

People & Families

NEW JERSEY COUNCIL ON
DEVELOPMENTAL DISABILITIES

VOLUME 1, 2024

MANEUVERING THROUGH THE BARRIERS



*Susan Coll-Guedes and her son Alex at Children's Hospital of Philadelphia.
Alex was in the hospital for nearly 300 days.*

COMMUNITY INNOVATION PROJECTS CIP

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local change.



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- ☒ Create and strengthen relationships with local associations and groups.
- ☒ Position people with developmental disabilities and/or their family members as active and engaged participants who influence the work and participate directly.
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The purpose of the Developmental Disabilities Councils, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building, and systemic change that contribute to a coordinated, consumer and family-centered, consumer and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

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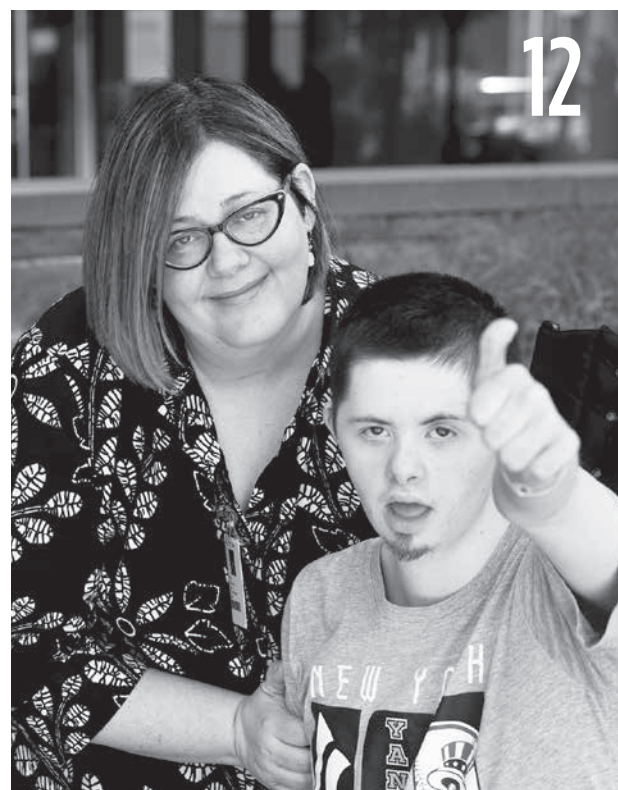


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Beverly Roberts' name is synonymous with advocacy and access to quality health care. This summer, "Bev," 73, passed away suddenly and unexpectedly. She had committed her entire career to advocating for people with developmental disabilities.



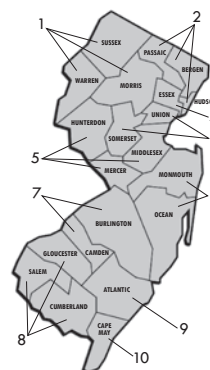
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There has been a shift in the entertainment industry towards inclusivity and diversity, and people with disabilities are finding representation. Long marginalized and underrepresented, individuals with disabilities are now carving out meaningful careers in film, theater, and television, enriching the storytelling landscape with their perspectives and talents.



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Advocate for Independence

Gary Rubin, 58, was bravely outspoken about the need to close institutions and the vital importance of treating all people with respect and dignity. An active member of the New Jersey Council on Developmental Disabilities for nearly 15 years, Gary died in late June 2023 following a short illness.



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A Valuable Tool for Emergency Managers

Register Ready is a free statewide service that allows New Jersey residents with disabilities, as well as their families, friends, and associates, an opportunity to provide information to emergency response agencies, as part of their 24/7 response. It can be a vital, life-saving resource for people with disabilities that makes it more likely people will receive needed assistance during an emergency.

from the Executive Director ■

A Tribute to Those We Lost

It is with heartfelt sorrow that we dedicate this issue of *People and Families Magazine* to three New Jersey advocates we lost last summer.

Gary Rubin was active member of the New Jersey Council on Developmental Disabilities for nearly 15 years. He died in late June 2023 following a short illness. Beverly Roberts passed away suddenly on August 25, 2023. She had committed her entire career to advocating for people with developmental disabilities. In July, we also lost Norman Reim, a former staff person at the Council who served as editor of this magazine for nearly 20 years.



Gary was a longtime member at Community Access Unlimited (CAU) in Elizabeth, NJ, where he worked and lived with support in a range of progressively independent housing situations—most recently, he moved into his own condo. Gary was a respected member of his community, a leader at the local, state, and national level, and a well-known advocate for the civil rights of people with I/DD.

I'll always remember Gary as a dedicated outspoken advocate. Gary used his life experience to advocate for what he wanted and Gary always tried to help others advocate to live their best life. Gary wasn't afraid to speak up and speak out and always used his voice to help make the world better for people with disabilities.

Bev began her work in the field in 1989 when she became the Director of The Arc of New Jersey's Mainstreaming Medical Care Program. For the next three decades, she handled the statewide non-profit's health care advocacy, promoting quality medical, mental health, and dental care for people with I/DD.

Bev was the consummate professional, who positively impacted the lives of countless people.

Norman was a strong advocate for people with disabilities and worked at the NJCDD as the Director of Communications. He served as the second editor of this magazine for many years and helped to plan advocacy changing the landscape of disability services in New Jersey.

Losing staunch advocates so close together is so hard for so many. Where we find some level of peace is in remembering to ask ourselves—*What would Gary say or do? What would Bev say or do? What would Norman say or do?* We will all benefit by asking those questions to guide and shape our further advocacy efforts.

This issue pays tribute to those we lost, while spotlighting issues and leaders of today. We explore the need for meaningful representation of people with disabilities in the entertainment industry, maneuvering through barriers in accessing needed services and supports, and Register Ready, a valuable tool for emergency managers.

Wishing you all well until our next issue of *People and Families Magazine*!

Warm Regards.

Mercedes Witowsky

Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities



NJCDD COMMITTEE UPDATES

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

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

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

The Council conducts four public meetings each year. The Council's Executive Committee meets throughout the year to handle matters concerning the Council when it is not possible for the full Council to meet and monitors the Council's Standing and Ad Hoc Committees.

The Council's standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee. Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy Committee. The Diversity Equity and Inclusion (DEI) Sub-Committee meets under the State Plan Committee and the Advocate Advisory Sub-Committee meets under the Executive Committee. The following is a snapshot of some of the committee highlights.

Executive Committee

Paul Blaustein serves as chair of the NJCDD Executive Committee. The Committee acts on behalf of the 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 of the Council's committees.

The following are recent Executive Committee activities:

- The Executive Director reviewed the agenda for the next Council meeting on November 2, 2023. The meeting will take place in the Hilton Garden Inn in Hamilton. We ask all

Council members to attend in person, with exceptions for special circumstances. Members of the public are invited to attend in person or virtually. For virtual attendees, captions will be available for several languages.

- The Exec Comm reviewed the collaborative efforts of NJCDD, the Statewide Family Support Planning Council, and DDD to expand individual and family participation in the Community of Practice program, to encourage utilization of self-directed services, and bring families together to share experiences accessing community supports and services.
- The Acute Stabilization beds on the grounds of the New Lisbon Developmental Center are becoming available gradually, due to the need to attract and train qualified staff. The Exec Comm was pleased that only one individual, at their request, was transferred to the Developmental Center. The other individuals all returned to their homes or were transitioned to other homes in the community, after their treatment was completed.
- Several candidates for NJCDD membership are in process at the Governor's Office of Appointments. We are hopeful for positive action during the "lame duck" legislative session following the November election.
- We continue to be disappointed in the quality of the Letters of Intent received for the Council's Community Innovation Project grant program. NJCDD is seeking truly innovative ideas that are readily replicable throughout the state.

State Plan Committee

Helen Steinberg is chair of the NJCDD State Plan Committee. The role of the State Plan Committee is to manage federal requirements related to the development and implementation of the Council's Five-Year Plan.

- The Planning Committee worked on the 2022-2026 Five-Year Plan for a year and a half, gathering information from public comments, focus groups, and in-depth conversations with the Ad Hoc Committee on Equal Access to DD Services. ACL notified the Council on

September 30, 2022 that the 2022-2026 Five-Year Plan was approved for full implementation.

