

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 2, 2021

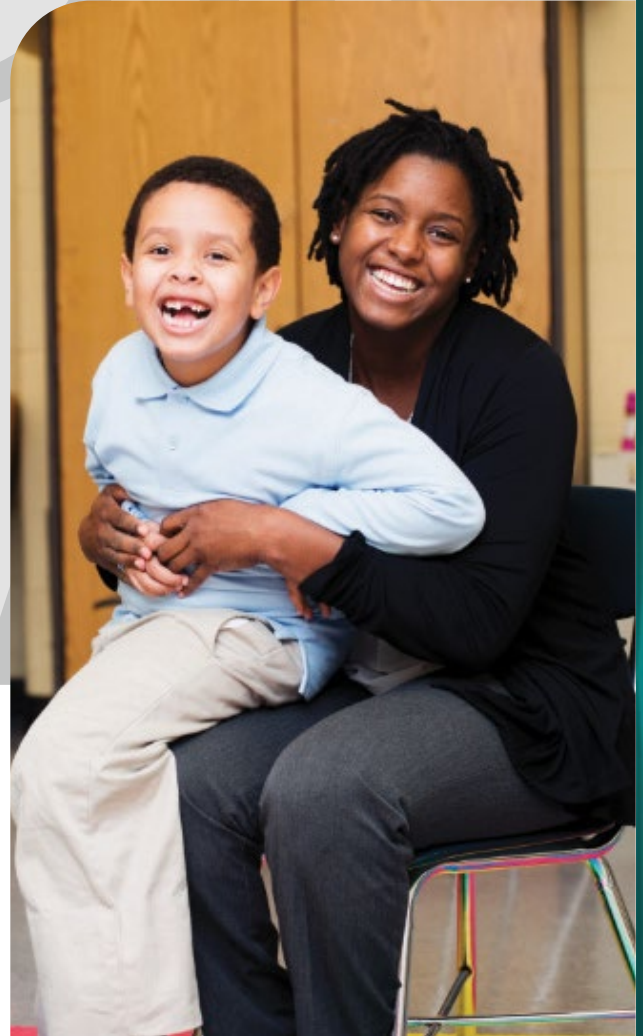


*In Loving Memory
of Rebekah Novemsky*

A Wife, Mother, & Tireless Disability Advocate

Subscribe to **ADVOCACY iN ACTION** e-newsletter

New Jersey's resource
for developmental
disabilities news
and updates



events & reports

Keep up-to-date on NJCDD's virtual programs, events, and public meetings

disability news

Stay informed on important developmental disabilities news from around the state

programs & engagement

Learn more about the NJCDD's programs for advocates and families, as well as new ways to participate



PUBLISHER New Jersey Council on Developmental Disabilities

CHAIRPERSON Paul A. Blaustein

EXECUTIVE DIRECTOR Mercedes Witowsky

EDITOR Gary L. Brown

EDITORIAL BOARD MEMBERS

Kelly Boyd, NJ Office of Emergency Management

Mike Brill, Family Advocate

Michael Brower, Esq., Disability Rights NJ

Peg Kinsell, Statewide Parent Advocacy Network

Kevin Nuñez, NJCDD Council Member

Diane Riley, Supportive Housing Association of New Jersey

Beverly Roberts, The Arc of New Jersey

Carole Tonks, Alliance Center for Independence

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Jeremy Einbinder, Jonathan Jaffe, Elizabeth Ortiz

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SELF-ADVOCATE MEMBERS

Todd Emmons, Andrew McGeady,
Myrta Rosa, Gary Rubin,
Kevin Nuñez, Ryan Roy

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

Sarah Aziz, Walter Fernandez,
Safiyah Muhammad, Tara Montague,
Paul A. Blaustein, Margaret Kinsell, Elizabeth Dalzell,
Helen Steinberg, Kara Kushner

PUBLIC MEMBER

TBD

FEDERALLY-MANDATED MEMBERS

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

Peri Nearon, Division of Disability Services
Jonathan Seifried, Division of Developmental Disabilities
Nicole Buten, Ed.D., Office of Special Education Programs
Phyllis Melendez, Division of Medical Assistance
and Health Services
Karen Carroll, Division of Vocational Rehabilitation Services
Dawn Mergen, Division of Family Health Services
Joyce Jelley, The Boggs Center on
Developmental Disabilities at Rutgers University
Gwen Orłowski, Esq., Disability Rights NJ

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

Subscriptions to *People & Families* are free and are available through the Council office or by e-mail at njcdd@njcdd.org. Please include your name and address. Articles may be reprinted without fee by permission. Expressed opinions are not necessarily those of the Council's membership. We welcome your letters and comments. Send them to Gary L. Brown, editor, NJCDD, PO Box 700, Trenton, NJ 08625-0700. Please include your name and town. Letters may be reprinted and edited for space.

New Jersey Council on Developmental Disabilities, PO Box 700, Trenton, NJ 08625-0700. TELEPHONE: 609.292.3745
TDD 609.777.3238 FAX 609.292.7114 E-MAIL njcdd@njcdd.org INTERNET www.njcdd.org

C O N T E N T S

6 LETTER FROM THE EXECUTIVE DIRECTOR

Rebekah Novemsky— Devoted Mother & Fierce Advocate for People with Disabilities



I met Rebekah in early 2013 when she was working at New Jersey Institute of Technology (NJIT) as a research support coordinator. I knew that while she found her work rewarding, that there was so much more she could do if she crossed over from the research side to the social service and family support service side.



7 NJCDD COMMITTEE REPORT

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. This issue includes a snapshot of some of the committee highlights.

COVER STORY

10 IN MEMORY OF REBEKAH NOVEMSKY

A Wife, Mother, and Tireless Disability Advocate

Rebekah Novemsky passed away from cancer on April 18 at age 55, surrounded by family and close friends. She is being remembered as a tireless advocate for her son, Liam and countless others in New Jersey with developmental disabilities.

16 MAKING UP FOR PANDEMIC LOSSES

Parents Organize to Advocate for an Extra Year of Special Education Services

A bill (S-3434 and its companion bill A-5366) was introduced to extend the age of eligibility for special education services beyond age 21. The bill allows students who would otherwise ‘age out’ for the next three years to be considered for additional services. The bill was signed on June 19 by NJ Governor Phil Murphy after swift and coordinated advocacy efforts.



22 NJ LEGISLATIVE DISABILITY CAUCUS EMPLOYMENT ROUNDTABLE

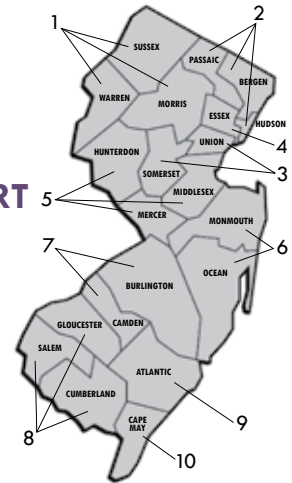
The NJ Legislative Disability Caucus held an employment roundtable discussion on April 27. Legislators, professionals and advocates discussed key issues impacting employment for people with disabilities. The Caucus serves as a bipartisan forum within the New Jersey legislature for lawmakers and their staff to consider the impact on the disability community when shaping all public policies in the Garden State.

24 FUNDING SUPPORTS IN THE COMMUNITY

Congressional Leaders Work to Rebalance Medicaid

Medicaid, the nation’s largest public health insurance plan, may get a major makeover soon. Lawmakers and advocates are looking for reforms that would rebalance the \$616 billion program to focus more funding on community-based care.

28 INFORMATION ABOUT FAMILY SUPPORT PLANNING COUNCILS



30 SPOTLIGHT ON ADVOCATES

New Jersey’s disability community is led by strong and vocal advocates who continue to push for more enriching lives for people with disabilities. This story highlights nine advocates who continue to have a positive impact on other people with disabilities.

36 NJCDD INTERNS

Realizing Their Professional Goals

Kerry McGrath and Emily Sciarrino were two recent NJCDD interns who look to continue working in the disability field. Both landed at the Council right before graduating from Seton Hall University with degrees in social work.

from the Executive Director ■

Rebekah Novemsky: Devoted Mother & Fierce Advocate for People with Disabilities

It is with heartfelt sorrow that I dedicate this issue of *People & Families* to Rebekah Novemsky.

I met Rebekah in early 2013 when she was working at New Jersey Institute of Technology (NJIT) as a research support coordinator. We met to discuss the project she was working on which involved evaluating and assessing a person's level of need and the impact that assessment would have on getting that individual the needed supports and services to live in the community.

I knew that while she found her work rewarding, that there was so much more she could do if she crossed over from the research side to the social service and family support service side.

Rebekah had already been connected on a personal level as a volunteer in Essex County's Family Support Planning Council #4 since 2002 as the loving mother of Liam who was just a few years old.

