan University, and has cerebral palsy.



**T**he Individualized Education Program (IEP) is a legal document developed by students, teachers, administrators, parents and other team members. The IEP helps students with disabilities achieve their goals.

According to the Individuals with Disabilities Education Act 2004, the IEP must focus on the student's preferences, interests, needs and strengths. All students, regardless of age or disability, should be involved in the development of their own IEP.

IEP meetings can be a source of contention between families and educators as they come together to determine the best ways to educate individual students. Historically, students did not attend their IEP meeting, if they did most sat quietly without much active involvement.

Often, public school districts do not provide students with the opportunity to develop their own educational paths. According to Peg Kinsell, student-led IEPs provide the opportunity to do just that. She feels that failing to provide opportunities for students to chart their own destiny can inhibit academic development.

Kinsell is the institutional policy director at Statewide Parent Advocacy Network (SPAN) and a member of the New Jersey Council on Developmental Disabilities (NJCDD). She feels students should be directly involved in their own educational development.

“If we don’t build the skills for students to lead these discussions and learn how to do some group decision making, when they turn 18 their parents still have to take care of everything,” Kinsell said.

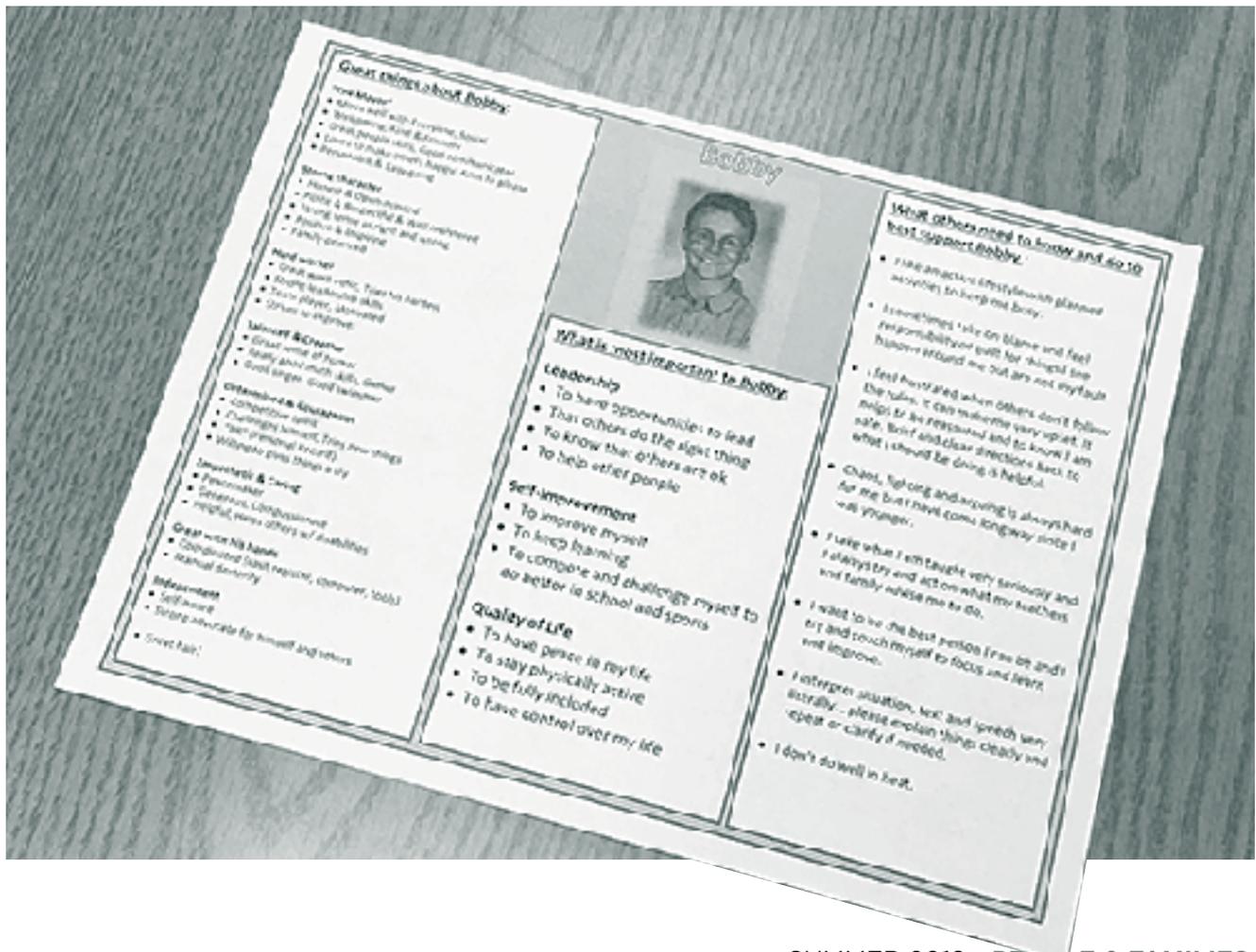
## Quania Kennedy & Bobby Kopac: Charting Their Career Paths