- The plan contains three broad goals in the areas of advocacy, capacity-building, and system change. The plan can be found at: <https://njcdd.org/njcdd-5-year-planning-2022-2026/>
- The Administration for Community Living (ACL) issued approval of the Council's Program Performance Reports for fiscal year FY2022.
- NJCDD will begin completion of the FY2023 Program Performance Report due by the end of this year.
- The Administration for Community Living approved NJCDD's FY2024 and FY2025 Annual Work Plans.

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, based on grantee performance.

The following are recent committee activities:

- The Grants Committee continues to review the four current grants awarded in Years 1 and 2 of the NJCDD Five-Year Plan. Year 2 contracts were awarded to three of the current grantees (Community Options, LeDerick Horne Speaks and The Arc of NJ) and a six-month extension was granted to the contract with LeDerick Horne Speaks so they can finish out the school year with the current schools. Each Grantee is asked to present the status of their grant activity before public meetings of the Council.
- The Grants Committee continues to make direct systems change to improve the lives of our vulnerable constituency by awarding contracts that meet the goals and objectives of our Five-Year Plan. For a listing of current grants, please visit the NJCDD website.

Public Policy Committee

Nantanea Koppstein 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.

- The tragic passing of a special education student on a school bus recently has evolved into a statewide call for review and revision of school transportation safety practices. The Public Policy Committee in coordination with the Regional Support Planning Family Council is actively involved in this effort.
- Governor Murphy signed legislation, P.L.2023, c.212 (A1174/S2057) that strengthens school-based emergency planning for students with disabilities. The law requires that students fully participate in safety/security drills; school staff receive annual training; and a student's records list any individualized accommodations the student needs. The legislation was prompted by NJCDD's 2019 Summit on School Safety.
- Assembly Majority Leader and Disability Caucus Co-Chair Louis Greenwald was honored for Exceptional Legislator at the September 28th Community Building Awards. For almost twenty years, Assemblyman Greenwald has been an ardent advocate for disability rights and services.

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, state leaders, educators, and Council members. It focuses on issues that affect those under the age of 21 and their families. The subcommittee is addressing:

- Support/advocacy needs of children and their families through COVID, including compensatory education.

- Access to Family Support Services through the Department of Children and Families, Children's System of Care.
- Seclusion and restraint, including racial, ethnic, and gender disparities which affect access and outcomes in special education.
- School safety.
- Helping to ensure positive outcomes and high expectations for students with I/DD.
- Ensuring that youth with disabilities are included in the State's plans to address the needs of youth who have Adverse Childhood Experiences (ACEs).
- School based mental health services.
- Students on home-bound instruction and those send home pending psychiatric review.

Subcommittee on Health and Wellness

Elizabeth Dalzell is the chair of the Health and Wellness Subcommittee. The Health and Wellness Subcommittee advises the Council on health and wellness matters that impact individuals with I/DD and their families, advises the Council on health and wellness legislation and policies impacting individuals with I/DD, and conducts activities that align with, and fulfill the goals and objectives of, the Council's state plan.

The most recent subcommittee meeting was held on October 17, 2023. Subcommittee members have been briefed on the work of the DEI subcommittee and the Hospital/Medical Setting Navigator Program as well as the Medical Resident Trainings conducted by the Boggs Center. The H&W Subcommittee will be collaborating with the DEI Subcommittee on this important project that focuses on improving hospital/health care experiences for people with disabilities.

In addition, H&W continues to focus on:

- Minority Access to Healthcare
- Medicaid Unwinding
- The continuation and expansion of Telehealth services
- Comprehensive Healthcare
- Dual Diagnosis of Mental Health and I/DD
- NJ S3000 Legislation implementation

Diversity, Equity, and Inclusion Subcommittee

The Diversity, Equity, and Inclusion (DEI) Subcommittee was established within the bylaws of the Council and in alignment with the goals of the 2022-2026 Five-Year State Plan. The important work of ensuring that there is diverse representation within the Council and its members, equity in practices, policies, messaging, communication and interactions with people, awareness of environmental impact on family and communities served, as well as openness and accessibility to information and all services provided by the Council is present throughout the planned goals and objectives.

Sarah Aziz is the chair and Annette Smith is co-chair for the DEI subcommittee. The DEI subcommittee is comprised of NJCDD Council members, members of the I/DD community and their family members, advocates/self-advocates, and state agency representatives.

The following are recent subcommittee activities:

- The most recent meeting was held on October 5, 2023. Members discussed the school bus safety initiative and related transportation issues.
- Work Group 1 is working to identify additional counties to continue the work of the Passaic Department of Human Services and William Paterson University. Additional counties are needed to survey I/DD individuals and families to ensure that residents receive needed county-based services.
- Work Group 2's most recent data collection tool, created by member Nelly Schoeman, containing online research as well as personal outreach with hospitals and urgent care centers, will be used to assist in the identification and troubleshooting of this system. Work Group 2 will partner on this initiative to assist in ensuring that cultural, ethnic, religious, gender, and other issues related to diverse populations when it comes to accessing health related services are taken into consideration.
- The Cultural Liaison initiative ended for Passaic and Hudson counties and will move

to Camden and Essex counties. More information and updates will be available once the next initiative is ready to launch.

Self-Advocacy Advisory Subcommittee

Ryan Roy serves as chairperson of the Self-Advocacy Advisory Subcommittee. It is comprised of all of the self-advocate members of the Council, as well as self-advocates from the community.

The subcommittee:

- Serves as a voice for New Jerseyans with I/DD by promoting self-advocate participation and peer advocacy that advances independence and inclusion.
- Advises the Council regarding self-advocate needs including ensuring full participation in all meetings.
- Advises the Council regarding policies, programs, and any other areas affecting self-advocates in New Jersey.
- Conducts activities that align with the goals and objectives of the Council's state plan.
- Reviews materials and other Council-produced information to evaluate and make recommendations regarding plain language approaches.
- Responds to additional requests made by the Council or in conjunction with other committees.

The group met on August 9, 2023 at the Hilton Garden Hotel and invited new self-advocates from outside of the council to take part in the quarterly meeting virtually. Three advocates from Spectrum for Living and their advisor attended the meeting and brought new energy to the group, sharing their lived experience and knowledge to the discussion. The group talked about their concerns around transportation and how working with other council members and advocates to lead training for paratransit professionals would be helpful to everyone who uses the accessible transportation system. The Spectrum for Living guests were invited to be regular members of the group moving forward. **P&F**

In Memoriam

Countless advocates, individuals, family members, and professionals continue to make meaningful contributions to the lives of people with I/DD in New Jersey. This segment pays tribute to those who have made meaningful contributions and have recently passed away.

Norman Reim

Norman “Norm” Reim, Jr. passed away at his home on July 28, 2023. Norm was a strong advocate for the disability community, working for many years in public relations for the New Jersey Department of Human Services and the New Jersey Council on Developmental Disabilities. A songwriter and singer, Norm never lost his love for music. He sang and played guitar for graduates of Partners in Policymaking.

Norm was a writer, editor, and blogger on disability issues. He served as editor and publisher of *People and Families Magazine*, and in 2019, wrote for the magazine on the passing of Ethan Ellis, former director of the NJCDD, with whom he had worked. Norm’s work was driven by his firm belief that it is wrong for anyone to be denied their equitable place in the human family.

If you are aware of the recent passing of someone who has made significant contributions to the New Jersey I/DD community please email a brief description to gary.brown@njcdd.org.



Susan Coll-Guedes Maneuvering Through the Barriers

By Maryann B. Hunsberger



Susan Coll-Guedes and her son Alex at Children's Hospital of Philadelphia, where he has been living for nearly 300 days.

Alex Guedes tripped on his pajamas in his bathroom and went down on his knee in December 2022. Alex has Down syndrome and a related condition called Atlantoaxial Instability (AAI), where the junction between the first two vertebrae is loose. Neurologic symptoms, paralysis, and even death can occur from an injury. “It wasn’t a big fall, but it was enough to shift things in the neck to become dangerous,” explained his mother, Susan Coll-Guedes.