I offered Rebekah a job at a social service agency to become a family mentor because she was a mom and knew how to relate to moms like no one else could. She took on the family mentor role during the fall of 2013. We became instant colleagues, friends and supports for each other.

I knew at that moment that the world would be a better place for individuals with disabilities and their families.

As a family mentor—Rebekah really became everyone's mentor. She mentored families, she also mentored staff who had family members with disabilities. She mentored people with disabilities as they advocated for their rights and the rights of others with disabilities.

Rebekah was eventually hired as the family support liaison at the New Jersey Council on Developmental Disabilities (NJCDD) in the summer of 2018. She helped hundreds of parent



volunteers across the state organize meetings and have a voice.

She was diagnosed with stage IV colorectal cancer in August 2020. Rebekah died at her home in Maplewood, NJ surrounded by her loving family and friends, on April 18, 2021.

Rebekah leaves a powerful legacy of how one person can enrich so many lives. She was a devoted mother and fierce advocate for people with disabilities. She will be sorely missed.

This issue pays tribute to Rebekah while spotlighting disability advocates who will carry on her greatest work and many accomplishments while recognizing all the future advocacy work that will mark her presence.

Mercedes Witowsky

Mercedes Witowsky
Executive Director

New Jersey Council on Developmental Disabilities



NJCDD COMMITTEE UPDATES

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

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

Council members include 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 following are recent committee activities:

- The Executive Committee anticipates approval at the August 12, 2021 Council meeting of the amended bylaws that were introduced during the May 20, 2021 Council meeting. An orientation session may be advisable to fully prepare all Council members for implementation of the amended bylaws.
- Several people were nominated by the Governor's Office of Appointments to join the Council. Ryan Roy has completed the approval process and has been officially

appointed to the Council. Annette Smith's and Kyle Picone's nominations are in process. Michael McCarthy has been nominated by the Governor and his name has been submitted to the State Senate for confirmation.

- A suitable location has not been found for a potential November in-person Council meeting on our currently scheduled November 20 date. We anticipate a return to in-person meetings starting with our February 2022 meeting. The Committee discussed the advisability of hybrid meetings, with both in-person and remote alternatives. The potential for public remote participation was discussed to engage more members of the public in the work of the Council.
- The Biden Administration has proposed a \$10 million increase for FY2022, to be allocated among the 56 DD Councils. NJCDD anticipates a small supplemental appropriation funded by underspending of another Council.
- NJCDD received two Letters of Intent to apply for CIP grants, which will be reviewed to determine if the Council should invite full applications to be submitted.
- Following the anticipated approval of the amended bylaws the proposed Sub-Committee on Diversity, Equity and Inclusion will focus on Black, Hispanic, Asian, Native American and LGBTQ+ individuals with developmental disabilities in New Jersey.

State Plan Committee

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

- The Planning Committee worked on the 2022-2026 Five-Year Plan for a year and a half, gathering information from public comments, focus groups and in-depth conversations

with the AD Hoc Committee on Equal Access to DD Services. The information was compiled and analyzed and a plan was developed through the hard work of Considine Communication Services (CCS).

- The Plan was developed and approved by the State Plan Committee, and presented to the Executive Committee, where it was unanimously approved. The draft plan was presented to the Council and approved in May. And after consulting with designated state agencies to ensure that the State Plan is aligned with state law, we obtained the necessary and appropriate State Plan assurances.
- The next step is to get the approval of the Administration on Community Living (ACL). ACL has extended its deadline to September 30, 2021.

Grants Committee

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

- The committee continues to meet regularly to review the Council's newly approved Five-Year Plan. All Grants awarded must coincide with the aforementioned plan.
- Committee members discussed targeted activities that will begin to shape the first and second year of the new plan.

Public Policy Committee

Kara Kushnir is chair of the NJCDD Public Policy Committee. Andrew McGeady is the vice-chair of the NJCDD Public Policy Committee. The role of the Public Policy Committee is to review legislation and public policy materials made available by Council staff and other sources. After discussing these

materials, the Public Policy Committee recommends positions and follow-up actions.

- Bill S-3434 which provides an extended school year for special education students impacted by pandemic protocols was the subject of numerous meetings and advocacy efforts. It was signed by Governor Murphy on June 16, 2021, after intensive public pressure.
- Bill S-3000, the Medicaid Pediatric Care Network Adequacy Act, was approved by both legislative houses on June 30, 2021, and was awaiting the Governor's signature as of this writing.
- The Public Policy Committee continues to focus on access to services. A DDAN Summit was held with Acting DHS Commissioner, Sarah Adelman and DDD Deputy Director, Jonathan Seifried on July 9, 2021. The reports of several DDAN committees, including Employment, Housing and Medicaid/Adequacy of Funding were given. Adelman stated, "We are working towards the same goal as advocates".
- The National Association of Councils on Developmental Disabilities (NACDD) invited NJCDD to present at its August 2021 Conference on the topic of "Effecting Change". Participants hosted a discussion on the passage of the extended school year for special education students through federal pandemic recovery funding. Assemblywoman Pamela Lampitt (D); Public Policy Committee Member and NJSPAN Director Peg Kinsell; Rebecca Span of the Education Law Center Advisory Board; Subha Bolisetty, parent and advocate; and Bob Titus, parent and NJCDD staff member presented.

Subcommittee on Children and Youth

Peg Kinsell is chair of the NJCDD Subcommittee on Children and Youth. The NJCDD Subcommittee on Children and Youth (C&Y), comprised of more than a dozen parents, advocates, community leaders, educators and Council members, 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 through COVID
- Racial inequity & disproportionality in special education

Subcommittee on Health and Wellness

Elizabeth Dalzell is the chair of the Health and Wellness Subcommittee. The Health and Wellness Subcommittee advocates for individuals with developmental disabilities to have the same access to quality healthcare as their peers. Sub-committee 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 material for serving individuals with developmental disabilities.

The subcommittee meets quarterly and has been:

- Addressing oral health within the I/DD population through a completed grant with Columbia University, through two dental summits, and through a partnership in the NJAAP Inclusive Healthy Communities Grant.
- Improving medical care for individuals with I/DD through a completed grant with The Boggs Center on Developmental Disabilities, through the creation of a care management survey, and through a partnership in the Rowan Inclusive Healthy Communities Grant.
- Assessing and addressing vaccine hesitancy and increasing vaccine rates in the I/DD Community by planning a Community Innovation Memorandum of Understanding.
- Monitoring and responding to health care concerns such as health network adequacy requirements, gaps in behavioral health services for individuals with I/DD, and safety in the community. **P&F**



supportive shining
passionat

positive
heroine

generous
unique colorful

creative

awesome

giving

frie

ca

sm

fu

com

de

de

tolerant

faithful

missed

standing

mpion

ful

ing

able

com

thought

stoic

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

de

happy
sincere
unapolo

d
mom
trustin

e inspiring
ive
ited

te
voca
ment
table

joyful

selfless
fearless

creative

awesome



In Memory of Rebekah Novemsky

A Wife, Mother, and Tireless Disability Advocate

By Jonathan Jaffe

In December, Rebekah (Becky) Novemsky appeared on *NJ Spotlight News* to share the story of her son, Liam, who has cerebral palsy, and whose life was frozen because of the pandemic.

For Liam, she said, there was no more paid internship, no more therapy sessions and no more trips to the community pool.

Rebekah shared the story in the hopes the state would prioritize people with developmental disabilities when it was time for the COVID vaccination to be released to the public.

That was the last time many in the disability community saw Rebekah in the spotlight. The Maplewood mother of two passed away from cancer on April 18 at age 55, surrounded by family and close friends. She is being remembered as a tireless advocate for Liam and the countless others in New Jersey with developmental disabilities.

“Rebekah leaves a powerful legacy of the difference one person can make as she enriched so many lives,” said Mercedes Witowsky, executive director, New Jersey Council on Developmental Disabilities (NJCDD). “Patient, honest, compassionate, kind, warm, empathic, graceful, classy, generous, courageous, loving, friendly, thankful,

passionate, energetic, fearless, open-minded yet committed to a core set of values and beliefs, she had a distinct presence and never shied away from a challenge.”

Assistant Department of Human Services Commissioner Jonathan Seifried, who oversees the state Division of Developmental Disabilities, said the division remains “deeply saddened” about the untimely passing of Rebekah.

“Rebekah was a tireless advocate for individuals with intellectual and developmental disabilities and unwavering in her efforts to help others,” Seifried said. “She was a compassionate and strong person who will be greatly missed. Our condolences are with her friends and family at this difficult time.”

Following Rebekah’s years of advocacy work, NJCDD hired her in the summer of 2018 to serve as a family support liaison at the NJCDD, alongside Kyoko Coco, her trusted colleague and friend.

