

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

FALL 2017

Medicaid and Special Education

*Photo courtesy of North Jersey Elks
Developmental Disabilities Agency (NJEDDA)*



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For People with
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NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

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

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Join our #SaveMedicaidNJ Campaign

Recently, disability advocates nationwide played a critical role in blocking federal legislation that would have slashed Medicaid funding and crippled the disability service system that we have fought decades to secure. While this is a major success for people with disabilities and their loved-ones, the fight to protect Medicaid is far from over. We still need your help to protect Medicaid for children and adults with disabilities in our state and across the country.

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Cuts to Medicaid would harm many programs and services for people with disabilities, including those for students in special education classes

—Photo by Rebecca Shavulsky



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Throughout the summer and early fall of 2017, the NJCDD and developmental disability advocates across the state have been active in reaching out to legislators, agency representatives, and candidates to outline key areas of concern for individuals with disabilities and their families in our state and to begin laying the groundwork for our advocacy agenda over the next four years.

21 LORRIMER SANCTUARY Bringing the Great Outdoors to People with Disabilities

On a 14-acre parcel of land nestled within Bergen County, New Jersey, a 1200-foot nature trail lays. What makes this beautiful patch of land unique is that it has been made fully accessible for people with physical and developmental disabilities. New Jersey Audubon, who manages the nature trail system known as the Lorrimer Sanctuary, has established wildlife educational opportunities that can be appreciated by people with developmental disabilities at any age.

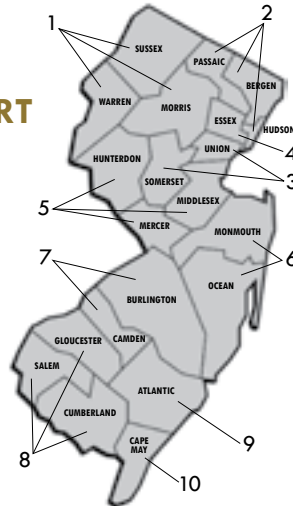
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24 MEDICAID AND SPECIAL EDUCATION

Medicaid is a key funding source for many of the services individuals with disabilities rely upon to live full and productive lives. But Medicaid covers far more than just healthcare. Among those who would be hardest hit by cuts to the program are school-aged children with disabilities who use Medicaid-funded supports and services that make healthy learning possible.



28 INFORMATION ABOUT FAMILY SUPPORT



30 WHEN IT COMES TO GUARDIANSHIP, THERE ARE NO SIMPLE ANSWERS

Parents, siblings, and other family members may often struggle with the idea of becoming legal guardians for their loved-ones with intellectual and developmental disabilities. After all, how can an individual with disabilities have the ability to build a rich and meaningful life if they don't have the legal right to self-determination and independence? Fortunately, in New Jersey, families can tailor their rights to guardianship and supported decision-making to suit the needs of the individual with disabilities.

36 KEVIN NUÑEZ Advocacy is a Way of Life

Kevin Nuñez and his twin brother Abner both have cerebral palsy, and Kevin has been an advocate for both of them for as long as he can remember. Last year, however, his role as an advocate reached new heights as he became a member of the New Jersey Council on Developmental Disabilities. As a strong and outspoken disabilities advocate, Kevin has tackled DSP wages, Medicaid, and a number of other disability issues.

39 THE ANNUAL NJCDD ELECTION QUESTIONNAIRE

On Election Day this year, New Jersey voters will decide on who will lead our state over the next four years as Governor. The NJCDD reached out to the major candidates in the gubernatorial election race, Lieutenant Governor Kim Guadagno and Phil Murphy, to get their perspective on issues important to state residents with developmental disabilities and their families. We share with you the responses we received.

from the Executive Director ■

Join Our #SaveMedicaidNJ Campaign



It seems apparent to all of us that the past few months have been deeply disturbing and active for the disability community. In Washington, DC, some leaders seem determined to dismantle Medicaid, the safety net for millions of Americans. In New Jersey, the state system for people with disabilities continues to go through critical changes that have at times been difficult for families and self advocates to work with.

In these challenging times, the Council has lost a committed and valuable leader, as Stephanie Pratico has decided to step down as Council Chair. We regret that loss and wish Stephanie the best as she moves forward in her advocacy activities. Fortunately, we are able to welcome a new chair of our Council. Paul Blaustein, of Edison, a vocal advocate who has taken on this important role, will lead our charge to fight for the future of Medicaid and self advocate and family involvement in changes in New Jersey. We welcome Paul and appreciate the guidance and wisdom he brings at the leadership level.



Kevin Casey

We also want to thank Myrta Rosa for stepping in as Acting Council Chair during the transition between Paul and Stephanie. Fortunately, we will still have Myrta's guidance and insights available to us, as she remains Vice-Chair of the Council (a position she was voted in to at our Council meeting on July 27).

But as unsettling as it has been to listen to the debate on cutting Medicaid, the immediate response from the disability community has been superb.

I believe that Medicaid has remained intact, to date, because of the many phone calls, emails, letters, and one-on-one conversations that people with disabilities, their lived-ones, and other disability advocates have had with elected leaders, stressing the critical importance of this federal program and demanding their support. In Washington, demonstrations involving national advocacy groups such as ADAPT have been nothing short of heroic.

I am proud the New Jersey Council on Developmental Disabilities (NJCDD) has been on the front lines of the intensive, on-going battle within our state. We remain fiercely non-partisan, only focused on raising awareness of issues and policies that can be detrimental to people with

developmental disabilities and their critical support network.

In our advocacy role, we have authored opinion-editorials that have been placed in major news outlets across the region, underscoring the value of Medicaid and the need for federal lawmakers to support the needs of people with developmental disabilities. We have worked closely with our advocacy partners, lending a unified, ever-increasing voice to amplify this important issue across all sectors of government.

Many of you have written letters to the editor that have been placed in media, as well, showing our elected leaders that we are engaged and mobilized for a fight that will take as long as required. We are not silent, nor do we plan to be. The stakes are too high.

The NJCDD has worked on many of the public affairs projects you have seen in recent weeks. For example, I was happy to recently appear on a morning radio show in New Brunswick with a host who quickly recognized the importance of people within the disability community speaking up.

We are calling our work the **#SaveMedicaidNJ** campaign, which was a key focus area of our Developmental Disabilities Advocacy Summit held on October 13.

This fight is nowhere near over, sadly. We must continue to monitor the ongoing, ever-changing push for healthcare legislation that continually attacks Medicaid, as many on Capitol Hill are focused on the mid-term elections next November and the role this front-burner issue will play.

We all know what is at stake: Medicaid pays for trips to the doctor, for prescriptions, for medical equipment, for day programs, and for any and all emergencies. It permeates through all special education services, for the salaries of Direct Service Professionals, for supported employment, and on and on.

Together, over the past 40 years, disability advocates have fought every fight head-on. We celebrated the passage of the *Americans with Disabilities Act* in 1990 and have made tremendous strides to ensure compliance, modification, and full accessibility across society.



We have systematically built and shaped a system that takes people with developmental disabilities out of the shadows of institutions and into the daylight of community integration and inclusion.

But we must be constantly vigilant, evident in the debate we hear each day in Washington to cut our lifeline of benefits.

We have committed this magazine, as well as all the other resources at our disposal, to educate the public about the push to slash Medicaid. Learn the latest on our campaign website, www.savemedicaidnj.org, on our blog, on social media, and elsewhere.

We vow to remain vocal and vigilant, as the stakes are too high to be quiet. We need voices like yours to elevate the conversation, and hope that you will contact us to get involved. We need supporters to write letters, to call elected officials, to meet with our advocacy partners and to share their stories with the media.

We must be the constant drumbeat, steadily reminding our decision makers that Medicaid preserves the quality of life for millions of Americans. Without it, we are afraid, progress in this country will be driven back by decades.

Together, we cannot let that happen. Join us. Get involved. We need you.

Contact us at www.savemedicaidnj.org

Kevin Casey
Executive Director
New Jersey Council on Developmental Disabilities

Stephanie A. Pratico, Chairperson of the New Jersey Council on Developmental Disabilities, Resigns

At the New Jersey Council on Developmental Disabilities' (NJCDD) summer council meeting on July 27, Stephanie A. Pratico, Chairperson of the NJCDD since August of 2014, announced that she would be stepping down from her role on the Council effective August 01, 2017.

In accordance with the Council's By-Laws, a new Chairperson must be appointed by the Governor of New Jersey. Between August 01 and the end of September, the NJCDD's newly elected Vice Chairperson, Myrta Rosa (who was elected to this position at the July 27 Council Meeting), served as Acting Chairperson of the Council. On September 27, it was announced that NJCDD Council member Paul Blaustein has been appointed by Governor Chris Christie as the new Chair of the Council.

"We very much regret Stephanie's decision to step down as Council Chair," said NJCDD Executive Director Kevin Casey. "During the time that she has served on the Council, Stephanie has lead our advocacy efforts with vision, optimism, and determination. Her



Stephanie A. Pratico served as Chair of the NJCDD from August 2014 to August 2017

insights, both as a parent of two children with disabilities and as a seasoned advocate, have been a valuable asset to the NJCDD and have never failed to leave an impression on legislators and other decision makers who shape the policies that affect our disabilities community," he added.

Since joining the NJCDD in August of 2014, Ms. Pratico played a key role in shaping the Council's advocacy goals and activities. She actively worked to ensure that New Jersey residents

with developmental disabilities and their loved ones had a seat at the table with policymakers in the planning and implementation of support services and programs that affect their daily lives. As the Council held public meetings and worked to develop the goals and objectives for its 2017-2021 5-Year Plan, Ms. Pratico showed great leadership in ensuring that individuals with developmental disabilities from across New Jersey had the opportunity to influence the development of the Plan. In 2016, she was appointed by Elizabeth Shea, Assistant Commissioner of the NJ Division of Developmental Disabilities (DDD), to serve on DDD's newly formed Family Advisory

Council (FAC), enabling her to ensure that families have as much involvement as possible in policies developed by the Division. The FAC serves as an official advisory group for family members of individuals with developmental disabilities who are served by DDD, and provides direct input in all areas of family support, including the Supports Program, Community Care Waiver, and with regard to individuals living both in-home and out-of-home.

