

# People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SUMMER 2018

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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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### **Bidding Farewell to Kevin Casey, and Sustaining His Legacy of Advocacy**

At the end of May, the NJCDD's executive director, Kevin Casey, officially retired from his position at the Council. Over his three-year tenure leading the Council's staff, Kevin worked to make the NJCDD a stronger and more effective advocate for the individuals and families the Council represents. Looking forward, the NJCDD is committed to continuing what Kevin started, and determined to be an agent for positive change in the developmental disabilities community in New Jersey.



## 20 KEVIN CASEY

### **Advocacy is the Highest Calling**

On May 31, Kevin Casey retired from his position as Executive Director of the New Jersey Council on Developmental Disabilities, concluding a 48-year career spent serving individuals with developmental disabilities and their families. We take a look back at his contributions to the Developmental Disabilities community in New Jersey over his three-year tenure at the NJCDD.

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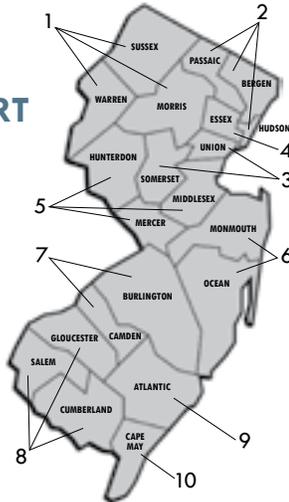
The 2018 Midterm Elections are highly anticipated, with 435 seats in the U.S. House of Representatives and 35 seats in the U.S. Senate contested. Across the country, there are more than 35 million eligible voters with disabilities, but only 16 million voted in the last major election. This year, disability advocacy groups are hoping to build disability voter turnout at the polls.

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### The Developmental Disabilities Advocacy Network

The developmental disabilities community is currently facing some of the greatest challenges seen in a generation—from the availability of affordable and accessible housing options, systems funding, DSP salaries, potential cuts to Medicaid and other social services, and more. Now, disability advocates across New Jersey are coming together to work toward protecting and advancing the rights, opportunities, and service systems for people with intellectual and developmental disabilities in our state.

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### A Closer Look at the NJ Comprehensive Assessment Tool

The New Jersey Comprehensive Assessment Tool (NJCAT) is a mandatory assessment tool used to determine eligibility for DDD-funded services, and to allot funds for an individual’s support services budget. It assesses an individual’s support needs in three main ways: self-care, behavioral, and medical. While some experts and consumers praise it as a useful method for determining the support needs for individuals and families, others criticize it for being challenging to complete and sometimes ineffective at allocating appropriate funding.

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A good education is one of the most important things to gain in life. But sometimes, life’s most important lessons aren’t found inside the pages of a book.



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“Frozen Icicles in the Mountains in Virginia Because it was a Stormy Day”, Acrylic on Canvas, by Tammy Heppner

from the Council Chairperson ■

## Bidding Farewell to Kevin Casey, and Sustaining His Legacy Through Advocacy

Kevin Casey devoted his entire professional career to serving individuals with developmental disabilities and their families. He enriched countless lives through his dedicated service in several states, including New Jersey. Kevin's efforts have made the NJCDD a stronger and more effective advocate for the individuals and families the Council represents. We are fortunate that he chose to commit the last few years of his distinguished career to serving as Executive Director of the NJCDD.

Kevin has been a highly visible and influential advocate for our population. I have attended numerous events with him, including legislative hearings, sessions with the leadership of DHS, and Medical Assistance Advisory Council meetings. Kevin consistently asked the most penetrating questions, challenged those in authority when appropriate and always spoke the truth to those in power. It has been a privilege for me to work with Kevin, to learn from him and above all, to be inspired by his splendid example. He has been a wonderful partner and teacher.

It is now the responsibility of all Council members and staff to honor Kevin by sustaining his legacy through our absolute commitment to serve individuals with developmental disabilities and their families. I am highly confident that Kevin has left his mark upon all of us. The Council is fully prepared and engaged to meet any challenges that will be encountered in the years ahead, and to continue being a voice for the individuals and families whom we serve and represent.

The NJCDD will continue to focus on collaboration to strengthen our state and national advocacy efforts. The Council has worked with the Statewide Family Support Planning Councils, the New Jersey Family Support Coalition, The Arc of New Jersey, the Alliance for the Betterment

of Citizens with Disabilities, the NJ Association of Community Providers, and nearly 30 other disability advocacy groups to establish the New Jersey Developmental Disabilities Advocacy Network (DDAN); bringing together self-advocates, family advocates, provider associations, and other advocacy organizations. The DDAN has set advocacy priorities to deliver a clear message to our political leaders, legislators, and state and federal agencies that serve individuals with disabilities. The Council has increased its financial and staff support for self-advocates and family advocates. We are restructuring our grant program, to bring together people and organizations with the expertise and resources to design and implement system change, which will directly improve the quality and availability of DD system services.

Finally, the Council voted unanimously to appoint Mercedes Witowsky as the new Executive Director of the NJCDD. Mercedes will be Kevin's successor; as a proven advocate, leader of the Council staff, and manager of our grants program. She has devoted her professional career to advocacy for and service to individuals with developmental disabilities and their families. Mercedes was a leader in establishing both the DDAN and the Family Advisory Council, which meets monthly with the leadership of DDD to ensure that family voices are heard. She is well known, trusted, and respected by all participants in the DD services system. We are delighted to have Mercedes as the Council's new Executive Director. Please join me in wishing Kevin Godspeed in his well-earned retirement and welcoming Mercedes as the new leader of the Council Staff.

*Paul A. Blaustein  
Council Chairperson  
New Jersey Council on Developmental Disabilities*

## New Jersey Council on Developmental Disabilities Announces New Executive Director

*Mercedes Witowsky was named the new Executive Director of the NJCDD. She will begin in July, 2018.*



On May 31, the New Jersey Council on Developmental Disabilities (NJCDD) announced Mercedes Witowsky as its new executive director. Witowsky will lead the daily work of the NJCDD in its mission to advocate for individuals with intellectual and other developmental disabilities in New Jersey. Witowsky will begin as executive director in July.

“Mercedes has devoted her professional career, in positions of increasing responsibility, to serving individuals with developmental disabilities and their families,” said NJCDD Chair Paul Blaustein. “She has served as a leader in advocating for the rights of individuals with disabilities to make informed choices, control their own lives and direct the necessary services

they receive. Mercedes has earned the trust and respect of self-advocates and families, service providers, leaders of government agencies and legislators, through her commitment to serving the most vulnerable residents of our State. I am confident that Mercedes is the perfect choice to be the Council’s Executive Director. I look forward to working with her to advance the Council’s agenda of collaborating with all stakeholders, to improve the lives of individuals with developmental disabilities and their families.”

In addition to Witowsky’s nearly four-decade private sector career supporting individuals with intellectual and developmental disabilities (I/DD), she has championed multiple family

advocacy efforts across the state. For the past four years, Witowsky has dramatically increased the knowledge base of families throughout the State, as Chair of the Family Support Planning Council. Witowsky has been a driving force in establishing a Family Advisory Council to the NJ Division of Developmental Disabilities (DDD), providing valuable input to DDD as the system transitions to Fee for Service. Witowsky led the creation of the NJ Developmental Disabilities Advocacy Network (DDAN), bringing together stakeholders to establish and implement a collective advocacy agenda. All of Witowsky's advocacy efforts have focused on strengthening the voices of self-advocates and families to communicate their needs to service providers and government agencies.

On the national level, Witowsky served for 15 years as the NJ representative to the American Network of Community Options and Resources (ANCOR), a leading non-profit trade organization representing more than 1,400

private community providers of services to individuals with disabilities across the country. Witowsky earned her teaching degree in Special Education from Kean University. She is also the proud parent of Anthony and Tina, a young lady with multiple disabilities.

"I am honored to be chosen to serve as the Council's Executive Director and eager to begin the next chapter of my lifelong commitment to empower individuals with I/DD and their families while working with State program administrators, providers and other stakeholders in always striving to provide information and improve access to supports and services," said Witowsky.

Established in 1971, the NJCDD is funded by the federal government and the state of New Jersey. The Council is authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act, and in New Jersey State government by NJSA 30:1AA 1.2 and is codified in Title 10 of the State Administrative Codes. State law places the Council "in but not of" the New Jersey Department of Human Services.

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

# Low Medicaid Rates Preventing Children from Getting ABA Therapy

By: Michael Ollove

From: Stateline — June 12, 2018

Reagan Wright, who is nearly 14, is devoted to all things American Girls, and dreams of becoming a veterinarian. For a child with autism spectrum disorder, Reagan is considered high-functioning. Which isn't to say, her mother Emily Wright emphasizes, that Reagan is not a handful.

"There are social issues," Emily said.

"Troublemaking and keeping friends. She says inappropriate things. And there are outbursts. Lots and lots of meltdowns." The Wrights pulled Reagan out of public school this year, and she now is taught at home through a state-approved, virtual school.

Reagan's medical providers recommend she undergo applied behavior analysis, one of the most common and effective treatments for children with autism. Referred to as "ABA" for short, the intensive treatment rewards children with autism for substituting positive behaviors for problematic conduct.

Yet, while the South Carolina Medicaid agency has approved Reagan for the treatment, her mother Emily says it's unlikely she'll be able to find a provider willing to accept the amount of money South Carolina Medicaid pays for ABA.

"They won't say how long their waiting lists are, but I'm told it'll take years," Emily said.

The reason, according to a class action federal lawsuit filed last month against the South Carolina Department of Health and Human Services, is that its Medicaid reimbursement rate for ABA "is among the worst in the nation and

has severely limited and will continue to limit children's access to medically necessary legally required treatment."

A similar class action federal lawsuit was filed late last month in Northern California on behalf of young children with severe disabilities who, the suit alleges, were not receiving the approved in-home nursing care that the lawsuit contends would keep them from institutionalization. That case also alleges a shortage of available nurses willing to accept low Medicaid reimbursement rates.

Both cases assert that the states are violating the law by not providing medically necessary treatment and, as the South Carolina suit alleges, are causing "irreparable injury" to children in need of those services. Neither case specifically asks the states to pay providers more, but legal and health policy analysts say that could be the eventual result. Medicaid, which provides health care coverage to low-income people, is a joint federal-state program.

In recent years, courts, including the U.S. Supreme Court, have curtailed the ability of individuals to legally challenge Medicaid rates as insufficient, but some think that the South Carolina and California cases, focused as they are on children, might open a new and effective strategy.

"The argument isn't that you haven't paid an adequate rate, it's that I'm not getting services I am entitled to," said Dan Unumb, an attorney and

executive director of the Legal Resource Center at Autism Speaks, a group that advocates on behalf of those with autism and their families.

By coincidence, the lawsuits were filed at a time when the Trump administration is seeking to curtail an Obama-era directive calling for federal oversight of Medicaid reimbursement rates to assure that they are adequate to provide beneficiaries with access to health services.

## Lowest Rate

Medicaid reimburses medical providers less than other payers. According to the Kaiser Family Foundation, on average, Medicaid pays providers 72 percent of what Medicare, the federal health plan for the elderly, pays for the same services. The disparity is even greater between Medicaid and private insurers.

Those lower rates have a substantial impact on access to medical services. A 2013 analysis of federal data found that physician acceptance rates of new patients in Medicaid was significantly lower than in Medicare or private insurance, particularly in states with lower Medicaid payment rates. That means longer wait times to see providers and having to travel farther from home to get health care.

Although the Medicaid statute says that the rates paid must be “sufficient to enlist enough providers so that care and services are available,” recent U.S. Supreme Court cases have narrowed the ability of individuals to challenge Medicaid reimbursement rates.

But alongside those rulings have also been a string of federal cases involving a Medicaid benefit for children called “Early and Periodic Screening, Diagnostic and Treatment” services. EPSDT mandates comprehensive screening and health care services for children under 21 enrolled in Medicaid, guaranteeing them appropriate preventive, dental, mental health, and developmental and specialty services. In legal disputes, courts have consistently sided with children and families to ensure they receive the services to which they are entitled.