The 22-year-old man also has autism and Ehlers-Danlos syndrome, a genetic condition that makes him susceptible to injuries that can require surgery to repair. Because his developmental disabilities and medical issues are so complex, he requires a feeding tube and 24-hour skilled nursing care.

Alex entered Children’s Hospital of Philadelphia (CHOP) on December 12, 2022 to have his neck injury repaired. It was supposed to be a 2 week stay, but he remained there for nearly 10 months; his long stay started because he caught the flu soon after entering the hospital and it developed into pneumonia and intestinal failure.

Coll-Guedes said, “Instead of feeding him with a G-tube they did a central feeding line, which caused a fungal infection and sepsis. He had no food for 30 days after they took him off the central line. He was just on an IV. He dropped to 88 pounds. It was horrifying. We were planning his funeral. We wanted them to let him go so he wouldn’t suffer. The ethics board overruled us and wouldn’t allow him to go to hospice. He is considered to be in a protected class because of his Down syndrome, so they couldn’t let him die with dignity. They had to try everything to keep him alive because Pennsylvania is not a right-to-die state. When you think of scary things you want to have control over—decisions that are important—our family couldn’t even do what we thought was best for him.”

Alex surprisingly recovered, had his neck fusion surgery and is doing well now, yet he’s still hospitalized. Coll-Guedes and her husband, Mike,

parent their two other children in shifts, so one of them can always be with Alex. “We’re taking turns living at the hospital. They haven’t assigned a one-to-one for him as there is a nursing shortage. Without us being there, he will just sit for hours on end unable to even get a sip of water because he can’t ring the bell.”

Various systematic issues have kept him hospitalized. He was in the Community Care Waiver from ages 2 to 21. Then he went into DDD’s adult system, where his parents had to choose between two programs. The Community Care Program (CCP) provides a good budget, but no nursing care. The Supports Program provides nursing, but a smaller budget. “He had everything he needed as a child, since he was busy in school. You lose that as an adult, so you need a good budget to cover everything. But, the waiver was taken away and he lost the CCP budget that comes with it simply because he needed nurses. He went into the Supports Program, but the budget was not enough to do anything for adult life. DDD needs to change it so that the CCP includes nursing. But, they wouldn’t. So, Alex couldn’t leave the hospital.”

Coll-Guedes contacted Senator Chris Connors of the 9th District who appealed to Governor Phil Murphy’s office for help. Alex is now in the Supports Program with a CCP budget. “DDD provided the solution we needed so Alex could have nursing care through a nursing agency and a budget for life in the community, not a life in the hospital.”

Alex was ready to go home, but none of the nursing agencies near them had private-duty nurses available due to the nursing shortage. “I know people who went home with a promise of a nurse coming, but nobody came. I was crying and begging the nursing agencies to help us and they just said no. I posted a picture of Alex on Facebook, begging nurses to help us. People shared the post, but nobody responded. Everyone averts their eyes and you are just standing there begging for help. Anyone who wants to reject you can do that in the adult system. You’re left in precarious life or death situations. When they’re in school, the law says nobody can be rejected,

nobody can be turned away. But, this isn't how the adult system works."

Coll-Guedes was recently named the new chair of Regional Family Support Planning Council (RFSPC) #9. Despite being involved in disability advocacy and having connections to people within the disability community, Coll-Guedes still couldn't get her son's situation resolved. If someone like her can't find help, it's no wonder that the average parent of children with disabilities struggles. Finally, she found an agency willing to help. "We live in Atlantic County, but the only agency that had a nurse available is Newborn Nurses in Camden County. Home nursing is different from working in a hospital or nursing home. Home nurses don't get sick pay, signing bonuses, salaries, or insurance. They are like temp workers. So, it's hard to find one."

Just when the family thought everything was situated for Alex to go home, they learned he couldn't be released until the family obtained a specialized hospital bed with air in the mattress to prevent sores. "We need to prove that he needs this bed. It was denied by our primary insurance, and then by United Health Care Medicaid. Now DDD is trying to grapple with their own system of how they buy this bed. DDD said they would pay for it if they got two denials from the insurance company. It took two months to get the denials, which just came this week. Now we have to submit the denials to DDD. Until we get that bed, we can't get a discharge date."

Since Alex is medically cleared to go home, insurance stopped paying for his hospitalization and CHOP is absorbing the cost. "It's a failure of every system. I'm waiting for DDD to say they can't buy the bed. They'll probably say the company selling the bed is not a provider agency in the system, so they need to make them a provider. It takes about five weeks for that to happen. The whole thing involves so many people."

Coll-Guedes and her family have been living with uncertainty and grief since December. "They're keeping him alive but not letting him live his life. We were here for Christmas. Pretty soon,

"I think of the thousands of people like Alex who want to live in freedom, but are in hospitals, facilities and nursing homes because care workers aren't available for them to live safely in the community. Nobody talks about this. We're trying to gather these stories. We want to know what has happened to families like ours."

—Susan Coll-Guedes

they'll have apples, pumpkins and turkeys, and then Christmas trees. Will we still be here?

So many things associated with the hospital are traumatic to me. I can't even eat an omelet or cream of wheat at home because I get that at the hospital."

Coll-Guedes said Alex isn't giving up. "I feel like he's incarcerated, but he has resolve and perseverance. When the bed finally comes, I hope we will get a nurse. I know we won't get 24-hour care. I just want enough hours so I can go to work. We need to sustain ourselves and take care of our other children and pay our bills. I lost my job because of this. We can't be constantly put in this position of losing our jobs. I sleep at the hospital almost every night. My husband is a teacher, so once summer is over, it becomes really hard. The only reason we've been able to hold up is because CHOP is helping us. The team at CHOP never gave up."

She's concerned for other people facing these same roadblocks. "So many people with disabilities are going home to unsafe homes. We want our son to come home to a safe home with the right bed and the right care. Health insurance companies need to start providing more care at home. They need to be more flexible and do things such as increasing wages for people working in home care."



Susan Coll-Guedes and her son Alex

Coll-Guedes is collecting stories about families with complex behaviors or medical needs. "I know I'm not the only one. There are many people like us, but we're all in isolation and not aware of each other. I think of the thousands of people like Alex who want to live in freedom, but are in hospitals, facilities, and nursing homes because care workers aren't available for them to live safely in the community. Nobody talks about this. We're trying to gather these stories. We want to know what has happened to families like ours. Some have to put family members in group homes because it's so hard to find what they need living at home."

Coll-Guedes notes that this year marks the 33rd Anniversary of the Americans with Disabilities Act, which provides civil rights for

people with disabilities. "It's still not realized, at least not for Alex and not for our family. My son cannot advocate for himself. He needs someone to advocate for him all the time. I asked Senator Connors to write another letter to the governor and he sent it yesterday. Even with advocates, the disability system has so many barriers that make things impossible."

Editor's Update:

After 297 days in the hospital, Alex came home on October 3, 2023. Although he is eligible for 24/7 nursing care, it can be found only in a facility. The nursing/caregiver shortage is hitting the family very hard:

"It's like seeing a rainbow and looking for the end. It's an illusion," said Coll-Guedes. **P&F**

Bev Roberts Role Model, Advocate, Expert, Friend

By Brenda Considine



Beverly Roberts

If your life has been touched by developmental disabilities in any way, whether personally or professionally, it is hard **NOT** to have known Beverly Roberts. Her name is synonymous with advocacy and access to quality health care.

This summer, the disability community unexpectedly lost one of our best: Beverly Roberts passed away on August 25. She was 73 and had committed her entire career to advocating for people with developmental disabilities.

“Bev,” as she was known, began her work in the field in 1989 when she became the Director of The Arc of New Jersey’s Mainstreaming Medical Care Program. For the next three decades, she handled the statewide non-profit’s health care advocacy, promoting quality medical, mental

health, and dental care for individuals with intellectual and developmental disabilities (I/DD).