Most recently, Ms. Pratico led the NJCDD's efforts to urge federal legislators to reject the over \$1.4 trillion in proposed cuts to Medicaid that were included with Congress' 2017 Healthcare Legislation and the President's Budget Proposal for FY-2018. In op-eds, interviews with print and television news outlets, and in-person meetings with federal legislators in both political parties, Stephanie conveyed the enormous

influence that Medicaid funding has on the supports and services that are vital to the health and dignity of her family and her children in ways that were incisive, sincere, and deeply compelling.

"While her work as an advocate shows no signs of stopping, we at the Council will greatly miss her leadership. I hope you'll join us in wishing her well in all her future endeavors," said Kevin Casey.

The NJCDD would also like to recognize our new Vice-Chair, Myrta Rosa, for her leadership as Acting Chairperson in the months prior to the Governor appointing a new Council Chairperson.

Finally, we congratulate Paul Blaustein on his appointment as Chair of the Council. All Council members and staff look forward to continuing our advocacy mission under this new leadership.

Eye-Opening Documentary Highlights a Team of Swimmers With Autism

By: Taylor Pitman

From: The Huffington Post – October 03, 2017

A documentary about a swim team dives into the complexity of kids with autism and their successes in the pool.

"Swim Team" aired on PBS on Monday, October 2 as part of its "Point of View" showcase of documentaries. Filmmaker Lara Stolman puts the spotlight on the Jersey Hammerheads, a swim team in New Jersey made up of teens and young adults on the

autism spectrum, and its founders, Mike and Maria McQuay.

Stolman's 11-year-old son was diagnosed with autism in 2008. Since the family lived in a neighborhood with several backyard pools, Stolman made it a priority to have her son learn how to swim as soon as possible. While doing research, she learned about the Jersey Hammerheads and the

mission behind the team.

“Families raising children with developmental disabilities are often told what their child can’t do or won’t do, and our children are often segregated from their typical peers at an early age,” Stolman told *HuffPost*. “Coach Mike told me he was starting a new team and his team would ‘dominate the competition.’ He was saying ‘yes’ despite all the ‘no’s’ I had been told.”

Though her son was too young at the time to swim on the team, Stolman knew the Hammerheads’ story needed to be told. Her documentary covers Mike and Maria’s relationship with their son, Mikey, a swimmer on the team who has autism and a passion for animals. She also explores the lives of other team members, including one swimmer who has autism and Tourette’s syndrome, loves shopping at Goodwill, and has a



Promotional poster for the documentary film, *Swim Team*

job around town, and another who learns more about his diagnosis from his mom, becomes a leader of the Hammerheads and later becomes captain of the swim team at his high school.

Stolman said it was “a joy” working with the swimmers and noted that she felt like she was part of the team while filming.

“At first, they all waved at the cameras and crew and it took some time to teach the children on the team not to make faces and wave,” she said. “But pretty soon, they all became used to us and forgot what we were doing there.”

Stolman hopes “Swim Team” educates people about autism

and the abilities of people who have it.

“Too often, these kids and adults are excluded from public school, community recreation and employment opportunities and yet they have so much to offer,” she said.

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Stay informed on important
developmental disability news from
around our state



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

Saddle Brook Autism Advocate Leads NJ Disability Pride Parade

By: Lauren Kidd Ferguson

From: Saddle Brook-Elmwood Daily Voice – September 29, 2017



Disabilities advocate Ryan Roy with his wife and daughter.

A Saddle Brook autism advocate was named grand marshal of the 2017 New Jersey Disability Pride Parade.

Ryan Mathew Roy, who lives in Saddle Brook with his wife and young son, lead hundreds of people representing a wide range of disabilities during the seventh annual march in Trenton.

The purpose of the parade is to bring people, organizations, and businesses from throughout New Jersey together to raise awareness and celebrate pride with the disability community.

“Having a disability is very natural and beautiful part of human diversity,” said Roy, who is on the autism spectrum.

He said he believes in the power of empathy.

“Developing empathy has helped me be the ‘voice’ for myself and other friends who are on the

autism spectrum, as well as how to understand how having an ASD affects their life,” he said.

Roy is a graduate of Partners in Policymaking, an 8-month leadership developmental and advocacy education program for adults with developmental disabilities and parents, sponsored by the New Jersey Council on Developmental Disabilities.

He also serves on the Bergen Regional Advocacy Network for Bergen County’s People’s First, Bergen County Community Transportation Advisory Committee, Saddle Brook’s Access for All Committee, the Board of Directors for The Learning Community for Person Centered Practices, and the Post 21 Club, and is a peer mentor for Neighbour’s Inc.

The parade took place on Saturday, Oct. 7, in Trenton.

Brenda Considine Receives A 2017 Ann Klein Award From the Community Health Law Project

The New Jersey Council on Developmental Disabilities and the Editorial Board of *People & Families Magazine* is proud to congratulate one of our long-time writers, Brenda Considine, for being honored by the NJ Community Health Law Project at their annual Ann Klein Awards ceremony.

Brenda has been a writer for *People & Families* for more than 20 years, but has been a developmental disabilities and special education advocate for far longer. She has held professional positions in the field of government relations and public policy as it relates to people with developmental disabilities and their families since 1984.

She began as a research intern at Douglass Developmental Disabilities Center working with children with autism. Later, she served as Autism New Jersey's first Director of Legislative Affairs, where she worked to engage families in influencing policy at the state and federal level; edited and produced clinical and advocacy communications, consumer guides, and resource directories; and helped to establish the agency's parent education programs, and robust information and referral capacities.

As Director of Government Affairs at The Arc of New Jersey, Brenda coordinated grassroots education campaigns to increase funding for community-based housing, improve special education options for students with significant disabilities, and establish a system of Family Support Services in New Jersey and organized annual Get Out the Vote campaigns. Since 1996, she has managed and

expanded the New Jersey Coalition for Special Education Funding Reform.

In 1997, she and her husband, Rick, founded Considine Communication Strategies, providing comprehensive communication services to state agencies, non-profit organizations, advocacy groups, and small businesses dedicated to serving people with developmental disabilities. As a writer, trainer, strategic communications planner, and policy consultant, she has been the principle author of influential legislative and administrative policy reports in the areas of special education and human services, along with scores of advocacy guides and booklets designed for families. She testifies frequently before the New Jersey legislature and leaders in Washington, DC on matters of disability policy. She has served as a trainer for the New Jersey Council on Developmental Disabilities' Partners in Policymaking and Project Take Charge programs. For more than 20 years, she has been a contributing writer for *People & Families* magazine and since 1994, has served as editor in chief of *Common Ground*, an NJCDD-funded publication designed to engage a diverse community of stakeholders in special education.

Brenda has held volunteer and board positions at the Alpine Learning Group, Advocates for Children of New Jersey (ACNJ), the Commissioner's Advisory Council for Special Education, the New Jersey Task Force On Special Education. She has also been trained to serve as a Court Appointed Special Advocate (CASA) for foster children in Mercer County.

She and her husband Rick live in Hopewell New Jersey. They are proud parents to two amazing young adults—Penner, age 23 and Callie, age 21.

The Community Health Law Project's Ann Klein Advocate Awards have been held each year since 1988 to honor Ann Klein, former Commissioner of the New Jersey Department of Human Services, who was instrumental in establishing a community-based system of care for people with mental and physical disabilities. Past honorees have included legislators, scientists, advocates, corporate leaders, reporters, and entertainers. Past Masters of Ceremonies have included Governor Brendan Byrne, actress Olympia Dukakis, and former Attorney General Robert Del Tufo. Proceeds from the event are used each year to support student interns in law, social work, and public policy, and for the general support of CHLP services and programs.

The 30th Annual Ann Klein Advocate Awards took place on Thursday, October 19 at The

Wilshire Grand Hotel in West Orange, NJ. This year's Ann Klein honorees are:

Brenda Considine, President & CEO, Considine Communication Strategies

Gary S. Horan, President & CEO, Trinitas Regional Medical Center

Gail Levinson, Executive Director (Retired), Supportive Housing Association of New Jersey (SHA)

James Romer, Director, Mental Health Crisis Services, Monmouth Medical Center

Laura Williams, Executive Director, The Arc, Ocean County Chapter

(Mike Lione Accessibility Award Winner)

Eileen Goff, President/CEO (Retired), Heightened Independence and Progress (hip)



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Nonprofit Wants To Create 130K Jobs For People With Disabilities

By: Shaun Heasley

From: DisabilityScoop.com — September 27, 2017



Photo Courtesy of Creative Spirit

A new effort with the backing of some major names in the advertising industry is launching with an ambitious goal: create 130,000 jobs for people with developmental disabilities by 2020.

Leaders of several New York advertising agencies are coming together to form the non-profit Creative Spirit, which will work to grow employment opportunities for those with intellectual and developmental disabilities at advertising, media, marketing, and technology firms across the country.

The group is looking to make a dent in what they say is an estimated 8 million Americans with intellectual and developmental disabilities who lack integrated employment.

“This is a global crisis, and likely the most profound human rights employment issue of our time, yet it goes unsolved,” said Laurel Rossi,

co-founder and CEO of Creative Spirit and chief marketing officer at the marketing agency Rauxa. “We believe that if the private sector comes together with its collective voice—and with the use of technology—that we can solve this problem at scale.”

Creative Spirit is launching this week with a series of activities at Advertising Week in New York where an initial campaign to promote the nonprofit was unveiled. Plans include a \$200,000 media push to create awareness of the need for integrated employment at fair wages for people with developmental disabilities.

