

# People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 1, 2021



## PASSING THE TORCH WHILE USHERING IN A NEW AGE

Ellie Byra (seated) with her husband, Peter;  
daughter, Tian; and son, Matthew

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**DESIGN AND LAYOUT** CranCentral Graphics, LLC

**CONTRIBUTING WRITERS**

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe

**PHOTOGRAPHY** Rebecca Shavulsky

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**NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES**

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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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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

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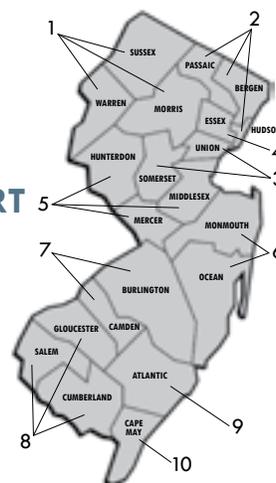
When it was signed into law in 1993, the Family Support Act promised to be a turning point and new approach. It was the first time that legislation created a statewide system driven by families, and responsive to what they deemed necessary. The goal of the Act was to provide “whatever it takes” to help families stay together, preventing the premature need for residential services.



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Family members have a wealth of knowledge about overcoming daily challenges. Family members and an advocate offered to share their wisdom and inspire others by expressing: advice I would give to my younger self.

from the Executive Director ■

## Passing the Torch While Ushering in a New Age

This issue of *People & Families* is dedicated to two Council members who have recently retired. After serving people with disabilities and their families for decades, Ellie Byra and Bill Testa have retired.

Ellie Byra served as the voice for her son, Matthew, as well as thousands of other young men and women with disabilities across the state. Bill Testa served people with disabilities and their families for 38 years with caring, intellect and compassion.

Getting to know strong advocates like Ellie and Bill was similar to living within the pages of history books. Ellie and Bill participated in so many aspects of how today's supports and services are designed and implemented. Ellie and Bill have left a mighty handprint on my life and the lives of thousands of individuals with I/DD and their families. We are all better for their contributions.

I thank both Ellie and Bill, on behalf of the entire disability community, for their immeasurable contributions to the field. As we pass the torch to new members, I am extending a warm welcome to Sarah Aziz, our newest Council member. I'm sure she will add value to the Council.

The torch was also passed to new leadership within the NJ Department of Human Services (DHS). Carole Johnson recently stepped down from her role as DHS commissioner to join President Biden's COVID-19 Response Team as testing coordinator. Carole actively supported our efforts to improve the lives of people with disabilities and their families.

After serving as Deputy DHS Commissioner, Sarah Adelman was appointed acting commissioner. We are fortunate to have Sarah in her new role. We are confident that Sarah will lead the way in giving individuals with I/DD access to the needed supports and services to lead self-directing lives in their communities and to listen to the voice of families when their adult children with disabilities need their voice to live their best life.

This issue of *People & Families* highlights the continued work of our newly-formed Legislative



Disability Caucus. We continue to gain interest from more legislators, supporting agencies, and members of the disability community.

Key issues impacting children and youth are highlighted in two separate articles. First, the impact of New Jersey Supreme Court's Opinion 56 on non-attorney advocates' ability to help parents of special education students during Individual Education Plan (IEP) meetings and mediation conferences. This opinion makes it more difficult for people who are not lawyers to advocate for people with disabilities.

This issue also highlights the Family Support Act and how the system falls short of its original intent. When it was signed into law in 1993, the Family Support Act promised to be a turning point and new approach. The goal of the Act was to provide "whatever it takes" to help families stay together, preventing the premature need for residential services.

Unfortunately, New Jersey's family support system has morphed into a fee-for-service system that falls short of its intent while leaving families struggling to get what it takes to meet their needs and the needs of their loved ones.

During the past year, COVID-19 has presented increased challenges that individuals and families continue to meet. In spite of school closings replaced with online instruction, day program closures, staffing difficulties, and other pandemic-related challenges we continue to press on. This year has brought unimaginable challenges for us all. During challenging times, it can be difficult to maintain focus on our goals.

But, I remain confident that as we turn the corner towards post-pandemic life we all will continue to focus on our roots—serving *People & Families*.

*Mercedes Witowsky*

Mercedes Witowsky  
Executive Director,

New Jersey Council on Developmental Disabilities

The graphic features a white banner with the text "NJCDD COMMITTEE UPDATES" in a bold, blue, sans-serif font. The banner is set against a background of several upward-pointing arrows in various shades of blue and grey, creating a sense of growth and progress.

# NJCDD COMMITTEE UPDATES

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

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

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

The Council conducts four public meetings each year. The Council's Executive Committee meets throughout the year to handle matters concerning the Council when it is not possible for the full Council to meet and monitor 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 following is a snapshot of some of the committee highlights.

## Executive Committee

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

The committee recently:

- Welcomed Executive Committee member, Gwen Orłowski, executive director, Disability Rights New Jersey.
- Established an Ad Hoc Committee to Review the Council's By-Laws. Gwen Orłowski will serve as Ad Hoc Committee Chairperson.
- Reviewed plans for the Council Retreat to discuss the draft of the Five-Year State Plan.
- Previewed the first full meeting of the Legislative Disability Caucus, focused on the impact of COVID-19 on individuals with disabilities.

## State Plan Committee

Helen Steinberg is the NJCDD Chair of the State Plan Committee. The role of the State Plan Committee is to manage federal requirements related to the development and implementation of the Council's Five-Year Plan. The Council has engaged the services of Considine Communications Strategies (CCS) to facilitate the development of its 2022-2026 Five-Year Plan.

Phase 4 of the process is underway.

- In January, the NJCDD had a planning retreat to review and consider the goals and objectives. Nearly every council member was in attendance and took part in the event.
- Based in input, changes were made, and a draft 2022-2026 Five-Year Plan was presented to the NJCDD and approved at their meeting on February 11, 2021.
- The Ad Hoc Committee on Equal Access to DD Services continues to meet and provide input.
- The Council approved draft plan and background information was published on the NJCDD website for public input through April 2.

## Grants Committee

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

- The Family Crisis Handbook is available for download to help families with dual diagnosis.
- The Training and Resource Data Bank is a valuable tool for families and advocates

looking for knowledge and training materials.

- Information about current grants is available at <https://njcdd.org/njcdd-current-grants/>.

## Public Policy Committee

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

- The Public Policy Committee met once since the new year. The Committee discussed follow-up to the Legislative Disabilities Caucus and the necessity to use opportunities afforded to address longstanding issues, including employment, transportation and waiting lists for housing through legislator meetings and collaborations.
- The Committee also discussed the effect of NJCDD in legislation for the mitigation of COVID-19 related issues, including vaccine distribution and visiting rights in concert with the Disability Action Committee's numerous bills that have been developed by the legislature.
- Changes for Workability reform were endorsed by the Committee in support of the recommendations of the DDAN Employment and Work Issues workgroup. The NJDCC offered its support for the legislation when it came up for a vote in Assembly and Senate Committees.
- Input on a variety of issues concerning youth and education was received for future action.

## Subcommittee on Children and Youth

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

The committee is addressing:

- The important role of non-attorney advocates in special education.
- Improving the system of family support services for those caring for a child under the age of 21.
- Access to specialized child health care services.
- Special education services, assessments and transition services during COVID restrictions.
- Seclusion and restraint.
- School safety.

## Subcommittee on Health and Wellness

The Health and Wellness Subcommittee, chaired by Elizabeth Dalzell, advocates for individuals with developmental disabilities to have the same access to quality healthcare as their peers. Subcommittee goals center around the training of health care providers, the development of materials that enable self-advocates and families to exercise their right to appeal adverse health care decisions, and the assembly of beneficial resource materials for serving individuals with developmental disabilities.

- The H&W Subcommittee has overseen the completion of two separate grants. The first, with Columbia University, addressed the barriers to dental care for individuals with I/DD, and was the catalyst for two well-attended dental summits.

The second, a training program for medical providers developed by The Boggs Center on Developmental Disabilities, was presented at a national conference, and is available for review on the NJCDD website.

- Through a partnership with DRNJ, the subcommittee also facilitated the development, and distribution of, a bulletin addressing appeal requests within the NJ Comprehensive Assessment Tool (NJCAT).
- The Subcommittee continues to address various health-related concerns, such as women's health, and safety in the community, through partnerships with IHC grantees, and is assessing individual and family experiences with managed care organizations.

## Ad Hoc Committee on Equal Access to Developmental Disability Services

Safiyah A. Muhammad is Chair of the NJCDD Ad Hoc Committee on Equal Access to Developmental Disability Services. The ad hoc committee advises the NJCDD during the state planning process and works to help ensure equal access to services.

- Three regular meetings and one special meeting of the Ad Hoc Committee were held since January 2021.
- The Ad Hoc Committee on Equal Access held 4 workgroups with advocates and family members to make recommendations to the the 2022-2027 5-Year State Plan.
- The Ad Hoc Committee reviewed and made recommendations to the NJCDD mission, vision, and Goal #1 and Goal #2 of the 5-Year-Plan. **P&F**



*Ellie Byra with her son, Matthew*

# PASSING THE TORCH

By Jonathan Jaffe

## Editor's Note:

*This three-part segment gives fitting tribute to recent retirees, Ellie Byra and Bill Testa who have made immeasurable contributions to people with developmental disabilities and their families. It also introduces new Council member, Sarah Aziz, a mother of a teenaged daughter with autism.*

## A Tribute to Ellie Byra A Loving Mom, Caring Friend and Fierce Advocate

To truly understand what drives a disability advocate like Ellie Byra, pick a place in history. On any given day, this lifetime volunteer was likely doing something of importance on behalf of people with developmental disabilities.