Quania Kennedy and Bobby Kopac are recent graduates of Monroe Township High School and Edison High School, respectively.

Kennedy began attending her IEP meetings in middle school. She played her most active role in her educational planning during junior and senior year of high school. Kopac started attending his meetings as a high school freshman.

“The IEP meetings can help you understand the things that you can accomplish in the future,” he said. “Never give up,” Kopac said, offering inspiration.

*Understanding likes, dislikes, strengths and weakness are keys to an effective IEP.*





*Bobby Kopac (seated far right) leads his IEP meeting. His mother, Jodi Kopac is seated third from the right.*

Kopac was diagnosed with autism when he was two years old. He feels that getting diagnosed early “helped create a path” for his educational and emotional development. He also developed a strong interest in sports at an early age. He participates in swimming and track & field.

He says that competing in sports and meeting more people made him a better person. Academically, Kopac feels strongly that individualized attention helped improve his performance. His grades improved since he started leading his own IEP meetings.

According to Kennedy, one of the most transformative accommodations she received in school was the ability to have extra time for tests while taking them in a separate room.

“I was in a general ed classroom with no extra time and all the pressure around me,” she said. “So, I told them I needed the extra time and sculpted notes which help me better.”

Sculpted notes are annotated notes included with reading materials. They help keep students on track. Kennedy says they help her mitigate the challenges she has due to her memory retention issues.

“In the textbook, I would have trouble comprehending the text that I’m reading so the sculpted notes always helped me because

### **Skills Used When Leading an IEP meeting**

- Choosing mediums to communicate progress (graphs, writing, pictures/ videos)
- Paraphrasing technical/jargon-laden language
- Reading and writing in context
- Using technology such as presentation and word processing software
- Introducing people
- Explaining the purpose of an IEP meeting
- Thinking and planning for the future
- Goal setting
- Time management
- Meeting facilitation
- Listening and responding with relevant and appropriate answers
- Asking relevant questions
- Advocating - expressing opinions
- Presentation skills
- Reading body language
- Compromising/reaching consensus
- Closing, summarizing decisions made

they would have the questions to answer,” said Kennedy.

She feels strongly that students should advocate for themselves. “If you advocate for yourself, that’s your plan,” said Kennedy.

Both Kopac and Kennedy are focused on their professional goals. Kopac feels he could be a successful coach or mentor, given his penchant for sports and childcare. Kennedy is deciding if she wants to pursue the clinical or administrative side of medical assistance.

These students guided the direction of their academic futures, and are determined to succeed. Awareness of their own strengths and weaknesses positions them better for more fulfilling lives.

Kinsell agrees that most students are more aware of their own potential than others. She feels students could benefit from increased self-awareness earlier in life.

“It has to be more than just standing a student in front of a room without preparation,” said Kinsell. “They need to develop skills like basic communication, how to lead a meeting. They also

need to be aware of their individual rights. It’s never too early to start developing these skills.”

When Kennedy started attending her IEP meetings in middle school she didn’t participate much. Kennedy took charge during high school. Because she went to a large high school, she felt she needed to advocate for herself.

“Your teachers don’t really get to know you,” said Kennedy. “They don’t really understand your best learning style because they’re focusing on so many other students. So, I felt that it was important for me to voice my opinion with confidence.” This fall, Kennedy will attend a nine-month medical assistant program at Brookdale Community College.

Kinsell believes that students determining their own educational plans should be the standard from the very beginning of the educational process.

“I think students should start building their skills from kindergarten,” she said. “The sooner students start actively participating in the process, the sooner they are going to be comfortable enough to lead.” **P&F**



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# Community Care Program Frequently Asked Questions



*Please Note: All individuals receiving DDD services must have active and current Medicaid*

## What is the Community Care Program?

The Community Care Program (CCP) enables New Jersey to receive a federal match when state funds are used to provide approved services that assist Medicaid beneficiaries live in the community and avoid institutionalization.