The idea for Creative Spirit originated in Australia in 2009. Earlier this year, two people with developmental disabilities were hired at Rauxa’s New York and Costa Mesa, Calif. offices as a pilot program in this country.

Already, those behind Creative Spirit say they have more than 50 employers including A&E Networks and the advertising agencies Fallon, Joan Creative and Deutsch who are looking to offer positions. The nonprofit said it will provide employment specialists and other supports to help participating companies effectively incorporate new hires with autism, Down syndrome, and other disabilities.

Those with developmental disabilities who

are interested in finding a job can sign up on the group's website to learn about available opportunities.

"There are few times when you can truly impact the industry status quo. We have that opportunity—right here, right now—with the launch of Creative Spirit, and we are really proud to bring the cause to life in North America," said Andy Bird, chief creative officer at the advertising agency Publicis New York.

The New Jersey
Council on
Developmental
Disabilities



Want to Become a Council Member?

To recommend yourself or someone else to be a member of the Council, follow the steps below:

On the website: www.state.nj.us

On the top, blue tab, choose → Government

On the left hand side, choose → Governor's Office

On the top, red tab, choose → Administration

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Follow the instructions for submitting the required information, and be sure to include that you are interested in becoming a member of the New Jersey Council on Developmental Disabilities.

Or contact the Governor's Appointments Office:

Phone: 609-777-0251

Fax: 609-777-0331

Council Members are appointed by the Governor. Membership is open to New Jersey residents who have a developmental disability or are immediate family members of someone with a developmental disability.

Council members review the state's service systems for people with developmental disabilities, advise policy makers on the best ways to change those systems to better serve the population, and promote the goals of the federal Developmental Disabilities Assistance and Bill of Rights Act. Members review and award grants to spark innovative projects throughout New Jersey. The Council and its individual members also advocate for people with developmental disabilities and their families on an on-going basis.

For more information about the Council visit our web site: www.njcdd.org

Disability Advocates Arrested Protesting Medicaid Cuts

By: Michelle Diamant

From: DisabilityScoop.com — September 26, 2017

Over 100 disability rights advocates were arrested while protesting Medicaid changes in a proposal to overhaul the nation’s health care system. Hours later, the GOP plan appeared doomed.

U.S. Capitol Police forcibly removed 15 activists—many in wheelchairs—from a Senate Finance Committee hearing on Capitol Hill on Monday, September 25 after their roaring chants of “no cuts to Medicaid, save our liberty” delayed senators from proceeding.

The protesters were dragged from the hearing room as lawmakers looked on. Another 166 demonstrators were arrested in the adjacent hallway.

Some were charged with disruption of Congress, while others were cited for crowding, obstructing or incommoding and a portion of the demonstrators also faced charges of resisting arrest, according to Capitol Police.

The majority of those detained were members of the disability rights group ADAPT who came from across the country to oppose the Graham-Cassidy bill, which would repeal the *Affordable Care Act* and fundamentally alter Medicaid.

By Monday evening, the Republican proposal appeared to be nearing collapse as Sen. Susan Collins, R-Maine, joined Sens. John McCain, R-Ariz., and Rand Paul, R-Ky., in announcing that she would oppose the measure. With Democrats and independents against the plan, Republicans could not afford to lose more than two votes from their own party.

Collins’ announcement followed the release of a preliminary analysis of the Graham-Cassidy

bill from the nonpartisan Congressional Budget Office indicating that the plan would leave “millions” without health insurance.

The GOP proposal would grant states significantly more discretion over health care and impose first-ever caps on Medicaid. Under the plan, federal spending on Medicaid would be reduced by about \$1 trillion between now and 2026, according to the CBO analysis.

That would leave states to chip in more of their own funds or cut costs by reducing payments to providers, restricting eligibility, slashing optional services or enhancing program efficiency. States would likely resort to a mix of those approaches, the budget office said.

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Disability advocacy groups have united against the proposal, arguing that cuts to Medicaid would lead states to curtail home and community-based services, which are considered optional.

“Forcing disabled people and seniors into institutions just to pay for tax cuts, which is what this bill does, is not equality. It’s not liberty,” said Dawn Russell, an ADAPT organizer from Denver. “Graham-Cassidy is a policy for a much crueler and meaner country than this one, and the people who support it should be ashamed of themselves.”

The renewed push to repeal the *Affordable*

Care Act came as the clock ticked for Republicans. Thanks to a procedural maneuver, a health care bill could pass with only a simple majority by Sept. 30. Beyond then, however, 60 votes would be needed.

Even with momentum for the Republican plan waning, disability advocates are continuing to push their members to call senators.

“The danger right now is if Senate offices think that folks aren’t as outraged about this bill as the last, so every individual voice adds to the overwhelming wall of pressure we’re fighting to maintain,” said Julia Bascom, executive director of the Autistic Self Advocacy Network. **P&F**

Disability in FOCUS

Presenting Facts Sharing Views Starting Conversations

Take a closer look at important DD issues!

Visit the NJCDD's Blog, **Disability in Focus** each week to get the latest news and views from around the state and across the country about our developmental disabilities communities. And be sure to join the conversation by sharing your own views on the topics we discuss.

We Can't Wait to Hear From You!
Visit us at www.njcdd.org

Make it Happen

NJCDD

NEW JERSEY COUNCIL ON
DEVELOPMENTAL DISABILITIES

Public Policy and Advocacy Update Fall 2017

By Robert Titus,
Public Policy Coordinator, NJ Council on Developmental Disabilities

The combined efforts of the Morris County Special Parents Group, the Statewide Regional Family Support Planning Councils, and the NJ Council on Developmental Disabilities (NJCDD) to initiate heightened state attention with regard to family input produced an October 13th **Developmental Disability Advocacy Summit** in Hamilton. In advance of this event, meetings with key legislators took place. This article is meant to provide clarity on what has transpired as of the time of this magazine's publication.

Family advocates Kathy Wingfield, Kathy Freeman, and Tara Montague, along with Robert

Titus from the NJCDD, met with NJ Assembly Majority Leader Louis Greenwald and Legislative Director Jennifer Lehman, and with Jade Mostyn from the Majority Office on September 21st. There followed a productive hour-long meeting with the Majority Leader and commitments to future collaboration towards resolving issues faced by families in the I/DD community. Noting that we all face a "black hole" of inactivity pending the election of a new administration, it was suggested that families and advocates utilize the time between now and January, 2018 to articulate and formalize their requests concerning DHS/

DDD policies into possible legislation by working with Jennifer and Jade. Robert Titus has begun to facilitate further meetings with the participants following the Summit on October 13.

Assemblyman Greenwald is a longtime friend of and advocate for the intellectual and developmental disabilities (I/DD) community. He sponsored bills to address the problem of institutionalization in meaningful ways, despite the opposition of members of the Democratic base and families uncomfortable with deinstitutionalization. At the meeting, he challenged the participants to provide answers that he vowed to promote with legislation. All family members agreed: "Is this not what we all want: to have input into decision-making? We must be responsive to this outreach!"

This was a promising start to our efforts. Our next meeting was with Women and Children Committee Chair Pamela Lampitt on September 22 in Voorhees. Assemblywoman Lampitt was awarded the NJCDD's Community Building Award for Exceptional Policymaking in 2016 for her dedication to advancing integration through legislation for the I/DD community. Attending were family members Joe and Michaelle Hall, Kathy Freeman, Kathy Wigfield, and Robert Titus. Several issues we brought up to Assemblywoman Lampitt: (1) How do other states handle payment for fee-for-service. Do states receive electronic payment, for example, from Supplemental Security Income (SSI)? (2) In Pennsylvania, until what age are people with disabilities covered through their parents' employer?

The Assemblywoman presented a sensible initiative: family members can submit names of experienced and family-friendly persons for leadership appointments in the incoming administration. The best way to address departmental policies is to be on the new administration's "radar". The family participants then described how this has already begun at other events.

Advocates Ann Martinelli, Peter Philips, Dinah Fox, and Robert Titus met with

Assemblywoman Valerie Vainieri Huttle, Chair of the Assembly Human Services Committee, on September 27, 2017 to address the concerns of families who are assisting a loved one to self-direct their supports and services. After introductions, Peter thanked her for her consistent support, especially for the Committee hearing on June 15, to address the concerns of our community.

Assemblywoman Vainieri Huttle and her staff listened attentively as Dinah described frustration at not being at the table when decisions are made that directly affect in-home care. Currently, the advocates said, families are not part of policy discussion. Our adult children must live with the consequences of all decisions that are made by inexperienced officials.

Also outlined were the continuing issues with the new fiscal intermediary, Public Partnerships, LLC (PPL); the need for indemnification from DHS regarding individuals or family members being the employer of record; having a choice of the agency with choice model (as in the past) or a vendor fiscal intermediary (PA is currently doing this); lack of health and other benefits for full time direct support staff; and not being able to access increased budgets until fee-for-service implementation is completed.

The Assemblywoman did appear to be surprised at the continued difficulties families are encountering with PPL at three months post transition. Advocates reiterated that only 100 families with self-hired staff (out of thousands total) have transitioned.

Assemblywoman Vainieri Huttle addressed each concern and offered specific suggestions. She will continue her ongoing conversation with Commissioner Connolly regarding the indemnification, health and other benefits, and the individual budget issues. She strongly encouraged families to reach out to the gubernatorial candidates now and once we have a new governor, to press him/her with these issues. Also, the

Assemblywoman recommended reaching out to the transition team immediately after the election to ensure that knowledgeable voices will be heard. She intimated that the self-directed community is smaller than the provider-managed community, and that it will be an uphill battle. Robert Titus expressed an opinion that the administrative changes have made keeping a loved one at home more difficult, at least in the short run. Ann noted after the meeting that legislators in general do not understand the urgency of the issues that self-directed employers face in everyday practical terms. She noted, “We have to use our voices to draw in every legislator and the typical taxpayer with the message ‘self-directed supports and services save the state money!’”