Lawyers for the plaintiffs in the South Carolina and California suits are leaning on that history in their cases. While both clearly involve the issue of the low Medicaid reimbursement rates, they are mostly leaning on the EPSDT statute, arguing that it requires states to provide “medically necessary” services to children. The suits do not say the states should raise their rates, but if the plaintiffs prevail, that might be the result.

According to an Autism Speaks survey of 33 states earlier this year, South Carolina paid the lowest rate to ABA technicians, \$17 an hour. By contrast, Alaska paid \$76 an hour.

More relevant to South Carolina is that its neighbors, Georgia and North Carolina, pay more than \$70 an hour.

As comparatively low as the South Carolina rate is, it was even lower, less than \$14 an hour, until last July. Raising the rate to \$17 an hour increased by more than 50 percent the number of providers of autism services willing to accept Medicaid patients, according to the state health department, which responded to e-mailed questions from Stateline.

The state says that now about half of the autism service providers in the state—166 individual and 24 group providers—accept Medicaid patients.

## ‘It’s Maddening’

Nevertheless, South Carolina is set to increase its rate again, to \$31 an hour July 1. That would still be among the lowest rates in the country. The health department said that it expects the new rates will further increase the number of practices accepting Medicaid patients and spur new practices to open.

Reagan’s mother, Emily Wright, remains doubtful. “It’s wonderful, and I’m grateful they raised the rate, but that won’t help with recruitment,” she said. “If you were just getting out of school, why would you come here instead of Georgia and North Carolina?”

Reagan, the oldest of three children, was diagnosed with autism relatively late, at age 12.

Before that, doctors seemed to think she suffered from anxiety, obsessive compulsive disorder, and attention deficit hyperactivity disorder.

She qualified for Medicaid after she got her diagnosis and it was confirmed by the Department of Disability and Special Needs. Last summer, her mother said, the state Medicaid agency approved Reagan for 30 hours of ABA treatment a week.

Reagan’s caseworker provided a list of eight providers in central South Carolina who offered ABA treatment, but Emily discovered that only two of them accept Medicaid. “And the two that do take Medicaid are not accepting new patients,” she said. The wait, she was told, could be years.

Emily said that she and her husband, who own a small construction business, could have bought health insurance for Reagan on the state’s health insurance exchange, but they found that the only carrier on the exchange—Blue Cross Blue Shield—doesn’t cover ABA services. (The rest of the family is on a catastrophic health

plan called “Medishare” that is legal under the Affordable Care Act.)

For about two months in the fall, the family paid for ABA services out-of-pocket, but only for 10 to 15 hours a week. Emily said that Reagan’s behavior changed dramatically. “She was more polite. She argued a little less. She was able to accept changes and things that didn’t go her way without so many meltdowns.”

But it was expensive, about \$600 a month, so the Wrights were forced to stop the treatments. Since then, Emily said, “I’m seeing regression in her now.”

Emily said she and her husband hope to resume some ABA treatments, but it will be costly and still far less than Reagan needs.

“It’s maddening. There’s this wonderful therapy that would help, but we can’t get it. And every day my child is not improving, even though she’s got so much potential. One day she could live on her own. She could drive a car. It’s possible. Are those things guaranteed without [the treatment]? I just don’t know. I can’t say.”



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# Families Strained by Caregiving Responsibilities, Survey Finds

By: Michelle Diamant

From: DisabilityScoop.com — June 12, 2018

A snapshot of thousands of caregivers across the country finds them overwhelmed by the demands of their loved ones with developmental disabilities and deeply concerned about the future.

In a survey of more than 3,000 caregivers, 95 percent said they were stressed out with nearly half describing themselves as very or extremely stressed.

Family members and friends reported spending an average of 57 hours each week in a support role for those with disabilities assisting with everything from feeding to dressing, providing behavior supports and managing finances. Caregivers said these obligations are affecting their abilities to address personal needs, tend to other family duties, and stay afloat professionally.

The findings come from the Family & Individual Needs for Disability Supports, or FINDS, Community Report released in June by The Arc of the U.S. and The University of Minnesota's Institute on Community Integration. It's based on responses from 3,398 unpaid caregivers across the country who responded to an online survey conducted between January and April 2017.

Of those polled, 80 percent identified as a family member who lived with a person with an intellectual or developmental disability. More

than half said they had no plan for what would happen to the person they support in the event that they are no longer able to provide care.

About a quarter of caregivers said their loved ones were on waiting lists for government-funded services. Those surveyed reported difficulties

finding help from direct support professionals or through respite care.

Many caregivers said they had to reduce their work hours, decline promotions or quit altogether in order to provide care.

Overall, the report authors concluded that their findings “reflect the ever-increasing reliance on families to provide the bulk of supports to individuals with I/DD.”

“In every aspect of life—from education, to employment, to planning for a stable future—we as a society are failing in our support of caregivers of people with disabili-

ties and falling short of our obligation to improve the quality of life of people with disabilities,” said Peter Berns, CEO of The Arc of the U.S.

“This report paints a picture of the day-to-day needs of caregivers and should ignite action to address the gaps that stop us from achieving full inclusion of people with disabilities in the community throughout their lifetime,” Berns said.

***“In every aspect of life—from education, to employment, to planning for a stable future—we as a society are failing in our support of caregivers of people with disabilities and falling short of our obligation to improve the quality of life of people with disabilities.”***

—Peter Berns,  
CEO, The Arc of the U.S.

# NJ's Medicaid Transportation System in Line for Major Overhaul

By: Lilo H. Stanton

From: NJSpotlight.com — June 13, 2018

State lawmakers want to give New Jersey more effective tools to manage its nonemergency Medicaid transportation network while requiring more of those directly involved with this long-criticized system of private drivers and shuttles that is essential to connecting vulnerable residents with care.

A pair of Assembly Democrats introduced legislation Monday to reform the program by requiring tighter inspections of cars and drivers, more

detailed record-keeping and greater state oversight of the five-year transportation contract, which cost taxpayers \$180 million last year and served some 135,000 Medicaid patients. The bill would also make it easier for the state to levy larger fines for contract violations and allow it not to pay drivers when an individual they were scheduled to transport did not receive medical services.

The state has contracted for many years with LogistiCare, a national transportation leader based

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in Atlanta, that operates in dozens of states; LogistiCare collects a per-person fee and subcontracts with close to 100 private cab companies, specialized shuttle groups, and individuals to drive Medicaid clients to and from medically necessary healthcare appointments.

While many involved agree LogistiCare has worked hard to try and address concerns, advocates for individuals with disabilities and mental illness said too many of their clients are still left stranded by delayed or no-show rides. Some Medicaid members have in the past reported being harassed, disrespected, or left fearful by drivers' actions.

### 'A Lot of Money, a Lot of People Who Rely on This'

"We want to make sure people get to their medical appointments, and on time," said Assemblywoman Joann Downey (D-Monmouth), who sponsored the bill with Assemblyman Nicholas Chiaravalloti (D-Hudson). The measure is scheduled for a hearing Thursday in the Assembly Human Services Commission.

"We're talking about a lot of money and a lot of people who rely on this," Downey said, "and when we started looking at this [issue], we saw a lot of things that needed to be strengthened to improve services and reduce cost."

The problems have seemed to ebb and flow over the years, noted Debra Wentz, president and CEO of the New Jersey Association of Mental Health and Addiction Agencies, despite efforts to improve the system. "Dependable, reliable, on-time transportation is so critical," she said, especially for people with multiple chronic health conditions.

### Fines for Contractor

A review published in March by the nonpartisan Office of the State Auditor, which operates under the Legislature, found problems with the current monitoring and reimbursement system and urged the Department of Human Services,

which oversees Medicaid, to improve how it oversees this work and assesses damages. The state fined the contractor more than \$900,000 between July 2014 and June 2017, or about \$25,000 a month—roughly 0.17 percent of the fees the company earned each month, the auditor noted.

The auditor's report—which echoed concerns raised in earlier reviews by state and federal officials—also caught the attention of members of the Assembly budget committee, who pressed DHS Commissioner Carole Johnson to explain how her department could do better. The issue was already on her radar, she said, and staff was working to make improvements.

"Ensuring quality and reliable transportation services for Medicaid recipients is vitally important, which is why we are implementing reforms to improve vehicle, staffing, and performance standards," Johnson told *NJ Spotlight* yesterday. "We've also had ongoing discussions with legislators and stakeholders as we work toward a shared goal of strong oversight and accountability for this important service."

But Downey said legislation is needed to allow the state to more effectively manage the contract and ensure compliance. The bill also spells out new requirements for LogistiCare, which she planned to meet with on Tuesday, and the independent drivers they hire.

### Stricter Rules for Drivers

Lori Bonderowitz, vice president of LogistiCare New Jersey's operation, told *NJ Spotlight* the company looked forward to discussing the bill with stakeholders. "The vast majority of what is called for in the legislation is already included in our existing non-emergency medical transportation contract with the state," she said. "It's important to note, the new contract has addressed many of the issues identified in the audits and has raised the bar on performance standards, mandated greater use of technology and increased state oversight."

Among other things, the bill (A-4131) requires all drivers to arrive within 15 minutes of the scheduled

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pick-up time. It requires they be properly licensed, pass a criminal background check, and have properly registered and inspected vehicles that have the capacity for at least four people, including the driver. Cars or vans with more than 150,000 miles would need to pass a more rigorous inspection process to qualify.

In addition, drivers would need to receive special training on the system and protocol and to provide passengers with "appropriate and courteous treatment" and "engage in positive interactions." This training would need to be carefully documented and drivers could be fired if the records are incomplete.

Drivers would need to document all their runs in detail, with passengers' names, the scheduled and actual pick-up and drop-off times, and note when medical providers requested transportation or when special handicapped-accessible vehicles were used. The transportation broker, now LogistiCare, would need to keep similar records.

These logs would be updated daily and shared with the DHS on request.

The legislation also calls for significant changes to the state's oversight system, including establishing a process to verify that Medicaid members receive the needed care. It calls for the DHS to designate an employee—someone outside the Division of Medical Assistance and Health Services, which oversees the contract—to regularly audit the system and review all documented complaints.

This staffer would need to submit monthly reports to the DHS commissioner, the division director and LogistiCare, according to the bill, and could urge the commissioner to assess penalties when appropriate. These fines could be deducted from the state's monthly payment to the broker and could ramp up over time, until the problem is resolved.

"It's an enormous thing to oversee, in general, but that's not an excuse," Downey said. "We're trying to help pull this all together."

# Lawmakers Looking to Find More Dollars For Direct Caregivers

By: Lilo H. Stanton

From: NJSpotlight.com — June 14, 2018

Senate President Steve Sweeney is determined to find at least \$20 million more to pay healthcare workers who provide critical daily assistance to disabled individuals in New Jersey as part of the ongoing budget negotiations between the state Legislature and the Murphy administration.

Sweeney (D-Gloucester) told *NJ Spotlight* that increasing the Medicaid reimbursement for these nonclinical direct-support professionals, or DSPs, is a priority for him and other lawmakers, given the important work they do in homes, schools, and workplaces for some of the state's most vulnerable residents. Pay for these jobs starts at \$10.50 an hour; New Jersey's minimum wage is \$8.60.

The Senate president led the fight during last year's budget battle to include \$20 million in the current state spending plan, which functioned as a one-time bonus. He said he would "fight to make sure" it is also included in the budget for the coming fiscal year, which must be adopted by the end of June.

Social-service policy experts also flagged this issue in their transition policy report to Gov. Phil Murphy, who took office in January, but the fiscal year 2019 budget proposal he unveiled in March did not include additional money for DSP pay. That raised concerns for frontline workers, agencies that employ them, and individuals and families they serve. Members of the Assembly budget committee also questioned the decision at a hearing in May.