The CCP provides needed services for adult individuals age 21 and older living with their family or in various other unlicensed settings, or in licensed residential settings.

Individuals enrolled in the CCP cannot be simultaneously enrolled in another Home and Community Based Services waiver program—such as Managed Long Term Services and Supports or the DDD Supports Program.

A complete list of CCP services is available here: [www.nj.us/humanservices/ddd/services](http://www.nj.us/humanservices/ddd/services).

## What are the eligibility requirements of the CCP?

- Individual must be determined eligible for DDD services pursuant to N.J.A.C. 10:46; and
- Individual must meet Medicaid/CCP financial eligibility; and
- Individual must have:
  - Reached the top of the CCP Waiting List pursuant to N.J.A.C. 10:46C; or
  - Been declared an Emergency (risk of imminent peril or homelessness) pursuant to N.J.A.C. 10:46B;
- Individual must be determined in need of ongoing CCP services, whereby their needs cannot be supported on the Supports Program; and
- Individual must meet ICF/ID Level of Care (LOC).

## Please Note:

- Individuals who do not meet the above criteria will be denied access to CCP services.
- Individuals who are not demonstrating an ongoing need for support, through access of services through the Supports Program, may be denied access to CCP services.
- Housing is not a CCP Medicaid service.
- Individuals who are denied access to CCP services have a right to a Medicaid fair hearing pursuant to N.J.A.C. 10:49.

## What is ICF/ID Level of Care ?

Per the federal Centers for Medicare and Medicaid Services, *“Intermediate Care Facilities for individuals with Intellectual Disability (ICF/ID) is and optional Medicaid Benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence.”*

To meet the requirements for ICF/ID level of care, an individual must have substantial functional limitations in at least three activities of adult living, one of which is self-care, and must meet all of the following:

- Have a diagnosis of developmental disability or a related condition;
- Be in need of continuous active treatment related to the diagnosis of his/her developmental disability;
- Require a 24-hour plan of care related to his/her developmental disability;
- Require aggressive and consistent training due to an inability to apply skills learned in one environment to a new environment;
- But for the waiver service(s), the individual would require institutionalization; and
- Cannot be supported on the Supports Program.

## What if my situation is not urgent but I am interested in CCP services for the future?

You can request to be added to the CCP Waiting List by completing the Request for Community Care Waiver Waiting List form. The form and additional information about the waiting list is available here: [www.state.nj.us/humanservices/ddd/services/ccw/ccwwl.html](http://www.state.nj.us/humanservices/ddd/services/ccw/ccwwl.html). Your support coordinator can help you be added to the list.

## What if my situation is urgent?

DDD's Intensive Case Management Unit will evaluate requests for emergency access to CCP services. If you feel your situation is urgent, contact your support coordinator. Your support coordinator will complete a Request for Intensive Case Management form with you, and will also ask you to put your request for emergency access to CCP services in writing. Once completed, your support coordinator will upload the form and letter to your electronic file. A DDD Monitor will review the request to see if they can help your support coordinator identify additional supports or services. If all services and supports are in place and may not be meeting your needs, staff from the Unit may make a home visit to discuss your urgent circumstance. The Unit will advise you and your support coordinator on next steps.

## Will I be able to receive DDD services while I am on the CCP Waiting List?

Yes. Anyone who has been determined eligible for DDD and is Medicaid eligible can enroll into the Supports Program and receive services. You can remain on the CCP Waiting List while receiving services in the Supports Program. NJ Division of Developmental Disabilities | June 2019 Page 3 of 3.

## How will I know my number on the CCP Waiting List?

Letters are mailed out every year to all individuals who are in the priority category of the CCP Waiting List to notify them of their number on the list.

## I am on the CCP Waiting List but my name hasn't been reached. What happens if my circumstances change?

If your circumstances change, contact your support coordinator to discuss:

- additional services that may be available through your Supports Program budget;
- supports that may be available from family or friends, or through your insurance or other sources; and/or;
- the possibility of requesting an NJCAT reassessment.

If the matter is urgent, your support coordinator and his/her supervisor will help determine if you should request emergency access to CCP services.