Peter provided a list of six suggestions for DHS to Chair Vainieri Huttle, summed up as:

- 1) Delay the current transition to the new Fiscal Intermediary (FI) until April 1, 2018, allowing PPL to test systems and be fully prepared to appropriately handle the transition from Easter Seals of NJ.
- 2) Appoint competent administrators to the Department of Human Services (DHS) and Division of Developmental Disabilities (DDD).
- 3) Respect consumers, parents, and guardians by assuring that **NO CHANGES, WITHOUT INPUT FROM CONSUMERS**, will take place in the future. All changes to delivery systems must be developed with input from informed, competent users and documented.
- 4) A new Request for Proposals (RFP) for a fiscal intermediary (FI) requiring a Vendor/FI, (currently PPL), and AWC (Agency With Choice, formerly Easter Seals). This dual system is used in Pennsylvania and satisfies the needs of all

consumers. Those that want total control and responsibility as the employer of record can chose the Vendor/FI while others will have the option of AWC, where the FI is the employer of record thereby shielding the families from payroll and billing liabilities.

- 5) A commitment from the candidates for governor that all full-time employees employed in the Self-Directed Services (SDS) program will have access to employee benefits comparable to those of state employees in benefits and costs.
- 6) A complete review with consumer input of newly required training programs being implemented by DDD for SDE families with the objective of eliminating redundancies and insuring effectiveness. Parents and capable consumers have already trained staff to meet there needs. Proposed training is not needed, will cause disruption, and will be costly to the state; there must be a simpler legal process to prove training has taken place should a lawsuit arise.

After the meeting, Dinah agreed to use these proposals for discussion at the October 13 Advocacy Summit. Following the Summit, advocates are developing an action agenda to be used in collaboration with legislators, their staff, and the newly-elected administration. Meetings with other key legislators are scheduled through the fall. Strong and informed family voices are still needed. Contact the NJCDD Statewide Family Support Coordinator Kyoko Coco (kyoko.coco@njcdd.org) or Public Policy Coordinator, Robert Titus (robert.titus@njcdd.org) to volunteer.

Many thanks to Kathy Freeman, Kathy Wigfield, Joe and Michaelle Hall, Ann Martinelli, Dinah Fox, and Peter Phillips for contributing to this article. **P&F**

Lorrimer sanctuary



Bringing the Great Outdoors to People with Disabilities

By Jonathan Jaffe

At the New Jersey Audubon in Franklin Lakes, NJ, the Lorrimer Sanctuary is where Broadway Respite, a day program for people with disabilities in Fair Lawn, NJ came to learn about the environment on a recent trip in September. Guide Patrick Scheuer holds a pinecone that was found on the trail. (also pictured: Nick G. and Ally G.)



Stefania S. touching a turtle shell

For Valerie MacFie, creating a wildlife trail for people with developmental disabilities is money well spent.

And so, in her role as a trustee with the John Ben Snow Memorial Trust, she made sure New Jersey Audubon had the funding to create a new feature at the Lorrimer Sanctuary in Franklin Lakes, ensuring all people have the opportunity to enjoy the splendor of nature. Additional funding to the wildlife trail was graciously provided by the E.J. Grassmann Trust.

“I have a sister with special needs, so these trails are near and dear to my heart,” MacFie said. “The work being done at Lorrimer sanctuary really spoke to me, especially as it seems that outdoor educational opportunities for people with developmental disabilities tend to disappear as they get older. It becomes harder for them to enjoy the environment. It is an opportunity that should be available for a lifetime.”

The 1,200-foot-long trail system, part of a sanctuary bequeathed to New Jersey Audubon in 1956, meanders through a 14-acre parcel in otherwise busy Bergen County. The woods are filled with oak, maple, ash, and beech trees, as well as a garden with a variety of native flowers and planted evergreens. There are plenty of birds and butterflies at the fingertips of those who pass through.

The accessibility trail, right off the parking lot, is open throughout the year to groups from local day programs, which accommodate people with developmental disabilities. The trail is wide and smooth for those who may need assistance from wheelchairs, walkers, and other accessibility devices.

The trail, along Ewing Avenue, opened three years ago. The first grant from the John Ben Snow Memorial Trust funded construction of a trail fully compliant with the federal *Americans with Disabilities Act*. Then, the trust followed up with additional support for programming, making it possible for New Jersey Audubon to develop programs and create educational materials for people with disabilities.

Patrick Scheuer, sanctuary director, said one of the popular programs for people with disabilities is a scavenger hunt. New Jersey Audubon staff place a variety of items off the trail, such as a deer antler, a turtle shell, a bird’s nest, and a feather, used for the hunt.

Through the grants, New Jersey Audubon was able to purchase technology, such as tablets, that visiting groups can use to learn the songs of various birds in the sanctuary and to readily access images.

One such group is Broadway Respite and Home Care in Fair Lawn, which services people with developmental disabilities in day programs, residential facilities, and in-home services. The day program serves people ages 21 and over.

“We go on trips every day and we like to keep things interesting and educational, and to allow for skill development,” said Alex Perri, director of day habilitation services at Broadway. “We are always online, looking for things that can be fun. So we decided to reach out to New Jersey Audubon and we learned all about Lorrimer sanctuary.”

Perri said her clients “absolutely loved” visiting the sanctuary, learning more about the environment and exploring. “That’s really the goal of our program,” she said. “And New Jersey Audubon fits perfectly.”

Broadway now sends about three groups a year to the Lorrimer sanctuary during the warmer months. Many of the participants have autism, cerebral palsy, or other disabilities that limit mobility. The tour, each with between 10 and 15 participants, typically begins at 10am and wraps up by noon.

During a recent trip on a late summer day, Eionnia Perrington of Teaneck was taking a tour with Scheuer. Perrington, who has autism, said she was drawn to the butterflies as she participated in a scavenger hunt.

“I really like being here and walking the trails,” Perrington said. “It’s so much fun.”

Scheuer said there are plenty of programs this fall that are ideal for people with disabilities.

There is an apple cider-making class, featuring an antique press. Participants learn about apple trees, collect apples, and feed them into the hand-operated press.

There are also tours that show the changing leaves, migrating birds, and other signs of harvest season.

“What really makes this nature sanctuary special is its close proximity to one of the most densely-populated regions in the country,” Scheuer said. “This is a rare open space that has been preserved as a sanctuary, designed to attract wildlife, but is also fully accessible to people with disabilities.”

Lorrimer sanctuary also includes a visitors’ center, with an exhibit and lecture room, winter bird feeding station, interpretive displays, hands-on exhibits, and a gift shop, the proceeds of which benefit the sanctuary.

Learn more about the Lorrimer sanctuary at www.njaudubon.org **P&F**

Broadway Respite program participants learn about indigenous plants and animals. (From Left: Chris P., Melissa M., Billy Joe M., Mark H., Guide Patrick Scheuer, Kyran C.)





Medicaid and Special Education

By Brenda Considine

In 2015, Medicaid paid nearly \$4 billion in school-based services including nursing, social workers, medical equipment, and speech, occupation, and physical therapies.

—Photo courtesy of North Jersey Elks Developmental Disabilities Agency (NJEDDA)

Six-year-old Yolanda might think that the time she spends with her teachers and therapists is just for fun. The room is filled with brightly colored soft foam tubes, puzzles, rollers, and swings. But the therapies she is receiving as part of her special education services are being delivered by credentialed professionals, and the ‘games’ are very intentional, designed to strengthen and flex muscles, build communication skills, and improve her ability to grasp. These services, and those of hundreds of thousands of other New Jersey School children, are funded in part through Medicaid.

Medicaid is a successful government-operated, single-payer health program established in 1965 as part of President Lyndon Johnson’s “Great Society.” The nation’s largest single source of health insurance, Medicaid covers one out of five Americans with very low income—more than 72.5 million people, including 40% of the nation’s children. In New Jersey, more than 540,000 children receive insurance through Medicaid.

Medicaid and Medicare are sometimes confused: Medicare is a government-run, single-payer universal health insurance program for everyone 65 and older, and is funded through

federal payroll taxes. Medicaid is a state and federal program of health coverage for low-income Americans of any age. The program is administered by states under general rules from Washington, DC and has become the biggest source of federal funding for states.

Medicaid in Schools

For the last 30 years, Medicaid has been extended to help cover the cost of health-related services delivered in a school setting. According to the Centers for Medicare and Medicaid Service (CMS), in 2015, Medicaid paid for nearly \$4 billion in school-based ‘health-related’ services for eligible students, including nurses, social workers, physical, occupational and speech therapists, and medical equipment such as walkers and wheelchairs. It also pays for preventive and comprehensive health services for poor children, including immunizations, screening for hearing and vision problems, and management of chronic conditions like asthma and diabetes.

“Medicaid is a critical part of infrastructure and funding for schools, and helps fund many programs, including the Early Periodic Screening Diagnostic and Treatment (EPSDT) benefit,” explained Peg Kinsell, director of institutional and policy advocacy at the Statewide Parent Advocacy Network (SPAN). Under EPSDT, children and adolescents under the age of 21 have guaranteed access to a robust set of comprehensive and preventive health services, including regular well-child exams; hearing, vision and dental screenings; and other services to treat physical, mental, and developmental illnesses and disabilities. The EPSDT benefit also covers medically necessary supplies and equipment that help students in schools, such as hearing aids, eyeglasses, wheelchairs, and other assistive technology to help students hear and see.

Medicaid funding in schools benefits all children, not just those enrolled in the program. In a recent survey of school superintendents, almost half reported that they use the reimbursement their districts receive for services provided to Medicaid-eligible children to expand health-related services and supplies. This includes programs that monitor the healthcare needs of

Long-Term Benefits

Children who are eligible for Medicaid Health Care Coverage:

- Do better in school.
- Miss fewer days due to illness or injury.
- Are more likely to finish high school, attend college, and graduate from college.
- Have fewer Emergency Room visits and hospitalizations as adults.
- Earn more as adults.