"The personal-care workers who go into their homes and communities to provide direct care

and to help them with daily needs are performing some of the most important duties imaginable," Sweeney said. "It is shameful that they are too often underpaid and underappreciated. The budget is tight, but this is a priority that I am determined to fund."

## Negotiating a Budget Compromise

Representatives from the Legislature and the Murphy administration are now negotiating a compromise to the \$34.7 billion budget proposal. But a revenue crunch has already forced the state to suspend spending, including delaying nearly \$500 million in hospital-aid payments scheduled to go out later this month.

The Senate president's commitment to DSP wages was welcome news to family members and care providers, who joined forces last year to form the Coalition for a DSP Living Wage to address what they said has become a crisis. There are now 25,000 DSPs providing daily care—personal tasks, physical assistance, communication, and more—for 22,000 New Jersey residents with intellectual or developmental disabilities, a population that is growing and has increasingly complex needs as it ages.

The situation has resulted in a staffing shortage, the coalition said, with low pay and strenuous demands driving DSPs into other jobs and making it hard to find replacements. Provider agencies report a 44 percent turnover rate and a 20 percent vacancy. In addition, DSPs often work multiple jobs and receive food stamps and other welfare benefits to be



*NJ Senate President Steve Sweeney was joined by NJ Senators Paul Sarlo and M. Teresa Ruiz to announce a plan to push for additional funding for DSP salaries at a press event at the State House on June 15.*

able to provide for their own families, advocates said.

“This is a crisis situation. People are just not going to get services,” explained Thomas Baffuto, who heads the coalition and serves as executive director of The Arc of New Jersey, which advocates for and assists individuals with disabilities and their families. “We’re not going to be able to sustain the system. We’re not going to be able to grow.”

### **Hoping for Higher Salaries**

In fact, the coalition would like to see a more robust, sustained investment in DSP wages, which average \$11.36. The goal is to increase the pay to roughly \$16 an hour, over five years—an increase of \$1.25 a year.

The group calculates this would cost \$72 million in the first year, with \$36 million in state funds and an equal match in federal dollars.

Baffuto said coalition members are talking to lawmakers on both the Senate and Assembly budget committees and officials at the Department of Human Services, which oversees Medicaid, in hopes of securing a long-term plan for more investment. “These are not minimum-wage jobs. They’re more important than minimum wage jobs, and we just can’t compete” with other industries, like fast-food chains that offer starting pay as high as \$13 an hour, he said.

“These are really wonderfully devoted people who do this work,” agreed Gail Frizzell,

an Arc board member and the mother of a 32-year-old with significant disabilities. “They’re helping these individuals with a life of connectivity and quality that they can’t achieve on their own because of their intellectual or developmental disability.”

While Sweeney has not committed to the five-year plan for new dollars, he appears open to a long-term solution. “We will also look to better commit to the continuation of the pay increase by incorporating it into the state’s Medicaid rules,” he said. “Those in need will not be forgotten and those who care for them should not be shortchanged.”

DHS Commissioner Carole Johnson is also focused on sustainable change; the governor’s pledge to increase the state’s minimum wage to \$15 would also benefit DSPs, she has noted. (Murphy’s budget proposal does include \$16.7 million, which will trigger a federal match, to boost hourly pay for another group of frontline health workers, personal-care assistants, or PCAs, who assist elderly and disabled individuals with dressing, bathing, and daily tasks.)

### Putting Others First

“New Jersey’s most vulnerable residents deserve the best, and our direct-support professionals put the needs of others foremost every single day, which is why we remain eager to find a long-term solution to this concern,” Johnson said yesterday.

Frizzell said a sustainable plan for improvement is essential to aging parents of adults with disabilities, like her, who fear what will happen to their children after they die. “Parents are really worried,” she said. “They don’t know what they’re going to do. There’s not a workforce to replace them when they go.”

Frizzell’s daughter, Lauren, can’t walk, talk, eat, or dress herself and she suffers from regular seizures, but she is able to live independently thanks largely to the five DSPs who care for her in shifts. When her longest-serving aid—a 70-year-old woman who had been with her since age nine—decided to retire a few years ago, Frizzell said it took six months to find a proper replacement.

“Lauren isn’t sick. She doesn’t need a nurse,” she said, “but her very survival depends on these DSPs.” **P&F**

## 2018 MIDTERM ELECTIONS

### New Jersey’s **GENERAL ELECTION** will take place on **Tuesday, November 6.**

This year, New Jersey voters will decide on who to elect as our **Representatives in the U.S. Congress.** Voters will also vote for a **U.S. Senator**, and some may also vote for local government positions such as mayors or school board members.

**To vote in the General Election, residents who are at least 18 years old MUST be registered to vote by TUESDAY, OCTOBER 16.**

Need Help to find out whether YOU are registered to vote?  
Visit the NJ Division of Elections’ website at  
[www.njelections.org/voting-information.html](http://www.njelections.org/voting-information.html)

## UPCOMING EVENTS

### NJCDD COUNCIL MEETING

Thursday, August 9, 2018  
10:30am – 2:00pm

Hilton Garden Inn Hamilton  
800 Route 130  
Hamilton, NJ 08690

All Council meetings are open to the public—If accommodations are required, please contact the NJCDD offices at 609-292-3745

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### POLICY IN ACTION: SYMPOSIUM FOR PARTNERS GRADUATES

#### *SAVE THE DATE*

Saturday, September 22, 2018  
9:30am – 3:00pm

Princeton Marriott at Forrestal Village  
100 College Road East  
Princeton, NJ 08540

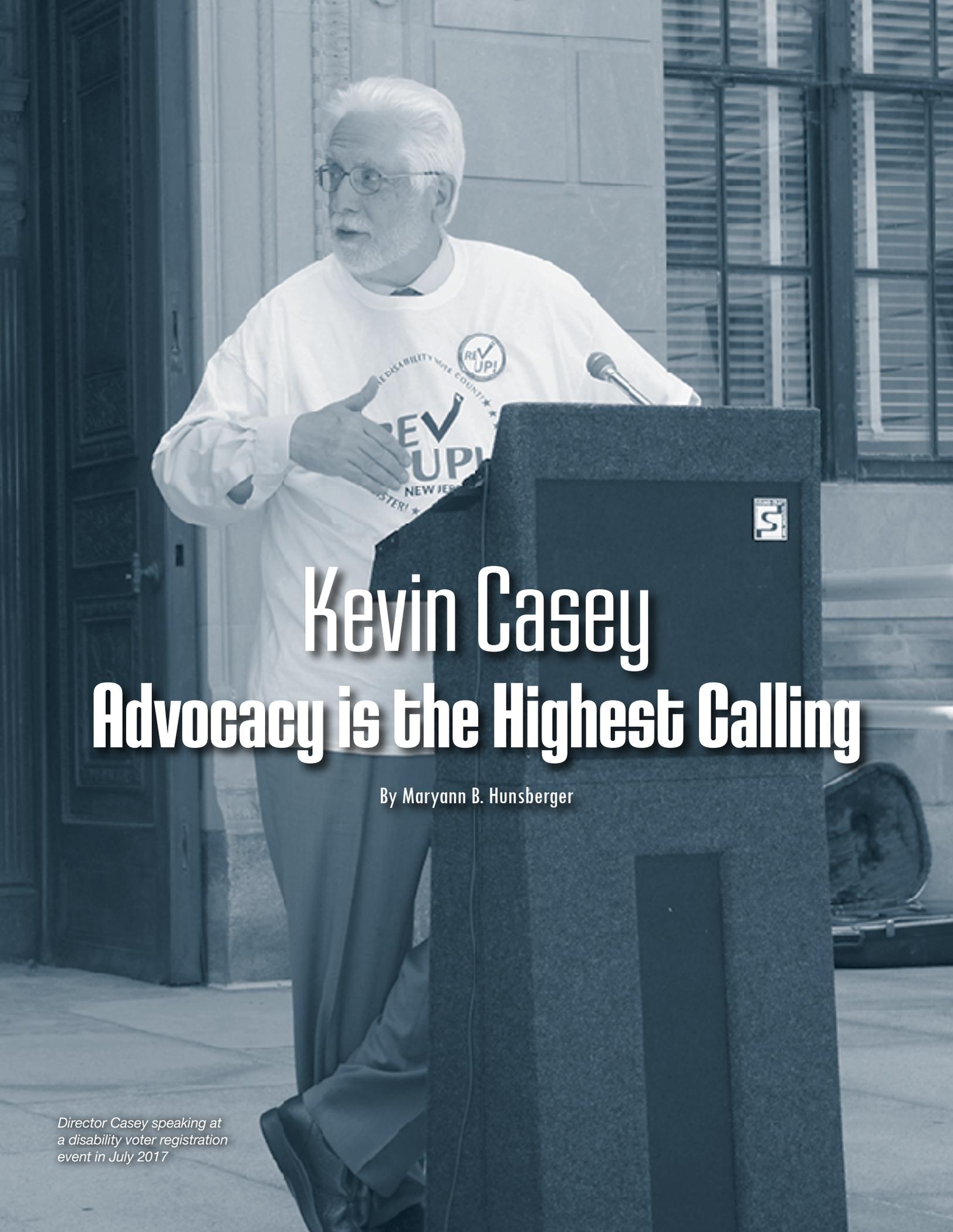
Keynote Speaker: Nicole Jorwic, JD; Director, Rights Policy;  
The Arc of the U.S.

This event is open to New Jersey Partners in Policymaking  
graduates **ONLY**.

Look out for more details and registration information soon!

Contact **Jaime McGeady** by email at [Jaime.mcgeady@rutgers.edu](mailto:Jaime.mcgeady@rutgers.edu)  
or phone at 732-235-9613 with any questions about the event.

Conducted in Collaboration Between:  
The Boggs Center on Developmental Disabilities  
& New Jersey Council on Developmental Disabilities  
& Disability Rights New Jersey



# Kevin Casey

## Advocacy is the Highest Calling

By Maryann B. Hunsberger

*Director Casey speaking at  
a disability voter registration  
event in July 2017*

## *After 48 years in the disability field and three years as the executive director of the New Jersey Council on Developmental Disabilities (NJCDD), Kevin Casey retired on June 1.*

Casey started his career working at a state institution in Illinois. “I knew immediately it was no way for people with developmental disabilities to have to live. I resolved early in my career that I’d help to build community programs for people with developmental disabilities so institutions wouldn’t be necessary.”

Casey said he has worked at “just about every level of the system of services for people with developmental disabilities. I’ve seen good stuff and not so good stuff. Probably the best thing I’ve seen in my career—and that I’m proudest of being part of—is the development of self-advocacy organizations and the influence of self-advocates and families. That has been terribly important.”

Myrta Rosa, the Council’s vice chair, is one of those self-advocates. Rosa spent many years in institutions before moving into the community. She said, “I learned how to become a vice chairperson from Kevin. It is easy to understand what he talks about because he makes everything clear. He is a very good advocate who always puts people with disabilities first. He never leaves us out of the planning process. He has been a very good person to work with.”

Mercedes Witowski, former chair of the Statewide Family Support Planning Councils, the parent of a grown daughter with a disability and, as of July 2018, the new executive director of the NJCDD, said she was thankful for Casey’s leadership. “We were fortunate to have him. Kevin recognized the many moving parts and rapid changes in New Jersey’s systems for supporting people with intellectual and developmental disabilities. This was key to his embracing the needed advocacy in New Jersey. He supported people with intellectual and developmental

disabilities and their families with the utmost integrity and commitment; we will always remain grateful for his leadership and for listening to families across the state.”

Tom Baffuto, the executive director of The Arc of New Jersey, stated that Casey “brought terrific priorities to the Council during his tenure. And his tenure has been far too short. He brought with him a broad federal public policy perspective, and his experience in that area helped us in New Jersey with employment, transportation, and housing issues. He not only brought good priorities to the state, but he worked hard to fulfill those priorities on behalf of the Council.”