## I want to live more independently but do not need 24/7 support. What are my options for housing and services?

There are a number of housing and service options for individuals who want to live more independently but do not need 24/7 support, including:

- Housing Voucher—this is a rental subsidy you can apply for that is available through DDD and the Supportive Housing Connection. You will need to work with your support coordinator to make sure your budget can fund the services you need within the desired rental unit. Information about housing vouchers is available here: [www.nj.gov/humanservices/ddd/resources/community](http://www.nj.gov/humanservices/ddd/resources/community).
- Sheltered Boarding Home—this is a facility that provides food, shelter, monitoring of self-administered medication, and financial management.
- Residential Healthcare Facility—this is a facility that provides meals, housekeeping/laundry, financial management, supervision of medication, and provision and oversight of personal and support services under the direction of a nurse. **P&F**

**More information about the Community Care Program is available here:**  
[www.nj.gov/humanservices/ddd/services/ccw/index.html](http://www.nj.gov/humanservices/ddd/services/ccw/index.html)

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

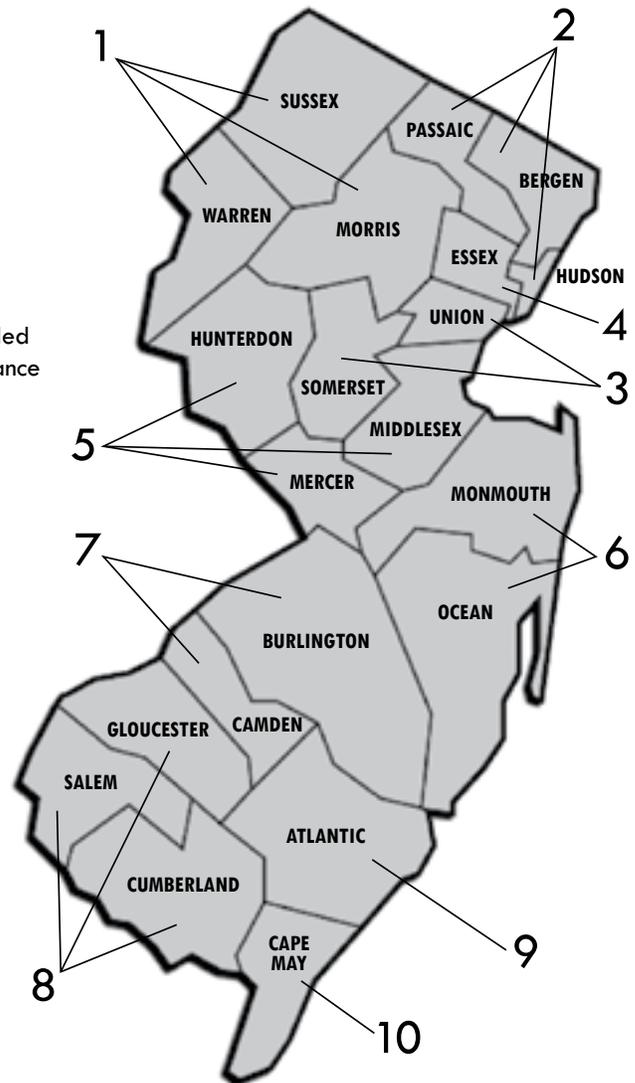
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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](mailto:kyoko.coco@njcdd.org)

Or visit our website at [www.njcdd.org](http://www.njcdd.org) and follow the link to Family Support & Facebook page at [www.facebook.com/NJFSPC](http://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.njccd.org](http://www.njccd.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](mailto:rfspc1@gmail.com)  
**Chair:** Margaret Hefferle  
**Vice Chair:** Gabrielle Bohon

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**  
**PO Box 443**  
**Jersey City, NJ 07302**  
**e-mail:** [RFSPC2@gmail.com](mailto:RFSPC2@gmail.com)  
**Co-Chairs:** Frank Fiore, Dorothy  
Blakeslee

Meets the third Monday of the month  
Secaucus Public Library  
1379 Paterson Plank Rd.  
Secaucus, NJ 07094  
6:30 p.m.—8:30 p.m.

## 3 SOMERSET, UNION

**RFSPC#3**  
**e-mail:** [rfspc3@gmail.com](mailto:rfspc3@gmail.com)  
**Chair:** John Brewer  
**Vice Chair:** Bonnie Brien

Meets the third Tuesday of each month  
Arc of Somerset County  
141 S. Main St.  
Manville, NJ 08835  
7:00 p.m.—9:00 p.m.

## 4 ESSEX

**RFSPC#4**  
**e-mail:** [rfspc4@yahoo.com](mailto:rfspc4@yahoo.com)  
**Chair:** Yolanda Smith  
**Co-Chair:** Phyllis McNair  
**Vice-Chair:** Eileen Hurley

Meets the first Wednesday of each month  
Bloomfield Civic Center Music Room  
84 North Broad St.  
Bloomfield, NJ 07003  
7:00 p.m.—8:30 p.m.