Rebekah helped hundreds of parent volunteers across the state organize meetings and have a voice. She jumped at opportunities, such as becoming a “Certified Charting the LifeCourse Ambassador” and ensured trainees attending the council’s “Partners in Policymaking” series had the tools they need to succeed.

She also served as staff liaison to the NJCDD Children and Youth Sub-Committee, while providing staff support to the New Jersey Developmental Disability Advocacy Network Employment Workgroup.

But her stellar work at the NJCDD only tells part of the story of a lifetime of giving to people with disabilities and their families.

Born in 1965, Rebekah grew up in Maplewood and earned a psychology degree from Douglass College in New Brunswick, which propelled her to her first job helping others. She worked at a non-profit organization in New Brunswick, working to rehabilitate people released from prison. That is where she met her future husband, Tom Orbzut, who just happened to land a job next door at another non-profit.

Eventually, they both moved to New York City, where Rebekah studied Urban Policy and Planning in the masters' program at The New School, and continued to work for non-profits. A full decade after they first met, Tom and Rebekah started dating and eventually got married, welcoming Liam in 1998.

Because Liam was born with disabilities, Rebekah stayed home for two years to care for him. Then she started volunteering for organizations that helped families dealing with disabilities and was quickly offered a full-time job. The couple had a second son, Milo, born in 2002. (Milo graduated in June from Columbia High School with plans to attend Muhlenberg College.)

Rebekah became connected to her friends the NJCDD in 2013 while working at New Jersey Institute of Technology (NJIT) in Newark as a research support coordinator.

"I knew that while she found her work rewarding, that there was so much more she could do if

she crossed over from the research side to the social service and family support service side," Witowsky said, noting Rebekah had already been connected on a personal level as a volunteer in Essex County's Family Support Planning Council #4 when Liam turned four years old.

Witowsky offered Rebekah a job at a social service agency to become a family mentor because of her strong ability to relate with parents with disabilities on a personal level. She accepted the position at Community Access Unlimited in Elizabeth the fall of 2013.

"I knew at that moment that the world would be a better place for individuals with disabilities and their families," Witowsky said. "As a family mentor, Rebekah really became everyone's mentor. She mentored families. She also mentored staff who had family members with disabilities, as well as mentored people with disabilities as they advocated for their rights and the rights of others with disabilities."

In 2015, Rebekah took on the office of Vice Chair of the Statewide New Jersey Family Support Planning Council, a volunteer position, despite a demanding full-time job and caring for her family. Serving as

a council leader took countless hours of talking on the phone and crossing the state for meetings, as she continually plotted her next strategy for advocacy.

During all of this, Rebekah was active in the Statehouse as an advocate. She testified before the Senate and Assembly Budget committees as well as the Assembly Human Services, Education and Transportation committees. She also helped form the New Jersey Family Advisory Council and the state Department of Children and Family Collaboration Committee.

And she did even more. Rebekah served for six years on the Executive Committee of the NJ Family Support Coalition and for three years on the NJ

"As a family mentor, Rebekah really became everyone's mentor. She mentored families. She also mentored staff who had family members with disabilities, as well as mentored people with disabilities as they advocated for their rights and the rights of others with disabilities."

—Mercedes Witowsky
Executive Director,
NJCDD

Association of People Supporting Employment First (NJ APSE). It is the only national organization focused exclusively on “Employment First” to facilitate full inclusion of people with disabilities in competitive employment—a goal Rebekah had for many, including Liam.

And all of this advocacy work made her ideal for her next and final chapter, working for the NJCDD.

“Rebekah will be remembered as a team builder; she appreciated everyone’s opinion and really listened to what others had to say,” said Coco, her fellow Family Support Coordinator at the NJCDD. “It was great spending time with her because she always appreciated you, encouraged you and felt she understood you, personally and professionally.

“She was my mentor. She was my sister and I really miss her,” Coco added. “Her existence was a blessing to the world; she had so much to share. Even though she is no longer with us, what she provided to us all continues to live in this world.”

Assemblywoman Mila M. Jasey (D-27th Dist.), who represents Maplewood, worked closely with Rebekah on proposed legislation regarding school safety and security drills.

“It is an issue where everyone wants what they believe is best for students, but disagreement exists as to the most effective way of accomplishing this while minimizing trauma to our students,” Jasey explained. “Unbelievably, she approached me because during a drill her son, who uses a wheelchair, was literally left in a stairwell while teachers and administrators attended to a building evacuation.

“She was understandably upset and angry, but channeled her emotions into helping me draft a

bill that would create standards to ensure that no student will be left behind in any emergency situation,” the assemblywoman added.

The bill, A-1069, “requires certain documentation of needs of students with disabilities during school security drills and emergency situations and in school security plans, and which requires staff training on the needs of students with disabilities in emergency planning.” Jasey introduced the bill in November.

“In concert with Rebekah, we have worked on amendments, and I commit to you that we will do all in our power to see it passed and signed into law,” Jasey said.

Locally, in her hometown of Maplewood, Rebekah’s passing continues to be a struggle, prompting her friends to name a garden in nearby Union Township in her name, in honor of children with special needs. They also organized a GoFundMe campaign to support Tom and the two boys.

“The passing of Becky has shocked so many in our community. Not many of us knew that she had been ill,” said Gabrielle Graziano, who launched the fundraising page. “I was not one of Becky’s closest friends but that didn’t matter. Whenever she ran into you, be it at the Tuscan playground, which hold my fondest memories of her, or in town, you felt a connection. Her generous kind heart was palpable.”

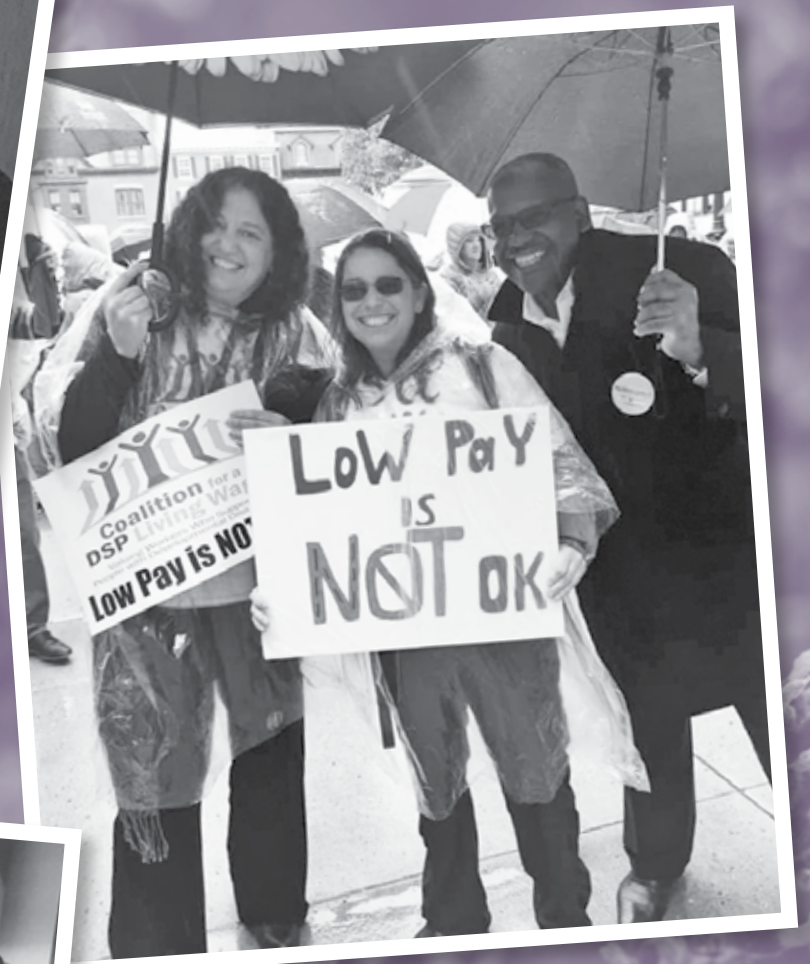
“Becky was dedicated to her family and fighting for the rights of people with disabilities,” she added. “Becky and Tom worked as a team to care for their children. With the loss of income and financial challenges ahead, the family could use as much help as possible from our loving community.” **P&F**

“Her existence was a blessing to the world; she had so much to share. Even though she is no longer with us, what she provided to us all continues to live in this world.”

—Kyoko Coco
Statewide Family Support
Coordinator

To donate to the GoFundMe campaign, go to:

<https://www.gofundme.com/f/obrzut-novemsky-family-fundraiser/donate>





Making Up for Pandemic Losses

Parents Organize to Advocate For an Extra Year of Special Education Services

By Brenda Considine

Laura Colnes had never written to a legislator before. A 7th grade language arts teacher by profession, she was certainly not a lobbyist or political player. But she was a persuasive writer with a mission: to help her 21-year-old son with autism get ready for life.