(from the Center for Budget and Policy Priorities)

eligible children with certain conditions such as asthma and diabetes as well as operating clinics within schools to provide dental care to Medicaid-eligible children.

Medicaid Funding and Special Education

Medicaid is a significant funding source for special education in the Garden State. According to data released by the Washington, DC-based Center on Budget and Policy Priorities, New Jersey spent nearly \$287 million on school-based Medicaid services, some \$143 million of which came from the federal government and the rest from state dollars, according to the center’s report. Only Texas, Michigan, and Illinois received more federal funding.

Though it makes up a small fraction of federal money that public schools receive, Medicaid is considered a vital funding supplement for schools to provide federally mandated special education services through the *Individuals with Disabilities Education Act* (IDEA). Adopted in 1975, federal funding for IDEA has fallen short of the congressional promise of “full funding” of 40% of costs—in fact, the federal share in 2015 to help states cover excess costs is roughly \$15 billion—just 16% of the cost.



A variety of in-school therapies and services for students with developmental disabilities are funded in part by Medicaid dollars.

—Photo courtesy of North Jersey Elks Developmental Disabilities Agency (NJEDDA)

Since 1994, New Jersey has participated in a federal program, Special Education Medicaid Initiative (SEMI). The program assists school districts by providing partial reimbursement for medically related services listed on a student's Individualized Educational Program (IEP). Under the program, New Jersey school districts are required to maximize their participation in the program. In exchange, districts receive 35% of the federal aid, with the remainder going to the state. The SEMI program focuses on compliance and makes sure Medicaid is billed for certain health-related services considered medically necessary in each student's Individualized Education Program (IEP), including IEP meetings and evaluations.

The New Jersey Medicaid Administrative Claiming (MAC) program augments the SEMI program by recovering some of the costs associated with school-based health and outreach activities, such as client assistance to access Medicaid services, care, planning, and coordination for medical or mental health services, and facilitating an application for Medicaid. Such innovations have enabled the state to make local education

dollars go further toward meeting the legally required needs of special education students and those with disabilities.

Considerations for Families

In 2013, the regulations regarding Medicaid parental consent for school-based services changed. Prior to accessing a child's public benefits or insurance for the first time, and annually thereafter, school districts must provide parents/guardians written notification and obtain a one-time parental consent. In most cases, Medicaid benefits at school are a win-win-win for families, students, and districts. However, Peg Kinsell warns, it can sometimes hurt families.

"We have seen cases of a child getting Medicaid services while at school, only for the parents to find out that Medicaid has reduced hours of home care. If families have intensive services, such as home-based nursing or are part of a waiver, they should be cautious. It all depends on how the services are coming into the home."

Kinsell also advises families to reconsider the issue of consent each year, even if the question does not come up at the IEP meeting.

“Families should know that once they sign permission at the IEP meeting, it is good indefinitely. That signature is your consent until you take action to withdraw permission,” she said.

The school district is required to provide services to each child pursuant to the IEP, regardless of Medicaid eligibility status or a parent’s willingness to consent. Parents have the right to withdraw consent to allow for Medicaid billing at any time by contacting the school district.

Funding In Peril

Changes to Medicaid have been at the center of political debate around health care reform, and these are of great concern to school leaders. In a recent interview with National Public Radio, Sasha Pudelski, assistant director of policy and advocacy at AASA, The School Superintendents Association, noted that virtually every student in special education could be affected by cuts to Medicaid.

“The main concern is, by this major federal disinvestment in Medicaid, we’re going to have states having to pick up the tab,” she explained.

According to the Center for American Progress, local education agencies and schools might see an average 20 percent drop in federal Medicaid funding over ten years. That would constitute a \$600 million reduction over ten years, or \$16 million less to New Jersey (2.7 percent of the nationwide cuts). The Center for American Progress also projects that 839,382 New Jersey students enrolled in Medicaid or the Children’s Health Insurance Program (CHIP) could be affected by proposed cuts to Medicaid. These proposed reductions could eliminate salaries for 339 school nurses, 267 school-based social workers, 219 school counselors or psychologists, and 270 speech-language professionals within the state.

One of the proposals for Medicaid reform being considered in Washington is to establish “block grants” which allocate a specific amount of money, rather than the open-ended promise of funding now in place. When states opt for block grants, schools may no longer receive a dedicated source of funding based on reimbursement toward cost of services. Instead, they could be forced to compete for a share of an overall statewide funding

What type of services does the School-Based Services program cover?

- Evaluations
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Psychological Counseling
- Audiology
- Nursing
- Specialized Transportation

allotment with hospitals, doctors, and health clinics. Advocates fear that schools could lose a guaranteed subsidy and Medicaid recipients in schools might lose a guaranteed right to a robust set of comprehensive and preventive health services, such as early diagnosis and treatment, eyeglasses, and assistive technology devices.

By The Numbers

1. One in five Americans is covered by Medicaid.
2. Medicaid is the nation’s largest health care provider.
3. Medicaid covers 40% of America’s children—over 30 million children.
4. Medicaid covers half of all births in America.
5. One in five Medicaid dollars is spent on children.
6. 2/3 of the school districts that bill Medicaid use the money to pay salaries of employees who work directly with children such as school nurses and therapists.
7. Medicaid reimbursement constitutes the third largest federal funding stream to our nation’s public schools.
8. Medicaid costs roughly \$553 billion dollars, with \$346 billion coming from the federal government and the remaining \$204 billion from States.
9. Nationwide, more than \$4 billion in Medicaid goes to schools, or roughly 1 percent of all Medicaid. **P&F**

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

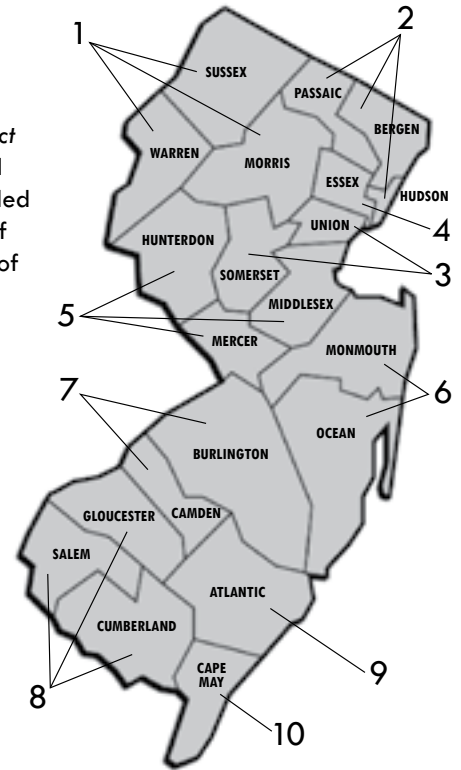
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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 living at home with their families. 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 or individuals 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.

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 a developmental disability.

The system of Family Support shall include, but not be limited to:

- | | | |
|---|--|--|
| <ul style="list-style-type: none"> • after school care • cash subsidies • communication and interpreter services • counseling services • crisis intervention • day care • equipment and supplies | <ul style="list-style-type: none"> • estate and transition planning • home and vehicle modification • home health services • homemaker assistance • housing assistance • medical and dental care not otherwise covered • parent education and training • personal assistance services • recreation services | <ul style="list-style-type: none"> • respite care for families • self advocacy training • service coordination • specialized diagnosis and evaluation • specialized nutrition and clothing • therapeutic or nursing services • transportation • vouchers |
|---|--|--|

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
PO Box 12
Pompton Plains, NJ 07444
e-mail: rfspc1@gmail.com
Chair: Margaret Hefferle

Meets the third Tuesday of each month
at Morristown Memorial Hospital
100 Madison Ave.
Level B, Conference Rm. #2
Morristown, NJ 07962
7:00 p.m.—9:00 p.m.

2 BERGEN, HUDSON, PASSAIC

RFSPC#2
PO Box 443
Jersey City, NJ 07302
e-mail: RFSPC2@gmail.com
Co-Chairs: Frank Fiore, Fel Lim

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

3 SOMERSET, UNION

RFSPC#3
PO Box 5997
Hillsborough, NJ 08844
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
PO Box 1742
Bloomfield, NJ 07003
e-mail: rfspc4@yahoo.com
Co-Chairs: Rebekah Novemsky,
Yolanda Smith

Meets the first Wednesday of each month
Bloomfield Civic Center Music Room
84 North Broad St.
Bloomfield, NJ 07003
7:30 p.m.—9:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5
e-mail: rfspc5nj@gmail.com
Co-Chairs: Paul Blaustein, Cheryl Crick

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
Lakewood Municipal Bldg.
231 Third St., 2nd floor
Lakewood, NJ 08701
7:30 p.m.—9:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
PO Box 700
Trenton, NJ 08625
e-mail: rfspc7@gmail.com
Chair: Lisa O'Keefe

Meets the fourth Tuesday of each month
The Arc of Camden County
215 West White Horse Pike
Berlin, NJ 08009
7:00 p.m.—9:00 p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
PO Box 700
Trenton, NJ 08625
e-mail: RFSPC8@gmail.com
Co-Chairs: Sandra Backensto,
Lisa Parles

Meeting dates posted at njccd.org
River Winds Community Center
1000 Riverwinds Dr.
West Deptford, NJ 08086
6:00 p.m.-7:30 p.m.