The news came from Tom Baffuto, Executive Director of The Arc of New Jersey, in a prepared statement:

“It is with profound sadness that I report our beloved friend and colleague Beverly Roberts passed away today. Words cannot express the loss to our community. Beverly dramatically touched the lives of thousands of individuals in the course of her 33 years at The Arc of NJ. She directly helped so many people and her incredible advocacy made New Jersey a better place...Our thoughts and prayers go out to her family, those in The Arc family and everyone who knew her...”

“You Should Talk to Bev”

Anyone with a question or problem with the health care system got the same advice: “You should talk to Bev Roberts.” With amazing clarity, Bev helped people understand some of the most complex, yet necessary, elements of the support system for people with I/DD. She did it with kindness, patience, and grace. Her work was advocacy-focused on every level. Lawmakers, state leaders, and all bureaucrats knew her by name. Providers, clinicians, and doctors knew her and called often with questions. And families across New Jersey knew her. In fact, whenever anyone had a question, needed a referral, needed advocacy help, or faced a challenge, they would be referred to Bev.

She had an encyclopedic knowledge and understanding of the health care system, and offered information on both a large and small scale—doing webinars, making presentations, and holding an annual conference for thirty years—and speaking directly to families, one-on-one, as they worked to navigate the maze of federal entitlement programs and the state Medicaid program.

She was the state’s leading expert on SSI, SSDI, Medicaid, and Medicare. Individuals and organizations across the state—and the country—considered her *the* person to contact for help and information. She conducted hundreds of workshops for individuals, families, and professionals, sharing her knowledge and giving them the tools they needed to access services.

Across her career, she helped tens of thousands of individuals with I/DD and their families obtain and maintain critical supports and services. No matter how complicated the issue, Bev would research a solution, help the families to understand, and never give up until a solution was found.

“We Need to Ask Bev to Serve on This Committee”

Whenever there was an issue around the health of people with I/DD, Bev was the first person contacted to weigh in on the issue or join a taskforce. Often, she was the only community member asked to participate in state administration workgroups. If there was an entity convening to discuss an issue or publish findings, Bev was included.

In her years, she served on scores of committees and task forces, including the Medical Assistance Advisory Committee (MAAC), the advisory group to the NJ Division of Medical Assistance and Health Services (DMAHS), and, most recently, a DMAHS run workgroup focused on implementing the new Medicaid WorkAbility law. Bev generously served on this magazine’s Editorial Board and the Council’s Health and Wellness Subcommittee. She authored countless publications and received a number of prestigious awards from local county chapters of The Arc, The Arc of NJ, the NJ Council on Developmental Disabilities, PLAN NJ, the Community Health Law Project, and more.

Honors and Accolades

Bev was remarkably humble. While she never sought awards or recognition, others saw her contributions and celebrated them. In the course of her career, she was honored by scores of organizations, including the Community Health Law Project with a prestigious Ann Klein Advocate Award and with a Lifetime Achievement Award from the NJ Council on Developmental Disabilities and the American Academy of Developmental Medicine and Dentistry. In addition, she was recognized by The Arc of NJ, The Arc of Bergen and Passaic Counties, The Arc of Warren County, The Sussex County Arc, the NJ Association of Community Providers, PLAN NJ, the American Academy of Developmental Medicine and Dentistry, and the Centers for Medicare and Medicaid Services for her dedicated advocacy work.

An Advocate

Bev sought to arm people with the information they needed to succeed, and was a relentless advocate for the disability community. She was respected by policymakers, colleagues, families, and self-advocates. She was at the forefront of so many critical advocacy issues. Her passion to help others guided everything she did, and so many people with I/DD are living better lives because of her hard work.

Whenever there was an issue involving the health and safety of individuals with I/DD and their families, Bev was instrumental in advocating



Bev was recognized for her work throughout her career. In 2006, she was honored by the Community Health Law Project (CHLP) with the prestigious Ann Kline Award, (L-R) Douglas Oberreit, Trustee at CHPL; Bev Roberts; Congressman William Pascrell.

with state and national leaders to ensure the best possible outcome. She helped to change public policy, regulation, and legislation which affected people with I/DD in order to ensure their access to quality medical care.

“She always fought so hard for people with I/DD,” said Tom Baffuto, Executive Director of The Arc of NJ. “She believed our role as advocates was to fight back against any injustice, whether it impacted all New Jersey residents with disabilities, or only just a handful. She was an incredible person who cared greatly about the people we serve. We will miss her unwavering advocacy, her extraordinary intellect, and her drive to make New Jersey the best possible place for people with intellectual and developmental disabilities and their families.”

Some of her most high-profile work was in the area of women’s health care. She co-wrote a workbook—*Let’s Talk About Women’s Health: What Every Woman Should Know*—and she produced a companion video on the same topic. In 2005, she co-authored a chapter of *Ending*

Intimate Abuse: Practical Guidance and Survival Strategies.

A Professional Role Model

Bev’s passion for her work was evident in everything she did. It inspired those around her to work even harder. She always had time for her colleagues, teaching them and assisting them to be better advocates.

“She believed wholeheartedly in the mission of The Arc and strived to fulfill that mission every day,” noted her long time colleague and friend, Celine Fortin, Associate Executive Director of The Arc of New Jersey.

If there was work to be done, Bev rolled up her sleeves.

She conceptualized and initiated an annual health care conference focusing on relevant and pressing issues. The event brought together families, health care professionals, staff, clinicians, policy makers, and providers. As editor of *Health Times*, a newsletter, she kept readers informed about developments in health care issues affecting those with disabilities.

And she was a frequent guest speaker, donating her time and expertise to parent groups and nonprofits to learn more about issues in accessing medical care.

The News and The Reaction

As the word of her passing spread, social media threads grew as people reacted to the news. Parents, leaders, and friends offered thoughts and recalled how Bev had helped them. Here, in the words of people whose life she touched so deeply, is a snapshot of Bev.

“Bev was an inspiration to all of us that advocate for individuals with developmental disabilities...I knew she was always available to answer any question I had regarding complex insurance issues...She was kind, compassionate, modest...May we strive to carry on your legacy of kindness.”

—LF

"She was an incredible person who displayed courage, humility, heart, and spirit as an advocate for families with children and adults with disabilities. Endeared to all in the disability community, we regarded Bev as our friend, champion, colleague, and guru for her wealth of knowledge, most for the generosity of hope shared when supporting individuals, families, and professionals alike."

—MR

"We are one of the families she helped with our son's Medicaid. Because of her help, he is able to secure and maintain his placement at a wonderful agency. Beverly you will be missed, and our family honors your legacy."

—RR

"Always the consummate advocate, she left 'no stone unturned' in her work on behalf of individuals with disabilities."

—WD

"What a beautiful and giving soul. She touched so many. She helped me for several years navigate the complex systems of Medicaid, DDD, SSDI, and more for my daughter. What a wealth of knowledge! And always there to help! Our world lost an angel..."

—JW

"Beverly was a tireless and passionate advocate, expert in the field and warm human being who moved mountains systemically and one person at a time. Her knowledge, fervor, compassion, work and heart all were exceptional. She will always be remembered

and her legacy will live on in the thousands whose lives she positively touched..."

—DW

"...a titanic force for good, and the closest thing to a real-life guardian angel I have ever met...I am honored beyond words to have worked with you, and to have been changed by your advocacy..."

—EW

"I wish everyone had someone to advocate for them as Bev did for people with disabilities. She was passionate, dedicated and unwavering; but also kind and pleasant as she served those who needed a strong voice to speak with them and on their behalf. I am heartbroken, but also grateful that I had an opportunity to get to know her. She will never be forgotten. Her legacy will continue to be an inspiration for anyone who wants to make this world a better place."

—RV

"Her kind soul and bright spirit touches us all. A tireless advocate. An endless fountain of knowledge. A staunch warrior against injustice and inequity. A kind voice. A gentle hand to those in need. A bright smile. A life lived in service to others who live in the margins."

—PP

"Beverly was always there for us, no matter what. I always said that she had forgotten more than I would ever know. She was truly an angel in how she cared for everyone and went out of her way to help everyone..."

—LL

In Bev's honor, The Arc of New Jersey established a memorial fund, which will be used to further her vision of increasing access to healthcare for people with I/DD and ensuring that professionals are educated to support them.