In December of 2020, inspired by the swift passage of the Bridge Bill, which allowed New Jersey high school athletes affected by the pandemic to return to school for a second senior year, Colnes started writing letters. She contacted every lawmaker she could—all 120 members of the New Jersey legislature, as well as the New Jersey Congressional delegation in Washington D.C.—to see if a similar bill could be drafted to help students with disabilities.

She made her case and asked a question: “What could be done for special education students like her son Sammy?” A student at The Bancroft School in Haddonfield, Sammy was on track to ‘age out’ of special education in June 2021 but had missed vital community-based transition services for more than a year.

“Sammy had exactly three months on a jobsite before things shut down. It was no one’s fault. It was the pandemic. But it just wasn’t enough,” she said.

While all students experienced losses and setbacks as a result of the pandemic, perhaps no group of students suffered more than the state’s oldest students with disabilities. Set to graduate by virtue of ‘aging out’ of special education in June, students who turned 21 in the 2020-2021 school year lost 18 months of direct services at a critical time. Many regressed.

The vast majority of students with disabilities graduate before they age out, but a small handful—roughly 700 students each year according to New Jersey Department of Education (NJDOE) data—remain in school until the school year in which they turn 21. Typically, students have more complex needs and are likely to need support services from the Division of Developmental Disabilities (DDD) as adults.

“Virtual learning simply could not help these students with employment skill-building, job sampling, travel training, all these really important pieces, plus connection to adult service providers,” noted Peg Kinsell, Policy Director at

SPAN Advocacy and Chairperson of the NJCDD Subcommittee on Children and Youth.

Unable to access community-based learning, most, if not all, of these students were not ready for adult life when graduation day was supposed to happen.

The Legislature Takes Action

Colnes heard back from only two legislators: The office of Senator Steve Sweeney (D-West Depford), and Senator Dawn Addiego (D-Medford). Both asked questions, but then she heard nothing more. In early February, Colnes learned that a bill had been introduced and would be heard in the Senate. She and two other moms registered for the Zoom hearing and testified in favor of the bill. It passed.

From there, the bill moved quickly through the Senate, where it passed on March 25, 2021 by a vote of 36-1.

Slow Down

Then, things seemed to stall. The bill had not been heard in the Assembly and graduation day was approaching. It would be mid-May before the bill saw movement. This time, when Colnes showed up to testify before the Assembly Education Committee, she was overwhelmed.

“There were so many parents there. I was sobbing,” she said.

Subha Bolisetty of Randolph was one of those parents. Like Colnes, Bolisetty had never gotten involved in public policy or grass roots advocacy, and had never testified before the legislature.

Driven by deep concerns about her 21-year-old son Saket’s loss of skills during COVID, she spoke with her school district early about compensatory education but was told her son would not be eligible. When she learned about the legislation from leaders at the NJCDD, she knew she wanted to get involved.



Laura Colnes with her son, Sammy

“It was a game changer for me to testify... a very teachable moment,” said Bolisetty. “After that, I started calling legislators and talking to their staff about how important this bill was. It became my homework. Every day when my son got on the bus, I got on the phone,” she recalled.

One of the bill’s most visible champions was Senate President Steve Sweeney, himself the father of a daughter with developmental disabilities. A prime sponsor of the bill in the Senate, Sweeney noted that the bill provided “a bridge to independence” and would allow students to regain the skill-based training that was stolen by COVID-19. He called the measure “a crucial lifeline” to students on the brink of aging out.

In the Assembly, 18 lawmakers joined prime sponsors Valerie Vaineri Huttle (D-Englewood), John McKeon (D-Madison), and Pamela Lampitt (D-Voorhees) in co-sponsoring the bill. In a press interview, Assemblywoman Lampitt noted “... among the most profoundly interrupted have been our students with



Subha Bolisetty of Randolph with her son, Saket

A bill (S-3434 and its companion bill A-5366) was introduced to extend the age of eligibility for special education services beyond age 21. The bill allows the individualized education program (IEP) team to make decisions about what services will be needed and for how long. The bill allows students who would otherwise ‘age out’ for the next three years to be considered for additional services.

While any student can file a claim for compensatory education for up to two years, advocates felt that

a proactive statewide policy was needed so that parents were not fighting battles alone, one at a time.

The new law, P.L.2021, c.109, requires school boards to provide the services included in an (IEP) for students who reach the age of 21 during the 2020-2021 school year, the 2021-2022 school year, and the 2022-2023 school year, provided that the IEP team, which includes the parent, decide that the student requires additional services, including transition services.

special needs. Extending classes for another year will ensure that these students receive the full education they need and deserve as they transition into adult life,” she said.

A Critical Time

The bill was heard by the Assembly Education Committee and the Assembly Appropriations Committee. And, on May 20—just weeks from most commencement ceremonies—the bill passed by a vote of 74-0.

Because of last minute amendments in the Assembly Budget Committee, however, the bill had to go back to the Senate for concurrence, delaying its passage for two more weeks. In an unusual bipartisan fashion, 38 members of New Jersey’s 120-member legislature from both sides of the aisle had, by that point, signed on as co-sponsors of the bill.

It was June 3 when the bill finally landed on the governor’s desk for his signature.

The journey to the governor’s signature was not without its twist and turns—and all at a very critical time.

“This was happening in late spring, just as schools and families were making graduation plans. It was important that students who would be eligible for the bill did not agree to accept a diploma. We needed the governor to take action quickly, and parents needed accurate information,” said Kinsell.

“I was tracking the bill and we were waiting, but it was really tough. Saket’s school was closing and the bill it was taking a long time to get signed. We did not know what to do,” recalled Bolisetty.

NJCDD’s Children and Youth Subcommittee took the lead in helping to make sure that parents and advocates had the information they needed to advocate, and were organized to let their views be known.

In late May, NJCDD organized a coalition of agencies, including SPAN Advocacy, The Arc of New Jersey, ASAH (representing parents

in private special education schools) and the Education Law Center. Together, they developed and distributed a Q&A fact sheet so families would understand the issues. Using social media and email outreach lists, they reached as many families as they could. Scores of organizations, from large statewide agencies to small parent support groups, organized, rallied, and shared information with families.

More Help Needed

Still, families needed more direct help.

“We knew we had to do more,” said Witowsky.

“The clock was ticking, and these students were on track to graduate. Families needed to know what action to take, and it couldn’t wait,” she added.

Working with leaders at The Education Law Center, and in collaboration with the New Jersey Special Education Practitioners (a group of parent-side special education lawyers), the Council, together with its coalition partners, organized two virtual town hall meetings. The goal was to help parents understand their

rights and responsibilities in a rapidly changing environment. After a short summary of the bill and its provisions, event leaders dedicated two full hours to Q&A with a panel of attorneys who donated their time. With less than a week’s notice, more than 200 parents took part in the town hall events.

Once the bill reached the Governor’s desk, the classic grassroots advocacy movement quickly shifted into high gear. For two weeks, social media was ablaze with action alerts and parent messages urging that people contact the office of the governor. Phone numbers, email addresses, and fax numbers were provided. Frustrated parents called reporters and turned to social media, as phone lines in the Governor’s office went unanswered, and voicemail boxes were full and unable to accept messages.

While all students experienced losses and setbacks as a result of the pandemic, perhaps no group of students suffered more than the state’s oldest students with disabilities.

Media coverage continued to grow as well, with nearly daily coverage in print, online, and broadcast TV about the parent advocacy effort—and the apparent delays at the office of the governor.

Even lawmakers weighed in on the need for quick action. In a press statement, Senator Dawn Addiego (D-Medford) said, “It is crucial that the governor signs this legislation sooner, rather than later. These are our most vulnerable students who will have the most difficulty recouping the knowledge and skills lost due to remote instruction. Those on the brink of aging out need to know before the end of the school year if they will be transitioning to adult programs, or if they can return for full time instruction.”

Signed

Two weeks after the bill reached his desk, on June 16, Governor Phil Murphy announced that he was signing the bill.

“At that moment, you could practically hear the collective sigh of relief from families,” said Witowsky.

“I was teaching that day, and had learned that the announcement was coming. When I got the call and told my students, they all cheered,” recalled Colnes.

Bolisetty remembers that her son was so excited by the news that he began jumping up and down.

As he made his announcement, the Governor noted that the pandemic had been especially hard on students with disabilities who rely on school programs to ensure they have the skills and services they need to be successful following graduation. In a press statement, he said:

“Many students with disabilities were unable to receive the education and related services necessary to prepare them for a successful transition into adult life and are far less prepared for the aging out process than they would be during normal times.”

—Governor Phil Murphy



Sammy Colnes exits his school bus.

The bill will not cost school districts or local tax payers anything. The services will be fully funded through the federal American Rescue Plan (ARP).