9 ATLANTIC

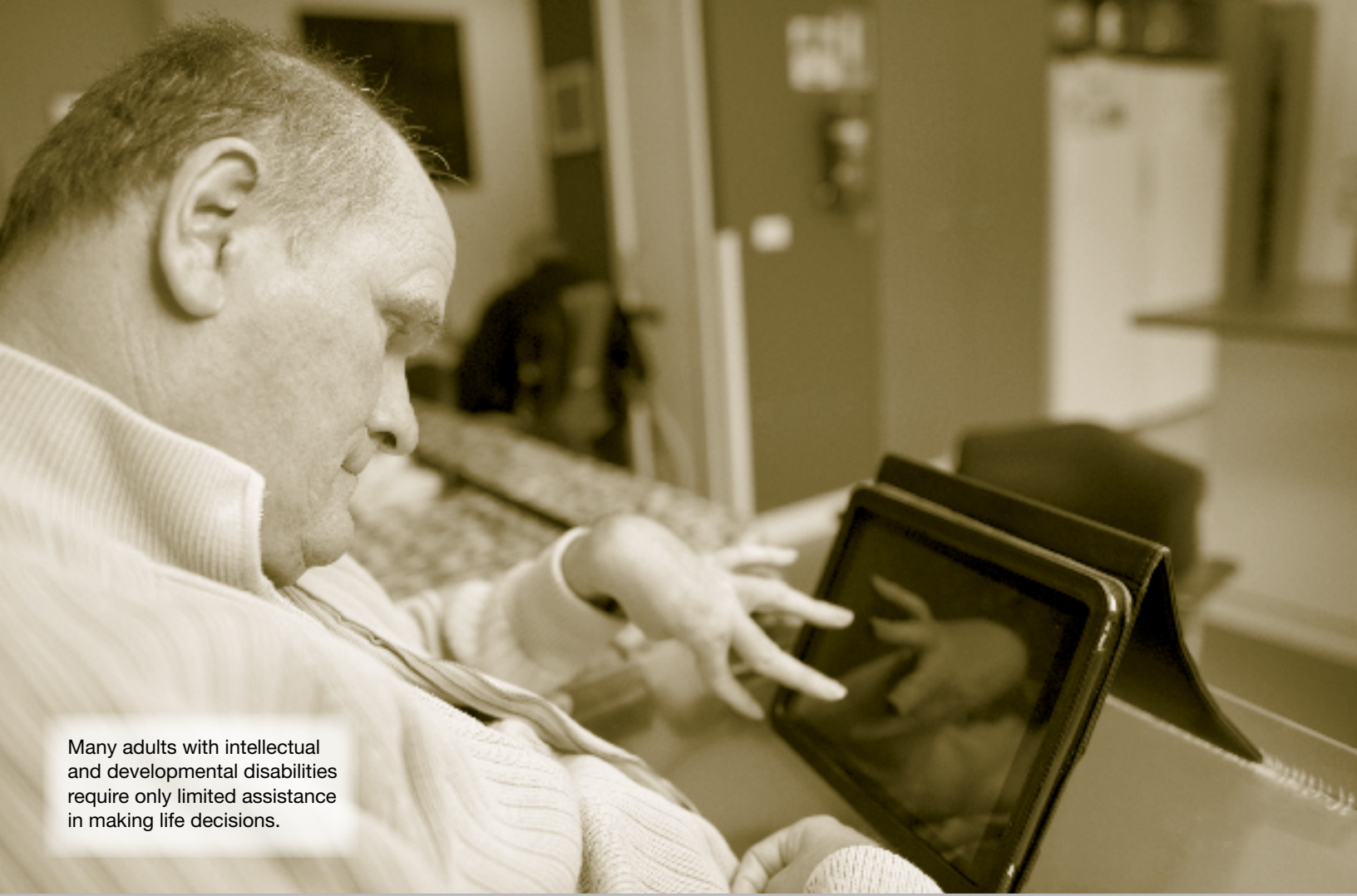
RFSPC #9
PO Box 700
Trenton, NJ 08625
e-mail: RFSPC9@yahoo.com
Chair: Mary Ann Philippi

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

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 for July, August, December,
and January
Cape May Special Services School
148 Crest Haven Dr.
Cape May Court House, NJ 08223
Meeting times TBD



Many adults with intellectual and developmental disabilities require only limited assistance in making life decisions.

When it Comes to Guardianship, There Are No Simple Answers

By Brenda Considine

In the last half century, much has improved for adults with intellectual and developmental disabilities, with an ever-growing emphasis on increased autonomy, self-direction, independence, and maximized inclusion in the community. Parents of young children with disabilities are urged to advocate for their child's freedoms and help them learn to advocate for themselves. Still, many parents are surprised to learn that at eighteen—the “age of majority” in New Jersey (or, the age in which an individual legally becomes an adult)—the law considers all young people, regardless of disability, to be

capable of making medical, financial, legal, and other decisions on their own. At that point, the young adult with intellectual and developmental disabilities may need help in the form of a surrogate decision maker.

Guardianship

If a New Jersey Superior Court Judge finds that an individual has serious limitations in making decisions, and deems that person as lacking the ability to provide “informed consent,” the judge can take away some or all of the person's rights and transfer those rights to a guardian.

While many parents and caregivers view guardianship as a necessary tool to keep their adult child with disabilities secure, safe from exploitation, and healthy, full guardianship (called “plenary guardianship”) should be viewed as a solution of last resort because it removes an individual’s fundamental right of self-determination. Accordingly, the process has a series of safeguards: a licensed physician, psychologist, or psychiatrist needs to provide a current assessment indicating that the individual lacks the capacity to make informed decisions; the case must go before a judge; and there is a need for attorney representation, both for the prospective guardian and the individual in question. Even with full guardianship, the individual typically retains the basic right to privacy; the right to vote; the right to develop friendships; and the right to have romantic and sexual relations, get married, and have children, unless the court has specifically removed these rights.

Informed Consent

The decision about whether an individual needs a guardian often centers around the concept of “informed consent.” According to S. Paul Prior, an attorney who specializes in disability law and who has a brother with autism, an individual under guardianship is technically not capable of giving legally valid informed consent in all but a small handful of circumstances. For example, an individual under guardianship still retains his or her right to vote unless that right is specifically taken away by court order.

“While informed consent is the job of the guardian, efforts should still be made to elicit meaningful input from the person with a disability, and to carefully consider that input,” said Prior.

The Role of A Guardian

We asked Ira M. Fingles, Esq. of Hinkle, Fingles, Prior and Fischer about the role of a guardian.

P&F: *What does a guardian do?*

IMF: “The guardian makes virtually all decisions about the care and treatment of the individual with disabilities, referred to in legal terms as the “ward.” The guardian decides whether to consent to surgery, or to a change of placement, such as from a group home to an apartment. The guardian would attend the service planning conference and decide whether to consent to the plan of services. The guardian would also decide whether or not to evoke the legal rights of the ward. For instance, if the guardian is dissatisfied with the services an agency provides the ward, the guardian would have authority to challenge that decision.

The guardian also makes all decisions about the property of the ward, unless that property is in a trust or consists of social security benefits. In these cases, it is the trustee and representative payee respectively who would decide how to handle this property.”

P&F: *Who should serve as guardian?*

IMF: “Since the guardian is the individual’s chief advocate, the guardian should be someone who has a deep and lasting interest in the ward and who is willing to take the time to familiarize him or herself with the needs of the ward. Typically, parents, nondisabled siblings, or other family members are the best candidates. Ideally, that person should live close to the ward, but this is not always possible. The guardian should also know or become familiar with where to turn for professional help.”

“Full guardianship flies in the face of the direction we should be moving.”

*—Peg Kinsell,
Director of Institutional and Policy Advocacy, SPAN*

“This is both a moral and legal obligation of the guardian.”

“Informed consent can have a dimension beyond any requirements of law that is rooted in respect for the dignity of life and the inherent value of every human being,” he added.

Consent has three key elements:

- 1) Capacity—The person must have the mental ability to understand the question at hand, and the known or expected consequences.
- 2) Information—The person must have information that outlines the nature of the decision or procedure in question and the possible consequences, both good and bad. It must be provided in a form that can be understood. The individual might need the information presented in a unique way, or perhaps repeated over several sessions.
- 3) Voluntariness—The person must give consent willingly and free of coercion. Forced consent is obviously invalid, but the problems of obtaining voluntary consent run deeper than this. Advocates must consider if the person with a disability is giving consent because:
 - he/she is under the custody and control of the person seeking consent and is fearful of alienating them
 - he/she wants to please the person seeking consent
 - he/she wants to appear more “normal,” i.e., like a typical person of his or her age
 - he/she lacks experience making decisions
 - he/she is unable to obtain independent advice



For each decision, it is the guardian’s responsibility to support self-direction to the maximum degree appropriate.

The absence of any one of these elements may make the consent ineffective.

Legal Options and Alternatives

Many parents will turn to full guardianship out of concern for their adult child’s safety and well-being, but there are alternatives that can help individuals retain the dignity of decision making for themselves. In fact, with the right supports, the vast majority of individuals with disabilities are able to play a primary role in decision-making.

“Often, full guardianship flies in the face of the direction in which we should be moving,” said Peg Kinsell, director of institutional and policy advocacy at the New Jersey Statewide Parent Advocacy Network (SPAN).

Guardianship is not an “all or nothing” matter. It can be temporary or permanent, depending on the needs of the individual. The types of decisions covered by guardianship also vary. Full guardianship may be appropriate for individuals who have been found incapable of making or expressing any decisions, whereas limited guardianship covers

decision-making around residential, educational, medical, legal, vocational, and financial issues. It may be appropriate for people who have been found capable of making and expressing some, but not all, decisions

“The law requires that the court consider whether limited guardianship might be appropriate before granting full guardianship,” explained Ellen Nalven, M.Ed., executive director of PLAN/NJ, a non-profit organization that provides legal, financial, and independent living supports. Studies show that even after evaluating the applicability of limited guardianship, as many as 90 percent are established as full guardianships.

There are other options for surrogate decision-making. A Power of Attorney (POA) can cover both the person and their property and finances, and can be revoked or changed at any time, based on need. The individual with a disability must be able to understand, on a basic level, that they are appointing someone to make decisions on their behalf and must be able to consent to it. A comprehensive POA can address not only financial issues, but also less immediate but important concerns such

“You spend years intervening for your child with schools and other institutions so that they can be included and as independent as possible. And then you reverse all that by stripping their power of choice and dignity by taking over as guardian.”