Baffuto was impressed with how Casey revamped the Council’s grants process. “He put together a very efficient and fair process by putting out RFPs (requests for proposals) and by having a grants committee to review everything. Everyone thought it was a great move forward and a more effective way to distribute grants. He aligned the grants to the priorities of the Council. It became a more open, responsible, practical process.”

Baffuto felt the most important factor about Casey’s work was that, “he was so invested in getting information out to families and self-advocates. He was absolutely committed to getting families and self-advocates involved in the work of the Council and he used their input in formulating priorities.”

Council Chair Paul Blaustein, the parent of a son with disabilities, was impressed that Casey devoted his entire professional career to serving individuals with developmental disabilities and their families. “He could have earned significantly more money in other pursuits, but chose to serve our most vulnerable people. It has been



Kevin joins a delegation of New Jersey disabilities advocates in planning for visits to Capitol Hill in Washington, D.C. In 2016

a privilege for me personally to work with him, to learn from him, and to be inspired by his splendid example of service to others. I was very fortunate that Kevin was in that position when I was first appointed to the Council and when I was appointed chairperson.”

Blaustein went on to recount a scene from the last episode of the television series *M\*A\*S\*H*. As Captain B.J. Hunnicutt was getting ready to leave South Korea, he told Hawkeye Pierce that he couldn’t imagine what the place would have been like if he hadn’t found him there. “That’s how it was with Kevin. He has been such a major influence on the Council with his devotion to serving and his examples of wisdom and experience. He leaves it significantly better than when he arrived.”

Blaustein appreciates how Casey invigorated the advocacy activities of the Council and brought them out in the open. “He was very active in testifying in front of legislators and speaking up at Department of Human Services (DHS) and Division of Developmental Disabilities (DDD) meetings. He

knew when to speak the truth, to pressure when necessary, and when to influence gently.”

Casey stressed the importance of this balance. “Advocacy is the highest calling. You have to learn when to be friendly and when to be very aggressive and be prepared to do both. This is the key.”

Colleen A. McLaughlin, the associate director of the Boggs Center on Developmental Disabilities, found Casey’s advocacy impressive. “Kevin has always been steadfast in listening to and promoting the importance of the voice of people with disabilities and their families. We are grateful for the value he placed on the advocacy of people and families as illustrated through support of Partners in Policymaking, the Family Support Planning Councils, topics addressed in the NJCDD’s *People and Families* magazine and similar efforts.”

Carole Tonks, the executive director at the Alliance Center for Independence, found Casey’s support of grassroots advocacy to be impressive. “Kevin was extremely supportive of our efforts to increase the capacity of people with

developmental disabilities to participate in the voting process. REV UP - NJ, established by the Alliance Center for Independence three years ago, is part of a national effort to engage people with developmental disabilities in the election process. Under Kevin, the Council has dedicated time and resources to ensure the success of the grassroots effort. In addition, Kevin has spoken at, and the Council lent its support for, the ACI-sponsored Annual Disability Pride Parade and Celebration.”

Blaustein pointed out, “Kevin always advocated as someone who was clearly not out to toot his own horn, but out of sheer concern for the people the Council represents. He has been a delight to work with. I’ve learned a great deal from him. He had a great influence on all of us. In selecting a new executive director, we sought to recruit his successor, not his replacement. It’s

up to us to sustain what he’s accomplished, to do those things he’d have liked to do if he had more time.”

Tonks added, “We appreciate all that Kevin has done to promote the independence of people with developmental disabilities in New Jersey. He will be missed.”

Casey said, “I want to thank the Council and their staff for their very hard work. I’ve very much enjoyed my time at the Council and feel we’ve been able to get some good things done in New Jersey. Although we’ve made a lot of progress over the years, a lot still needs to be done in terms of building community programs. I urge the council to be an assertive, aggressive advocate for people with developmental disabilities in the future.”

Casey plans to remain involved with advocacy on an independent basis now that he is retired. **P&F**

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*In his final year as Executive Director of the NJCDD, Casey was a driving force behind the establishment of the Developmental Disabilities Advocacy Network. The Network held a summit earlier this spring.*



# Nothing About Us Without Us

## *Why Disability Voting Matters*

By Jonathan Jaffe



### **On Tuesday, November 6, the midterm elections will occur.**

This is the big national vote that political pundits have been hyping since the 2016 national election. With all 435 seats in the U.S. House of Representatives and 35 seats in the U.S. Senate contested, this is the first clear indication of the President's prospects for reelection in 2020.

Pundits within the disability community have been closely watching the various polls, showing that Trump's approval rating is consistently around 40-42 percent. That is incredibly relevant, as it indicates a strong chance of Democrats winning many swing seats in both houses of the 115th Congress, now Republican-run.

Here's why it matters: In 2014, Barack Obama was at 42 percent approval in Gallup's polling just before the midterms—similar to Trump—and his party lost 13 seats in the House. In 2010, Obama was at 45 percent approval—and Democrats lost a net of 63 seats.

Other elections show similar struggles for the sitting President. In 2006, George W. Bush was at 38 percent, and Republicans lost 30 seats. In 1994,

Bill Clinton was at 46 percent, and Democrats lost 53 seats.

There seems to be an immutable law underneath all of this. Unless something extraordinary happens that upends the entire political world and the President's popularity surges, his first midterm election is going to yield weak results for his party.

### **Engaging the Base**

Many in the disability community see the November 2018 elections as a turning point, an opportunity to entice, persuade, and encourage candidates for office—from both parties—who are sympathetic to the needs of people with developmental disabilities.

There are more than 35 million eligible voters with disabilities. Yet only 16 million people with disabilities voted in the 2016 election. People with disabilities still face many barriers to voting—ranging from physical access barriers at polling places and a lack of accessible transportation, to poll workers grossly under-trained to operate the accessible voting machines or who don't know the voting rights of people with disabilities.

“The disability community will be more engaged and keyed up in this election because of the type and level of threats that have come out, the intense media coverage, and the fights in Statehouses about budgets,” said Mike Oxford of Lone Star, TX, a community organizer with ADAPT, a national grassroots disability rights organization with chapters in 30 states.

“I’m seeing an uptick in interest, and it is not surprising,” Oxford said. “In my 34 years of doing this work, I’ve learned that when the disability community feels threatened, it rises up. When you keep hearing about budget cuts, time and time again, you know that now is the time to get involved.”

In 2012, according to a study conducted by Rutgers University, 30 percent of people with disabilities reported difficulty in voting compared to eight percent of people without disabilities. A 2016 Government Accountability Office (GAO) report on polling place accessibility found that 107 of 178 polling places surveyed, or 60 percent, had one or more potential impediments to voting.

Advocates say now is the ideal time to aggressively promote an agenda that has not been a focus on Capitol Hill over the past two years. There is a desperate need for candidates who want to tackle entitlement reform and preserve Medicaid and the Americans with Disabilities Act. To do that, there must be full accessibility at polling places, which would enable people with developmental disabilities to become a stronger voting bloc that cannot be ignored.

This movement is an effort to elevate the voices of people with disabilities, rather than the scientists, parents, teachers, or doctors often asked to serve as advocates. The true experts on disability are the people with disabilities themselves.

## A Midterm Agenda

The push to increase representation of people with disabilities at the polls has been a national

effort with local outreach. Many advocates interviewed for this story are part of non-profit, non-partisan organizations. They are not Left or Right-leaning. They are squarely focused on supporting policies that directly help and preserve the lives of people with disabilities, while educating their constituents about the absolute importance of voting.

Maggie Leppert, a campaign organizer with *#CripTheVote*, a nonpartisan campaign started on Twitter to engage voters with disabilities and encourage politicians to have a national conversation about disability rights, said there are many critical issues in the midterm elections.

“First, and perhaps most obviously, is healthcare, including the Affordable Care Act (ACA) and Medicaid,” she said. “It is essential that Medicaid and Medicare funding be increased, not cut, and that protections for pre-existing conditions under the ACA are upheld.”

Leppert said there is also a strong effort this year to oppose proposed legislation known as “HR 620,” which passed the House and now sits in the Senate, as of mid-

May. This legislation creates a waiting period for individuals to sue businesses for noncompliance with the law.

During that period (six months or longer), a business has to show only “substantial progress” toward correcting the problem, rather than actually correcting it. Many believe the legislation essentially allows businesses to delay complying with the ADA.

“Discrimination is still widespread and we cannot afford to soften our laws on this issue,” she said.

Creating new employment opportunities for people with disabilities is also vital.

“We need to establish more support for people with disabilities, especially intellectual and developmental, to access employment. We need SSDI reform so that people with disabilities are able to



*“RevUp!” Stands for “Register!  
Educate! Vote! Use your Power!”*

work and earn money to live independently without risking losing their benefits,” Leppert said.

#CripTheVote is also working with other disability advocates to continue the deinstitutionalization movement. “We need more supports so that people served by these institutions aren’t simply moved when they are closed but rather transitioned into a place where they can live among the community,” she said.

For Dennie Todd, a disabilities specialist with the New Jersey Council on Developmental Disabilities, a big issue is voter access. She is a poll worker in Medford, where election officials do trainings every two years, including instructions on ADA compliance.

“There needs to be uniformity across all polling places in the country,” she said. “In New Jersey, we are hearing different stories from all 21 counties that voting booths are not accessible, and people in wheelchairs need to be lifted over curbs. I refuse to put a handicap accessible sign at my polling place because it is not handicap accessible.”

James Charles Dickson, Co-Chair of the National Council on Independent Living’s Voting Rights Committee, also believes more people with disabilities need to run for office. “There are more candidates with disabilities running for office around the country this year, and we need their voices,” he said.

He also said there remains little consistency among states when it comes to the availability and quality of health care, as well as access to resources to help people secure the services they need. There are wait lists for respite care, wait lists for childhood services, and no clear focus on how to change all that.

“There are cuts in services, varying, depending on where you live,” Dickson said. “On the federal level, it is horrible how long it takes to process an SSDI application. People need to get involved. The

House voted to abolish the Affordable Care Act in many states, which was actually Medicaid. We have seen a tax on the ADA. And some in Congress keep threatening to cut Medicaid.”

Leppert said many politicians do not talk about issues relating to the disability community in their campaigns.

“We are not questions in the debates,” she said. “We are not part of their slogans or platforms. It takes a substantial amount of digging to find most politicians’ stances on these issues, if they have any at all. Much of this is due to the

misconception that people with disabilities do not vote; politicians do not think that this is an important community to engage. That needs to change.”

## Rev Up for November 6

The REV UP Campaign, which in New Jersey is coordinated by the Alliance Center for Independence and supported by the New Jersey Council on Developmental Disabilities, coordinated its third-annual National Disability Voter Registration Week (NDVRW) for the week of July 16–20, encouraging people with disabilities to register to vote, learn

the issues in the midterm elections and prepare to cast a ballot on Nov. 6. (REV UP stands for Register! Educate! Vote! Use your Power!)

The overarching goal of the REV UP Campaign is to increase the political power of people with disabilities. Through the nonpartisan campaign, the American Association of People with Disabilities (AAPD) and partners around the country are doing everything possible to create a strong, lasting base of politically active citizens within the disability community.

“With numerous events and activities around the country during this time, we also hope to garner attention from media and candidates running for office,” said Zach Baldwin, Director of Outreach at AAPD, in Washington D.C.

***Of the more than 35 million eligible voters with disabilities in the United States, only 16 million voted in the 2016 elections. Advocacy groups are working to educate people with disabilities about their rights as voters, and to encourage them to get out and vote.***

The REV UP Campaign has released a 2018 NDVRW Toolkit, which includes a guide on how to organize voter registration events, ideas on other ways to participate in the voter drive, sample social media posts and graphics, and other resources.

The REV UP Campaign has also developed a candidate questionnaire.

“It is a great tool to help the disability community learn more about the candidates, specifically how the candidates would address issues that impact people with disabilities,” Baldwin explained.