Let's take March 18, 1992. That's when Byra was sitting in the State House, staring down a state Assembly committee. She was serving as a voice for her son, Matthew, as well as thousands of other young men and women across the state with severe disabilities. She was calling for more funding to serve families, allowing them to be more self-directed in deciding the needs of loved ones.

"Only in America could a mother be changing a dirty diaper in the morning and in the afternoon be sitting before a group of legislators who yield such power over peoples' lives," she told lawmakers. And then she began her testimony....

Fast forward, to, say, March 24, 2005. Byra is back in front of the Assembly, noting more wisdom lines on the faces of many of the lawmakers over the past 13 years, but issues regarding people with developmental disabilities were still as prevalent as ever.

Byra still wanted to discuss self-directed care. Her focus was "Real Life Choices," through the support of the Medicaid Waiver, and the need for the state to properly fund the popular, community-based program.

"It does not make sense that 64 percent of the people with developmental disabilities are receiving less than 5 percent of the DD budget of \$1 billion," Byra informed lawmakers that day. "I know

what many of you must be thinking now: 'Doesn't Mrs. Byra know that these are difficult years?' The answer is 'Yes, I do.' They have been difficult years since the day my son was born...."

And let's just select one more date: April 27, 2016. Byra was at the New Jersey Adventure Aquarium in Camden. There were smiles and hugs all around. That's because Byra was receiving one of the most prestigious awards presented by the New Jersey Council on Developmental Disabilities (NJCDD). Byra was celebrated with a standing ovation, honored for a lifetime of advocacy on behalf of Matthew and so many others.

Byra accepted the "Elizabeth Boggs Family Member Advocate Award" in front of a cheering crowd of supporters who have observed her magic for four decades.

"Ellie has always done things with the intent that opportunities not just be available for Matthew, but available for all families," said Deborah M. Spitalnik, Executive Director of The Boggs Center. "She always had a larger perspective and has been a leader in the family support movement."

Of course, in presenting the award that April day, the NJCDD needed to begin Byra's story in 1981. And, as Byra retired from the council at the end of 2020, that's where *People & Families* will begin her story, as well, to celebrate a lifetime of amazing achievement on behalf of the disability community.

Matthew was a five-year-old boy in 1981, attending the Warren County Day Training Center. Byra, who had earned a master's degree in special education from Southern Connecticut State College, was deeply concerned about his future.

# PASSING THE TORCH

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Was there anything more for Matthew than going to these day programs? Did he have any type of future?

Byra became president of the Day Training Center Parents' Association and quickly jumped into an effort to launch the New Jersey Day Training Coalition, comprising other concerned parents and supporters who demanded opportunities for children with disabilities other than attending day programs.

Byra's work became the seeds for a national movement, driving politicians and other decision-makers to agree that people with disabilities need to be active parts of the community. Even with Matthew at such a young age, Byra was convinced that she could help him in a way that no one expected: Having him enroll as a student in the local school district in Flemington and ultimately earning a high school diploma alongside his peers.

"When we moved to New Jersey in 1981, I remember calling The Arc of Hunterdon County and asking what was available in terms of early intervention and respite," she recalled. "I was told there was no respite offered; we needed to take care of that on our own."

Not only was Matthew stuck at the Day Training Center, it appeared, there was no transportation provided either. Byra and her husband, Peter, spent hours a week in the car, back and forth. "I came to New Jersey with years as a special education teacher, so I understood this was not something that should be happening."

Byra's mission became clear: Join with other parents of children with disabilities and fight for them to attend public schools. From one meeting to the next, Byra began to make an impact. That was evident in the late 1980s, when Matthew became the first student from the day training center to ride a school bus to attend a Day Training Center middle

school, with the support of a full-time aide, and was educated in the same classroom as his peers.

Matthew became a part of the school fabric, even volunteering as water boy for the high school's basketball team.

The long road culminated with a grand, historical accomplishment in 1998, when Matthew, at age 22, became the first student with severe disabilities to graduate with his classmates at Hunterdon Central High School.

"One of Matthew's fellow students, who became a great friend, wrote her senior essay about how fearful she was with having Matthew in her class, worried he would keep interrupting," Byra recalled. "She got to know him and wrote that he made the biggest imprint on her, in all of her years in high school."

Transitioning...Now what?

Matthew was 22 years old; his education and support was no longer the responsibility of the local school district. He had a high school diploma; he wanted to work.

Byra found a friend in Bob Nicholas, who was heading the state Division of Developmental Disabilities. He, too, wanted to ensure as many children with disabilities were able to attend neighborhood schools, as opposed to state-run Day Training Centers.

"Ellie did not want Matthew living in a group home," said Nicholas, who served as state Division of Developmental Disabilities (DDD) director from 1989-1998. "She wanted him to live with inclusivity in the community with the opportunity to work. So, we were able to work together to provide enough self-directed services and gave the family a budget for what she wanted to have in terms of a plan."

Nicholas, who had worked with Byra for years on a number of DDD committees, considered her to be a pioneer. In the late 1990s, there were typically two paths that a person with disabilities could

***"Ellie has always done things with the intent that opportunities not just be available for Matthew, but available for all families. She always had a larger perspective and has been a leader in the family support movement."***

—Deborah M. Spitalnik,  
Executive Director of The Boggs Center.

follow. He or she could end up in an institution or live in a group home. Byra saw a third path in community-based living, now the preferred option for so many New Jersey families when their children reach the age of 21.

“I didn’t want Matthew to go and sit in a day program and do the same thing every day across from the same person, for the rest of his life,” Byra said. “So when he graduated high school, he went to work as a volunteer at Hunterdon Medical Center.”

Matthew started out shredding documents in the human resources department, and then filed charts and other small jobs that could be performed with the help of his aide. At one point, he was cleaning tables in the lunchroom. At the next, he was affixing labels to IV bags. Twenty years later, he retired from the hospital—never taking a penny of pay.

“We never asked for money because Matthew did not have competitive employment at the hospital,” Byra explained. “I didn’t want there to be a bad taste in the mouths of those at the hospital. I wanted to make sure they would be willing to take others with disabilities and also give them the opportunity to volunteer and be part of the community.”

While Byra, 77, and her husband, Peter, 79, are living out their golden years in Flemington, Matthew is living in the community—just as the family always wanted. He resides 13 miles away, in Hillsborough, in a shared living arrangement with a family who takes care of him. It is not easy. At age 44, Matthew needs assistance with walking, feeding and other basic needs, as well as care for seizures.

Byra’s interest in the disability community has gone far beyond advocating for Matthew. Besides serving 12 years on the NJCDD, Byra also was heavily involved in The Arc—a leader of the Arc of Warren County, the Arc of Hunterdon County, and the Arc of New Jersey. She also served nine years as a member of Disability Rights New Jersey’s Board of Directors, as well as on countless committees over the decades.

Byra notes she has been an advocate for people with disabilities for 64 years. Byra’s sister, Karen,

who was born severely disabled, lived a long life and died in 2018. “She and Matthew had the same genetic make-up,” Byra said. “I was only 13 when she was born, so I have had experience about the needs of people with disabilities my whole life.”

Byra is also widely known for her work with family advocates, lobbying for the passage of the NJ Family Support Act of 1993. She has led NJCDD’s Regional and Statewide Family Support Planning Councils, as well as serving as a consistent resource for the DDD. She even worked with individual families who had questions about specialized services through the public schools.

“Ellie has always seen the larger perspective, especially as a leader in the family support networks,” Spitalnik said. “She always wants to make things available for families and was always respectful of the people who provide the support.”

Spitalnik noted that Byra hosted an annual tea for the family support network. She made sure to invite care providers, recognizing all they do for people with disabilities and their families, Spitalnik said.

As Byra looks toward the next chapter of her life, she notes that the disability community in New Jersey is “always trying,” with good people facing bad budgets, year after year.

“But then you step back and look at what has been accomplished over the long term,” Byra said. “I often think about when my sister was born. Kids were not allowed an education, there were no group homes and there was no respite for family. You can say we have come a long way, but still have a long way to go.”

She loves it when DDD and families can work together. So does her friend, Bob Nicholas, now retired near Knoxville, TN.

“I haven’t seen Ellie in a number of years, but she was always very special to me,” Nicholas said. “She had a wonderful combination of compassion and persistence. In those DDD public meetings, she would always be there, her sleeves rolled up, with strong opinions and ideas. I had strong opinions and ideas, too. And when those meetings were over, she would come over and give me a hug.

“A lot of those days, I really needed her hugs.”

## **A Tribute to Bill Testa** **Serving Others with Care, Intellect and Compassion**

Growing up in a working-class neighborhood of Rockaway in the 1960s, Bill Testa received an early education regarding the plight of people with developmental disabilities.

He will tell you about Gail, the girl with severe autism who lived down the street. She was always rocking back and forth on her front stoop. The local kids would mock her and throw rocks at her. Testa and his brothers would give chase, stopping whoever could be caught.

Testa, who just retired as executive director of The Arc/Morris in Parsippany, also shares the story of Pat, the sister of one of his neighborhood friends. She was always gone during the week, but would reappear on weekends. Local kids knew she was slow, but had no idea she was a full-time resident at the North Jersey Developmental Center in Totowa.