***—Brenda L. Figueroa,
Parent***

as life care planning, personal decision planning, medical and health care planning, and long-term care planning in a way that protects savings and income from the increasing costs of care in the future.

Brenda Figueroa is setting up a POA for her 17-year-old son who is on the autism spectrum. She is handling the paperwork herself by working with a notary to use model documents provided by the National Resource Center for Supported Decision-Making, and finds that the process is less complicated and less costly than guardianship.

“You spend years intervening for your child with schools and other institutions so that they can be included and as independent as possible. And then you reverse all that by stripping their power of choice and dignity by taking over as guardian,” she said.

In New Jersey, a court can also grant “conservatorship” to protect the finances of an adult who agrees. Since a conservatorship is granted by court order, it is legally stronger than a POA. Conservatorship in New Jersey does not cover the “person” (meaning the individual’s physical well-being). The proceeding must be voluntary, where the individual needing assistance petitions the probate court to appoint a “conservator” to manage his or her affairs.



Sometimes, a micro board or Circle of Support can help individuals with disabilities take part in decision-making.

If the individual is subject to financial manipulation or abuse, a “protective proceeding” could address exploitation more quickly than guardianship, and without the need for doctors’ reports about competency. The process does not require proof that the individual is incapacitated; only that he or she has been influenced by a predator, such as a family member, caregiver, spouse, or “friend,” and needs protection. The process is relatively quick, and often intimidates and immediately stops a predator from further action.

What Parents Need to Know Before Applying for Guardianship:

- Attendance at school IEP meetings is not dependent on a guardianship relationship. A parent can still be involved in educational planning unless the individual expressly indicates otherwise.
- Parents can still remain involved in medical issues, and might be asked to give consent as next-of-kin in an emergency.
- All applications for guardianship require an up-to-date assessment from either a psychologist or a psychiatrist licensed in the State of New Jersey, or from a licensed medical doctor.
- A guardian can be a family member, another interested person, or an agency such as the state Bureau of Guardianship Services.
- A co-guardian can also be named, each with equal decision-making authority, and must be involved together in all decisions or consents.
- Once a guardian or co-guardians have been appointed by the NJ Superior Court, only the court can modify or change the guardianship order.

Source: NJ Division of Developmental Disabilities:
<http://www.state.nj.us/humanservices/ddd/services/guardianship/>

Supported Decision-Making

Regardless of the legal structure for protection, many advocate using a process called “supported decision-making” that can help an individual by providing information they need to provide input on important decisions. This approach is about working closely with the individual and using as many forms of communication as needed.

“A person who is unable to communicate or understand may need a guardian for some things, but the vast majority of people are able to play a primary part in their decision-making, even if they get a little help to do it,” said Jonathan Martinis, Esq., project director for the National Resource Center for Supported Decision-Making.

The supported decision-making relationships can be formal or informal, ranging from a person or group of people who talk “with” but not “for” the individual with disabilities, or formal micro boards or Circles of Support.

According to Rebecca Kasen, a staff advocate at Disability Rights New Jersey, everyone uses some type of supported decision making whether they realize it or not.

“You and I don’t make 100% of our financial decisions independently. We depend in some cases on experts, CPAs, mortgage professionals, or attorneys,” said Kasen.

Supported decision-making may require a variety of communication methods and may take a little longer than it would under full guardianship, but many believe it is well worth the effort. Monique Dujue Wilson uses supported decision-making with her 31-year-old son, Khary. He is nonverbal and has a dual diagnosis of bipolar disorder, living in his own home with supports. Wilson secured full guardianship for Khary when he was 18, but does not recommend guardianship in most cases.

“As parents, we are always told that guardianship is the way to protect our children and decisions made in their adult lives,” said Wilson. “Alternatives to full guardianship were not really discussed or offered when Khary was 18, so I followed the advice to take over for him, with the assumption that I secured him the right to an independent adult life with real life experiences,” she added. **P&F**

RESOURCES

The Guardianship Association of New Jersey, Inc. (GANJI) is a not-for-profit organization of professionals, families, and individuals committed to supporting guardians and other surrogate decision makers in enhancing the lives of persons who require assistance.

www.ganji.org

Disability Rights New Jersey (DRNJ) is a private, non-profit, consumer-directed organization established to:

- Advocate for and advance the human, civil, and legal rights of NJ citizens with disabilities;
- Promote public awareness and recognition of individuals with disabilities as equally entitled members of society;
- Advise and assist persons with disabilities, family members, attorneys and guardians in obtaining and protecting the rights of individuals with disabilities; and
- Provide education, training and technical assistance to individuals with disabilities, the agencies that serve them, advocates, attorneys, professionals, courts and others.

<http://drnj.org/>

Statewide Parent Advocacy Network (SPAN) is an independent 501(c)3 organization empowering families as advocates and partners in improving education, health, and mental health outcomes.

<http://www.spanadvocacy.org/>

Hinkle, Fingles, Prior & Fischer can advise families on establishing appropriate levels of surrogate decision-making and responsibility for an individual with an intellectual or developmental disability.

<http://hinkle1.com/guardianship-protection/>

<https://www.newjerseyguardianshipattorney.com/alternativestoguardianshipnj/>

Planned Lifetime Assistance of New Jersey (PLAN/NJ) is a unique, not-for-profit agency that provides practical solutions, thus lessening the fear and anxiety families experience when planning for the future. With legal, financial, and independent living supports, PLAN/NJ's services ensure that people with disabilities are safe, secure, and thriving, now and in the future.

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

<http://www.supporteddecisionmaking.org/>

The New Jersey Department of Human Services, Division of Developmental Disabilities

<http://www.state.nj.us/humanservices/ddd/services/guardianship/>



Kevin Nuñez

Advocacy

is a Way

of Life

By Maryann B. Hunsberger

Kevin Nuñez has been advocating for as long as he can remember. The 30-year-old Willingboro, NJ resident and his twin brother, Abner, both have cerebral palsy. “I became an advocate by default. Abner is more intelligent, but he has more physical limitations. I’ve had to be his advocate for most of his life. So, I’ve always been an advocate, but I never did it in an official capacity till last year.”

Kevin completed the NJCDD’s disability advocacy training program, Partners in Policymaking, in 2007.

Last September, Nuñez became a member of the New Jersey Council on Developmental Disabilities. This isn't his first activity with the Council, however. He participated in the leadership-building program, Partners in Policymaking, in 2007, to improve his advocacy skills. A few years ago, he began thinking about serving on the Council. "It was a long process to apply. It has to be approved by both branches of the state legislature. If you aren't approved by the end of the year, you have to apply again the next year. I had to apply twice."

Nuñez serves the Council as the chair of the Planning and Grants Committee. "I help decide who gets the grants that the Council gives. For example, a few months ago, the committee approved a grant for the creation of a disability database to have a lot of disability resources in one spot. We also have input on the overall plans of the Council. We have to oversee the Council's Five-Year Plan."

As a Council member, two areas of advocacy specifically spark Nuñez's passion: the ongoing Medicaid debate and supporting Direct Support Professionals (DSPs). "These are the two biggest issues in the disability community. Nobody can afford to lose their Medicaid or have it watered down. And DSPs already lack adequate wages and benefits, so any possible cuts would add another layer to the DSP problem. Without Medicaid, there is no way to pay anyone. Disability advocates constantly have to beg for any spare change in the federal budget."

Nuñez speaks not only as an advocate, but also as someone who relies on DSP services. He would like to see a mandate giving these individuals a fair

wage and benefits, such as sick days. He believes DSPs need opportunities for promotions and growth. "They take you to the doctor but can't afford to take themselves to the doctor. They work double shifts on a few hours of sleep, which leads to burn-out, which leads to turnover. They leapfrog from company to company in the hopes of earning an extra dollar an hour. It's rare that they can advance

to become more than a DSP.

This is why many DSPs are forced to leave their jobs to get benefits and better wages."

Nuñez feels that he's losing a friend when a DSP has to leave. "They help you with very personal tasks, such as in the bathroom, and you grow to trust and bond with them. You learn each other's secrets and trust each other. You make each other laugh. It sucks when you know they have to leave eventually. You get tired of asking yourself when they walk in the door how long this will last. It's worse for nonverbal clients. Without speaking, try putting your shoes on the wrong

feet and see how long it takes someone to notice what is wrong and figure out what you need done. And when their DSP gets to know them and their needs, they have to leave, so the client goes from DSP to DSP. The cycle doesn't stop."

Informal advocacy is a way of life for the Nuñez family. "Even though we all advocate in our daily lives, I'm the only one who likes the formal aspect of advocating, so I keep my family informed on new policies affecting us. Abner is able to advocate for himself, but his verbal skills aren't always clear, so I translate what he is saying at times. I make sure he takes his medication on schedule. But, Abner is helpful to me, too. We confide in each other, lean on each other and

"We need to change people's perceptions of the disability community. We want to show that people with disabilities can have lives, can live on their own, and can do whatever anyone else can do with the right resources."

—Kevin Nuñez

look out for each other.” Abner agrees, saying, “Kevin may be a gift to the world from God, but he was my brother first.”

Since becoming a Council member, Nuñez updates Abner and his father, Felix, 50, on disability policies. “My father was our primary caregiver, but was injured on the job 20 years ago. What should have been a simple back procedure resulted in his being on disability ever since. My father has always advocated for the two of us. He is a doer, not a talker, who has always led by example and who does that very well. I think his example helped make me want to be an official advocate. He always told me nobody can read my mind, so I have to speak up.” Felix pointed out, “His legs may not work, but his mouth does. He has learned to master it as an incredible tool to help others.”

Nuñez also advocates informally at the day program he attends. “I’ve advocated for both clients and staff because what’s right is right and what’s wrong is wrong. If I see that someone needs something, I have to say something. If I see staff with a need, I help them, also. Being an advocate can go beyond the official things to the everyday life things. I participate in staff orientation for clients who don’t have families. I make sure those clients get cupcakes on their birthdays, and that the Christmas tree and menorah are up, since they don’t have families to go home to on those days. The little things matter.”