## 5 HUNTERDON, MIDDLESEX, MERCER

**RFSPC #5**  
**e-mail:** [rfspc5nj@gmail.com](mailto:rfspc5nj@gmail.com)  
**Chair:** Paul Blaustein  
**Vice-Chair:** Scott Cohen

Meets Second Saturday of each month  
South Brunswick Library, 110 Kingston Ln.  
Monmouth Junction, NJ 08852  
10:00 a.m.—12:00 noon

## 6 MONMOUTH, OCEAN

**RFSPC #6**  
**PO Box 76**  
**Lakewood, NJ 08701**  
**e-mail:** [rfspc6-chair@excite.com](mailto:rfspc6-chair@excite.com)  
**Chair:** Mike Brill

Meets the second Thursday of each month  
Brick Municipal Bldg.  
Council Rooms A&B  
401 Chambersbridge Road  
Brick Twp., NJ 08723  
7:30 p.m.—9:30 p.m.

## 7 BURLINGTON, CAMDEN

**RFSPC #7**  
**e-mail:** [rfspc7@gmail.com](mailto:rfspc7@gmail.com)  
**Co-Chairs:** Laura Kelly, Lisa Weissbach-  
Effrat

Meets the fourth Thursday of the month  
CPAC  
2500 McClellan Avenue Suite 110  
Pennsauken, NJ 08109  
**Odd numbered months noon**  
**Even numbered months 7pm**

## 8 CUMBERLAND, SALEM, GLOUCESTER

**RFSPC #8**  
**e-mail:** [RFSPC8@gmail.com](mailto:RFSPC8@gmail.com)  
**Chair:** Sandra Backensto  
Meeting times and dates TBD

## 9 ATLANTIC

**RFSPC #9**  
**e-mail:** [RFSPC9@yahoo.com](mailto:RFSPC9@yahoo.com)  
**Chair:** Mary Ann Philippi

Meeting times and dates TBD  
Arc of Atlantic County  
6550 Delilah Rd., Suite 101  
Egg Harbor Twp., NJ 08234

## 10 CAPE MAY

**RFSPC #10**  
**PO Box 199**  
**South Dennis, NJ 08245**  
**e-mail:** [RFSPC10@yahoo.com](mailto:RFSPC10@yahoo.com)  
**Chair:** Anne Borger  
**Vice-Chair:** Rose Kuprianov

Meets the third Thursday of the month  
during Oct., Feb., April, and June  
Cape May Special Services School  
148 Crest Haven Dr.  
Cape May Court House, NJ 08223  
6:30 p.m.—8:00 p.m.

# Position Statement on Restraints and Seclusion

The New Jersey Council on Developmental Disabilities (NJCDD) endorses the following statement:

*People with intellectual and/or developmental disabilities have the same basic legal, civil and human rights as all citizens.*

## Position

The use of physical restraints, seclusion and other aversive techniques have resulted in physical injury, psychological harm, trauma and even death to children and adults with I/DD. The NJCDD believes that the use of physical, mechanical and chemical restraints is inappropriate except in situations of imminent danger of serious physical harm to the individual or others. NJCDD strongly opposes the **inappropriate and/or unnecessary** use of restraints and other aversive interventions. Seclusion should not be used under any circumstances.

It is the further position of the Council that the State, through its applicable agencies, is required to define and prohibit those practices that pose an unacceptable risk of physical, psychological or emotional harm to people with developmental disabilities who reside in State-funded or regulated facilities or who receive State services or public education.

## Background Information

The use of physical restraints, seclusion, and other interventions is marked by inequality in power between the person delivering action and the recipient. Such interventions do not address the cause of the problematic behavior, and may create social isolation and trauma through the application of pain or fear. The use of such interventions should be replaced by the application of positive behavioral support within a trauma informed

environment. This should include a framework of moral and ethical values that focus on:

- Improving quality of life,
- Ensuring individuals with I/DD have the opportunity to be self-determined,
- Recognize behavior as a form of communication,
- Implementing interventions that emphasize the development and use of positive skills for greater independence, and,
- Making modifications to the context in which problem behavior occurs.