The campaign also works to educate candidates about issues of critical importance to the disability community. “We are encouraging people to use this questionnaire as a guide when they ask questions of a candidate,” Dickson said.

The REV UP Campaign seeks to influence candidates, the media, and election officials to recognize the disability community as politically active citizens and to pay attention to the issues that are important to the disability community, Baldwin said.

“The most important thing people with disabilities can do is to make sure they are registered to vote and to plan to vote in all primary and general elections,” Baldwin said. “From there, we need all the help we can get publicizing the REV UP Campaign and spreading the message of the importance of voting.”

People with disabilities are encouraged to visit [www.aapd.com/REVUP](http://www.aapd.com/REVUP) and learn what activities are happening in New Jersey. On July 16, REV UP NJ planned a kick off for National Disability Voter Registration Week at the Statehouse Annex, discussing ways to increase voter registration prior to the midterm election, said Carole Tonks, Executive Director, Alliance Center for Independence.

The REV UP Campaign aims to increase the political power of the disability community while also engaging candidates and the media on disability issues.

“Voting is crucial for any marginalized group of people,” Leppert said. “For too long, only White, non-disabled, rich men have spoken for the entire country. If all marginalized communities were to come together, we would vastly outnumber these voters and would be able to subvert



*The Alliance Center for Independence had a booth at the 2018 Abilities Expo in Edison to inform people with disabilities about the RevUp! campaign and to help expo attendees register to vote.*

the power structures in order to make the system equitable for all. We can make our voices heard.”

She suggests making Election Day a national holiday, to underscore its importance, with more coordinated transportation to polling places and expanded automatic voter registration—not just when people renew their drivers’ licenses.

### **Voter Registration Remains the Key**

REV UP is looking for advocates and individuals to promote National Disability Voter Registration Week through social media, email, or word of mouth. The REV UP Campaign has put together a social media toolkit with sample posts and graphics at [www.aapd.com/NDVRW](http://www.aapd.com/NDVRW).

“As we get closer to the November midterm elections, we will begin to focus on ‘Get Out The Vote’ efforts and will again need advocates to rally together to encourage people with disabilities and their allies to go out and vote,” Baldwin said.

Leppert believes that politicians often benefit from in-group conflict among marginalized people.

“We will never achieve true equality by stepping on other communities,” she said. “All systems of oppression are connected, and therefore the solution to our oppression is connected.

“This means that all movements, including those that advocate for women, people of color, immigrants, and the LGBTQ+ community, need to be more inclusive of people with disabilities and vice versa.” **P&F**

# One Voice

## The Developmental Disabilities Advocacy Network

By Brenda Considine

**net-work** *noun*

*a group or system of interconnected people or things.*

**net-work** *verb*

*to make an effort to meet and talk to a lot of people, especially in order to get information that can help you.*

The word “network” is both a noun and a verb, so it is both a concept, **and** an action. And that is just the case for a newly formed advocacy network.

The Developmental Disabilities Advocacy Network came together for the first time last fall, bringing nearly 60 advocates representing 29 organizations. The purpose of the daylong summit was to identify common goals, establish a statewide advocacy agenda for the disability community, and to work together to advance that plan.

The Advocacy Network was established by the New Jersey Council on Developmental Disabilities (NJCDD), the New Jersey Regional Family Support Planning Councils, the Alliance for the Betterment of Citizens with Disabilities (ABCD), the New Jersey Association of Community Providers (NJACP), the Family Support Coalition, and about 30 other self-advocate and family advocate groups across the state. Together, they are working to establish a master plan of disability advocacy goals over the next several years.

Organizing for action is a central part of the mission and purpose of the NJCDD. By conducting advocacy, systems change, and capacity-building efforts that promote self-determination, integration, and inclusion, the Council is committed to advancing public policy and systems change that help individuals and families gain more control over their lives.

According to Myrta Rosa, a self-advocate who serves as Vice Chair of NJCDD, the network is an opportunity to get more advocates involved and have their voices heard.

“These people are fighting for their lives,” said Myrta.

Mercedes Witowsky, who joins the New Jersey Council on Developmental Disabilities as its new Executive Director this July, agrees.

“People with developmental disabilities, their families, service providers, and advocacy allies currently face some of the greatest challenges we have seen in a generation. It is critical that everyone impacted has information they need, can make informed decisions, and has the ability to respond in ways that are coordinated and effective,” she said.

One major outcome of the first summit meeting last fall is a comprehensive shared agenda. As broad as it is ambitious, the shared agenda addresses Medicaid, the NJCAT, direct support professionals’ salaries, housing, transportation, employment, health, safety, and quality assurance, Person-Centered/Self-Directed Services, and communication.

ISSUE	AGENDA
MEDICAID	For individuals with I/DD and their families, Medicaid is by far the MOST important of all programs that fund and regulate the services on which their lives depend. Recent proposals by some in Washington, which seek to significantly cut Medicaid funding or to impose block grants or other Medicaid caps, would be disastrous for individuals with disabilities and their families.
ADEQUACY OF SYSTEM FUNDING	Problems with system funding are the result of families and individuals with I/DD being excluded from the state budget process. Legislative hearings are generally dominated by provider concerns and occur after the budget is nearly in its finished form.
DIRECT SUPPORT PROFESSIONALS (DSP)	DSPs are the heart of the services system, but after nine years without wage increases, DSPs are shamefully compensated. Vacancies and turnover degrade the level of services available to those living in the community. This unaddressed issue is on the verge of becoming a full-blown catastrophe.
NJCAT (DDD'S TOOL TO DETERMINE ELIGIBILITY and BUDGETS for ADULT SERVICES)	The NJCAT does not fully capture the needs of individuals, nor does it sufficiently address mental health issues for people with I/DD. Many families see it as a tool to ration resources and services.
HOUSING	New Jersey's system for housing is underfunded, underdeveloped, and lacking in options. The system relies on Federal Section 8 housing vouchers, and rules restrict "congregate living" arrangements, leading to far fewer housing options.
TRANSPORTATION	Access Link shuttles and buses are limited. They do not cross state or county lines, and their outdated payment system requires exact change, rather than pre-paid tickets or a swipe cards. The state should explore alternatives including partnerships with private providers like Uber and Lyft.
EMPLOYMENT SERVICES THROUGH DVRS	DVRS must do more to support those with significant needs; offer a wider array of job development programs; expand their definition of "employment" to include "meaningful day activity"; and make greater efforts to collaborate with the state's business sector to develop more employment opportunities for individuals with a wider array of intellectual, physical, and behavioral challenges. DVRS should increase consideration of customized employment options.
HEALTH, SAFETY, and QUALITY ASSURANCE	There are significant gaps in quality and safety for individuals with I/DD across the service system. Families must have immediate and unfettered access to incident reports regarding a family member with disabilities, and more direct insight into how the State goes about monitoring system-wide incidents.
PERSON-CENTERED SERVICES/SELF-DIRECTED SERVICES	Recent changes have restricted - not expanded - the freedom, choice, and control to address individual needs that were previously available to individuals and families. Individuals and families want substantive and thoughtful planning that actually assists individuals with disabilities to achieve their life goals.
COMMUNICATION	Far too many families lack even a vague idea of how the "system" works, let alone how to successfully navigate it. Many of the challenges are rooted in an inadequate line of communication between state agencies, policymakers, and individuals and families. The State should partner with advocacy groups to fully disseminate information and obtain direct feedback from our community.



*Self Advocates, Family Advocates, Support Providers, and others representing 29 different DD advocacy organizations have joined together to establish a statewide advocacy agenda and to work toward advancing that plan.*

This spring, the Network hosted its second summit to flesh out the details of the community’s goals, and will soon be working in subcommittees to plan advocacy efforts around key areas identified.

Tom Baffuto, Executive Director of The Arc of New Jersey, has been in the field of advocacy work for people with I/DD for nearly four decades. He has an informed optimism about the Advocacy Network and its ability to move the needle around issues of shared importance

“Everyone involved is committed to these issues,” he said, “We may not always see eye-to-eye on the solution, but the dialogue is wonderful. Any time a diverse group of stakeholders come together to work on solutions to tough problems, it is a productive use of time,” he said,

Dan Keating, Ph.D., Executive Director of ABCD believes that advocacy is a team sport.

“There are so many facets to the lives of those with developmental disabilities—it is like a diamond with many faces—we need to represent all of those things and there is not a single one of us who has the right answer. We need a multitude of perspectives, the most important is that of the person with a developmental disability.”

Like Baffuto, Keating has been in the field for decades and has seen such efforts come and go. He knows that there will be disagreements as well as convergences of ideas.

“We have to get this right and we have to listen,” said Keating. “People with disabilities and their families are depending on us. We need to be sure we are listening to them—we all have to have a commitment to do that.”

One of the things that make this Advocacy Network different is its emphasis on engagement of self-advocates and families.

Keating adds, “I want to be sure our voice is the one that challenges the status quo and creates an expectation that people with disabilities can do more than we have given them credit for in the past.”

As the director of a provider organization, Keating says he has been clear with his members in this area too.

“We have to challenge ourselves to expect more,” he said. “We have to listen to each other—there are different perspectives. If it is going to work, it is because we took the time to listen to each other and to people with disabilities.”

Valerie Sellers, MA, is the CEO at the New Jersey Association of Community Providers

(NJACP). For the last year, she has been working as part of the action-oriented Coalition for a Direct Support Professional Living Wage, which is advocating for better pay for those who provide vital direct care services. The Coalition has a 5-year plan to raise the hourly rate from the current rate of \$10.50/hour to \$16.75/hour by 2022.

Buoyed by success in the 2017–18 State budget, which included a modest statewide bonus of \$20 million in funding for DSPs, Sellers and others in the coalition are excited to be part of the Advocacy Network, and to be broadening the scope of advocacy.

“There are some issues that are divisive, but this is one that is not—workforce issues are just as important to families and self-advocates as they are to providers,” she said. “The Advocacy Network is a great venue to identify common issues. We need each other to be successful.”

As he was preparing to retire from his post as Executive Director of the Council, Kevin Casey reflected on his legacy and the establishment of the Network and engagement of stakeholders.

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*Thus far, the DD Advocacy Network has held two summits, where advocates worked in groups to identify the highest priority areas for the developmental disabilities community. Moving forward, members will work in subcommittees to plan advocacy efforts around the key areas identified.*



*Members of the NJ Developmental Disabilities Advocacy Network at a Summit in Spring 2018*

“Families and self-advocates are sophisticated. They recognize when they are not being listened to. The system has got to develop by listening more to families and self-advocates—and involve them in more serious and meaningful ways in rule-making,” he said.

He is hopeful that the Advocacy Network he helped to establish will continue to grow in size and scope. “I think people are energized—and ready to take action.”

“I know that the advocacy community gets more done when it works together. This is crucial to getting the basic point of view across that people with disabilities deserve a fair shot and we need to work together to get that. We all have to speak in one voice,” he stated.

Mercedes Witowsky said that the Network would continue to be a Council priority

“My hope is to see the group expand its operational steering committee to include other key stakeholders and to develop and post “Issues Papers” to a special section of the councils website. We will be providing action alerts, updated information on the issues, and links to other events/opportunities for engagement,” she concluded. **P&F**

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

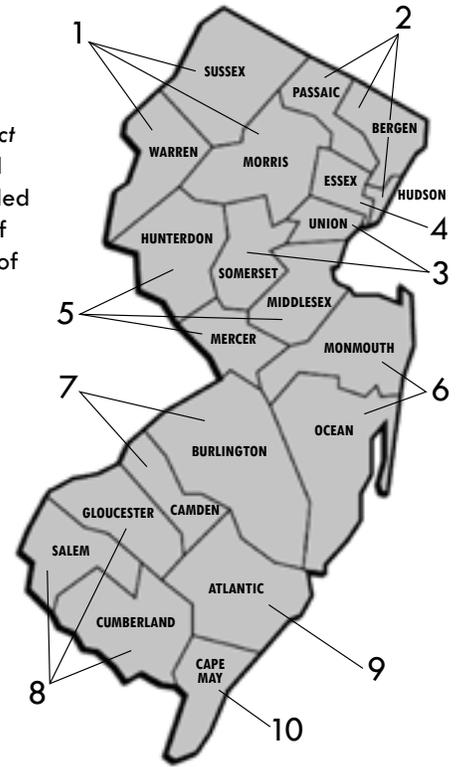
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

A number of regional councils were established in New Jersey by the *Family Support Act* of 1993 (see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and other forms of assistance that promote self determination, independence, productivity, and integration and inclusion in all aspects of community life.