He is now writing a book about his life. He refers to it as an autobiography with a purpose. He hopes to show people that life can be good, even when it is difficult. He has titled the book, *Life Sucks, But that Doesn’t Mean You Can’t Love It*. “We get so caught up in our day-to-day routine and forget to look at the good things we have in life. Although the bad will always be there, and we



Kevin Nuñez volunteering at the NJCDD's 2012 DD Awareness Day Event at Six Flags Great Adventure

can't deny it, one of my goals is to remind people to look at the good. Every day has a thousand obstacles and I don't get a break from my disability, but I am still able to do so much. I feel that looking at life this way is helpful to me.”

Nuñez said he hopes to take the Council in a good and positive direction. He also hopes to see the Council and people with disabilities get more recognition. “A stigma exists in the community about disability. We need to change people’s perceptions of the disability community. We want to show that people with disabilities can have lives, can live on their own, and can do whatever anyone else can do with the right resources. We’ve come so far from the 1960s and 1970s, but we are still in a little box. I’d like to see the general public realize more about people with disabilities. And I’d like to help the Council achieve that. The people at the Council give up their time and energy to advocate. More people need to know about the Council so they can take advantage of all the good things the Council does.” **P&F**



★ ELECTION 2017 ★

The Annual NJCDD Election Questionnaire

On Tuesday, November 07, New Jersey voter will choose our next governor. Whomever voters choose to lead our state government over the next four years, it is important for residents with disabilities and those who know and love them to have a clear understanding on where our candidates for governor stand on issues most important to our developmental disabilities community.

Over the past several months, *People & Families Magazine* repeatedly reached out to

the campaign offices of New Jersey's Republican and Democratic candidates for Governor, Kim Guadagno and Phil Murphy, and presented each of them with a list of four questions that address major issues of importance for New Jersey residents with developmental disabilities and their family members. For this year's questionnaire, we worked alongside advocates in disability housing, DSP living wages, and special education to craft the questions we posed to each of the candidates.

As of the publication of this issue, only Democratic candidate, Phil Murphy, has submitted a response to the questionnaire. His responses are printed below, and have also been published on the NJ Council on Developmental Disabilities' blog, *Disability in Focus*. Any response received from Kim Guadagno's campaign will also be published on the blog. You can view the NJCDD's blog at <https://njcdd.org/disability-in-focus-2/>

Below is a complete list of the questions asked along with the full and unedited responses submitted by Phil Murphy.

QUESTION 1:

Submitted by the Editorial Board of the Special Education publication "Common Ground"

Prior to 2008, special education students in New Jersey were funded based on their level of need. Each student was placed into one of four need tiers, with higher per-pupil state funding associated with the higher need tiers. As part of the School Funding Reform Act of 2008, New Jersey adopted a census-based model. Each district's resident student population is multiplied by the statewide average rate of special education classification (roughly 14.7%) to determine the number of special education students. This funded count is then multiplied by the special education per-pupil funding amount in order to calculate the total special education funding allotted to the district. SFRA also wealth equalized two thirds of this amount, splitting it up into a state and local share, and then funds the remaining third entirely from the state. The formula has not been fully funded.

Numerous studies, work groups, and education organizations have called for a return to the "head count" "tiered" funding based on intensity of need. Advocates call for a special education funding mechanism that is adequate, efficient, equitable, predictable, flexible, transparent, fully



Phil Murphy

placement-neutral, and is accountable for both spending and student outcomes.

What are your plans to address this issue?

Response by Phil Murphy, 2017 Democratic Candidate for NJ Governor

I have consistently supported the school funding formula—the only formula that has been blessed by the Supreme Court. Over the past 8 years, Governor Christie has underfunded the school funding formula by over \$9 billion, never

allowing it to work. However, the formula is not without flaws and we must ensure special education funding is provided adequately and fairly. Funding our schools and special education services is not just fair to kids, it's fair to all New Jersey residents. It will relieve the pressure that has been placed on schools to cut costs by cutting corners. As governor, I will work to ensure we get back to standing for the right things in our state—starting with fairly and sufficiently funding our schools and special education programs.

QUESTION 2:

Submitted by the New Jersey Supportive Housing Association

The ability of people to find a home that is affordable, accessible, and safe is an increasingly impossible dream for 30% of New Jerseyans. This number rises dramatically for people living with disabilities. At the same time, people living with special needs whose options were extremely limited only a decade ago, are ready to move into communities with increased independence given the right supports. But far too many are living with aging parents, and time is running out. The affordable housing crisis is real and more acute than ever.

What priority would you give to making more affordable options available to those living on limited incomes? What strategies would you employ to address the lack of affordable housing in the state?

Phil Murphy Response:

As governor, I'm determined to make New Jersey the most inclusive and most accessible place to live, work, and raise a family for people with disabilities. That goal begins with our state government and includes affordable access to housing. The shortage of affordable housing is a crisis. We can start by stopping the diversion of money away from affordable housing funds for other needs—a practice that Governor Christie and Lieutenant Governor Guadagno have mastered. I will also tackle the problem of foreclosures head on. We have to make it easier for people to stay in their homes, and I have proposed that we use Wall Street mortgage settlement money to purchase vacant foreclosed properties and repurpose them as affordable housing. And I support the expansion of successful programs like the Neighborhood Revitalization Tax Credit, where every public dollar invested has returned many times that in private dollars.

QUESTION 3:***Submitted by the New Jersey Coalition for a DSP Living Wage***

Around the country and here in NJ, there is a massive shortage of Direct Support Professions (DSPs) who support people with intellectual and developmental disabilities to live in the community and achieve meaningful, productive lives to the best of their abilities. NJ families and providers are having great difficulty recruiting, hiring, and retaining individuals to fill DSP positions. Turnover rates are high (44%); vacancy rates are high (28%); and, overtime is out of control. One significant factor is the pay rate. The average hourly rate for a DSP is \$10 per hour (\$20,800 a year). By contrast, those who perform similar work in state-run Developmental Centers are paid an average of \$45,000 a year, have pensions, salary increases, and other benefits.

Given that the NJ Division of Developmental Disabilities (DDD) intends to remove every person with developmental disabilities from the State's Waiting List by having their needs and supports met in the community, what solutions might you suggest for addressing the scarcity of DSPs?

Phil Murphy Response:

I understand that Direct Support Professionals provide invaluable services and critical one-on-one care to help individuals with intellectual and developmental disabilities integrate into their communities and achieve greater independence. And I fully recognize the need to increase their wages and that reimbursement rates for institutions that pay these wages need to go up as well.

QUESTION 4:***Submitted by the members of the New Jersey Council on Developmental Disabilities***

Over the past several months, disability advocates in New Jersey and across the country have been deeply troubled by proposed federal cuts to Medicaid. In Congress, bills in the House of Representatives and the Senate called for deep cuts of as much as \$880 billion over a ten-year period. In addition, the President's budget proposal calls for added cuts of over \$600 billion. While even small cuts or caps to the program would cause harm to the over 900,000 New Jersey residents with disabilities who rely on Medicaid, the deep cuts proposed by Washington would be catastrophic.

What steps would you take to protect Medicaid for New Jersey residents with disabilities? If cuts to the program become a reality, how would you propose New Jersey respond to the loss of funding?

Phil Murphy Response:

As I've repeatedly said and have stated clearly on my website, improving the lives of people with disabilities is a top priority. As such, I will fight to protect Medicaid coverage for them as well as all of the 1.8 million New Jerseyans who now depend on Medicaid/CHIP. I will work with our federal delegation to fight any Republican plan to convert Medicaid into a state block grant program, which would slash billions in federal funding to New Jersey and hurt our state's most vulnerable families. As governor, I will also explore all ways to make Medicaid more efficient, including making better use of technology and pursuing waivers that will allow Medicaid to be administered in a way best suited to the needs of our state.

WHAT TO KNOW BEFORE YOU VOTE

A Guide for Voters with Disabilities

Voting during an election is an important way that Americans take part in their government. Whether voting in national, state, or local elections, it is our right and responsibility to help decide on the people we want to represent us. This year's Election Day is Tuesday, November 7, 2017.

As an American, it's important to remember that you have the RIGHT to vote if:

- You are 18 years old or older
- You are a United States Citizen
- You are properly registered to vote in the election district where you live

Sometimes a person is disqualified from voting based on the NJ State Constitution:

- If a state judge has issued an order saying the person does not understand what voting is because of the person's disability
- If the person is in jail, or on parole or probation because the person has been convicted of a serious crime

Individuals with developmental disabilities should know:

- People with disabilities have the right to vote
- People with disabilities who live in developmental centers and group homes have the right to vote
- People with disabilities who have guardians have the right to vote
- People with disabilities who are waiting on line when the polling place closes have the right to vote
- People with disabilities have the right to make their own choices for candidates
- People with disabilities do not have to tell anyone who they are voting for
- People with disabilities have the right to choose someone to help them in the voting booth

REMEMBER! Only a judge has the right to decide that a person with a disability is not allowed to vote because of their disability! A judge must issue a formal order, based on expert evidence, that the individual does not have the ability to understand what the act of voting is.

If there is no judge's order saying that a person with a disability does not understand the concept of voting, a person with a disability who meets the other requirements that everyone else has to meet, has the constitutional right to vote! **P&F**



NEW JERSEY
REGIONAL

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PLANNING COUNCILS

ARE YOU THE FAMILY MEMBER
OF A PERSON WITH DEVELOPMENTAL DISABILITIES?

Interested in becoming a better advocate for your community?
Join your local Family Support Planning Council!



Learn more about the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) systems and help spread information to other families



Organize public forums and providers fairs to help families learn changes and connect to local resources



Make recommendations to the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) about the supports and services families need most



Become a positive force for change in your community

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