Depending upon an individual's age and state educational/service system, different factors apply:

## Students

Students with I/DD are entitled to a free and appropriate public education within the least restrictive environment. These rights are guaranteed under the Individuals with Disabilities Education Act (IDEA). "Seclusion refers to involuntarily confining a student alone in a room or area from which he or she cannot physically leave; it does not include a timeout - a behavior management technique that is part of an approved program, involves the monitored separation of (an individual) in a non-locked setting, and is implemented for the purpose of calming."<sup>1</sup>

The overall use of restraints and seclusion has been reported to disproportionately affect students with disabilities.<sup>2</sup>

## Adults

"Restraint Use' refers to the restriction of an individual's freedom of movement either partially or totally by physical contact imposed by staff (Personal Control Technique), the application of a

physical device (Mechanical Restraint) or through the use of medication (Chemical Restraint).” Refer to Division Circular #20. Restraints are further defined as:

1. Approved: Restraints implemented with prior approval and written order, in accordance with the administrative regulations and policies of the appropriate division, or as part of an approved behavior treatment plan.
2. Unapproved: Restraints implemented without the prior approval/order or not in accordance with the administrative regulations of the Division, or not as part of an approved behavior treatment plan.”<sup>3</sup>

The NJCDD supports Trauma Informed practices, as well as Positive Behavior Interventions and Support (PBIS), an applied science that uses educational methods to expand an individual’s behavior repertoire and systems change methods to redesign an individual’s living environment to first, enhance the individual’s quality of life and second, to minimize his or her problem behavior. The proactive nature of PBS stands in sharp contrast to traditional approaches, which have emphasized the use of aversive procedures that address problem behaviors with reactive, crisis-driven strategies such as restraints<sup>4</sup>.

NJCDD supports the proposed federal legislation “Keeping All Students Safe Act” (H.R. 7124, 115th Congress). **P&F**

Approved May 23, 2019

<sup>1</sup> United States Government Accountability Office (GAO), GAO-19-418T Restraint and Seclusion, February 27, 2019

<sup>2</sup> GAO, K-12 Education: Discipline Disparities for Black Students, Boys, and Students with Disabilities, GAO-18-258, (Washington, D.C.: March 22, 2018)

<sup>3</sup> DIVISION CIRCULAR #14, NJ DEPARTMENT OF HUMAN SERVICES, DIVISION OF DEVELOPMENTAL DISABILITIES 11-1-2007

<sup>4</sup> Positive Behavioral Support: Evolution of an Applied Science, Journal of Positive Behavior Interventions, Volume 4, Number 1, Winter 2002, pages 4-16, 20



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[imeijas@spanadvocacy.org](mailto:imeijas@spanadvocacy.org)



# Position Statement on Direct Support Professionals

## Position

The direct service professional (DSP) crisis is the foremost challenge to the long-term services and supports (LTSS) system that serves individuals with intellectual/developmental disabilities (I/DD). Research demonstrating the impact of low wages, limited competency-based training opportunities and career pathways, ineffective supervision, and growth in the need for support across disability and aging sectors have predicted the crisis currently confronting New Jersey.

The New Jersey Council on Developmental Disabilities believes that evidence-based practices must be widely implemented to increase the ability of individuals, families, and employers to recruit, retain, and ensure the competence of DSPs to improve the quality of life and outcomes of supports provided to people with I/DD. A comprehensive approach must address the need to build capacity within the DSP workforce, and should include the following:

- Development and implementation of a statewide plan to address the causes that drive the DSP crisis, including low wages, ineffective hiring practices, limited competency-based training and career pathways, poor supervision, and lack of professional recognition;
- Allocation of sufficient funds to establish reimbursement rates that lead to living wages and the benefits necessary to attract and retain qualified DSPs in home and community-based services;
- Adjust rates paid for services to correspond with minimum wage increases and pay DSP's at least 25% above the state's minimum wage;
- Adopt the national code of ethics and core competency areas for direct support professionals<sup>1</sup> and frontline supervisors<sup>2</sup> statewide and align professional development and performance appraisals accordingly;



- Provide credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in system policies and sufficiently funded to create incentives for DSP participation;
- Develop and implement practices that support Direct Support Professionals to effectively assist people with I/DD to live active, engaged, and valued lives in their communities;
- Ensure careful oversight in self-directed services and ethical administration in provider agencies in order to adequately train, support, recruit, and retain DSP's and to ensure opportunities for mentoring and professional development through worker recognition;
- Evaluate and implement the use of technology as an option for support while simultaneously providing relief to the increased demand for support and support workers.