And Testa will tell you about one of his closest childhood pals, who moved into the neighborhood when the boys were pre-teens. Bobby was from Spain; he and Testa became fast friends. There would be sleepovers and big trips to see the Knicks play in that famous 1970 season. But it wasn't until years later that Testa learned his childhood friend's sister, Anna, had Down syndrome, when Bobby reached out to The Arc for help.

"I had a mild speech impediment as a kid," Testa recalled. "And 55 years ago, a kid had a heightened awareness of any level of his disability. But it was not until I became an adult that I realized I was impacted by so many people with special needs growing up in my neighborhood."

Following his early days on Rockaway, Testa attended the County College of Morris and earning an undergraduate degree at Montclair State University before becoming an outreach worker for Morristown Memorial Hospital in 1979.

He then became a social services technician for the Morris County Board of Social Services from 1980 to 1982 before joining the The Arc/Morris in 1982. While at The Arc, he earned a graduate degree in Social Work Administration from Fordham University.

Testa said his early experiences evolved into a lifetime mission of creating a county in which people with intellectual disabilities and their families are valued and have the opportunity to achieve their highest level of self-sufficiency, independence and inclusion possible.

And, so, it was a shock to The Arc/Morris board early last year when Testa announced his retirement, after 38 years of service. Not only was he leaving the largest provider of services for people with developmental disabilities and their families in Morris County, but he also completed his tenure on the New Jersey Council of Developmental Disabilities, where he volunteered for the past decade.

The Arc of Morris, founded in 1954, grew enormously under Testa. He cut the ribbon on a number of group homes, created in-home, weekend and after-school respite programs, launched supported employment initiatives, opened adult training centers, purchased the Flanders School and continually sought new opportunities to enhance the lives of people with developmental disabilities and their families.

Testa, 63, launched his career just at the moment the Community Care Waiver was launched in New Jersey via the state Department of Human Services, bringing together a patchwork of state and federal resources to fund the services and supports an individual needs to live in the community. It was a time, he said, to witness the formation of the modern-day deliverance of care and compassion, relocating people with developmental disabilities from institutions back into their neighborhoods.

"We were excited to be breaking so much ground," Testa said. "As a kid who was so rooted in his community—and saw the flaws in the system—working for The Arc was an absolutely incredible place to be in the early 1980s. We were watching the world change for people like Gail and Pat and Anna. Their experiences fed my sense of what was right and wrong, as well as my sense of social justice. Through the waiver, we were bringing back an entire population who was literally removed from society."

Laura Williams, executive director of The Arc/Ocean chapter, had the chance to work with Testa in the early 1990s in Morris County, when he was her supervisor. She recalled Testa was very hands-on administrator, recalling that he once called a group home when he drove by and noticed that one of the residents wasn't wearing proper shoes.

"Bill would never hesitate to give you feedback and set high expectation," she said. "People working for him enjoyed the benefits of his constructive criticism. It is a supervisor style that I use today, from what I learned from Bill."

## A Proud Policy Wonk

In his role with the NJCDD, Testa had a strong interest in public policy. As a provider, he brought a unique and much-needed perspective to state legislation. He served as the voice of families as proposed laws were discussed and debated at the State House, underscoring that the disability community was a broad constituent base, affecting small neighborhoods in Rockaway to the largest cities in the state.

There was a struggle, he said, to offer a unified voice for the developmental disabilities community, as there are so many perspectives and needs from individuals, family members, group homes, institutions, etc.

"A lot of my work for the Council focused on self-advocacy and supporting that effort any way we can," Testa explained, noting he also had the opportunity to work on a committee that hired the last two executive directors of the NJCDD.

In meetings with the NJCCD's Public Policy Committee, Testa always commanded respect based on his extensive knowledge of legislative affairs, delivered in a very down-to-earth style, said Bob Titus, the Council's public policy coordinator.

"When Bill spoke, people in the room always stopped what they were doing and listened intently," Titus said. "They knew that Bill lived his entire life always wanting what is best for the people he served. His main interest was that people have an inclusive life in the community and a good network of support. Bill took his role very seriously."



*Bill Testa retired and ended his tenure with the Council.*

Williams said Testa was always the go-to resource in regards to the Community Care Waiver, joking that he is likely the only person who ever read the federal policy document from cover to cover.

"He knew exactly how New Jersey draws down funds from the federal match of supports," William said. "Bill's focus was creating a New Jersey waiver that maximized the federal match to secure additional support for people. He was our expert on that."

## Retiring So Young?

Disability advocates just assumed Bill Testa would be their leader for life. There was no one else, it seemed, who could possibly have a better understanding of the needs of people with developmental disabilities in Morris County and how it all ties to the rough-and-tumble world of Trenton politics.

"Bill knew all the rules and regulations; he was our resource for everything," said Wally Bender, who, along his wife, Ann, served at different times as president of The Arc of Morris. "Bill wasn't just

# PASSING THE TORCH

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an administrator. He ruled from the heart. He really cared for the clients he was responsible for. He went out of his way to know all 300 of them.”

Bender, who also served as state president of The Arc, has known Testa for more than four decades, ever since his daughter, Lisa, was born with Down syndrome. “All of this time, Bill looked after Lisa,” said Bender, 75. “And when it came time three years ago for Lisa to move out of our home, Bill made sure she was in a well-supervised group home in Ledgewood, where she now shares a three-bedroom condo with two others with comparable capacities. Bill has always been there for us—from cradle to group home.”

Bender’s sentiment is not unique.

## Accolades Flow In

Once the Morris County Commission learned of Testa’s retirement, the governing body quickly adopted a resolution honoring him for nearly four decades as an advocate and friend to people with developmental disabilities. Testa was lauded as a tireless advocate for expanding non-institutional living opportunities, campaigning from Morristown to Trenton to move people out of institutions.

“Mr. Testa, you were there in 1983 when The Arc/Morris Chapter opened its first group home. Since then, you have helped to build The Arc/Morris into an organization that houses and serves more than 120 adults and is a crucial part of New Jersey’s long-term care system ... Your dedication will never be forgotten, and tonight we want to say thank you for all that you have done,” said Deputy Commission Director Deborah Smith, in presenting the framed resolution.

For a very modest Testa, all the retirement honors are wonderful, but nothing new.

Through his career, Testa was constantly honored for his advocacy work. Back in 1994, he earned an “Outstanding Career Accomplishments & Community Service Award” from the New Jersey Council of Community Colleges. Three years later, he was back on stage to accept the “Outstanding Professional Achievement, Public Policy Award”

by the National Conference of Executives of The Arc and then, back home, earned the “1999 Leadership Award” by the Morris County Human Relations Commission.

The list goes on, but Testa wishes the focus of this article be about The ARC/Morris and what has been accomplished to help not only those kids from his Rockaway neighborhood, but to thousands of people with developmental disabilities and their families yesterday and tomorrow.

“Thirty-eight years is a long time; you reach a point when you decide to do other things,” Testa said. “You hand off the stewardship to talented individuals to move the ball forward. I would rather go out when I’m still good and capable and people will say ‘He always made a strong contribution,’ rather than just be a guy who stuck around and faded away.”

## NJCDD Welcomes Sarah Aziz

As the 44-year-old mother of a young teen with autism, Sarah Aziz is eager to focus her term on the NJCDD to advocate for young families and ensuring strong educational opportunities for children who require specialized services.

“It appears the overwhelming majority of my fellow council members represent families with much older children,” said Aziz, who lives in Monroe Township (Middlesex County). “With my daughter, Layla, just 13 years old, I believe I bring some different perspective.”

Moreover, Aziz noted she is of South Asian-American descent, providing more ethnic diversity to the perspectives of the council.

“As a younger mother, it is very isolating to have a child with a disability,” she said. “You often make your friends through your kid’s Girl Scouts, or sports or band or whatever. Layla does not participate. It is important to have people from different generations on the council, so they can hear our point of view as they make decisions.”

Aziz, who is a certified public accountant, was confirmed to serve on the council in October 2020. She has been assigned to serve on the Children and

Youth Subcommittee, in which she can focus on special education and work towards ensuring New Jersey families can better understand the IEP process.

“If English is not your first language, it is very challenging to understand an IEP,” Aziz said. “I can only imagine how much more difficult it must be if you are an immigrant enrolling a child with disabilities into the American school system. Can you imagine navigating through special education law while getting acclimated to a new country?”

Aziz, a native of Jamesburg, said the process of raising a child with autism has been difficult. “I have a lot of empathy and understanding of what immigrant parents have to contend with, which I look forward to sharing with the council.” **P&F**



Layla Aziz with her mother Sarah

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# DEPARTMENT OF HUMAN SERVICES CHANGES LEADERSHIP

By Maryann B. Hunsberger

Carole Johnson served as New Jersey's Department of Human Services (DHS) Commissioner from January 2018 to January 15, 2021 when she stepped down to join President Joe Biden's COVID-19 Response Team as testing coordinator.

During her tenure, she pushed New Jersey's addiction treatment system to align with clinical best-practices. Johnson tweaked Medicaid to help poor residents pay for autism-related care, prevent diabetes or quit smoking; and invested

heavily in child-care support for working families. Governor Phil Murphy said, "We're sad to see her depart the administration, but are excited that she'll be taking a critical role serving President Biden and Vice President Harris in the White House as our nation continues to battle the COVID-19 pandemic."