Donations to the memorial fund can be sent to The Arc of NJ office or completed online at www.arcnj.org. **P&F**

BREAKING BARRIERS

People with Disabilities in Film, Theater, and Television

By Brenda Considine

When the curtain lifted this fall at the Belasco Theatre in New York City, seven actors on the autism spectrum made their Broadway debut. They are starring in a new musical, “How to Dance in Ohio,” based on the 2015 HBO documentary by the same name. It is a story about people on the cusp of the next phase of their lives, facing hopes and fears, ready to take a momentous first step.

They are not the only actors with disabilities to grace the Great Bright Way. In 2019, Ali Stroker made history by becoming the first actor in a wheelchair to win a Tony Award for her role in the 2019 revival of *Oklahoma!*

In recent years, there has been a shift in the entertainment industry towards inclusivity and diversity, and people with disabilities are finding representation. Long marginalized and underrepresented, individuals with disabilities are now carving out meaningful careers in film, theater, and television, enriching the storytelling landscape with their perspectives and talents.

Changing the Narrative

Hollywood has a history of reducing characters with disabilities to stereotypes and using them as plot devices or sources of inspiration (a strategy known as “Inspiration Porn” by disability activists). Characters with disabilities were typically cast as secondary roles or caricatures, their stories overshadowed by their disabilities and their individuality overshadowed by clichés.

But the call for representation that reflects the diverse experience of people with disabilities has grown louder, prompting a wave of change in how these individuals are portrayed onscreen. Filmmakers, writers, and advocates are working to replace stereotypes with nuanced, authentic narratives.

Scott Steindorff, a Hollywood producer and director, is something of a unicorn in the entertainment industry. Dubbed “Hollywood’s Book Man,”

he is best known for his adaptations of high-profile literary best sellers. The founder of Stone Village Films, he is a producer, playwright, and director, having produced critically-acclaimed projects including *Station Eleven*, *Jane Got a Gun*, *The Lincoln Lawyer*, and *Love in the Time of Cholera*. He has worked with A-list talent like Natalie Portman, Scarlett Johansson, Robert Downey Jr., and Dustin Hoffman.

He also has autism. His newest project is a documentary titled *Understanding Autism*.

When it comes to disability inclusion, Steindorff believes that “Hollywood and the entertainment industry in general has a long ways to go.” Steindorff, who describes himself as “not a fan of ‘sensationalized autism,’” said, “We talk about diversity and representation but the conversation is never about intellectual and developmental disabilities. There needs to be another seat at the table. The studios should be employing people with I/DD—they have so much talent and they don’t get the opportunities.”

The data supports this. People with disabilities make up more than 20% of the population, but only 2% of on-screen characters have disabilities. Less than 1% of writers in Hollywood are disabled.

David DiIanni, the director of Film Academy 360 in Livingston, NJ, is trying to change that. He is working to create more opportunities for people with disabilities, both in front of and behind the camera. Originating in 2009 as a film studies class at a private special education school, Film Academy 360 focuses on self-expression and vocational exploration, not only teaching technical skills but also helping creative minds develop confidence and self-esteem.

“It was a little bit of an experiment when we first started,” said DiIanni, who has worked as a TV producer in New York and Italy. “I thought at first that it would be an opportunity to build social skills, but it has evolved into so much more.” Through his

work, he sees students with creative voices that need to be heard, and students with technical skills that can open career doors.

“Even if the work is not a huge commercial success, it can foster more understanding and acceptance,” he noted.

Film Academy 360 participant Dominic is featured on the program’s website, and hopes to make professional films in the future. The 31-year-old graduate of William Paterson University said he “has learned how to use cameras and sound equipment, the importance of being quiet while filming a scene, how to make a scene more dynamic using close-ups and camera angles, and how to transfer material from a camera onto a computer.”

“It has been great because I get first-hand experience with the equipment and with the process of writing a script and then turning that script into a film,” he noted.

Dominic said that his social connections at the program have allowed him to “...talk to people who have an interest in film and have helped him understand the importance of communicating with people, as filmmaking is a collaborative profession.”

The award-winning program has completed professional projects for The Guggenheim Museum, RWJ Barnabas, NEXT for AUTISM, Tenna, and Bloomberg TV.

Visibility and Authenticity

Visibility plays a crucial role in challenging societal biases and dismantling stereotypes. When people with disabilities are visible in the entertainment industry, it sends a powerful message that they are part of the fabric of society, with dreams, aspirations, and talents just like anyone else. Talented individuals are proving that their disabilities do not define them, and their skills can shine through their work.

Furthermore, authenticity in representation is essential. When characters with disabilities are played by actors who actually have those disabilities,



Hollywood film producer, writer and director, Scott Steindorff. His new documentary is, in part, an exploration of his own diagnosis of autism as an adult.

it lends a level of realism that can't be replicated by other performers. This authenticity fosters a connection between the character and the audience, allowing for a more immersive experience that can lead to empathy and understanding.

This is true especially in children's programming. Netflix's *Ada Twist, Scientist* is an educational animated series written for a young audience. The show features eight-year-old scientist Ada Twist, a Black female character, and her two best friends. In an episode written by New Jersey native Niya Wright, Ada's cousin with autism comes for the afternoon. Nassan stims, flaps, has a “melt down,” shows food preferences, and chirps

with joy when he is happy. The show's producers were also intentional in casting Justice Killebrew, a nonverbal Black teen actor on the autism spectrum, for the voice of Nassan.

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

The Power of Role Models

While there have been films and productions about people with disabilities, the push for representation by people with disabilities is relatively new.

One of the first and most recognizable actors with a disability is film star Marlee Matlin, an American actress, author, and activist. Deaf from birth, she has won the industry's most sought-after awards. She starred in the 1986 film, *Children of a Lesser God*, became the first deaf award winner in Oscar history, and, at the age of 21, became the youngest woman to earn the Academy Award for Best Actress.

In *The Peanut Butter Falcon*, we met Zack Gottsagen, an actor with Down syndrome who stars in the film about a young man who leaves the group home where his parents placed him to carve out his dream career as a professional wrestler.

Content producer Netflix created *Atypical*, a family drama and comedy about the everyday life of



Students who take part in Film Academy 360 have the opportunity to produce original content and learn production skills.

a teen with autism. Sam Gardner is played by Keir Gilchrist, a non-autistic actor. After the production took criticism for that casting decision, writers created five characters with autism, all played by people on the spectrum.

Netflix also produced *Special*, in which Ryan O'Connell stars as Ryan, a 28-year-old gay man with cerebral palsy who moves out of his mother's home and seeks to create a life of meaning. O'Connell not only stars in the show, he wrote and produced it.

While many films and productions featuring people with disabilities are about disability, some are not.

Netflix's blockbuster hit show, *Stranger Things*, stars Gaten Matarazzo as Dustin. He has a rare genetic disability which affects his teeth and bones. While his condition is easy to see on screen (he has missing teeth and a lisp) his disability is unrelated to the story—he is simply another teenager trying to fight the paranormal forces of evil.

In HBO's film, *I Care a Lot*, Peter Dinklage was cast as the powerful and mercurial Roman Lunyov. One of the most well-known actors with achondroplasia (dwarfism), Peter has refused to play parts that make his size into a joke.

Maysoon Zayid, a Palestinian-American comedian, actress, and disability advocate, is using humor to break down barriers and address misconceptions. Her stand-up routines, including her TED Talk *I Got 99 problems... Palsy is Just One*, offer a

unique perspective on life with cerebral palsy, challenging viewers with laughter.

Industry Efforts

Funding for disability-focused projects, mentorship programs, accessible casting processes, and accommodations for professionals with disabilities are crucial steps toward fostering a more inclusive industry.

RespectAbility funds an innovative Entertainment Lab that aims to help develop and elevate the talent pipeline of professionals with disabilities working behind the scenes in television, film, and streaming. The program introduces participants to studio executives and other decision makers who will advise Lab Fellows on various aspects of the industry and their craft. Lab alumni currently are working at studios such as Disney, Netflix, Nickelodeon, Paramount Pictures, Sony Pictures Entertainment, and more.