While New Jersey was first, the state is not alone in the effort to help students with disabilities. In late June, New York Governor Andrew Cuomo signed a bill to extend services to students with disabilities through age 23. In Pennsylvania, Governor Tom Wolf signed similar legislation giving students who turn 21 an extra year of special education.

After the bill was signed, the parent education effort continued. Four more Q&A sessions—including two in Spanish—were hosted in order to help parents understand the timelines and

technical issues around requesting additional services. Updated fact sheets were also developed and made available.

Special education attorneys note that there have already been legal challenges stemming from districts who are attempting to deny extended services. To date, nearly all of the administrative law judge decisions on the matter have been in favor of parents seeking extra services under the new law.

“New Jersey parents are fighters,” concluded Witowsky. “We have a long history of being leaders in shaping and influencing public policy for people with disabilities.”

“I am in awe of New Jersey’s parents for their tenacity and commitment to this effort,” continued Witowsky. “This bill would not have passed had it not been for their hard work and tireless advocacy, and for the strong, courageous leadership on the part of lawmakers. A special thank you to Rebekah Novemsky who led the advocacy charge in this effort before her untimely passing in April.”

Colnes shares that sentiment and credits the bill’s passage to ‘relentless parent advocacy’.

“At a certain point, it became really hard to ignore us,” she joked.

This summer, Sammy Colnes, Saket Bolisetty—and hundreds of other older students with disabilities—got on the bus to start an extra year of services, and begin the transition to adult life.

For Bolisetty, the experience was transformative: she has applied to take part in the NJCDD program Partners in Policymaking, a 9-month training for families and self-advocates to prepare them for system advocacy work.

For Colnes, the bill was never just about the extra year.

“It was about recognizing our children have value and worth. They can be productive members of society if they have opportunity, but they did not get the opportunity.

“Now, they will,” she said. **P&F**

Resources

Recordings of all of the Town Hall sessions, Q&A forums, and all fact sheets can be found at:

<https://www.drnj-covid.org/valuable-resources>

Families in need of advocacy assistance can contact:

SPAN Advocacy: <https://spanadvocacy.org/>
(973) 642-8100

Education Law Center:

<https://edlawcenter.org/>
973-624-1815

Disability Rights New Jersey: <https://disabilityrightsnj.org/>
609-292-9742

ASAH, Serving the Private Special Education Community:

<https://www.asah.org/>
609-890-1400

Legislative Disability Caucus Employment Roundtable

By Jonathan Jaffe

There is a concentrated push among state lawmakers and business groups throughout New Jersey to hire more people with developmental disabilities.

That was the primary message of the latest Legislative Disability Caucus Roundtable, which focused on the theme of employment and highlighted a number of proposed bills in Trenton designed to allow more people with disabilities to join the competitive work force.

“There are many issues on the minds of one in four New Jerseyans who identify themselves with a disability and I’m glad this roundtable is focused on the issue of employment,” said NJCDD Executive Director Mercedes Witowsky.

Employment became a prime topic following a 2020 federal labor report that showed 70 percent of all people with disabilities are unemployed, compared to just 29.1 percent of those who did not identify as having disabilities, she said.

While the flurry of legislation is certainly a strong step in the right direction, attendees at the bipartisan roundtable agree there are many more pressing issues that need to be addressed to ensure opportunity for those individuals with disabilities to secure work and self-sufficiency.

“For employees, this is about dignity,” said Senate President Steve Sweeney (D-3rd Dist.), whose daughter, Lauren, has a developmental disability and a job. “For employers, this is about a community of untapped resources; eager, capable workers. The jobless rate for people with disabilities remains disproportionately high. We must do more to integrate them.”

“If you look beyond the disability, you will find a person anxious to be a productive citizen,” the senate president added. “The dignity of being employed is so important.”

Sweeney reported during the April 27 roundtable a number of Senate bills have been signed into law or introduced that encourage more employment opportunities for people with disabilities. They include:

- S. 3468—(2018-19) Establishes a task force to maximize employment for people with disabilities, signed into law in January. Sweeney is now working on “seating the board,” so meetings can commence.
- S. 1937—Establishes a task force to promote employment for people with disabilities within state agencies.
- S. 994—Requires state agencies and political subdivisions to make good faith efforts to purchase 5% of goods and services from a central, nonprofit agency.
- S. 995—Requires the state Department of Labor and Workforce Development and the state Department of Human Services to conduct an assessment of community rehabilitation programs and community businesses.
- S. 3455/A.5262—Revises eligibility requirements for the NJ Workability Program and the Personal Assistance Service Program.
- S. 3689—Permits exemption from certain civil service examinations for people with disabilities.

There are also a number of bills in the state Legislature coordinated through Assemblywoman Shanique Speight (D-29th Dist.), who also serves on the legislative disability caucus. Her bills, in which she is a sponsor, include:

- A. 5294/ S. 3418—Provides fast-track hiring and advancement of employment opportunities through the state for people with significant disabilities.
- A. 5296/ S. 3426—Provides more employment in state government for people with disabilities.
- A. 5298/ S. 3425—Establishes a recruitment and referral program, as well as extends affirmative action laws in public works contracts for people with disabilities.
- A. 5299/ S. 3427—Provides for disability-owned businesses to be included in business development programs, direct loan programs and certification processes. It also requires that a Chief Diversity Officer compile information on awarding of state contracts to disability-owned businesses.
- A. 5300/S. 3417—Creates a state contract set-aside program for businesses owned and operated by people with disabilities.

One disability advocate, Steve Gruzlovic, a board member of the Progressive Center for Independent Living, underscored the need for S. 3455 / A. 5262, created to break down barriers that prevent people with disabilities from qualifying for an employment waiver.

“Even when people with disabilities find employment, they often have an extra barrier of maintaining Medicaid eligibility,” Gruzlovic told state lawmakers. “This is vital so that they can continue to receive support services that assist them with everyday life.”

Sweeney echoed those concerns, as well as Assemblywoman Holly Schepisi (R-39th Dist.), who also participated on the video conference.

“Sometimes we do well-intended things with unintended consequences,” Schepisi said, noting the push to secure full-time employment for people with disabilities is causing them to be ineligible for Medicaid services, such as housing vouchers and disability payments.

Sweeney agreed, noting his daughter, Lauren, had to scale back from full-time work because she was earning “too much” and in jeopardy of losing benefits. So, instead, Lauren is volunteering certain days of the week at her place of employment

so she remains qualified for critical government services, he said.

New Jersey’s business community also must play a more significant role in securing employment for people with developmental and intellectual disabilities, said Michele Siekerka, president & CEO, New Jersey Business and Industry Association (NJBIA).

Her association has developed a working group with other business and commerce leaders throughout New Jersey to improve the economic outlook of people with disabilities.

“All people have a place in New Jersey’s economy,” Siekerka said.

She said the working group is identifying mutual needs as a way to expand partnerships and further educate local businesses about the benefits of specialized hiring and the need for on-site coaching. These business leaders, she said, must serve as the link between people with intellectual and developmental disabilities and the job sector.

Siekerka is also calling for state tax credits for businesses that employ this population, as further encouragement to accommodate people with special needs. NJBIA is doing its part, she said, noting there is now public recognition of companies who hire people with disabilities through the association’s inclusion award.

“I want to thank Michelle for the work of the NJBIA and the effort being put forward,” Sweeney told the group. “This could easily be ‘not my problem,’ so I greatly appreciate all that is being done.”

Siekerka noted that workforce development “is at the heart of what we do,” adding that “we are looking to people with intellectual and developmental disabilities as an opportunity to build workforce needs.

“It helps all of us.” **P&F**

Editor’s Note

The New Jersey Legislative Disability Caucus is a bipartisan forum within the New Jersey Legislature for lawmakers and their staff to consider the impact on the disability community when shaping all public policies in the Garden State through increased awareness and a greater understanding of the complexities of the disabilities service system and issues affecting individuals with disabilities and their families. Go to njcdd.org/legislative-disability-caucus/ for more information.



Funding Supports in the Community

Congressional Leaders Work to Rebalance Medicaid

By Brenda Considine

Medicaid, the nation's largest public health insurance plan, may get a major makeover soon. Lawmakers and advocates are looking for reforms that would rebalance the \$616 billion program to focus more funding on community-based care.

What Is Medicaid and Why Does It Matter?

While unpaid family and friends are the backbone of home caregivers in our nation, Medicaid is, by far, the leading source of funding for support and care for millions of individuals with disabilities. Since its inception in 1965, Medicaid has provided strong financial incentives for states to provide long-term care in nursing homes and institutions.

For nearly 40 years, states have been using a federal waiver process to provide long-term services and supports in the community and in people's homes. In New Jersey, where the vast majority of individuals with intellectual and developmental disabilities (I/DD) who are receiving services live in the community, Medicaid eligibility is required in order to access support services from the Division of Developmental Disabilities (DDD).