When Johnson became commissioner in New Jersey, she met with individuals with disabilities and their families at the Developmental



*Carole Johnson left her post as DHS Commissioner to work in the Biden Administration.*

***“NJ DHS and our life-sustaining programs and services are here to support New Jerseyans at every stage of life, from birth through aging. I will continue building on our efforts to serve New Jersey's most vulnerable residents, as well as making services available to many who need support for the first time as a result of COVID-19.”***

—Sarah Adelman,  
Acting DHS Commissioner



Disabilities Advocacy Network Summit. She listened intensely to their experiences and used the lived experiences shared to help guide her work as commissioner.

Sarah Adelman now serves as acting commissioner. Adelman earned a bachelor's degree in humanities and social science summa cum laude from Rowan University. She also earned a certificate in advanced healthcare leadership from Seton Hall University as a fellow in the inaugural class of the New Jersey Healthcare Executives Leadership Academy.

Adelman initially served as a deputy commissioner, overseeing the Division of Developmental Disabilities (DDD), Division of Aging Services, and the Division of Medical Assistance and Health Services, which operates NJ FamilyCare, the State Medicaid program. Together, these programs serve more than 1.7 million New Jerseyans. She also serves on the Board of the New Jersey Housing and Mortgage Finance Agency.

“Our priority has always been to provide the best services and programs for New Jersey

residents in need. With that goal in mind, we've been able to expand and improve benefits, especially during this ongoing public health emergency,” said Adelman.

She also stressed that Governor Murphy's administration has been focused on supporting high quality services for individuals with intellectual and developmental disabilities. “This administration was the first to recognize that a fair wage for direct support professionals (DSPs) serving individuals with intellectual/developmental disabilities (I/DD) must be higher than—and keep pace with—the minimum wage.” The current budget proposal builds on previous DSP wages to ensure DSPs are paid above the state's increasing minimum wage and to raise wages of managers and other more senior members of the I/DD frontline workforce. Additionally, DHS has provided \$72 million to a support temporary \$3 per hour emergency wage increases during the public health emergency.

Since congregate day programs closed because of the pandemic, residential providers like group

homes have been required to provide additional daytime staffing hours for the duration of the public health emergency. To support these higher staffing levels, DHS increased the residential daily rate. “While we are working to achieve widespread vaccination and to safely reopen day programs again as soon as we can, we know we’ll need this funding to continue for some time. For these reasons, Governor Murphy’s budget also includes funding to maintain this enhanced residential staffing through December 2021.”

DHS has also continued to provide 100 percent of state payments to day program providers, even after federal funds were discontinued. “The long-term viability of our day program providers is very important to our system and to DHS, and we are hopeful that additional requested federal funds may become available in order to sustain day providers.”

As the country moves closer to recovery from the pandemic, Governor Murphy’s budget continues several initiatives addressing the unique needs of individuals with both I/DD and mental health needs. “We recognize that driving progress on these interrelated challenges requires a sustained commitment over many years. That is why our budget supports infrastructure enhancement for the long term, including developing specialized group homes, analyzing patterns of utilizations, and supporting providers working in this space.”

DDD recently helped fund the cost of developing group homes that serve up to 100 individuals with acute behavioral and/or medical needs. DHS continues to work with Rutgers University and managed care organizations to evaluate service needs and analyze crisis stabilization utilization in New Jersey. DHS will soon develop three behavioral health stabilization homes to create a short-term, highly-structured and nurturing environment to stabilize up to 12 individuals and transition them back to their previous living arrangements or appropriate long-term placements.

This builds on what DHS has already done with Adelman as deputy commissioner, including expanding housing options for adults with I/DD, making access to health care easier during the pandemic through expanded use of, and payment

***“Our priority has always been to provide the best services and programs for New Jersey residents in need. With that goal in mind, we’ve been able to expand and improve benefits, especially during this ongoing public health emergency.”***

—Sarah Adelman,  
Acting DHS Commissioner

for, telehealth; and launching NJ ABLE, which allows individuals with disabilities to save tax free for eligible expenses without losing eligibility for Medicaid and other benefits.

With a number of people with I/DD living in long-term care facilities (LTCs), DHS has increased Medicaid LTC rates to raise direct care staff wages and support COVID-19 infection control and preparedness measures.

DDD continues to support working parents of children with and without disabilities during the pandemic under Adelman’s leadership. “DHS is focused on ensuring that child care services remain open and available at a time when utilization is unpredictable and programs are operating at reduced capacity, said Adelman. “We are providing as much assistance as possible to working families and child care providers, and will do so for as long as we can. We’re especially concerned about data showing how many women have faced difficult decisions to leave the workforce because of the challenges of child care during this crisis. We continue to find ways to support child care throughout New Jersey from all available resources.”

“NJ DHS and our life-sustaining programs and services are here to support New Jerseyans at

every stage of life, from birth through aging, said Adelman. “I will continue building on our efforts to serve New Jersey’s most vulnerable residents, as well as making services available to many who need support for the first time as a result of COVID-19.

“I also want to acknowledge that this past year has been a difficult one for many, especially for the many individuals dealing with grief, illness and social isolation. Every person who is struggling can access help and find a live person to talk to through our help lines.” **P&F**

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# NJCDD

## ESTABLISHES A LEGISLATIVE DISABILITY CAUCUS

By Jonathan Jaffe

When it comes to creating new opportunities for people with disabilities, Senate President Stephen M. Sweeney (D-3rd Dist.) is quick to share stories about his 28-year-old daughter, Lauren.

Like any proud dad, Sweeney will gush about how well his daughter has done as a staff member at a child care center in East Greenwich, where the kids lovingly called her “Miss Lauren.”

Because of Miss Lauren—who has Down syndrome—and other people with disabilities, Sweeney has led the charge to create the Bipartisan Disability Caucus in the New Jersey Legislature, which is reviewing current laws and issues impacting those with disabilities and debating new ones to enhance the quality of life in the disability community.

With Sweeney as chair, the caucus held its first meeting virtually on January 26 to discuss the impact of COVID-19. With the lingering pandemic taking a disproportionate toll on people with disabilities, the topic led to a wide-ranging discussion among policymakers.

Disability advocates shared their experiences regarding limited access to vaccines, testing, personal protective equipment, and critical care resources. They also aired concerns about the loss of educational services, therapy and behavioral supports and how it has affected transition to adult life and compensatory services.

“One of my big focuses is addressing the fact that government doesn’t do a good job hiring people with special needs,” Sweeney told *People & Families*. “In government jobs, you can earn health care insurance and retirement benefits. And I want

to make sure people with disabilities have that opportunity.”

Another hot topic is transportation, as the senate president believes NJ Transit’s program for people with disabilities “stinks.” There are limited runs, he said, and they can be unreliable, which makes it very difficult for people with disabilities to be reliable, timely employees. He also shared concerns about the paratransit system in Burlington County.

**The caucus has 29 founding members, with 11 coming from the State Senate and the remainder coming from the Assembly.**



*NJ Legislative Disability Caucus kicked off with a virtual briefing session on January 26.*

It stretches from the Delaware River to the Atlantic Ocean—which is great—but will not travel out of the county for those who need to go to Camden or Mercer counties.

“This caucus will be looking at what laws work, what doesn’t and what we need to do,” Sweeney said, adding these conversations allow lawmakers to raise awareness and share ideas, so fellow policymakers can make informed decisions on how best to address inequities.

Competitive employment needs to be another focus of the caucus, Sweeney said, noting that Gloucester County has a program for people with disabilities designed to provide life skills and job training so that they can secure gainful employment at age 21 and beyond. “I asked the county how many people they hired from this program,” Sweeney said. “And the director told me none.

“We need to give opportunities to people with disabilities,” he added. “How do we expect the private sector to hire them if government doesn’t hire them ourselves? The goal should be to hire them as full-time employees so they can earn

health insurance benefits. That is a big headache my daughter has experienced with working.”

Sweeney believes many people with disabilities want to work, but qualify for Social Security to make ends meet. “If my daughter can work full-time and earn her own benefits, why can’t we let her do it?” he asked. “If she loses her job, she can go back to Social Security. But why can’t we help them with meaningful employment? We don’t want money from the government. She wants to earn her own way.”

He said that many prospective employers have limited expectations in regards to what workers with disabilities can do. Sweeney is calling for a change of thinking, in which people with disabilities can more easily set the bar for their own abilities, rather than remain limited within the pre-conceived notions of a work supervisor.

“Give them additional training. Get them to the next step,” Sweeney said. “Let’s really see what a person can do. This caucus is going to focus on all aspects of life and the role people with disabilities should play. That is why I got into politics; I hated the way people with disabilities were treated.”

***“Give [people with disabilities] additional training. Get them to the next step. Let’s really see what a person can do. This caucus is going to focus on all aspects of life and the role people with disabilities should play. That is why I got into politics; I hated the way people with disabilities were treated.”***

—Steve Sweeney,  
New Jersey Senate President



With approximately 25 percent of adults in New Jersey having some type of disability, the caucus is hoping to create a louder voice for this huge constituency. The hope is for more opportunities for these residents to be more included and more represented in all aspects of life, despite progress after the passage of the American with Disabilities Act (ADA) 31 years ago. New Jersey is one of eight states that has formed a disability caucus within its state Legislature.

In Washington D.C, there is the Bipartisan Disabilities Caucus (BDC), formed 20 years ago, and serves as a forum for Members of Congress and their staff to discuss the many issues affecting people with disabilities nationwide. The primary purpose

of the caucus is to inform, educate and raise awareness on issues affecting people with disabilities. This caucus notes a widespread constituency, with 54 million Americans reporting a disability.