The councils work in partnership with the state's Division of Developmental Disabilities and Children's System of Care to advise on policy decisions that affect people with developmental disabilities 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](mailto:kyoko.coco@njcdd.org) Or visit our website at [www.njcdd.org](http://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:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers

Visit the NJ Council on Developmental Disabilities' web site at: [www.njccd.org](http://www.njccd.org),  
click on the link for Family Support, and the number corresponding to the  
Regional Family Support Planning Council in your area.

## 1 SUSSEX, WARREN, MORRIS

**RFSPC #1**  
**PO Box 12**  
**Pompton Plains, NJ 07444**  
**e-mail: [rfspc1@gmail.com](mailto:rfspc1@gmail.com)**  
**Chair: Margaret Hefferle**

Meets the third Tuesday of each month  
at Wegmans Market Cafe  
34 Sylvan Way  
Hanover, NJ 07054  
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](mailto:RFSPC2@gmail.com)**  
**Co-Chairs: Frank Fiore, Fel Lim**

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

## 3 SOMERSET, UNION

**RFSPC#3**  
**PO Box 5997**  
**Hillsborough, NJ 08844**  
**e-mail: [rfspc3@gmail.com](mailto:rfspc3@gmail.com)**  
**Chair: John Brewer**

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

## 4 ESSEX

**RFSPC#4**  
**PO Box 1742**  
**Bloomfield, NJ 07003**  
**e-mail: [rfspc4@yahoo.com](mailto:rfspc4@yahoo.com)**  
**Co-Chairs: Phyllis McNair,  
Yolanda Smith**

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

## 5 HUNTERDON, MIDDLESEX, MERCER

**RFSPC #5**  
**e-mail: [rfspc5nj@gmail.com](mailto: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](mailto: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](mailto:rfspc7@gmail.com)**  
**Co-Chairs: Laura Kelly, Kathy Freeman**

Meets the fourth Thursday of the month  
(Morning & Evening)  
Morning - 11:30 a.m. - 1:30 p.m.  
Cherry Hill Public Library; Main Floor  
1100 Kings Hgwy North  
Cherry Hill, NJ 08034  
Evening - 7:00 p.m. - 8:45 p.m.  
Bancroft School; Activity Center  
311 Walton Ave  
Mt. Laurel, NJ 08054

## 8 CUMBERLAND, SALEM, GLOUCESTER

**RFSPC #8**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC8@gmail.com](mailto:RFSPC8@gmail.com)**  
**Chair: Sandra Backensto**

Monthly teleconferences will be held  
in Jan - June 2018 in lieu of  
face-to-face meetings.  
For call-in information, email Co-Chairs

## 9 ATLANTIC

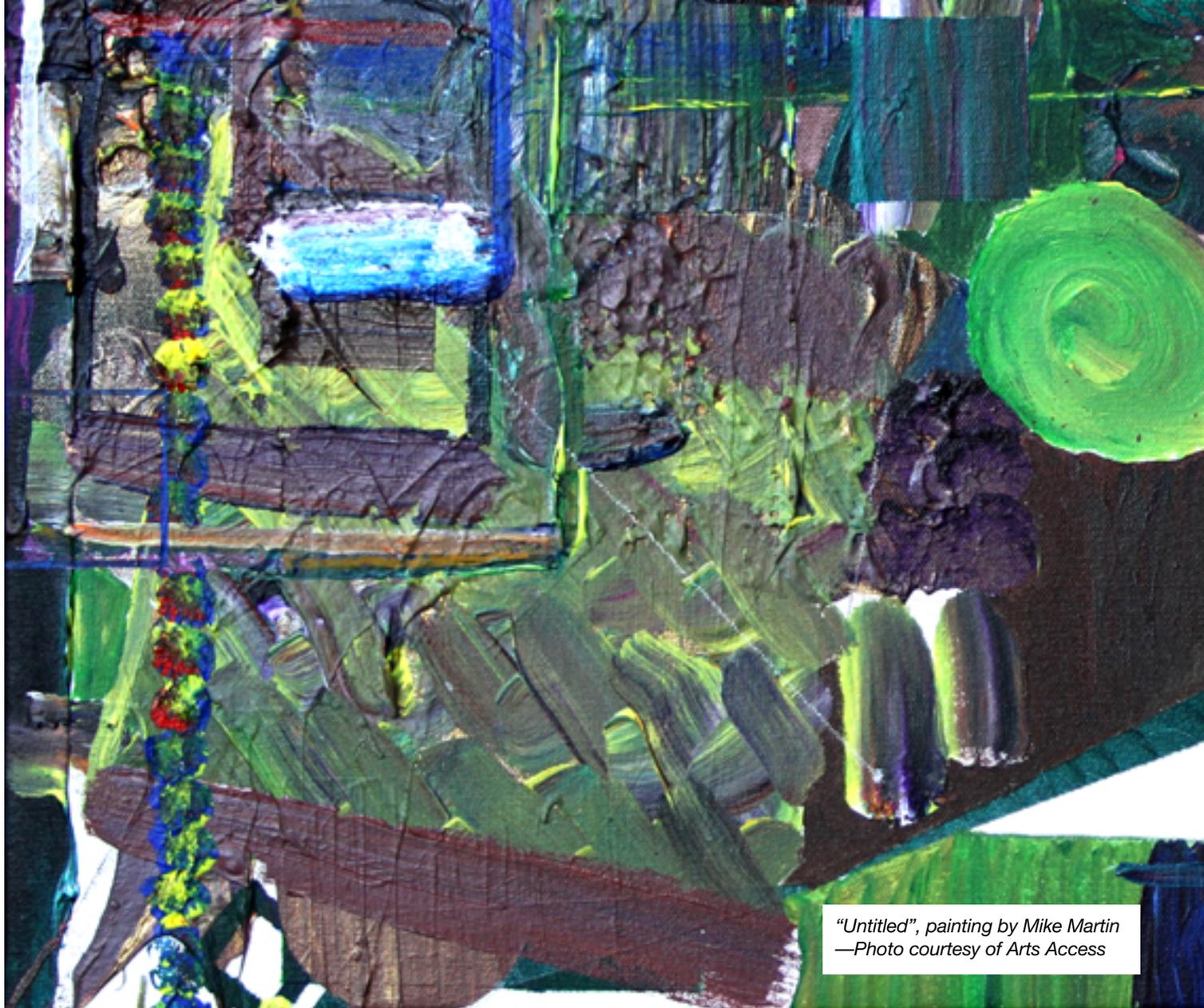
**RFSPC #9**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC9@yahoo.com](mailto:RFSPC9@yahoo.com)**  
**Chair: Mary Ann Philippi**

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](mailto: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



*"Untitled", painting by Mike Martin  
—Photo courtesy of Arts Access*

## Gifted Artists Find Expression Through Arts Access

By Jonathan Jaffe

For a few of us, art is a gift, a calling. It gives our lives meaning and purpose.

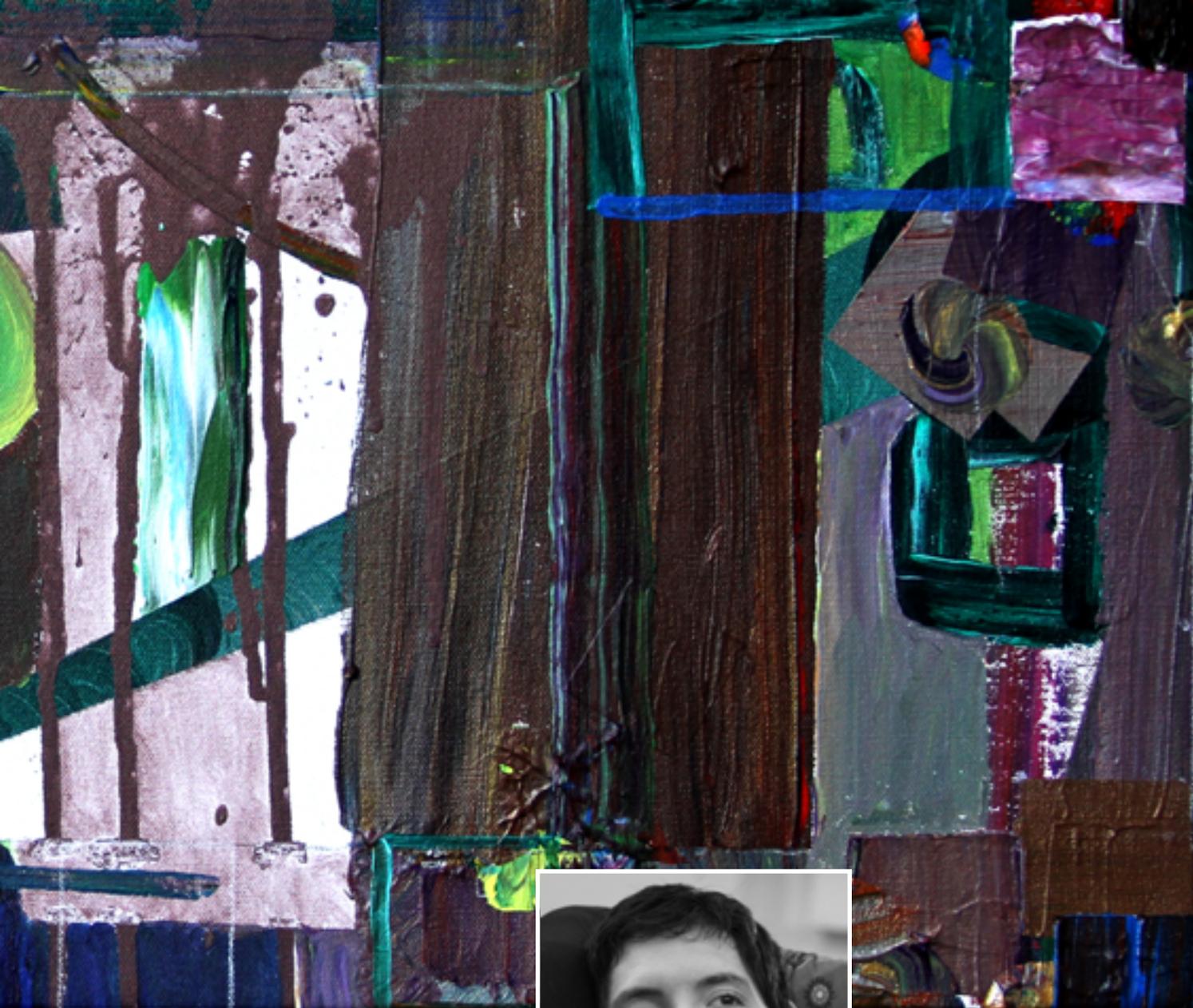
Artists with the Matheny Arts Access program are no different. Some simply enjoy creating, while others have found their life's calling in creation.

Arts Access is a program of the Matheny Medical and Educational Center, a specialized hospital and educational facility in Peapack that serves children and adults with medically

complex developmental disabilities. Many who participate in Arts Access are nonverbal, have developmental disabilities, and/or have limited or no control over the movement of limbs.

Yet, they paint, write poetry, choreograph dance pieces, compose plays, and design complex digital art.

"Arts Access provides a gift to people with disabilities that everyone else already has—the



freedom and liberty to express themselves without limits or boundaries, to make their mark on the world, to contribute their voices and gifts to the collective consciousness and the community,” said Eileen Murray, Director of the Arts Access program.