Medicaid:

- A federally-funded national health insurance program.
- Pays for services for those with low income.
- Covers 1 in every 5 Americans.
- All Americans who meet Medicaid eligibility requirements are guaranteed coverage.

Through participation in Medicaid, states are guaranteed federal matching dollars (at least 50 percent) for qualified services provided to eligible enrollees. States administer the Medicaid

program with flexibility to decide who and what gets covered, define health care delivery models, and develop methods for paying providers. In order to use federal Medicaid funds, states must develop plans that conform to national rules, but they can apply for waivers to test and implement approaches that differ from what is required by federal statute. This flexibility fuels innovation, but it also means there is significant variation across state Medicaid programs.

The American Rescue Plan Increased Medicaid Funding

Less than two months after taking office, President Joe Biden signed the American Rescue Plan (ARP), a 1.9 trillion-dollar package to help America get back on its feet. He signed the ARP on March 11, 2021, the one-year anniversary of COVID-19 being declared a pandemic by the World Health Organization.

US Senator Bob Casey Jr., (D-PA) Chairperson of the Senate Special Committee on Aging, fought to secure nearly \$13 billion for home and community-based services (HCBS) in the ARP. The bill squeaked through the Senate, with Vice-President Kamala Harris casting the tie-breaking vote. It narrowly passed in the US House of Representatives, largely along party lines.

Section 9817 of the ARP provides enhanced federal funding for Medicaid home and community-based services and certain behavioral health services. This one-year, 10 percent increase in federal matching funds (Federal Medical Assistance Percentages- FMAP) results in new, time-limited dollars that can be invested in home health and personal care, as well as services delivered under self-directed models, case management, rehab, and private-duty nursing.

Home and Community-Based Access Act of 2021 (HCBS Access Act)

The increased attention to Medicaid opened the door for leaders in Washington to shift the program priorities. Senators Bob Casey (D-PA), Maggie Hassan (D-NH) and Sherrod Brown (D-OH) in collaboration with House Representative

Debbie Dingell (D-MI) drafted a bill that would rebalance Medicaid's approach by establishing a mandatory, fully-funded HCBS benefit in Medicaid.

"The American Rescue Package made important investments in home and community-based care. But [Congress] must do much more. We must make HCBS a mandatory benefit in Medicaid and expand Medicare to cover more at-home, long-term care services... Health care—including access to long-term care—provided to people in their homes and communities should be a right, not a privilege," said Senator Casey in a press statement.

Lawmakers, with input from community agencies and advocates, have drafted the Home and Community-Based Access Act of 2021 (HAA).

Seen by many as a step in the right direction, HAA would fund a wide range of home care supports as alternatives to institutional care. States would be incentivized to rebalance supports in favor of home care because the program would operate with 100 percent federal financing.

Before formally introducing HAA, supporters of the measure asked for community input in key areas, including provider pay and rate structures; workforce development, including wages and benefits for direct service professionals; HCBS infrastructure in states that support family caregivers and providers; and other policies and programs.

New Jersey Advocates Weigh In

In late April, the New Jersey Developmental Disability Advocacy Network (DDAN) sent written comments in response to the draft Home and Community-Based Access Act of 2021. Launched in 2017, the 29-member DDAN identifies common goals in the area of disability policy, and works toward a shared advocacy agenda in response to the political and social services landscape in New Jersey and Washington, DC.

"We believe that the HCBS Access Act has the potential to create a dramatic shift in the ways in which we provide long-term services to people with developmental disabilities," said Mercedes

Witowsky, Executive Director of the NJCDD and a member of the DDAN workgroup on Medicaid. “At the same time, we are cautious that this effort does not upend New Jersey’s Comprehensive Medicaid Waiver or interrupt services for the 26,000 individuals with IDD currently being supported.”

In their comments, DDAN emphasized several key areas of system change—assessment tools, rate setting, adequate pay for direct care professionals, staff training, and better support for individuals with challenging behaviors—that would improve the system while preserving what is now working well.

According to Valerie Sellars, CEO of the New Jersey Association of Community Providers, the DDAN paper is the product of a very inclusive process.

“We had a lot of community-based focused perspectives at the table: providers, families, self-advocates and others—we all came together with different perspectives,” she said.

She believes the most critical element of any systems change is stakeholder engagement and participation.

“It is critical that families and self-advocates are able to help shape the system. We cannot work in silos—we need to be doing this together. We need to work in collaboration with government—not just respond to policy once its developed,” she stated.

DDAN’s paper urged that Medicaid recipients and their families be included in the design of the service delivery systems, and that states be required to offer stakeholders more substantive input into the HCBS planning process. They also underscored the need to provide coordinated, culturally-competent comprehensive services and supports to “help individuals achieve their best life,” including companionship services, non-medical transportation, and chore services.

In a cautionary note around staffing, they wrote:

“It must be noted that the HCBS Access Act cannot reduce waiting lists without recognizing the dire need for a quality, fairly paid, and trained workforce.”

DDAN stressed that any changes to Medicaid must place emphasis on the ability of individuals to self-direct services, and permit maximum person-centered self-directed services, including a requirement that states allow family caregivers to be employed to provide services when this is feasible and supported by the service recipient.

DDAN believes that managed care is an ineffective model for the delivery of home and community-based services for people with I/DD. They point to long wait times, network inadequacy, lack of specialized providers, outdated rosters of participating providers, and long travel distances to access care.

Working as part of the 40-member Disability and Aging Collaborative, the National Association of Councils on Developmental Disabilities (NACDD) signed on to a 13-page letter offering input to lawmakers in key areas. Like DDAN in New Jersey, the Collaborative broadly supported HAA because it would “provide access to people with disabilities to live the lives they choose, allow older adults to age in place, and include a clear lens for equity in both service delivery and the workforce that is providing those services.” They cautioned that changes must not result in loss of services to those who currently rely on them, and that access is expanded to meet the needs of all people with disabilities and aging adults, no matter their level of support needs.

Concerns for People with Intensive Needs

While most advocacy groups are in favor of the overall direction of the Act, some have expressed opposition. In a statement to lawmakers, Voice of Reason (VOR), a national advocacy organization, expressed concern that states would have a disincentive to continue funding Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICF/IDD). In New Jersey, ICF/IDD facilities operate primarily as the state’s five developmental centers.

VOR believes that the needs of those with severe and complex disabilities are being overlooked. In a letter to its members, VOR leaders wrote:



Unpaid family and friends are the backbone of home caregivers in our nation.

“(States) would simply close their ICFs and transfer the residents to HCBS settings. The problem with that approach is that the ICFs provide almost exclusively for those with the most severe and profound levels of intellectual disability and coexisting medical and behavioral challenges.”

The National Council on Severe Autism (NCSA) shares that view. While the group fully supports efforts to eliminate Medicaid waitlists and improve caregiver quality and pay, they too expressed concern that the Act could “dramatically restrict options for those with severe disabilities, particularly the severe cognitive and behavioral disabilities seen in severe autism.”

Lisa Parles, Esq., a New Jersey attorney whose practice focuses on disability issues, often handles legal cases for clients with complex needs. She is also the parent of a man with severe autism. Like others, she supports federal efforts to improve care and eliminate waiting lists, but is concerned about unintended outcomes.

“With any initiative, you have to look at all of the possible outcomes,” she warned. “We still have not moved beyond the old discussion that ‘large facilities are bad, and small facilities are good.’ There just are not data to support that idea.”

“If ICFs are not eligible for full federal funding, there are incentives for states to eliminate them. The Olmsted decision did not mandate the elimination of ICFs. It was about giving people choices,” she said.

“Too often the focus is only on the size of where someone lives, as if size or location ensures quality. If measurable outcomes and choice were paramount, think more of us in the disability community would actually agree,” she concluded.

Sellars understands the concerns but believes the answer lies in reforms and reallocation of resources.

“I am not suggesting we close our developmental centers. Not at all. What I am suggesting is that we look at resource allocation. I would never want to take that choice away, but how do you rationalize \$112M going to 1,100 people at five developmental centers,” she stated.

I think we need to look at consolidation and how some of those resources could be used to help more people, particularly those with co-occurring mental health issues and behavior challenges.

“It begins with conversations and planning. And we need to get all of the stakeholders talking.