It also reports on a widespread disparity in terms of education, with 28 percent of people 25 and older with a disability had less than a high school education. This compares with 12 percent for those with no disability. Meanwhile, just 13 percent of people 25 and older with a disability earned a college degree, comparing with 31 percent for those with no disability, according to the national caucus.

Sweeney recalls when Lauren was born that his family entered this whole new world of disability policy, care and advocacy. He remembers taking the family to a restaurant and seeing other diners stare at his baby daughter. “I’d say, ‘She’s beautiful, isn’t she?’ They would say they didn’t mean to stare,” Sweeney said. “But she didn’t need to be stared at. People with disabilities are who they are.”

He notes one substantial accomplishment has been the removal of the term “retarded” from all state laws. Sweeney helped pass an 81-page bill in 2010 that makes it illegal for state laws or



***“We’re getting tremendous support from a variety of organizations. Close to 30 agencies signed on to support the caucus.”***

—Mercedes Witowsky,  
NJCDD Executive Director

rules to identify anyone with a developmental or intellectual disability as "mentally retarded."

"We have a community of productive, hard-working citizens...The 'R' word should mean respect," Sweeney said.

The caucus has 29 founding members, with 11 coming from the State Senate and the remainder coming from the Assembly.

One of them is Assemblywoman Yvonne Lopez (D-19<sup>th</sup> Dist.), who was the former Executive Director/CEO of PRAHD, Inc. The non-profit had a partnership with the National Federation of the Blind of New Jersey, operating a Blindness Prevention program and specialized summer camp experience for blind and visually impaired children.

"Helping to lead these programs gave me special insight into the needs of our disabled community and I committed myself to supporting and advocating for the disabled as a Legislator," Lopez said. "I am equally humbled to join my colleagues on the New Jersey Legislative Disability Caucus to prioritize and develop policies for New Jersey's disability community at large. I am excited by the profound positive impact this group of legislators will have in better supporting people with disabilities and their families throughout New Jersey for years to come."

"We're getting tremendous support from a variety of organizations," said Mercedes Witowsky, NJCDD executive director. "Close to 30 agencies signed on to support the caucus."

Assembly Majority Leader Lou Greenwald (D-6<sup>th</sup> Dist), who also serves on the disability caucus, said the 2.2 million New Jerseyans who have some form of disability need to be part of the debate as the state Legislature begins carving the fiscal '22 budget. Lawmakers needs to build policy "in an ongoing positive way" to make the lives easier of people with disabilities, while making them more productive members of society, if they wish.

"It's about what they want and what their families want," Greenwald said. **P&F**



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# OPINION 56

## THE UNEVEN PLAYING FIELD JUST GOT HARDER

By Brenda Considine

*Every parent of a child in special education knows the overwhelming—and sometimes intimidating—experience of being alone in an Individual Education Plan (IEP) meeting with school district professionals. For decades, non-lawyer advocates have accompanied parents to IEP meetings, providing free and low-cost assistance. Now, that help and support has been threatened.*

\*\*\*

“Seva” is a Sanskrit term meaning selfless service. One of the most important parts of any spiritual practice, it has meaning in Buddhism, Pali, and Hindi. SEVA is also the acronym for a Special Education Volunteer Advocate, a unique program at SPAN Advocacy. Funded by a grant from the New Jersey Council on Developmental Disabilities (NJCDD), the program has trained more than 175 parents—English- and Spanish-speaking—to provide free support helping other parents prepare for and take part in IEP meetings. SEVA volunteers help parents build the knowledge and skills they need to advocate on their own behalf.

In September 2020, the role of SEVAs and other non-attorney advocates came under fire when the

New Jersey Supreme Court issued “Opinion 56.” The 10-page opinion makes it more difficult for advocates who are not lawyers to help parents of special education students in IEP meetings and mediation conferences. Opinion 56 states it would be unethical for non-lawyer advocates to “represent” students or “speak on their behalf” in IEP meetings and mediation conferences.

Opinion 56 was issued in response to a single confidential grievance filed by an unknown party. The Opinion states that some of the work of non-attorney advocates constitutes “the unauthorized practice of law.”

Special education is one of the few areas of law where non-lawyers are permitted to represent and assist parties. The federal law, IDEA, specifically allows parents the right to be accompanied and advised by a lawyer and also by “*individuals with special knowledge or training with respect to the problems of children with disabilities.*” 20 U.S.C. § 1415(h)(1).

Non-lawyers may also accompany and consult with parents in mediation conferences, but again, cannot “represent” the parents or “speak on their behalf.” Non-lawyers who do not “represent”

a parent are allowed to charge fees for attending administrative hearings in the Office of Administrative Law as a “consultant” about educational needs, but cannot speak on behalf of the parents or advise or coach the parents regarding evidence, arguments, or direct and cross-examination questions. Advocates believe that the fear of violating Opinion 56’s unclear language will discourage the use of non-attorney advocates, giving school districts another advantage over parents.

After Opinion 56 was released in late September 2020, the Newark-based Education Law Center (ELC) filed a formal request asking for an opportunity for public input. The New Jersey Supreme Court agreed, and temporarily suspended the Opinion.

Negative reaction to Opinion 56 was swift and strong. Leaders from nearly every child advocacy group in New Jersey and beyond, along with scores of parents, wrote to the New Jersey Supreme Court, to oppose the opinion.

“The playing field in special education proceedings is often uneven, and there is a chronic shortage of free and low-cost legal services available to parents,” said ELC Senior Attorney Elizabeth Athos in a prepared statement for the press. “Non-attorney educational consultants, who include advocates, play a critical role in enabling children with disabilities to receive an appropriate education and ensuring their rights are protected throughout the special education process.”

“The opinion demonstrates a disconcerting lack of

understanding of the power imbalance at IEP meetings between parents and schools, and the important role that non-attorney advocates play in leveling the playing field,” said Peg Kinsell, policy director, SPAN Advocacy and a member of the NJCDD Policy Committee, where she chairs that group’s Subcommittee on Children and Youth. Under Kinsell’s leadership, the NJCDD took up this issue, sending comments to the Court urging them to rescind the Opinion.

Jeannette Mejias is the director of the SEVA project at SPAN. She believes that the option to have non-attorney advocates support families at IEP meetings serves a bigger purpose.

“It builds confidence and capacity, just knowing that there is someone at your side. Many parents do not feel like an equal member of the IEP team. It is very intimidating,” she said.

***“Because of their training and experience navigating the special education system, New Jersey advocates are able to provide tremendous technical and moral support to parents at IEP meetings.”***

—The Council of  
Parent Attorneys and Advocates

### ***A SEVA Story***

Jeannette Mejias is the mother of two sons on the autism spectrum and SEVA Project Director at SPAN. In her own words, she describes her journey from “just a mom” to parent advocate and, now, the SEVA program director:

*“My oldest son led me to this work. I was just a mom trying to advocate for my son. I was not getting any answers. But I was praying a lot. I went to my church, and one day, the pastor introduced a guest speaker. It was someone from SPAN with information about autism services. Just hearing another mother tell me I was on the right path... that was enough. She was a stranger... but right away, she was a friend.*

*Later, my son’s doctor gave me the business card of someone he thought could help me—it was the same person from SPAN!*

*She was a godsend.”*

*The reason I am passionate about the SEVA model is because I am a product of this model. It works!*

Mejias said Opinion 56 has caused non-attorney advocates to be more cautious and has left families unsettled and nervous.

“They feel like they have less access and less support. If they wanted to bring a minister or friend, they have the right to do that. Those guests can speak. But not a non-attorney advocate,” she said.

According to Gerard Thiers, Executive Director of ASAH, a statewide association of private special education schools, the ruling will especially hurt families who do not have the resources to hire a lawyer.

“There are gross inequities faced by parents in special education, especially those who have low incomes, who have limited English proficiency, and those whose own literacy skills are low,” said Thiers.

“Opinion 56 disproportionately affects parents who cannot afford a lawyer because there are very few free and low-cost legal services with special education expertise available to parents,” he added.

The Council of Parent Attorneys and Advocates, COPAA, is an independent, nationwide nonprofit. Their members—attorneys, advocates, parents, and related professionals in all 50 states—work to protect the rights of students with disabilities at all stages of the educational planning and review process. COPAA submitted a detailed and lengthy letter to the court in opposition to Opinion 56.

They believe Opinion 56 fails to account for the parents’ statutory rights to bring individuals of their choice to IEP meetings as well as their First Amendment rights.

Kinsell agrees, pointing out that parents of children with disabilities often sit alone at a table of educators and experts who, by law, are supposed to be working in good faith in the best interests of the child.

“We have seen too many instances in which parents are quickly overwhelmed by lack of information, misinformation driven by local practices, and budget considerations that are not aligned with the needs of the child,” concluded Kinsell.