“The artists we serve have much to say, paint, dance, and write, but they haven’t had much opportunity to turn their inside creativity into outward expression,” she said. “Arts Access gives them that opportunity. For the artists, it’s freedom like no other.”

Discovering gifted artists was not the original aim of the program. Begun in 1993 by then



*Mike Martin is a painter, playwright, poet, and choreographer who had his comedic play “Court” performed last year and has had some of his paintings turned into hot-selling scarves and mugs—Photo courtesy of Arts Access*

Matheny Medical Director Dr. Gabor Barabas, Arts Access was born of a sincere belief in the power of artistic expression and was at first a more traditional art program.

Heather Williams, Performing Arts Coordinator for Arts Access, explains.

“At first, the goal of the program was to help our students participate in art-making,” she said.

“We used traditional techniques, called ‘hand over hand’ in which the instructor guides the student to make the art. We rolled wheelchairs in paint and over canvas, and other instructor-led activities.”

The students enjoyed the recreational nature, but over time expressed a hunger for more. As staff recognized that need, they began to explore a system that would make it possible for students to create the art they envision—with the assistance, but not the influence, of a professional artist.

Through much trial and error, the “Four Principles,” on which the program is based, were developed. Each one shapes the intense training of Arts Access’ professional facilitators, and ensures that each client is the real artist behind the work. Together they produce an unforgettable experience for people with development disabilities—to see their own creative vision played out in the work.

“As a professional dancer and choreographer, I understand how powerful it is to see my artistic vision become reality,” Williams said. “When I joined Arts Access, I was trained to become the hands and feet that made that real for another artist. I learned to take myself and my experience out of the equation, and to be a tool for someone else’s vision. It’s what the Four Principles are all about.”

The first principle is “Freedom of Choice.” This means that the client makes every single choice in creating the piece, whether it is a play, a painting, a dance, or a poem. Every artist, even those who are nonverbal, can indicate yes or no, even if it’s simply through eye movement in a specific direction.

The creative process begins with the question: “Do you want to work today?”

From that first choice, clients walk with the facilitator through a series of choices from the fundamental to the seemingly minor.

Keith Garletts is a professional illustrator and author, and a visual arts facilitator for Arts Access.

“Every choice is up to the artist, including in painting; like which way to stir when we mix two colors of paint,” Garletts said. “It may seem

trivial, but if the artist decides to stop mixing before the two colors are fully merged, which way we stirred makes a difference!”

The second principle, “Neutrality,” is harder to define. It means that the facilitator does nothing to influence the artist’s choices, Garletts explains.

“As facilitators we are trained artists ourselves, but I preach this one principle most of all—we cannot cheat the process by inserting ourselves between the artist and the work,” he said. “Subtle, unconscious things, like a nod when presented with an idea, can have an influence and change the artist’s vision.”

Similarly, the third principle of “No Preconceptions” challenges the facilitator to put aside his or her own training and let the student’s creative process play out.

“Very few of our facilitators come to us with experience with people with disabilities; they are professionals in their field,” Williams said. “It’s challenging to put aside our training about the ‘right’ way to make art, or what we know about schools of thought or traditional forms, to allow the artist’s vision to take the stage. But who am I to say what’s right? It’s not my job to ‘fix’ their work.”

The final principle, “Artists Assisting Artists,” addresses the high level of respect and integrity in the process. The artists and their facilitators treat each other as peers, and the artist is in charge. Together, the Four Principles combine to give the artist with disabilities an authentic experience with each discipline.

Garletts is clear about the results of the process. “This is not faked,” he said. “Our clients are every bit as talented as this art shows. Our work proves that given time and patience, everyone can be an artist. Some of us can be extraordinary artists.”

All of this hard work adds up to an experience that is profoundly affecting artists, each in their own way.

Tammy Heppner has been a part of Arts Access from its beginning. She has visual impairments and uses a wheelchair. She has limited use of her limbs.



*"Carousels in the Knoebels Park in Pennsylvania", by Tammy Heppner—Photo courtesy of Arts Access*

Nevertheless, Heppner has produced professional-grade paintings, which have been sold across the country, through shows and the Arts Access web gallery.

Heppner, who has been with the program since its inception, said she loves the feeling of producing work that others value. "It makes me happy when I sell paintings," she said. "I feel inspired when I think about people loving them."

Heppner is also a poet and author. She published a book of poetry, accepted as part of the

Montclair Literary Festival. Although she may be what some consider limited in ability to experience the world, Heppner says the inspiration for art surrounds her. "I get ideas for my paintings and poems by looking outside, by how I'm feeling, and from my imagination."

"I love Arts Access," she added. "Making art takes away all my frustrations, it's a way to describe how I'm feeling; I really enjoy it. The people here are great, I hope they never take this program away!"



Artist Tammy Heppner, who has participated in the Arts Access program since its inception, has created works of art that have been sold across the country.—Photo courtesy of Arts Access

Digital artist Josh Handler, who also uses a wheelchair and has limited mobility, agrees. “This program makes me feel worthy, and that my work is important,” he said. “It’s good creative time without limits.”

One of Handler’s most recognized pieces, titled “Fruit Salad,” has been turned into limited-edition mugs.

“I start every piece with a vision in my head,” he explained. “Most of the time it even has a title. But what you might think about what the title means probably isn’t what I envision. My apple doesn’t look like what you think an apple looks like. My art is one-of-a-kind; it’s my vision.”

Like any artist, bringing that vision to life can be challenging, even without the added challenge of overcoming multiple disabilities. Handler is undeterred.

“It is frustrating, trying to modify what’s on the screen to make it look like what’s in my head,” he said.

He works on his pieces one at a time, and a single piece may take a month or even two. He has big dreams for his art as well, producing a series of limited edition prints, some signed, from his city series.

Handler’s latest endeavor is to choreograph a dance piece, in which he has cast himself, along with more traditional dancers. He chose a song, “Your Eyes,” by Debbie Gibson. Handler is a super-fan of the singer, who he has seen on Broadway multiple times, and who he has met through her fan club.

Handler said choreography is a different kind of challenge. “I don’t know what it will be when

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“Rolled Over Tomatoes”, painting by Josh Handler  
—Photo courtesy of Arts Access



I start,” he said, speaking of his dance piece. “I have to focus on the work, on seeing what I want every person to do.”

Painter, poet, choreographer and playwright Mike Martin is perhaps Arts Access’ most famous artist, having had a performance of his play “Court,” a comedy performed last year, and having some of his paintings turned into hot-selling scarves and mugs. Martin has also been profiled in *TAPInto.net*.

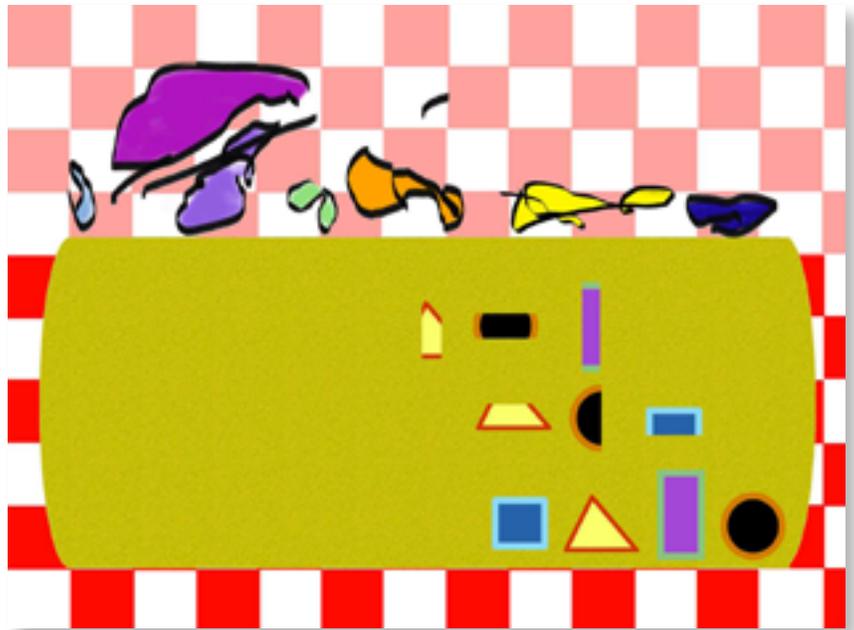
Martin uses a wheelchair and is nonverbal, with no control of his limbs. He communicates his choices to the facilitators through eye movements that signal “yes” or “no” to specific questions. While this process is painstaking, it has done nothing to dampen his flourishing artistic gift.

“Mike has been painting for almost 15 years and has created a significant body of work,” Williams said. “He is a tireless worker, evident in his detail-oriented work with pattern, texture, and color. His paintings and choreography are precise, almost mathematical, yet reveal Mike’s thoughtful personality and commitment to his art. Mike also creates works in the digital medium and creative writing genres, which convey similar qualities.”

There are more than 30 of Martin’s paintings in Arts Access’ collection, and as many as 10 are on exhibit at any time. He is now choreographing a dance piece, set to one of his poems, instead of music. It is the kind of creativity that the facilitators expect from Martin.

When dance facilitator Shannon Johnston, who has a Masters in Dance Education from Rutgers University, tried to help Martin choose music for his piece, nothing suited him. Finally, they hit on using one of his poems as the background.

“Mike is a perfectionist, and he’s not afraid to try something completely different,” Johnston said. “He is concerned about every movement of every dancer, down to their finger positions.” Martin is pleased with how it’s going, but stresses that this piece is “not done yet.”



“Fruit Salad”, digital art by Josh Handler. One of Handler’s most recognized pieces, it has been released on limited-edition mugs by Arts Access.  
—Photo courtesy of Arts Access

When asked to describe his feelings about creating and being a part of Arts Access, Martin chooses emotions like “proud, peaceful, content and alive.” He is especially joyful when he sees his friends and family wearing his scarves and sipping from his mugs.

Pride and empowerment inspires these artists. But Murray is quick to add their experience also changes the audience.

“When the artists are in Arts Access, their disability comes second or fades away entirely; what’s left are dancers, writers, directors, and painters,” Murray said. “The artists gain the power of choice, and with that comes empowerment; the ability to affect outcomes exactly in the way they desire. When people have choice, they have empowerment, they have freedom.”

Arts Access has been changing the way we see the world, for the artists, their facilitators and their audiences, for 25 years. Today the program is housed in a state-of-the-art facility on the Matheny campus, which was built in 1999, and houses the only fully accessible theater in the state. **P&F**

Learn more at [www.artsaccessprogram.org](http://www.artsaccessprogram.org).

# Striving for Fairness in Funding

## A Closer Look at the NJ Comprehensive Assessment Tool

By Brenda Considine

On its website, the NJ Division of Developmental Disabilities (DDD) makes clear that Division-funded services for adults with intellectual and developmental disabilities are *not* an entitlement and are dependent on resource availability.

Those last few words are worth repeating: ***“dependent on resource availability.”***

Each year, the New Jersey legislature distributes state funds, along with any federal dollars, to state agencies to carry out their work. For DDD, that means roughly \$1.8 billion in state and federal funds. With limited resources, and a “funding pie” that is not growing as fast as the need for services, how does DDD decide who is eligible for services and how much funding each person gets?

### **Determining Eligibility. Determining Need.**

The New Jersey Comprehensive Assessment Tool (NJCAT) is a mandatory assessment used to determine eligibility for DDD-funded services. It assesses an individual’s support needs in three main areas: self-care, behavioral, and medical. The NJCAT is a 30-40 minute questionnaire completed by parents and caregivers either online or over the phone with a representative from the Developmental Disabilities Planning Institute (DDPI) at Rutgers University. There is no paper version of the assessment tool, and once submitted, respondents cannot go back to make changes.

Responses to the NJCAT produce a score that DDD uses to establish a funding tier for an individual budget or to determine the reimbursement rate a provider will receive for that individual’s services.