We cannot see each other as enemies. We are in this together,” she concluded. **P&F**

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

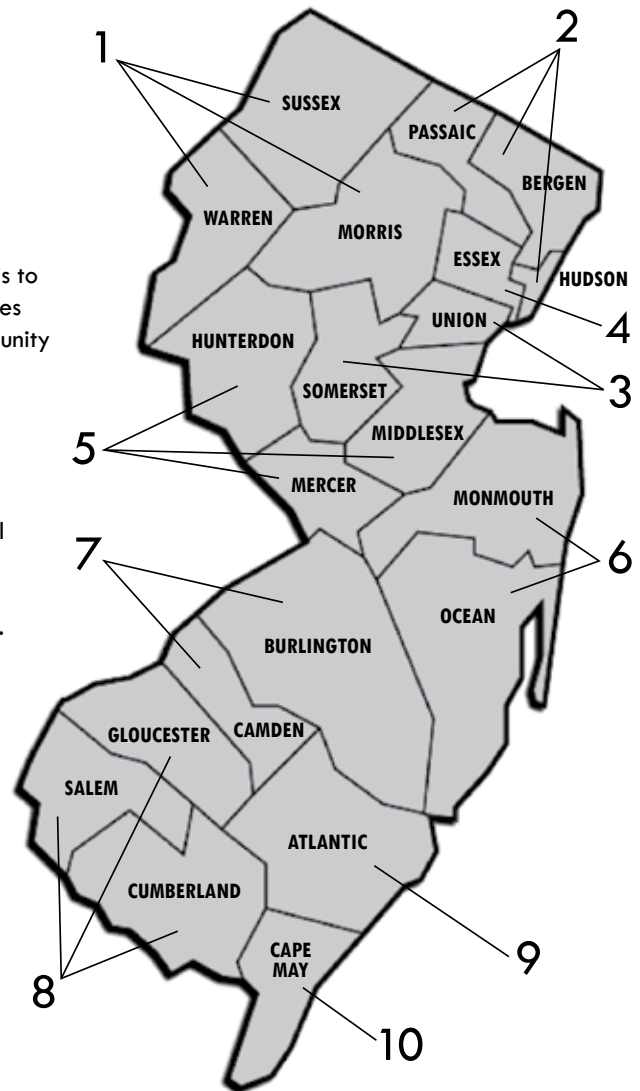
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

Or visit our website at www.njcdd.org and follow the link to Family Support & Facebook page at www.facebook.com/NJFSPC.

THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with developmental disabilities.

Visit the NJ Council on Developmental Disabilities' web site at: www.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
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
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
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.Essex@gmail.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
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
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
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
Co-Chairs: Amy Kiger, Elena Gardner
Meets second Thursday of each month

9 ATLANTIC

RFSPC #9
e-mail: 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
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.

SPOTLIGHT ON ADVOCATES

By Jeremy Einbinder & Elizabeth Ortiz

When one speaks of advocacy, they speak of representing one or more, people or groups on issues of injustice in one form another. To advocate is to publicly support or suggest an idea, development, or way of doing something.

New Jersey's disability community is led by strong and vocal advocates who continue to push for more enriching lives for people with disabilities. In this story, two groups of advocates are highlighted.

The first group—Bill Byrnes, Javier Robles and Norman have been advocating for decades in their respective areas.

The second group of advocates are members of the New Jersey Council on Developmental Disabilities. They participate in a variety of key Council-related activities including advocacy, policy development and grant funding.

Bill Byrnes works in the Delbarton School cafeteria. He inherited a rare metabolic disorder at a very young age.

He got a taste for advocacy at an early age when was a poster child for the Arc of Massachusetts. He says he's been advocating every since.

“My parents advocated for me when I was young and wasn't in a position to do it for myself,” Byrnes said in a previous article. “Now it's my turn to advocate for others that aren't in a position to.”



▲ Bill Byrnes, holding a newspaper article announcing his election to a Morristown Leveling Rent Board Member post.

He is passionate about advocating. He feels if he doesn't speak up, the disability population will lose their rights and services that they should be entitled to.

Byrnes is a frequent speaker at the Morristown council meetings. He lobbied hard for the passing of a state law changing how officials refer to people with behavioral health challenges.

He feels younger advocates should educate parents about the challenges people with disabilities face. He also feels that youth should learn how to advocate so they encourage others exercise their individual rights.

"I've been an advocate all of my life," Byrnes said, matter-of-factly.

Javier Robles sustained a life-altering spinal cord injury at the age of 16 as a result of a fall from a tree. This devastating injury propelled him toward a life of advocacy.

Robles is a Hispanic male who is a parent, an advocate and a professor. He describes himself as patient and one who knows his limits. Especially when it comes to how long he can wait to see things progress, as these changes are controlled by people. He says that time is too short.

Robles has been an advocate since his injury, his first challenge to his independence occurred one spring day, when he left his high school in Elizabeth, and decided to ride home in his wheelchair instead of taking the bus. By doing this Javier realized how inaccessible his town was for someone in a wheelchair.

He rode in the street for most of the ride home, because of the lack of curb cuts. He went to a council meeting in his home town of Elizabeth, New Jersey to advocate for increased accessibility throughout the town. He has been advocating ever since.

He strongly believes that he along with others advocate out of necessity, because they feel they have no choice, in order to make positive changes. Robles along with other advocates look forward to the day when they no longer have to fight for the simplest things, like curb cuts, and public accessibility. He refuses to sit back while society neglects and discriminates against people with disabilities.

"Until individuals with disability are just as equal as the rest of society there is a job to be



▲ *Javier Robles has been an advocate since suffering a life-altering spinal cord injury at the age of 16.*

done," said Robles. "Regardless of whether you're young or older this is a fight that we should be doing together, regardless of age or disability."

Robles feels that young people with disabilities should take the initiative. "All it takes is the will and desire to want to see change and make change, because they will be the new advocates of tomorrow."

Norman Smith is an advocate, a journalist, a husband and a father. He also has cerebral palsy.

He has been an advocate all his life—fighting for independence for 68 years.

"I'm passionate about advocacy, because I feel that if there is a wrong, I want to make it right," said Smith. "If there is a problem, I want to solve it. People should be treated equally. This is what drives me to advocate."

After graduating from Long Island University, Smith returned home to live with his parents. "I soon realized that my desire to be employed and to be an active advocate in the community for people with disabilities was a burden to my parents who were in their mid-60s."

Soon after returning home, he started looking for place to live, but it was very difficult to find an accommodating place where he can get the



▲ Norman Smith, Executive Director, Statewide Cils, Disability Action Committee in his Robinsville, NJ office

services he needed on a daily basis while maintaining his independence. The search became very frustrating while he watched his father's health decline.

So, he co-founded Project Freedom 37 years ago. Project Freedom is a 501(c)(3) non-profit organization that develops and operates barrier-free housing to enable individuals with disabilities to live independently. Project Freedom also provides supportive services including recreation, training and advocacy.

Smith feels younger advocates should communicate with facts and personal stories. He also feels that you should not expect people to understand your views. First, they must learn to make a connection—they must see the person first. One should know the system, have patience and not to be discouraged by setbacks.

According to Smith, "Failure is the next step to success."

NJCDD Advocates

Several NJCDD advocates deserve recognition, ranging in experience and background, all with the common goal of making life better for people with disabilities. Myrta Rosa, Todd Emmons, Andrew McGeady, Ryan Roy, Kevin Nuñez, and Gary Rubin are featured below.

Myrta Rosa

For Myrta Rosa, who has cerebral palsy, it is extremely important to be a representative voice. Rosa, 65, has lived in multiple places, but settled in Woodbridge Developmental Center 11 years ago, right around the time she became a Council member.

She considers her job to be speaking to people with problems and trying to accomplish "stuff that we never did before," in a general sense.

More specifically, she spends her time as an advocate making sure spaces are available for wheelchairs. Rosa tries to make it easier for people to move around as best as they can.

"I like to speak for people who cannot speak for themselves. They have a right to live like everybody else. I want them to be heard like I am. I like to speak about people with disabilities being respected like everybody else," she said.

Rosa makes a point that people with disabilities still have to make the best of their life as they can, despite their difficulties. They have to find a way of living like everybody else. She thinks that the Council does a great job of ensuring that.

"It makes me feel good that I'm helping others that cannot help themselves," she said.



▲ Myrta Rosa is an advocate and a member of the New Jersey Council on Developmental Disabilities.



▲ *Todd Emmons at his apartment in Voorhees, NJ*

Todd Emmons

Along the same lines, Todd Emmons also relishes in helping others who cannot help themselves, saying that he is “not only doing for myself, but doing it for 40 or 50 other people where I live.” Emmons also considers this a lifelong project.

“I’ve been an advocate all my life,” he said, “63 years.”

One of his roles on the Council is to listen during meetings. “I’m there for everybody, helping them with the meeting,” he said. “Whether something is good or not so good.” Emmons respects the mutual nature of the Council, which is made up of people with disabilities including himself. Sometimes he’s there to help people. He is also they are there to help himself.

“It’s an amazing feeling to be on a team that recognizes us as people, not for our disability. I feel thankful for that.” he added.

As far as younger advocates Emmons cautioned that they need to be more independent and be ready to stand up for themselves.

Andrew McGeady

Andrew McGeady serves as vice chair of the NJCDD Public Policy Committee, and he has been a Council member since 2009. McGeady, 34, has been an advocate since he was a teenager. His role as a Council member is to help establish and change policy for the advancement of people with disabilities to continue to live active and independent lives.