### **Editor’s Note:**

*On April 9, as People and Families was at press, the New Jersey Supreme Court Committee on the Unauthorized Practice of Law issued Opinion 57, superseding Opinion 56.*

*As a result of robust advocacy efforts, the Court has agreed that “non-lawyers with knowledge or training with respect to children with disabilities and their educational needs may advise, represent and/or speak on behalf of parent and children at meetings with the child’s school to develop the IEP, and at formal mediation should the parties be unable to agree to the IEP.”*

*They find that while this is, in fact, “the practice of law,” it is not the “unauthorized practice of law” when the non-lawyer has the requisite knowledge or training.*

*The Court was “guided by its determination of the public interest by the numerous comments received from parents, consultant, school administrators, teachers, non-profit organization and institutions.”* **P&F**

## **DID YOU KNOW:**

There are **nearly 250,000 students with disabilities**

**in New Jersey.** Given

IDEA’s mandate that student programs be reviewed and revisited at least once a year, there are nearly a quarter of a million IEP meetings in New Jersey each year.

## **RESOURCES**

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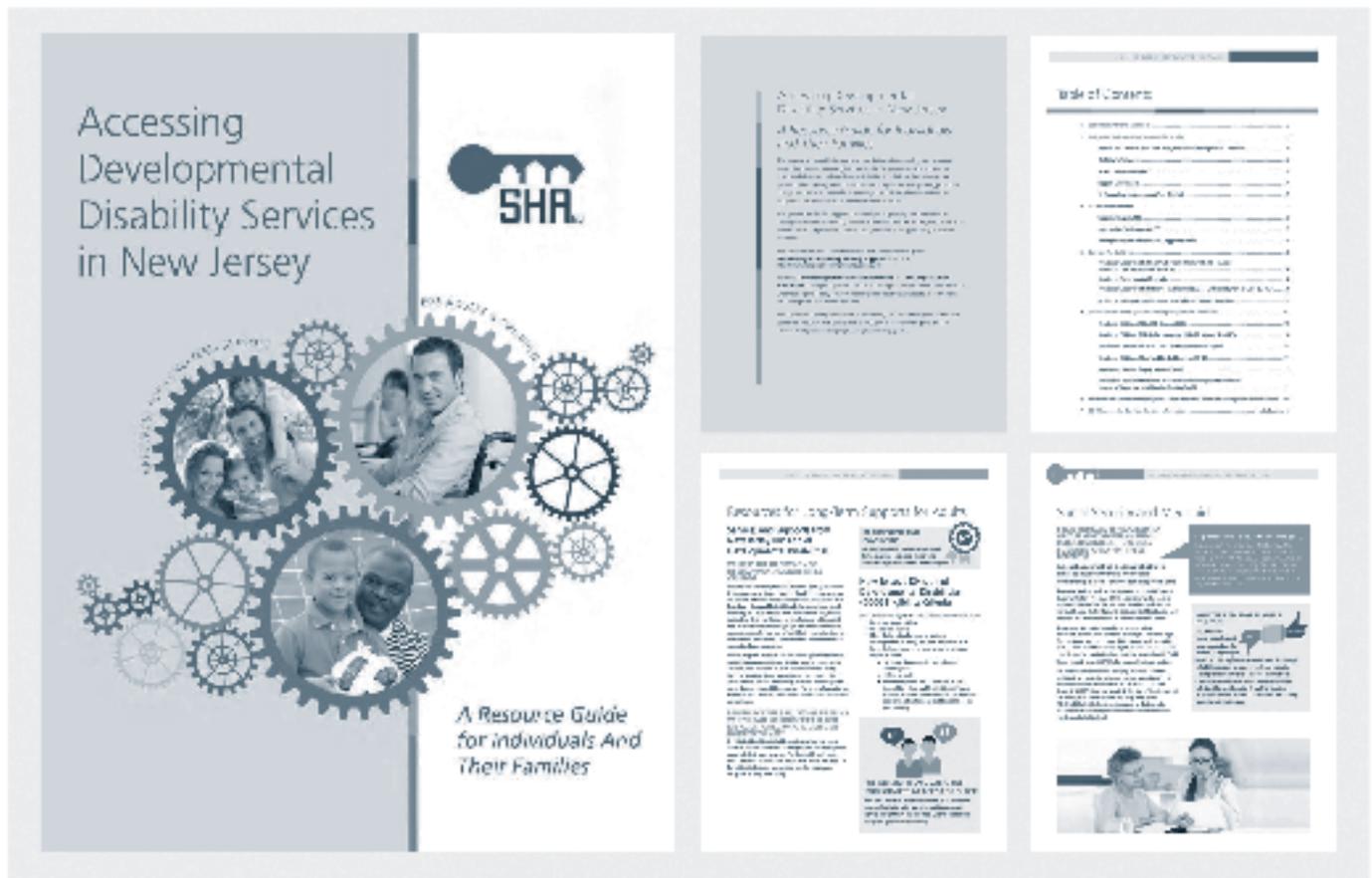
### **Read Opinion 56:**

<https://njcourts.gov/notices/2020/n201016a.pdf>



# Accessing Developmental Disability Services in New Jersey

## A Resource Guide for Individuals and Their Families.



The purpose of this guide is to provide basic information regarding how a person with a disability can access eligibility and intake for government-funded services.

Access the guide at  
<http://www.shanj.org/housing-hub/resource-guide>



Supportive Housing Association of NJ • [www.shanj.org](http://www.shanj.org)

This work was supported with a grant from the New Jersey Council on Developmental Disabilities.

# WHAT EVER HAPPENED TO “*WHATEVER IT TAKES?*” FIGHTING FOR THE FAMILY SUPPORT ACT



By Brenda Considine

Ask five New Jersey families caring for a child with developmental disabilities what they need for family support services, and you are likely to get five different answers.

- A mom in south Jersey needs funding to remove the carpet in her rented home and replace it with vinyl flooring, not only so her son’s wheelchair and IV pole can be rolled around with ease, but also so messes—often with bodily fluids—are easier to clean up.
- A single dad needs specialized child care for his son with autism from 2:30–6 p.m. on Saturday so he can keep his job.
- A senior citizen caring for her granddaughter with Down syndrome needs a counselor who speaks Spanish.
- A mom near the Jersey shore needs a vehicle with a lift, now that her son has grown out of a stroller and into a full-sized wheelchair.
- A mom outside Morristown needs a fence installed around her yard so her teenage son can play outside safely without eloping.

In theory, any of these services could be provided under the Family Support Act. In practice, few, if any, are.

When it was signed into law in 1993, the Family Support Act promised to be a turning point and new approach. It was the first time that legislation created a statewide system driven by families, and responsive to what they deemed necessary. The goal of the Act was to provide “whatever it takes” to help families stay together, preventing the premature need for residential services.

By law, the system must include 25 specific services: after-school care; cash subsidies; communication and interpreter services; counseling services; crisis intervention; day care; equipment and supplies; estate and transition planning; home and vehicle modification; home health services; homemaker assistance; housing assistance; medical and dental care not otherwise covered; parent education and training; personal assistance services; recreation services; respite care for families; self-advocacy training; service coordination; specialized diagnosis and evaluation; specialized

nutrition and clothing; therapeutic or nursing services; transportation; and voucher services.

The most important service, however, is this one: “...and other services as identified by the family.”

## A Big Transition

Twenty years after its passage, in 2013, there was a major change to the way in which The Family Support Act is implemented. The Department of Human Services, Division of Developmental Disabilities (DDD), which had overseen Family Support Services, was restructured. Services for children under the age of 21 were shifted to the Department of Children and Families’ (DCF) Children’s System of Care (CSOC) along with more than \$34M to cover the cost of children’s residential services and to fund family support services.

The vision was to create a single point of entry for children and families, break down barriers to service, eliminate silos, and provide services along a continuum of care. According to leaders in the family support movement, that vision has not been realized.

## Hard to Get Support. Hard to Get Services

PerformCare® is a national, full-service behavioral health managed care organization. They are under contract with CSOC to administer family support services to eligible families. A fact sheet on the PerformCare® website describing family support supports says that a telephone application takes about 20 minutes, but in practice, families report it can take months to get approved, and even longer to get services.

The Regional Family Support Planning Councils, established by the Family Support Act to plan and coordinate services at the local level, hear from frustrated—sometimes desperate—families in need of support services. One of the biggest problems families report is simply getting into the system. Data shows that more than half of families fail to complete the

### **Q: What is “Family Support”?**

**A:** *The Family Support Act defines family support as “a coordinated system of on-going public and private supports, services, resources, and other assistance, which are designed to maintain and enhance the quality of life of a family member with a developmental disability and his or her family.” (N.J.S.A. 30:6D-35).*

application and never make it to intake. Those who complete that step find a very high rate of denial, and very limited services. Even if approved, they must be reauthorized for family support services every year.

*“The process is way too complicated for a parent with two kids with ASD: I did not have hours and hours of free time to fill all forms and collect all documents,”* said one parent who responded to a survey by NJCDD.

Another said, *“Getting everything together took a lot of time and then when I sent everything in, I never heard back. Finally contacted them and was told there were reports that needed to be updated and there was no current psychiatric evaluation. My child did not need a psych eval to get services in district so one was not recently completed. Getting updated reports extended the process by 90 days. This process takes WAY too long for kids that clearly are eligible for services and have been receiving services through the district for 13 years!!!”*

The Annual Report on the Family Support Act recommends that leaders and staff in CSOC review the Family Support Act to understand how family support services are defined by the law. The report urges that CSOC staff should continue to receive training regarding I/DD, and explore how they will meet the unique needs of children with I/DD and their families.

*“Even after all this time, we find that some care managers in the CSOC system are not trained in*



*Helping to keep families together is the goal of The Family Support Act.*

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planning for and providing care to children with I/DD and those with dual diagnosis, and do not know about the Family Support Act,” said Kyoko Coco, statewide family support coordinator.