AXS Film Fund supports independent documentary filmmakers and nonfiction new media creators of color who have disabilities in their endeavors to tell stories, make films, and create content.

Activism

Tatiana Lee is an award-winning actress and model with spina bida.

In 2018, she accepted the Christopher Reeves Acting Scholarship at the Media Access Awards, for



her trailblazing efforts toward advancing disability awareness and inclusion. In an interview prior to the awards, she confessed that it is often difficult to make it as a model and actress who has a disability.

“I hated that no one looked like me,” she said. “I wanted to fight that, I wanted to change that.”

Lee was recently featured as one of the first models with a disability for fashion company Torrid. “People were excited,” she said in an interview, but she noted that while *audiences* may be ready for disability representation, the people in charge may not.

Lee also is an activist for people with disabilities, speaking at companies such as Apple about the importance of disability inclusion. Her activism includes outreach to producers and directors to remind them that failing to include people with disabilities is a missed opportunity. The data supports that assertion.

Show Me the Money

According to EnterpriseToday, the U.S. media and entertainment industry was worth \$717 billion in 2021; the global market at that time was worth \$2.2 trillion. In an analysis of branded Instagram posts between May 2021 and May 2023, Nielsen InfluenceScope assessed the performance of 24 creators with disabilities to determine their effectiveness and return on investment (ROI). They found that across all industries, the branded posts from disabled creators outperformed posts from creators without disabilities, in media value and engagement

actions, five times out of eight. In aggregate, posts from creators with disabilities scored 21.4 percent better in average media value than posts from creators without disabilities, and drove 20.5 percent more interactions.

The Role of the Viewer and Consumer

As with any cultural shift, change is often slow and rarely linear. Unconscious bias, lack of accessibility, and financial barriers still hinder opportunities for people with disabilities in the entertainment industry. Efforts to improve representation must go beyond casting and extend to behind-the-scenes roles as well, including writing, directing, producing, and technical positions.

Advocacy organizations, industry leaders, and government initiatives may play a role in driving this change, but so do viewers and consumers. By supporting media that values diverse representation, viewers send a clear message to the industry that authentic stories matter. By demanding change and embracing narratives that reflect a more honest exploration and representation of the human experience, viewers contribute to dismantling stereotypes and foster a more inclusive media landscape. **P&F**

RESOURCES

Film Academy 360:

<https://spectrum360.org/filmacademy360-spectrum360/>

RespectAbility Media Lab:

<https://www.respectability.org/entertainment-news-media/>

Hollywood Disability Toolkit:

<https://www.respectability.org/hollywood-inclusion/>

Neilsen Influence Scope:

<https://www.nielsen.com/insights/2023/with-limited-inclusive-content-in-traditional-media-brands-and-people-with-disabilities-are-finding-representation-on-social-media/>

AXS Film Fund:

<https://www.axsfilmfund.org/>

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

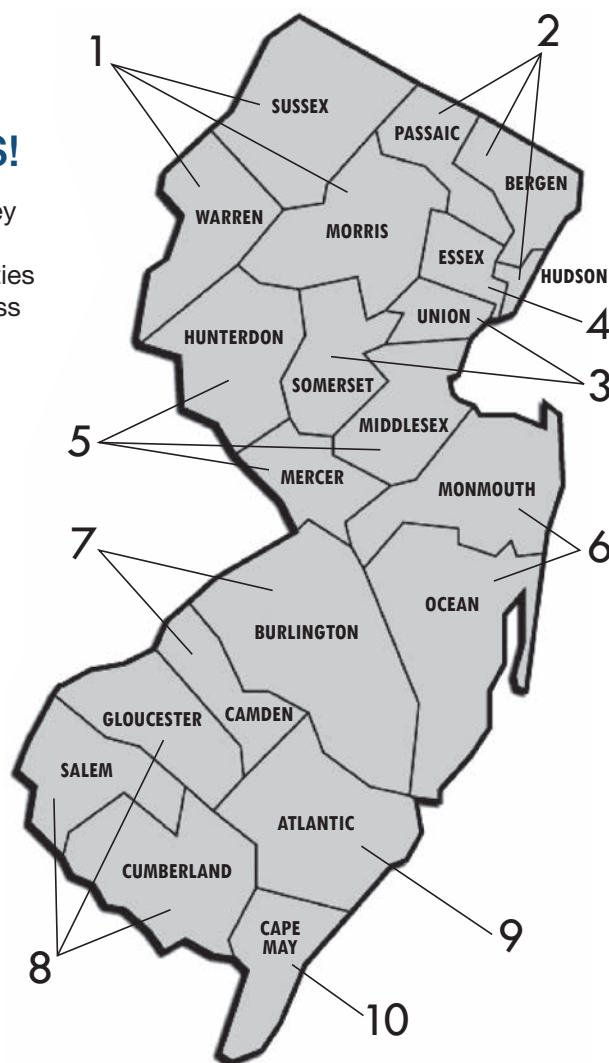
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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, 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

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

Visit the NJ Council on Developmental Disabilities' web site at www.njcdd.org, click on the link for Family Support, and click the number corresponding to the Regional Family Support Planning Council in your area.

1 SUSSEX, WARREN, MORRIS

RFSPC #1

e-mail: RFSPC1@gmail.com

Chair: Margaret Hefferle

Meets the third Tuesday
of each month

Wegmans Market Cafe
34 Sylvan Way
Hanover, NJ 07054

7:00 p.m.–8:30 p.m.

2 BERGEN, HUDSON, PASSAIC

RFSPC#2

e-mail: RFSPC2@gmail.com

Co-Chairs: Dorothy Blakeslee, Fel Lim

Meets the third Monday
of each month

7:00 p.m.–8:30 p.m.

3 SOMERSET, UNION

RFSPC#3

e-mail: RFSPC3@gmail.com

Chair: John Brewer

Meets the third Tuesday
of each month

7:00 p.m.–8:00 p.m.

4 ESSEX

RFSPC#4

e-mail: RFSPC4.Essex@gmail.com

Chair: Yolanda Smith

Meets the first Wednesday
of each month

7:00 p.m.–8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5

e-mail: RFSPC5@gmail.com

Chair: Paul Blaustein

6 MONMOUTH, OCEAN

RFSPC #6

e-mail: RFSPC6@gmail.com

Chair: Mike Brill

Meets the second Thursday
of each month

6:30 p.m.–7:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7

e-mail: RFSPC7@gmail.com

Chair: Laura Kelly

Meets the second Thursday
of the month

Odd months: 1:00 p.m.–2:30 p.m.

Even months: 7:00 p.m.–8:30 p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8

e-mail: RFSPC8@gmail.com

Chair: Amy Kiger

Meets second Thursday
of each month

7:00 p.m.–8:00 p.m.

9 ATLANTIC

RFSPC #9

e-mail: RFSPC9.atlantic@gmail.com

Chair: Susan Coll-Guedes

Meets the fourth Tuesday of
every even month

6:30 p.m. - 7:30 p.m.

10 CAPE MAY

RFSPC #10

e-mail: RFSPC10CM@yahoo.com

Chair: Anne Borger

Meets the third Thursday
of the month except January, April,
July, August, and December

6:30 p.m.–8:00 p.m.

All regional meetings are held virtually, except hybrid meetings at RFSPC #1. If you are interested in attending any meeting, please email the specific RFSPC to request a meeting link.

Remembering Gary Rubin

Advocate for Independence

By Brenda Considine



*Gary Rubin as a young man
—Photo by Irv Rubin*



*Gary Rubin
—Photo by Irv Rubin*



Gary, from an interview —[from YouTube]

Gary Rubin never minced words. If he was unhappy with you, something you said, something in the world—or anything for that matter—you knew about it. He was bravely outspoken about the need to close institutions and the vital importance of treating all people with respect and dignity.

An active member of the New Jersey Council on Developmental Disabilities for nearly 15 years, Gary died in late June 2023 following a short illness. He was 58.

Gary was a longtime member at Community Access Unlimited (CAU) in Elizabeth, NJ, where he worked and lived with support in a range of progressively independent housing situations—most recently, he moved into his own condo. A respected member of his community, a leader at the local, state, and national level, and a well-known advocate for the civil rights of people with I/DD, Gary was a force to be reckoned with.