## Background Information

Direct Support Professionals (DSP) are indispensable to individuals with I/DD and their families. DSPs provide essential supports necessary for individuals with I/DD to successfully live in our communities. DSPs help individuals with I/DD understand and exercise their right to make choices about their lives. DSP responsibilities are extensive and include supporting medical and behavioral health needs, and teaching workplace, social, and activities of daily living skills. DSPs also provide assistance with personal care and assist with mobility related needs. DSPs are responsible for completing documentation and complying with oversight and training regulations.

A well-trained, fairly-compensated DSP workforce is crucial to providing the necessary supports and services to 30,000 individuals with I/DD where they live and work. Effective, ethical, person-centered supports are the foundation of inclusive community life. State investment together with federal Medicaid match is the primary source of funding for services for people with disabilities and the provider agencies that employ DSPs. New Jersey's current Community Care and Supports Program's Medicaid rate structure, and recently enacted New Jersey minimum wage increases, will exacerbate the workforce crisis created by low wages, lack of affordable health insurance, high turnover (44%), and a shortage of staff (20% vacancy rate).<sup>3</sup> Demand for DSPs from private industry and other human services sectors is also high, leading to competition among industries for workers. From 2007 through 2017, the State of New Jersey did not increase the rates paid to licensed providers or individuals/families who self-direct services. These problems have been compounded over three decades, leading to a crisis that presents a grave threat to the lives of individuals with I/DD and their families.<sup>4</sup> **P&F**