Although the term “Family Support Services” is not defined in DCF regulations, the PerformCare website lists “available” family support services as respite care, including after-school, self-hire, weekend, and overnight; education advocacy; and assistive technology, including assistive devices; vehicle modification, and environmental modifications, such as widening doorways, ramps and grab bars. But in practice, families say these services are rarely, if ever, offered or provided.

Some of the services listed in the Family Support Act, such as day care and therapies, are specifically listed as an exclusion. And no one is getting a cash subsidy anymore, due to federal funding rules.

## No Way to Appeal or Advocate

Peg Kinsell, policy director at SPAN, has spoken to many families seeking family support.

“They fight for years just to get a few hours of respite care, and now are afraid to advocate for more services, for fear they will lose the limited services they now have,” she said.

Parents and advocates also find that the family support system lacks a meaningful working appeals process.

“There is not a clear way to go up the chain—and no statutory language and no appeals or enforcement mechanism for attorneys or advocates,” said one advocate.

## Show Me the Money

While the Family Support Act called for a new system, it did not guarantee new funds. As years have gone by, a continued failure to fund the system has caused an erosion in support and services, and the concept of “whatever it takes” has been overlooked. In fact, the fact sheet on Family Support Services produced by PerformCare® specifically states that “Family Support Services are not entitled or guaranteed and the ability to provide services to your child is contingent upon the availability of New Jersey Children’s System of Care (CSOC) resources.

It is not only a matter of how much money, but also where the money comes from that is important.

Initially, family support services were funded with state dollars. For years, advocates urged that federal Medicaid funds be used to aid this effort, expanding the pot of money that could be used. But federal Medicaid rules bar popular services, such as cash subsidy and cash-option respite.

One way to keep New Jersey’s family support system responsive and still benefit from the waiver funds is to set aside “state only” funds in

Susan Coll-Guedes considers herself an optimist, but admits she is growing very tired of fighting. The Atlantic County mom and educator has three children with I/DD. Her youngest two have autism. Her oldest child, 20-year-old Alex, has Down syndrome and Ehlers-Danlos syndrome. He uses a feeding tube, and was not able to support his own weight to stand until the age of seven.

Under a special Medicaid waiver, Alex gets 16 hours a day of in-home nursing care.

“There is not a group home in New Jersey that could serve Alex. Without this care, he would be in a nursing home or an institution,” she said.

But to keep him home, and keep her family together, she needs more help and a break from caregiving.

“I have not had a vacation for 20 years,” she said.

Several years ago, she reached out to secure home modification services, a service listed in the Family Support Act. She needed a stair lift and modifications to make her bathroom accessible and safe for her son.

“We needed a non-slip floor, a wider doorway, and a flat tub for bathing him. We told them what we needed, but we got nothing. The person they sent to our home offered to install a grab bar and told us to get some throw rugs at Target,” she recalled. For the stair lift needed to get her son to his bedroom, she had to put the \$18,000 tab on several credit cards. She was able to secure

#### **Q: What is Ehlers-Danlos syndrome?**

**A:** Ehlers-Danlos syndrome is a group of inherited disorders that affect connective tissues—primarily skin, joints, and blood vessel walls. People who have Ehlers-Danlos syndrome usually have overly flexible joints and stretchy, fragile skin.

partial reimbursement through a catastrophic health care fund.

“None of these things were offered through the Family Support Act,” she said.

Her family is vulnerable and needs the services they are getting. They are vital. “We are always threatened that we will lose our medical care; we are in a constant state of terror and crisis for fear our nursing hours will be taken from us,” she said. “We are afraid to make waves.”

In order to stay in the system for behavioral health supports, Susan’s family has to get re-approved every 90 days. “It’s a lot of paperwork, and every time, they tell me ‘there are so many families with so many needs’ and ‘other families need more’, so we have to wait.”

“We need to submit a ton of recent paperwork: medical records, evaluations, reports... it all has to be scanned and uploaded. We have doctor’s appointments every week. We are already overwhelmed. How can I get out to get these things scanned?”

“How is that family support?”

the family support system. This pot of money could be used to pay for services not allowed under the waiver, and to support those families whose child is not eligible for Medicaid.

This year, in spite of unprecedented need driven by the pandemic, family support services are not at the top of the state’s agenda. The 2022 budget released this spring is the state’s biggest ever, with increases to public pension, school aid, offshore wind generation, and tax reductions.

People with I/DD and their families were not overlooked: The budget offers a continuation of investment in DCF CSOC, increasing provider rates by nearly \$108M since 2020. In the area of DDD, the budget includes a \$41.7M increase in provider payments to phase in a wage increase for direct support professionals, and another \$94M for residential providers. There is also \$25M more for extraordinary costs in special education. But there is no increase for family support for the roughly

14,000 children with I/DD registered with CSOC, the majority of whom live with their families.

Under the direction of the New Jersey Developmental Disabilities Council, the Regional Family Support Planning Councils will assist the Children's System of Care in the allocation of funding for these services by making recommendations based on input they receive from families.

## Pandemic Support?

With many students home from school full time, the pandemic would seem like the right time to put family support services in overdrive, but according to Kyoko Coco, statewide family support coordinator, many families are so overwhelmed, they are not even asking for help.

“Due to COVID, everyone wants after-school respite, but that service is hard to find, since after-school programs are closed. Families need so much, but in-home respite may not work either. Even if respite is approved, families may be hesitant to bring someone into the home for fear of exposure to the virus,” she said.

Susan Coll-Guedes, the Atlantic county mom with three children with I/DD, needs extra help since she was forced to leave her job in order to

care for her children, ages 7, 9, and 20.

“Just when we really need it, there is nothing,” she said. “You really cannot have a medically fragile child in a global pandemic.”

## Fighting for the Family Support Act

“The system is broken, and it feels like there is an acceptance that ‘this is just the way it is,’” Coll-Guedes said. “It feels like the system is utterly stacked against the family. I have been doing this for 20 years—Alex is 20 now—and I have not seen any change.

“But this is all I know. I get up every morning and keep trying. I guess I am optimistic. But we have to do better,” concluded Coll-Guedes.

The NJCDD's Subcommittee on Children and Youth is working on that. They are meeting monthly to explore a wide range of strategies that could help shine a light on family support, elevate the discussion, and help make sure the Act is implemented as written.

“Twenty-eight years ago, thousands of New Jersey families fought hard for this. We need to make sure that the Act is implemented and that families with children are getting the supports they need,” said Kinsell. **P&F**

## RESOURCES

### Children's System of Care, Support for Families and Caregivers:

<https://www.performcarenj.org/families/resources/support.aspx>

### New Jersey Children's System of Care, Family Support Services for eligible families with children and with I/DD:

<https://www.performcarenj.org/pdf/families/family-support-services-facts.pdf>

### PeformCare® FAQ (Nov 2018):

<https://www.performcarenj.org/pdf/families/faq-developmental-intellectual-disabilities.pdf>

### Regional Family Support Planning Councils:

<https://njcdd.org/the-regional-family-support-planning-councils/>

# NJCDD SALUTES PEOPLE & FAMILIES EDITORIAL BOARD MEMBER FOR HERO AWARD

By Jonathan Jaffe

Beverly Roberts, who serves on the editorial board of this magazine, has been named among The Arc of New Jersey's "Heroes of 2020."

The 21 award recipients were acknowledged for their service during the COVID-19 pandemic, which changed the way we live, learn, work and socialize.

In describing its award, The Arc of New Jersey wrote: "Keeping people with I/DD safe while supporting them to live a meaningful life has been an enormous challenge. But for many, it is a challenge that they have met head on with dedication, creativity, perseverance and empathy. These are the Heroes of 2020 and it is our wish to acknowledge, commend and thank them for their unwavering commitment to people with I/DD and their families."

Roberts, who serves as director of the Mainstreaming Medical Care Program at The Arc of New Jersey, was nominated by Leone Murphy, Chair, Mainstreaming Medical Care Advisory Board.

Murphy writes: "I personally have had the privilege of knowing and working with Beverly Roberts for more than 30 years. She is a tireless advocate for children and adults who have I/DD, and their families."



*Bev Roberts is one of The Arc of New Jersey's "Heroes of 2020."*

Roberts has been at the forefront of major health care issues, facilitating a team of knowledgeable, progressive and informed health care professionals to address health care disparities.

"Beverly has undauntingly tackled the most challenging health care issues," Murphy writes. "She is considered the expert on many of the complex challenges facing people with I/DD such as accessing and navigating Medicaid, state and federal healthcare regulations and dual diagnosis."

Beverly's response to the COVID-19 Pandemic is not an exception, Murphy adds, noting Roberts obtains the most accurate and timely information from the state Department of Health, major hospitals and community providers and provides this data to policy and program decision makers.

"She leaves no stone unturned in advocating for those with I/DD and their families," Murphy wrote.