But it was not an easy path; it was the trauma of living in a state institution that forged an advocate.

Adopted at the age of 4, Gary was raised in Northern New Jersey. Irv Rubin, Gary's father, recalled adopting a son with known challenges.

"The beginning was really hard. Gary needed a lot of help at home, and in school, most teachers couldn't handle him—he had outbursts," recalled Rubin. Eventually, they found The Forum School, a private non-profit in Waldwick, NJ, where Gary thrived. After he 'aged out,' Gary was placed at Woods Services, a residential program in Pennsylvania.

"For the first time in my life, I knew where all the other kids like Gary went—they all had similar problems and they all got the help they needed," he recalled.

In 1985, Gary 'aged out' of special education, so Rubin sought to find a new placement for his son. It was then that the Division of Mental Retardation (now, the Division on Developmental Disabilities) placed Gary at Johnstone Training Center in Bordentown. It would be his home for the next seven years.

"That place was like a prison," recalled Rubin. "It was awful, awful, awful."

Gary lived at Johnstone until 1992, when it closed. At the time, Johnstone residents were considered to be among the most behaviorally-challenged in the state system. Those opposing the closure argued that the people who lived at Johnstone were not good candidates for life in the community; many questioned whether they

could survive outside the walls of the developmental center.

When Gary left Johnstone, he moved to Union County and received services from Community Access Unlimited (CAU). In leaving Johnstone and connecting with advocates at CAU, Rubin became an activist in the deinstitutionalization movement, and was among the first generation of self-advocates in New Jersey. Ironically, the Johnstone closure effort was led and supported by the NJCDD, on which Gary would later serve.

Self-Advocacy Pioneer

Gary worked to educate people not to judge others based on their abilities, and to avoid derogatory language like the "R" word. But his biggest soapbox was institutional closure, and the urgent need to create opportunities for ALL people with developmental disabilities to live in the community. Recalling the bad attitudes and mistreatment experienced and witnessed in the developmental center, he once said:

"I'm an advocate because I took way too much bullcrap when I lived in the DCs (developmental centers)...I just don't like to see others go through what I went through. I want to see others have a good life and not be judged by others."

In the 31 years since he moved out of Johnstone, Gary transformed from an individual advocate to a leader in the disability advocacy movement. His resume is impressive. He was a founding member of the New American Movement for People with Disabilities, an effort committed to social, political, and economic transformation for the equity of all Americans. A leader with Self Advocates Becoming Empowered (SABE), Gary traveled to local, state, and national conferences to educate the public about self-advocacy and the need to close institutions. He served as president of Helping Hands, one of the oldest and most visible self-advocacy groups for people with disabilities in the state. As a member of JumpStart, Gary met with self-advocates in schools and state institutions. He was often called in to meet with elected leaders and to testify at public hearings.



*Gary Rubin, with his brother on a family SCUBA diving trip in the Bahamas. Gary was a certified diver.
—Photo by Irv Rubin*

One of those hearings was in Vineland, NJ.

Tom Baffuto, Executive Director of The Arc of NJ who worked alongside Gary for many years, recalled a salient example of Gary's brazen style and singular vision.

The two men shared a ride to South Jersey in order to testify at a public hearing about efforts to close Vineland Developmental Center. Vineland is a state-run institution, not unlike the one in which Gary had lived. At the hearing, there were hundreds of pro-institution union members who had gathered to publicly oppose the closure and the subsequent loss of jobs.

"It was hostile territory," recalled Baffuto. "We were really outnumbered. Anyone else would

have been intimidated, but not Gary. He got up and told his story."

When the hearing was over and it was time to leave, Baffuto could not find Gary. As he and others began to search for him, concerns grew.

"I'll say this: he did not make any friends in that room. He could be unpredictable, and his language could sometimes be salty," Baffuto noted. "I admit, I was worried."

Eventually, he found Gary outside, smoking a cigarette, and chatting with union members about why it was vital to close the institution.

"Gary was always on message. It didn't matter who he was talking to," joked Baffuto. "His example reminds us all to be bold, be strong, be committed, and not to back down."

Statewide Impact, Statewide Recognition

Gary's introduction to the NJCDD started when he enrolled in the Council's innovative self-advocacy program, Project Take Charge, and later, in 2002, graduated from Partners in Policymaking (PIP). In 2012, he received the Jane Miller Advocacy Leadership Awards from the NJ Self Advocacy Project, and was subsequently recognized by NJCDD with the Colleen Fraser Self-Advocacy Award for his work and leadership. Fraser, like Rubin, was a firebrand, a fighter, and an outspoken advocate. In another twist of fate, it was Fraser's leadership on the DD Council in the early 1990s that helped to organize community support for the closure of Johnstone, literally opening the doors for Gary's pioneering advocacy work.

Paul Blaustein, President of the New Jersey Council on Developmental Disabilities, saw Gary as "an inspiration."

"He showed us how much one person could accomplish through courage, determination, and a commitment to help the most vulnerable people. Gary enabled me to better understand and care for my son. He encountered many of the same challenges that confront my son, but since Gary was better able to communicate his experiences, he helped me to better understand the life experiences that have left indelible imprints on my son's life and better enable me to help him achieve his most important life goals and live a better, more rewarding life," said Blaustein.

Blaustein vividly recalls Gary responding to a person who criticized the Council for encouraging residents to leave institutions.

"He said, 'Don't tell me about developmental centers. I lived in a developmental center and I know people do not belong there,'" said Blaustein.

Gary-isms

- "Labels belong on soup cans, not people."
- "We all deserve to be here."
- "I am my own boss."
- "We are all people. We are all fighting for the same causes in this world."
- "Don't take no B.S. from anyone."

"Gary was never afraid to speak up, sometimes to his own detriment. Even when he knew the risks, he had an innate sense about what was morally correct—he knew he had to say the truth—and he never hesitated a second. I always admired that about him. He did not waver."

—Walter Kalman,
Executive Vice President,
NJ American Association
on Intellectual and Developmental Disabilities

Paul Aronsohn, New Jersey's Ombudsman for Individuals with Intellectual and Developmental Disabilities and their Families, worked with Gary in the context of the NJCDD, as well as several self-advocacy groups. He remembers Gary as "a fighter."

"He was passionate. He was determined. And he had the courage and strength to speak truth to power—something that he did regularly and effectively," recalled Aronsohn.

Walter Kalman, Executive Vice President for the NJ American Association for Intellectual and Developmental Disabilities, has known Gary for more than 20 years, both personally and professionally, and he agrees.

"Gary was never afraid to speak up, sometimes to his own detriment. Even when he knew the risks, he had an innate sense about what was morally *correct*—he knew he had to say the truth—and he never hesitated a second. I always admired that about him. He did not waver," recalled Kalman.

Kalman noted that Gary spoke as an advocate for all his peers—not just for himself.

"I often see people engaged in advocacy but they are really focused on themselves and their own problems—not Gary—he would tell his story, but he was there for others. That is a big part of why he was successful," he said.

Kalman is currently working with colleagues on an innovative initiative that will be named in Gary's honor. The program—still in early stages of development—is intended to help fill a gap in state and federal funding programs so people with I/DD can get into their own homes.

Through the years, Irv Rubin made a point of seeing his son often. He arranged for Gary and his brother to get certified as SCUBA divers, and they traveled often to the Caribbean to dive as a family.

"I loved my boys," he recalled.

While he was a strong advocate for his son and "never, ever gave up on him," Rubin was not fully aware of Gary's impact and leadership role in the advocacy community. Sadly, it was Gary's funeral that brought it all together for Rubin, and allowed him to see his son through a new lens.

"Gary would tell me he did this and did that, and was president of this and that. I always said 'oh, that's great,' but really, I was just happy that he was doing okay. I never really realized what he was doing and how much impact he had. I took it for granted," said Rubin.

When he helped to clean out Gary's condo, Rubin said he was overwhelmed by all the

"Gary would tell me he did this and did that, and was president of this and that. I always said 'oh, that's great,' but really, I was just happy that he was doing okay. I never really realized what he was doing and how much impact he had. I took it for granted."