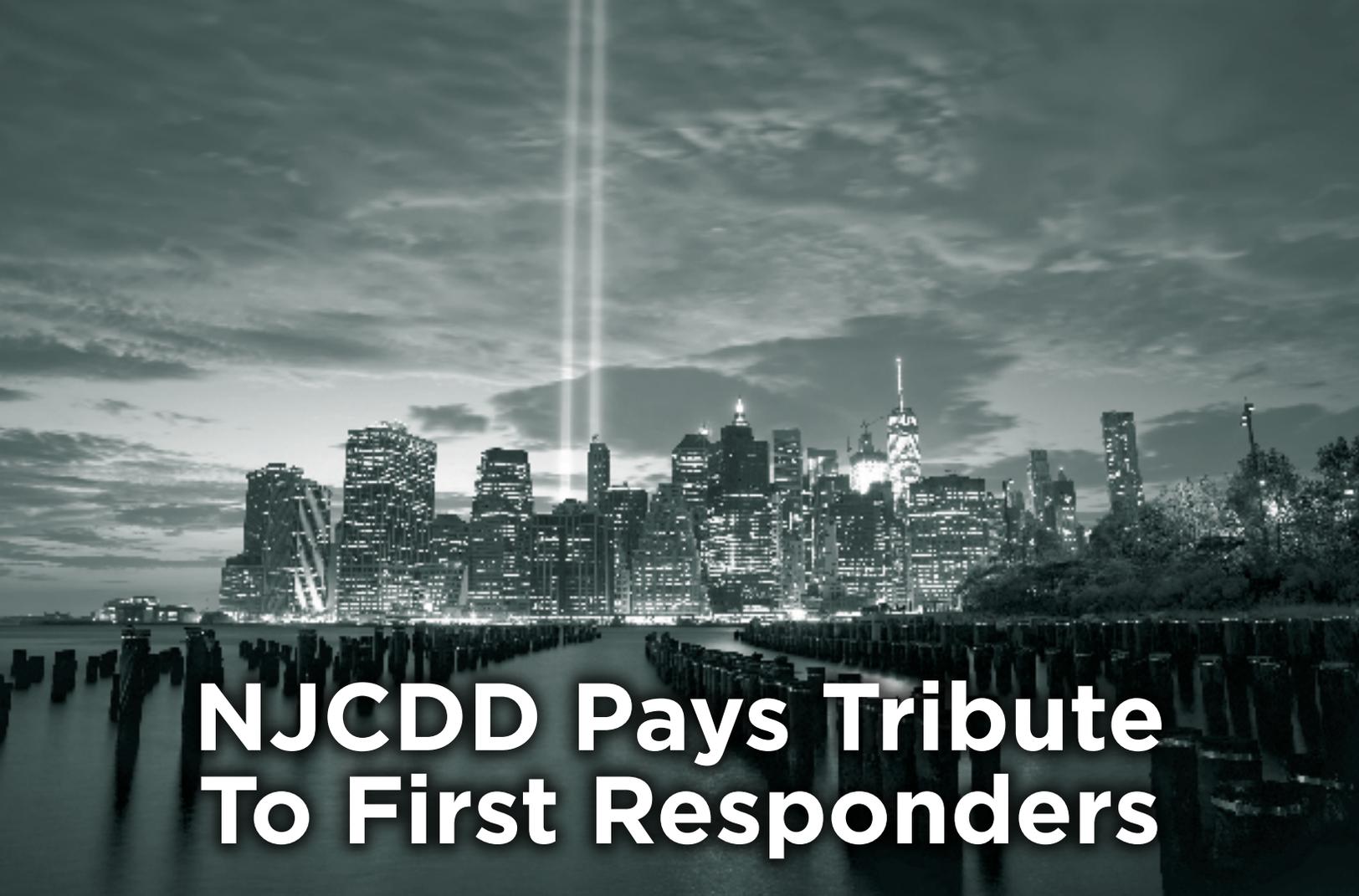
Approved May 23, 2019

<sup>1</sup> NADSP Code of Ethics - <https://www.nadsp.org/code-of-ethics-text/>  
NADSP Competencies - <https://www.nadsp.org/competency-areas-text/Centers for Medicare and Medicaid Services DSW Competencies> -  
<https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-core-competencies-final-set-2014.pdf>

<sup>2</sup> National Frontline Supervisor Core Competencies - [https://rtc.umn.edu/docs/National\\_Frontline\\_Supervisor\\_comp\\_7-2-13.pdf](https://rtc.umn.edu/docs/National_Frontline_Supervisor_comp_7-2-13.pdf)

<sup>3</sup> The Coalition for a DSP Living Wage, [njdspcoalition.org](http://njdspcoalition.org) website, April, 2019

<sup>4</sup> Public Policy Agenda for the 116th Congress, 2019-2020, Staff Draft, AAIDD, ANCOR, NACDD, The Arc, UCP, 2018



# NJCDD Pays Tribute To First Responders

By Gary L. Brown

September 11, 2001 will forever be associated with four coordinated terrorist attacks. One of those attacks claimed the life of former NJCDD chairperson, Collen Fraser.

**F**rasier was a passenger on the fourth plane, United Airlines Flight 93.

It was initially flown toward Washington, D.C., but crashed into a field in Stonycreek Township near Shanksville, Pennsylvania, after its passengers thwarted the hijackers.

The New Jersey Council on Developmental Disabilities (NJCDD) paid tribute to Fraser and first responders during its September 11 Council meeting in

Hamilton, NJ. Council leadership presented a ceremonial check to Celebrate the Children School (CTC). CTC developed first responder outreach kits.

“These kits will be used to help first responders communicate more effectively with people with intellectual disabilities during a crisis,” said Mercedes Witowsky, executive director, NJCDD.

The Council awarded the Hackettstown Elks Lodge #2331 a \$3,500 grant to

purchase the outreach kits for first responders.

The Hackettstown Elks purchased the kits from the CTC “Every police department in Warren County as well as five Morris County police departments will receive these free kits,” said Mary Thiele, Hackettstown Elks Lodge #2331.

Each kit contains tools to help first responders support people with disabilities during traumatic events. “We developed these kits based on what we know about sensory processing,” said Lauren Blaszak, executive director, CTC. “Sirens and flashing lights can cause sensory overload for some individuals



*Outreach kits help first responders communicate better with people with disabilities.*





Council leadership paid tribute by presenting a ceremonial check to Celebrate the Children School (CTC). CTC developed first responder outreach kits.

with disabilities. So, we wanted to give first responders tools to help them communicate better while minimizing anxiety levels.” CTC also provides free training sessions for first responders in how to use the kits. Sessions also include Q&A and tips from educa-

tors, experts in the field of I/DD, occupational therapists, and physical therapists.

“This rewarding project helps two key groups the Elks are extremely passionate about supporting,” said Thiele, “People with disabilities and first responders.” **P&F**

New Jersey Council on  
Developmental Disabilities

# NJCDD



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**Contact**

Gary L. Brown  
Communication Officer  
gary.brown@njcdd.org

-  Keep up-to-date on NJCDD events and announcements
-  Stay informed on important developmental disability news from around our state
-  Learn more about the NJCDD's programs for self-advocates and families, as well as new ways to participate



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Disabilities



The international disability advocacy movement has come to New Jersey, fighting for civil rights and equality in our state.

## Calling All Advocates



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- Make Positive Changes in the Community
  - Speak Your Mind
  - Take Action
- All People with Disabilities Welcome

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609-292-3745  
to find out how to join or start a  
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chapter in your area.



Lauren Blaszak, Executive Director, Celebrate the Children; and Mary Thiele, Hackettstown Elks #2331 display a first responder outreach kit.