The New Jersey Council on Developmental Disabilities salutes Beverly for her unwavering commitment and tireless efforts on behalf of the disability community. Congratulations on being named one of The Arc of New Jersey's 2020 Heroes. Thank you on being a hero every day for so many individuals with disabilities and their families. **P&F**

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

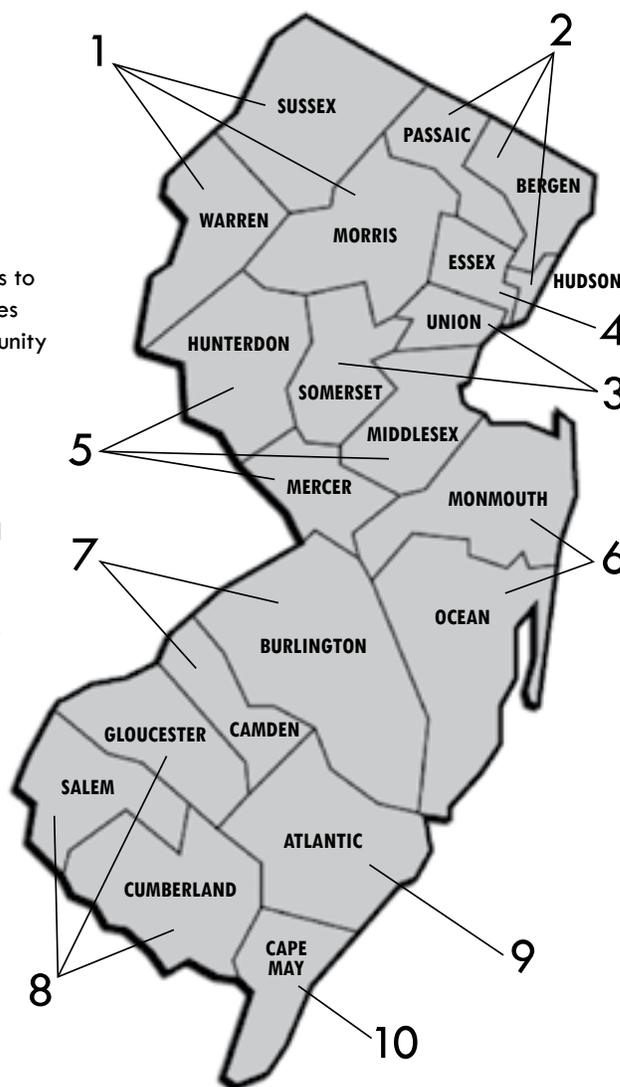
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

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:** Dorothy Blakeslee, Fel Lim

Meets the third Monday of each 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

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

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

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  
The Arc of Ocean  
815 Cedar Bridge Ave  
Lakewood, NJ 08701  
6:00 p.m.—7:30 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 second Thursday of the month  
Wegmans (Cherry Hill, NJ) 2nd Floor Cafe  
2100 RT-70W  
Cherry Hill, NJ 08002  
Even months: 7:00 p.m.—8:30 p.m.  
Odd months: 12:00p.m.-1:30p.m.

## 8 CUMBERLAND, SALEM, GLOUCESTER

**RFSPC #8**  
**e-mail:** [RFSPC8@gmail.com](mailto:RFSPC8@gmail.com)  
**Co-Chairs:** Amy Kiger, Elena Gardner  
Meets second Thursday of each month

## 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

Meets the third Thursday of the month  
except January, April, July August, and  
December  
Cape May Special Services School  
148 Crest Haven Dr.  
Cape May Court House, NJ 08223  
6:30 p.m.—8:00 p.m.

**DURING THE PUBLIC HEALTH EMERGENCY, ALL MEETINGS ARE  
HELD VIRTUALLY. If you are interested in attending, please  
contact a chair to request a meeting link.**

# ADVICE TO MY YOUNGER SELF

## Editor's Note:

*Taking care of a loved one with intellectual and developmental disabilities (I/DD) can be a rewarding and daunting experience at the same time. Sadly, family members can feel isolated and alone while navigating a bureaucratic service delivery system.*

*Family members also have a wealth of knowledge about overcoming daily challenges. Family members and an advocate offered to share their wisdom by expressing advice I would give to my younger self.*

*Hopefully, reading these passages brings comfort in knowing you are not alone.*

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Build social skills, confidence, and community connections to make friends. Learn all about your loved one's different abilities. Ask questions and seek answers to find a solution.

Darlene Reeves, family advocate

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Even if you are impatient to accomplish your goals, be persistent, be tenacious, keep your eye on the ball. Like the tortoise, slow and steady wins the race. Even when incremental progress is made, celebrate it as a victory and persevere... Your goals will be reached!

Debra L. Wentz, Ph.D.  
President and CEO

New Jersey Association of Addiction Agencies Inc.

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Do it now—do it forever. When my son was in 7th grade, I was still putting his shoes on for him every day. During 2008, I gave up touching anyone's laundry except my own and household linens. I now have 3 children who are young adults and fully responsible for their own clothes and a lot more.

It does not have to be perfect, and perfection is only measured by you. This was a hard one, but you can't measure your child against anyone else. They only need to do better than they did the last time. Even if you have to go back and touch up or correct, it is less that you have to do and more that they are doing. You should all be proud of each other at every step —proud of kids for expanding their horizons, proud of moms for giving up a little control (which is hard, so reward yourself, too!)

It does get better. We can't spend our days worrying and stressing about 'what if' or 'what will be—instead of being frustrated because of the challenges of reaching for the next rung of the ladder, build yourselves up with the foundation of the accomplishments and skills you are gathering. Stay positive, celebrate each step along the way, and enjoy the view at each level. This life as a parent

is a gift, not a competition. If you are building happy, meaningful lives, celebrate your success with each little thing—it adds up.

Jenni Clark, M.Ed., family advocate

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I would tell myself to start planning earlier. Take steps to create the adult life you want for your loved ones now, even though adulthood seems so far away.

Joan Migton, family advocate

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I am the mother of a 47-year-old woman who has Down syndrome. I would tell myself that "Everything is going to be okay. Don't worry about problems that may occur in ten or more years. Focus on the here and now. She will be fine and exceed your expectations.

Leone Murphy, family advocate

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Students with developmental and intellectual disabilities should be taught from early on to advocate for themselves in school. Their attendance to IEPs should not be reserved only for transition or exit meetings. They should be encouraged to formulate personal goals and work on plans to accomplish them.

Maria Anderson, Ed.D., family advocate

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There are blessings in every experience. You will find countless blessings in this one too!

Miwa Fiore, family advocate

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Pace yourself, because your child is going to need your energy and support for a lifetime. Research and always ask questions. Rest when you can and maintain your own health, so you will have the energy to focus on your child's needs.

Pamela Giacchi, family advocate

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As a parent and caretaker, give yourself a little time to mourn the life that you thought would be. Then dust off and move forward for your child. You have the right to mourn. But then when you move forward and figure out the new world for your child, doors open up and information becomes available because you are open to it. Listen to your own instincts, get trusted doctors, and talk to other special needs parents which are such a great resource of information.

Patricia Paton, family advocate

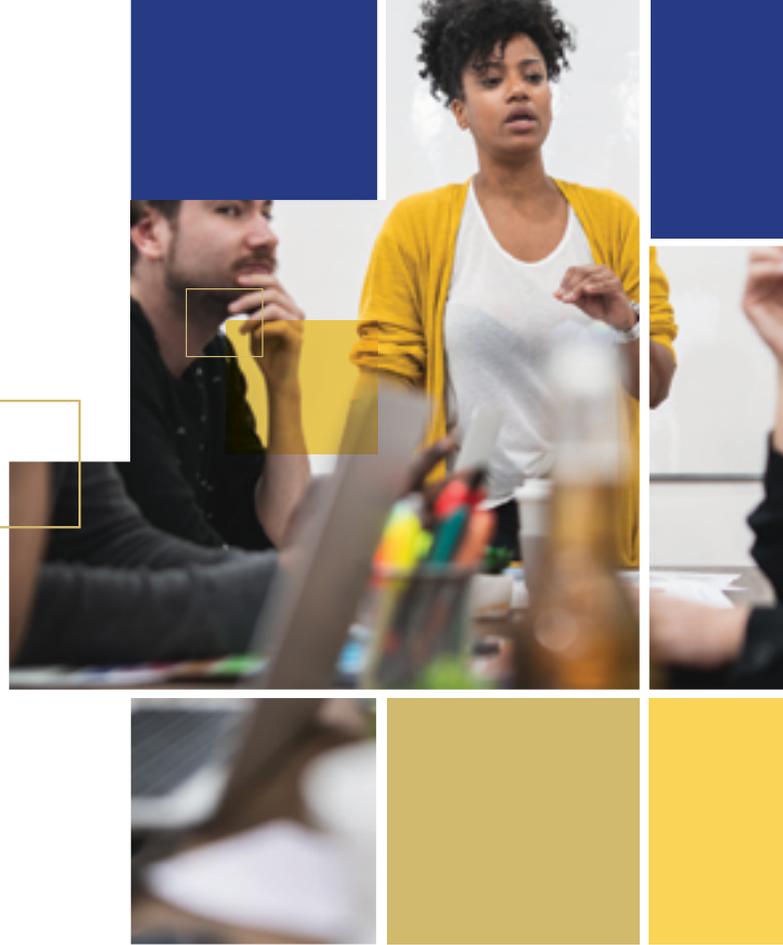
**P&F**

# COMMUNITY INNOVATION PROJECTS CIP

The New Jersey Council on  
Developmental Disabilities'

**Community Innovation Projects (CIP)**

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



## Primary Goals

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

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

## COMMUNITY INNOVATION PROJECTS REQUIREMENTS

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

## ACTIVITIES CAN INCLUDE



An innovative approach to a systemic challenge OR;



An activity that addresses a systemic problem that is being overlooked, OR;



An innovative project or pilot project related to the 5-Year plan that demonstrates a best practice.

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



*Bill Testa attending a charity walk.*