—Gary's father, Irv Rubin

certificates and plaques his son had. "He had tons of awards and things—some were still even in boxes," he said. "I had no idea."

Because this is a story about Gary, it is only fitting that Gary gets the last word. Asked to define a 'self-advocate,' Gary said:

"It is speaking up for yourself, putting yourself first. Not letting nobody take advantage of you. Not letting nobody make decisions for you. You are the boss. I am my own boss. I am my own person. Nobody gets to sit there and tell me what to think, what to do, what to say, whatsoever." **P&F**



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REGISTER READY

A Valuable Tool for Emergency Managers

By Jonathan Jaffe

During the darkest days of the pandemic, many people with developmental disabilities in New Jersey were left fending for themselves.

Direct services professionals were unable to stop by to provide the daily care required. People were unable to go to the supermarket, get to a COVID vaccine appointment, access cash from the bank, pick up a prescription, or have any easy way to leave their homes in an emergency.

While many of the reliable institutions suddenly collapsed, as the state's stay-at-home orders were followed by nervous residents and diligent authorities, a critical resource remained for people with disabilities: the state's special needs registry for disasters.

Register Ready—accessible at RegisterReady.nj.gov—is a free service that allows New Jersey residents with disabilities, as well as their families, friends, and associates, an opportunity to provide information to emergency response agencies, as part of their 24/7 response. Register Ready is a statewide system, although Ocean, Salem, and Monmouth counties also have their own systems.

This service helps emergency responders better plan to serve the state's vulnerable population in a disaster, pandemic, or other emergency. The information collected is confidential, held securely and only used for emergency response and planning. Residents are asked for their home address, phone, and email.

"The pandemic opened people's eyes to the needs of our most vulnerable," said Kelly Boyd, who has served for eight years as an access and

functional needs planner for the state Office of Emergency Management (NJOEM) in West Trenton, which runs Register Ready.

"The registry helps to save lives; I would say that it is invaluable," said Boyd, who also serves on the editorial board of this magazine. "I've been promoting the registry every day since I began working at NJOEM and the registry numbers have increased by about 8,000 during that time."

Paul Aronsohn, the state's ombudsman for people with developmental disabilities, said the pandemic exposed the fault lines in New Jersey's system of care. From the civil and human rights of people with disabilities to the challenges faced by students to the outsized demands placed on educa-

tors, group home staff, and families, everyone in the community was negatively and significantly affected by this public health emergency, he said.

"Register Ready can be a vital, life-saving resource for people with disabilities—one that makes it more likely people will receive needed assistance during an emergency," Aronsohn said. "The key is to make sure everyone who could benefit from it is aware of it. They need to know Register Ready exists. They need to know how to use it. And they need to know its critical importance.

"Moreover, we—as a state—need to think through and decide the best way to establish, maintain, and utilize such special needs registries," he added. "Currently, they exist at multiple levels of government—state, county, and municipal. This creates confusion. This raises questions of interoperability. Working together, we all need to figure this out."



Boyd noted the Register Ready numbers are not where they should be, as the latest tally shows that only 26,351 people are listed out of the 9.26 million residents of New Jersey. Of that total number, there are 607,000 residents under the age of 65 in New Jersey who report having a disability, according to 2022 U.S. Census figures.

During the summer, Boyd worked with her summer intern to expand marketing efforts, re-connecting with organizations that were contacted prior to the pandemic and reaching out to others to inform them about this important, free service.

“Many state agencies, community organizations, and disability-related organizations have given out brochures and shared our information in their newsletters since I began almost 8 years ago,” Boyd said. “That has been very, very important to get the word out.”

The outreach includes the state Department of Human Services (DHS), the state Department of State, the state Department of Children and Families, the state Department of Health, the New Jersey Hospital Association, the Family Resource Network, the American Red Cross, the ARC of New Jersey, Meals on Wheels, Access Link, Easter Seals, Autism New Jersey, NJ-211, and many other groups that serve people with developmental disabilities.

The NJOEM has also spread the word about Register Ready on social media, while county groups regularly host community events that highlight the registry and others, such as Access Link, which hands out thousands of brochures to its riders across the state.

Boyd noted that the registry will be modernized to help connect with more residents, noting county emergency officials have been helpful in making recommendations for ongoing improvement.

“I also plan to establish a working group to evaluate the system and see how else we can enhance it,” she said. “So far, three counties have

Registration Numbers for Register Ready		
COUNTY	INDIVIDUALS	FACILITIES
Atlantic	2260	46
Bergen	1391	6
Burlington	1912	19
Camden	1503	6
Cape May	745	5
Cumberland	1196	9
Essex	1597	1
Hudson	1043	1
Hunterdon	408	3
Gloucester	1276	26
Mercer	1051	18
Middlesex	2062	8
Monmouth	3340	90
Morris	1039	1
Ocean	1132	39
Passaic	773	2
Union	1581	2
Salem	268	10
Somerset	1013	23
Sussex	544	4
Warren	217	22
TOTAL	26351	341
Source: NJOEM		

volunteered to join this group—without an official announcement having been made yet.”

The largest amount of Register Ready registrants hail from Monmouth County, with 3,340 people listed, followed by Atlantic County, with 2,260, and Middlesex County, with 2,062. The least number of registrants come from rural areas, including Warren and Salem counties. That is alarming, Boyd said, as people with developmental disabilities in distant regions can be the most vulnerable if emergency responders do not know they exist.

Boyd said that emergency officials in New Jersey have learned plenty since the pandemic crashed down in March 2020. The state is better prepared and conducts emergency exercises for whatever may come next. She noted that emergency planners in other states regularly contact

the NJOEM for guidance in learning how to best respond to emergencies and disasters.

“It is nice to see others look at us for guidance,” she said. “We can all lean on each other and learn from each other.”

Joe Geleta, Director of the Office of Emergency Management at DHS, said the registry is part of a comprehensive program to safeguard vulnerable populations during an emergency. His department works with the State Police in implementing the state’s Emergency Operations Plan (SEOP), which has 15 distinct components.

DHS oversees mass care and emergency assistance, which includes sheltering, feeding, distribution of emergency supplies, and family reunification amongst its many tasks. As part of the plan, DHS also works with NJOEM and the county offices of emergency management.

During the COVID crisis, Register Ready was a key tool to keep open lines of communication, Geleta said, noting people with disabilities were able to receive timely information about COVID testing and vaccination sites, as well as food and PPE distribution.

There was plenty of information coming from the state Department of Health and other supporting agencies, such as the Group for Access and Integration Needs in Emergencies and Disasters, known as NJ GAINED, as well as volunteer and non-profit groups.

“Many of us continue to promote Register Ready as a valuable tool for emergency managers to assist them with their planning efforts, but more importantly, to allow those from the disability community to register in order to assist emergency managers with their planning efforts,” Geleta said.

Along with Register Ready, there are other state initiatives designed to safeguard people with disabilities during a crisis, he noted:

- **Pathways to Preparedness** DHS is providing training seminars to the disability community to better prepare for disasters. Each attendee receives the Pathways to Preparedness booklet, a “go-bag,” a solar charger, and a USB thumb drive with all pertinent information provided in the training. To date, the DHS has provided classes at Project Freedom in Mercer



Kelly Boyd, Access and Functional Needs Planner at Preparedness Bureau/Emergency Management Section of NJ in the Support Room Stage, Command Center.

County, the Alliance Center for Independence in Edison, the Midland School in Branchburg, and others.

- **Overnight Sheltering for the DAFN (Disability, Access, and Functional Needs)** Community DHS developed a program and training in coordination with the Alliance Center for Independence; it is now being offered through the county OEMs. The purpose is to familiarize people with disabilities with an overnight shelter experience. The program also provides emergency managers and volunteers an opportunity to understand and better assist in the needs of individuals with disabilities in a general population shelter during a disaster.

“Going forward, we need to make sure that people with personal, lived disability experience are not only involved in developing policies regarding emergency preparedness and emergency response; we need to make sure that they’re driving the conversation,” Aronsohn said. **P&F**

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