McGeady says that he is passionate about advocating because, “I know I am helping to make positive changes that impact and enhance not only the quality of my life, but the lives of people with disabilities and their families.”

He says that advocacy has been an effective tactic for other groups, and he believes it will prove to be as effective for the disability community. For younger advocates, his advice is simply for them to continue advocating for themselves.

“I and the Council,” he said “continue to advocate for the need for support and options for individuals to live independently and receive the proper support in order to do so,” said McGeady “I would also encourage people to find ways to advocate for themselves.”



▲ *Andrew McGeady at his home in Jackson, NJ*



▲ *Ryan Roy with his wife, Geethu Sebastian and his son Milo*

Ryan Roy

Ryan Roy is a 32-year-old advocate who has Pervasive Developmental Disability, not otherwise specified (PDD-NOS), a disability which manifests itself like autism.

Roy has been an advocate since he was 12 years old and prides himself on his wide-reaching impact, especially for people with autism.

“I’m an autism advocate for the people with disabilities, especially within the autism spectrum disorder in every county, and beyond the Garden State,” said Roy.

He coined the term “fabric importance,” which refers to formative years in the life of a person with a disability in which he feels advocacy is sorely needed. Above all, he prides himself on making a difference in people’s lives and emphasizes the importance of inclusivity in which people of all abilities live together in the broader community.

His advice for younger advocates echoes the words of rapper Eminem, asking, “if you had one shot, just one opportunity to seize everything you ever wanted, would you capture it, or just let it slip?” He then concludes that it is the responsibility of people with disabilities to be more aspirational in their lives.

Kevin Nuñez

After being recruited to join the Council while participating in Partners in Policymaking, Kevin Nuñez has worked with the Council for 15 years.

He officially joining the Council in 2016. Nuñez has always considered himself a bit of an outsider, finding himself commonly in “disability limbo,” in which he struggles to be part of the “mainstream” world as well as the disabled world. But that doesn’t stop him from speaking up, and encouraging other to do the same. He pointedly reminds advocates that there’s no degree for what they do, and it is something you figure out as you go along.

“The most important part of being an advocate for me is knowing that you’re speaking for others who can’t speak for themselves.” And he speaks through multiple outlets. He also encourages other advocates to speak up. Nuñez works with the local mayors’ office and with the scouts. He also writes his own blog. On the Council, he is particularly proud of helping with the last two five-year plans. Nuñez also chairs the Grants Committee.

“One of the biggest things we’ve done, he explained, we’ve really made the most of our grants



▶ *Kevin Nuñez at his home in Willingboro, NJ*

committee,” he said. “We finally were able to raise it to a higher standard, that can be respected by families, advocates, and stakeholders.” He emphasizes that it is vital that the Council has tangible programs that make a difference in people’s lives.

Gary Rubin

Gary Rubin has fond memories of working at his father’s scuba diving shop in East Hanover, NJ, where he spent his summers.

He moved out of his parent’s home when he was 15 years old. Rubin lived in a few different congregate care settings including the Woods School, E.R. Johnstone Training & Research Center, and North Princeton Developmental Center.

Living in these large congregate settings left a bad taste in Rubin’s mouth. Saying, “I’m an advocate because I took way too much bullcrap when I lived in the DCs (developmental centers).”

Rubin is a Council member. He also works part-time as a security guard. His advocacy began in New Jersey but reaches more broadly in his national role as a board member with Self



▲ Gary Rubin, at his security job at CAU in Elizabeth, NJ

Advocates Becoming Empowered (SABE).

“I just don’t like to see others go through what I went through,” said Rubin. “I want to see other P&F have a good life and not be judged by others.”



Common Ground Online
Increasing Dialog Among Stakeholders in
New Jersey’s Special Education System



The NJCDD’s publication for educators, parents, and other special education professionals and policy makers is available online!

- Read about current issues in special education
- Get updates on legal and legislative developments
- Find important resources and information

Visit
www.NJCommonGround.org
to sign-up for a free online subscription!

NJCDD Interns

Realizing Their Professional Goals

By Jeremy Einbinder

Kerry McGrath and Emily Sciarrino were two recent NJCDD interns who look to continue working in the disability field. Both landed at the Council right before graduating from Seton Hall University with degrees in social work.

McGrath is continuing her education at Rutgers University and pursuing a master's in social work, while Sciarrino is also continuing hers at Rutgers and pursuing a master's in applied behavior Analysis (ABA), a common treatment for people on the autistic spectrum.

McGrath and Sciarrino do not have disabilities themselves, but were both inspired by other people in their lives to pursue roles in the field of disabilities and to recognize the potential that people with disabilities have when given adequate opportunity.



Kerry McGrath at home in Carteret, NJ in front of family photo of her sisters, top right-Eileen, top left Lorraine, and bottom left Kathleen

For McGrath, her inspiration was her sister, who has Down syndrome. McGrath says that her sister regularly exceeded expectations despite her struggles.

“We kind of grew up close in age so while I was going through the school system, she was also going through it. But outside of that I saw the struggles that she saw in daily life from, you know, the sideways looks people would give; the

people underestimating what she could do," McGrath recalled.

Her sister was told on a regular basis that she wasn't smart enough to be in a particular class, or that she wasn't fast enough to be on a sports team. "Nevertheless, she persisted," McGrath said, "And constantly showed people that she can...do whatever she wants to."

McGrath's supervisor, Kyoto Coco, lauded her ability to work with the New Jersey Comprehensive Assessment Tool (NJCAT) which is used to help assess the support needs of individuals.

"Kerry analyzed both qualitative and quantitative data from over 1,000 respondents," Coco said. "She spent countless hours reading thousands of comments, categorized them, and presented findings in a way that the DDAN members can easily understand."

McGrath's report has since been submitted to the DHS acting commissioner and assistant commissioner. She also engaged in various legislative and public policy projects and she worked with Bob Titus, public policy coordinator, and assisted him to prepare for the quarterly New Jersey Legislative Disability Caucus.

Sciarrino, who has over three years of experience as a direct support professional (DSP), and first discovered her passion for disability advocacy while volunteering with the Special Olympics, says that her time at the Council, "really just opened my eyes to all of the different opportunities out there." She also learned more about what ABA therapy is and how it is closely related to social work.

According to Sciarrino's supervisor, Frank Latham, "Emily was a great intern for the Council based on her education, work and lived experience, all of which were helpful as she interacted with our advocates."

Latham said that Sciarrino had the opportunity to present to both the Council's People First groups and Youth Leadership students on the importance of advocacy and how it can be empowering.



SEVA

Special Education
Volunteer Advocates

www.spanadvocacy.org/SEVA

Supporting & Empowering Parents on their Advocacy Journey

WHY SEVA?

- ✓ Need support at your IEP meeting?
- ✓ Want to improve your advocacy skills?
- ✓ Have a student in need of transition to adult life services?
- ✓ Seeking a more inclusive setting for your child?



SEVA Provides

- ✓ Trained volunteers to support families at IEP and related meetings.
- ✓ Coaching to assist families in developing their advocacy skills.
- ✓ Information & resources for families.



Contact Jeannette to learn more:

jmeijas@spanadvocacy.org



Latham continued, “Emily was able to share some of her work, educational and personal experiences during presentation for the students and self-advocates. Emily has a great future in our field because she is knowledgeable, compassionate, well prepared and always willing to learn.”

To that end, Sciarrino found her time at the Council to be extremely valuable, saying, “I think probably the most valuable thing is when you're working with individuals with intellectual and developmental disabilities, you know, it's important to see these individuals for their abilities and not their disabilities, I feel like, you know just throughout my time as a DSP and through school, a lot of people just tend to label these individuals, because of their disabilities and I don't like to view them like that.” She feels like she can use her experience as a DSP to be a better therapist.

Both McGrath and Sciarrino feel like their time at the Council further solidified their passion for disability advocacy.

Sciarrino says that her experience in the disability advocacy field taught her to “put the person first and not their disability first.” She continued, I think that's something really important that I value, and that I want to continue to value throughout my career and throughout my graduate program.”

For McGrath, the focus became the importance of public policy on broader society. She explains, “I realized how much change I could make, and I realized how much of a positive influence I could have and that just definitely solidified that, one, I was in the right field, working with people with disabilities, and two, that working on a more macro scale, and working in more policy and governmental work was right up my alley.”



Emily Sciarrino graduated from Seton Hall University with a degree in social work.

It is important to realize that in a field as broad as disability advocacy, the micro and macro levels of work do not contradict each other, but rather support and reinforce each other. With Sciarrino firmly on the path of ABA therapy and direct support, and McGrath most suited for policymaking, their time at the Council seems to have helped them in their career journeys. **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.

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.

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

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



Rebekah Novemsky with her son, Liam