According to Jonathan Seifried, Acting Assistant Commissioner of the Division of Developmental Disabilities, (DDD), the NJCAT helps achieve two significant goals: providing individuals with the services they need and ensuring consistency across the service delivery system.

“The tool is a standardized assessment that ensures individuals with similar support needs have access to similar services. It also is intended to simplify the process by streamlining multiple assessments into a single tool,” he said.

### **Completing the NJCAT: “You really have to know what you’re doing.”**

Lisa Weissbach-Efrat, a licensed clinical social worker from Camden County, recently completed the NJCAT for her 17-year-old son, who is non-verbal. She describes him as “on the severe side of the spectrum,” with significant challenges in self-regulation. He has also has dual diagnosis of bipolar and pica, a disorder in which a person eats non-food substances with no nutritional value (i.e. wood, clothing, dirt, paper, chalk, drywall.) She believes the NJCAT score he received accurately reflect his needs, but admits that her professional experience helps when filling out such forms.

“Somebody with less experience would be at a significant disadvantage,” she said.

Although she is satisfied with the process and the results for her son, she is critical of the NJCAT.

“With someone who has intellectual disabilities or mobility issues, it is clear what they can and cannot do. For someone with autism, they may be *able* to do a task, but won’t. Or they may

need to be prompted or need to be redirected to do it. I had to use the ‘other’ and ‘comments’ section extensively in order to paint a clear picture of my son and the issues that we face,” she said.

Carla Johnson (\*) was also satisfied with the results of the NJCAT. A professional in the field of special education, she talked to other parents before she completed the survey for her 24-year-old son with Down syndrome.

“You really have to know what you are doing when you fill it out,” she said. “It does not assess what happens if the person is left unsupervised. The question should be: ‘If left alone in the house, how long would it take for them to get into trouble,’” she joked.

Jolene Miller (\*) also works in the field of special needs. Her child with Down syndrome recently transitioned into the adult system.

“The problem with the NJCAT is that families do not understand the questions. The questions ask for ‘yes’ or ‘no’ answers. I would like to see more room for families to explain their answers

so that professionals can gain a clearer picture of the person in need,” she said.

She also thinks the online process is flawed and especially hard for families who do not have access to a computer.

Oscar Wright (\*), a parent, believes that the questions are too general and parents do not understand how to properly answer.

“They ask a question like ‘can your child dress him or herself?’ The answer is ‘yes’ but with help. The NJCAT doesn’t allow me, as a parent, to explain that my child can dress himself only when I provide the clean clothing and fix their buttons or zipper. The question would be better stated ‘Can your child independently purchase and wash their own clothes and then dress themselves on a daily basis?’” he said.

For some families, the problems were not with the NJCAT, but with the system itself. Denise Buzz is the guardian for her 55-year-old sister, Angelique. Her difficulties came *after* her sister was assigned a budget of more than \$212,000 per year.

## TIPS ON COMPLETING THE NJCAT

**1) Imagine your child lives in his or her own apartment where you visit once a week. During your visit you ensure your child showers, brushes his or her teeth, and puts on clean clothes. You also make sure the laundry is done, meals are prepared, and the apartment is clean. You leave and return one week later—What do you find?**

- Has your child showered?
- Brushed his or her teeth?
- Is he or she wearing clean clothes?
- What does the apartment look like? Is it clean?
- What has your child eaten? Is there food in the refrigerator?
- What has your child been doing?

**The answers to these questions will help you assess your child’s self-care, independent living, and self-direction skills. If your child cannot perform these tasks without your intervention, prompting, directions, and assistance; then your child needs lots of assistance with these tasks. Be sure your responses on the questionnaire make this clear.**

- Think of your child on their worst day.
- Do not take into account the growth your child may have experienced over the last few years.
- Compare your child to a typically developing person of the same age. This form is often completed when your child is 21 years old. A typically developing 21-year-old may be living completely on their own or living in a dorm at college.

**Reprinted with permission from Hinkle, Fingles, Prior and Fischer. [www.hinkle1.com](http://www.hinkle1.com)**

“I found the NJCAT to be useful and easy to use, but now that the budget is allocated, DDD won’t let us use it. When we asked for a new hospital bed for my sister, they said no, even though we have \$110,000 left,” she said.

Daniel Szyper has had a similar experience. Daniel has Asperger’s syndrome, as well as psychiatric and medical challenges, including obesity and insulin dependent diabetes. He lives at home with his mother. Daniel is pleased with his budget for day services—\$32,000—but says the money exists only on paper.

“Right now, the only thing the DDD is funding is my gym membership,” he said. “I need housing—my mother won’t be around forever,” he added.

His mother, 78 year-old Mira Szyper, is frustrated and frightened because she has no family to care for Daniel when she is gone. When she completed the NJCAT for Daniel, she found it hard to understand.

“You have to know how to answer these questions,” she said. “They asked, ‘can he eat independently?’ and I said yes, but later, I found that the question means something different. The truth is this: he can eat, but he cannot plan his meals, shop for his meals, cook his meals, and clean up,” she said.

“Why can’t they sit down with us to ask the questions and explain things to us?” she asked.

In nearly half of the states in the nation, that is just what happens.

### **Another Way To Assess Need: Supports Intensity Scale**

Currently, 23 states, the District of Columbia, and three Canadian Provinces use the Supports Intensity Scale (SIS). Like the NJCAT, the SIS is a tool designed to evaluate the support needs of a person with an intellectual disability. Unlike the NJCAT, the SIS is a structured interview process administered by a trained professional in the human services field with a 4-year college degree. The interview takes about 2.5 hours. And unlike the NJCAT, the SIS is tested and nationally ‘normed’ so that there is fidelity in the instrument. In fact, the SIS is the only standardized norm-referenced tool that looks at support needs.



*Mira and Daniel Szyper at their home in Kendall Park, NJ.*

Margaret Nygren, Ed.D., Executive Director of the American Association on Intellectual and Developmental Disabilities (AAIDD), acknowledges that there are plenty of what she calls ‘home grown tools’ that attempt to do the same thing as the SIS.

“You need a tool that has been *normed* so that you can look at the score and know how this person compares to others in the same population. A lot of these ‘home grown tools’ have limitations because they are not normed,” she said.

“We don’t just give it to parents and tell them to fill it out,” said Dr. Nygren.

“The SIS assessment brings people together. Several people have to be interviewed, and ideally the individual himself or herself. It is labor intensive,” she added.

“By using a structured interview process, and having a test administrator who makes sure parents understand the questions and the process, there is less chance for error, and less chance to ‘game the system,’” she said.

The result is an accurate picture of someone's support needs.

## A Score is Not a Budget

SIS scores—or any assessment scores for that matter—do not set the budget for the individual. States do.

“States set the budget, based on how much the state is interested in spending and the number of people they have to spend it on,” Nygren said.

She sees states using the SIS as part of a larger system change.

“States often have a legacy system with some glaring inequities in the ways in which resources are allocated. They do not have more money to spend, but they want to spend it more equitably. Since they cannot make the pie any bigger, they want to be fairer in the way the pie is sliced,” she concluded.

Indeed, the NJCAT came into use as DDD was shifting to a fee-for-service model, and was looking to increase fairness and equity in the allocation of limited resources.

Dr. Daniel Keating, Executive Director of the Alliance for the Betterment of Citizens with Disabilities (ABCD) was part of a New Jersey task force that recommended the use of the SIS. In spite of the task force recommendations, DDD opted to use the Developmental Disabilities Resource Tool, (DDRT), a predecessor to the NJCAT.

“The problem with the NJCAT is that there are no independent standards of validity. We don't know for sure that it measures what it says it does, and we don't know about its reliability,” said Keating.

“This is where the SIS is better—you have to be trained to use the tool and you are objective. When there is no objective criteria, you end up with a lot of variation based on who fills out the form,” he added.

“I realize a different process would be expensive, but we have to recognize that the current process is flawed,” Keating concluded.

While no tool is perfect, Siefried believes that with the right training and support, the NJCAT assessment gives DDD the information needed to best assess an individual's needs.

“Where families or providers have questions in completing the assessment or believe a

reassessment is necessary, we are happy to provide assistance,” he stated, adding that DDD remains open to future improvements.

## Navigating the NJCAT

Maria Fischer, Esq is the mother of a 25-year-old daughter who receives services from DDD, and an attorney who specializes in disability law. Every year, she and her colleagues at Hinkle, Fingles, Prior & Fischer, Attorneys at Law, handle scores of cases for families who believe the NJCAT failed to adequately capture the needs of their son or daughter.

“I am a mom so I know how parents set their child up for success by providing ‘invisible supports.’ We do things that enhance independence without even realizing it,” she said. “If questions were framed differently and parents were given

### (\* ) “PLEASE DO NOT USE MY NAME.”

Nearly a dozen families were interviewed for this story; roughly half asked that their names not be used. Carla Johnson, Jolene Miller, and Oscar Wright are pseudonyms used because the parent/caregiver asked that *P&F* keep their names private.

- “I work in the field and I am afraid I could lose my job if my name was made public. It would not look good for my employer,” said Jolene Miller.
- “Parents don't want their names used because we are totally vulnerable to a system we don't understand and that our children depend on for their lives,” said Carla Johnson. “My son finally has a great program and great supports. I would not want to risk it.”
- “People are afraid of the system. We do not want retaliation,” said Oscar Wright.

When asked about these comments from families, Siefried emphasized that the Department of Human Services does not tolerate retaliatory behavior.

“We encourage families to communicate concerns to the Department and in fact individuals and families routinely request reassessments by the state,” added Seifried.

better instructions, the NJCAT would do a better job at capturing need,” she said.

Fischer believes that when completed correctly, the NJCAT forces parents to confront the degree of disability their child faces.

“They have to answer all the questions as if their child were typically developing. They have to ask: would a typical 21-year-old really need the help I am providing?” she said.

Like many parents, Fischer believes the NJCAT fails to capture deficits around judgment and decision-making

“There is not a single question about responding to an emergency. The NJCAT does not fully assess the ‘supervision piece’ of things. They may not need a lot of services—but what happens when something goes wrong?”

Fischer knows first hand what happens when families do not know how to answer the questions.

“Families who fill the form out badly get very low scores and as a result, they get very low budgets for their child, some as low as \$19,000 for a day program—a person with that budget cannot even go to a day program every day,” she said.

She also said that the person can be deemed not to have substantial limitation, and that may require an appeal—a process that can take more than a year and often requires legal assistance.

Families and individuals have the right to appeal. It is the process where a person requests a formal change to an official decision. The person

making the request must do so in writing, usually within a certain time frame. In most cases, submitting additional or new supporting documentation when requesting an appeal is required.

When faced with an unfavorable decision, the first step is to contact the person, district, or agency directly. If you’re not satisfied with the result after going through a review process or re-evaluation, you may submit a complaint, and request a reconsideration or a mediation. If that doesn’t resolve the problem, you can file an appeal or due process. (See the resources section for more details)

DDD will consider a request for NJCAT reassessment only for individuals who have an assigned Support Coordinator, and a completed Person-Centered Planning Tool (PCPT) and Individualized Service Plan (ISP). The link to the form is in the resources section of this article.

In some instances, the appeal is well worth it. Fischer recently handled a case in which the individual’s case manager completed the form and indicated that the person had no behavior problems, but the individual had a history of significant behavioral challenges over the course of years. Based on her advocacy, the individual went from a budget of \$117,000 to \$317,00, an increase of \$200,000.

“Parents fill out many forms, but they will need help and guidance as they complete the NJCAT. It is one of the most important forms they will ever fill out for their child,” she concluded. **P&F**

## RESOURCES

**The Arc of New Jersey has recently launched a “DDD Eligibility ‘Go Bag’”. It describes, step-by-step, the process for DDD Eligibility and includes information about the NJCAT and the appeals process.**

<http://www.thearcfamilyinstitute.org/resources/dddgobag.html>

### **NJCAT - Q&A**

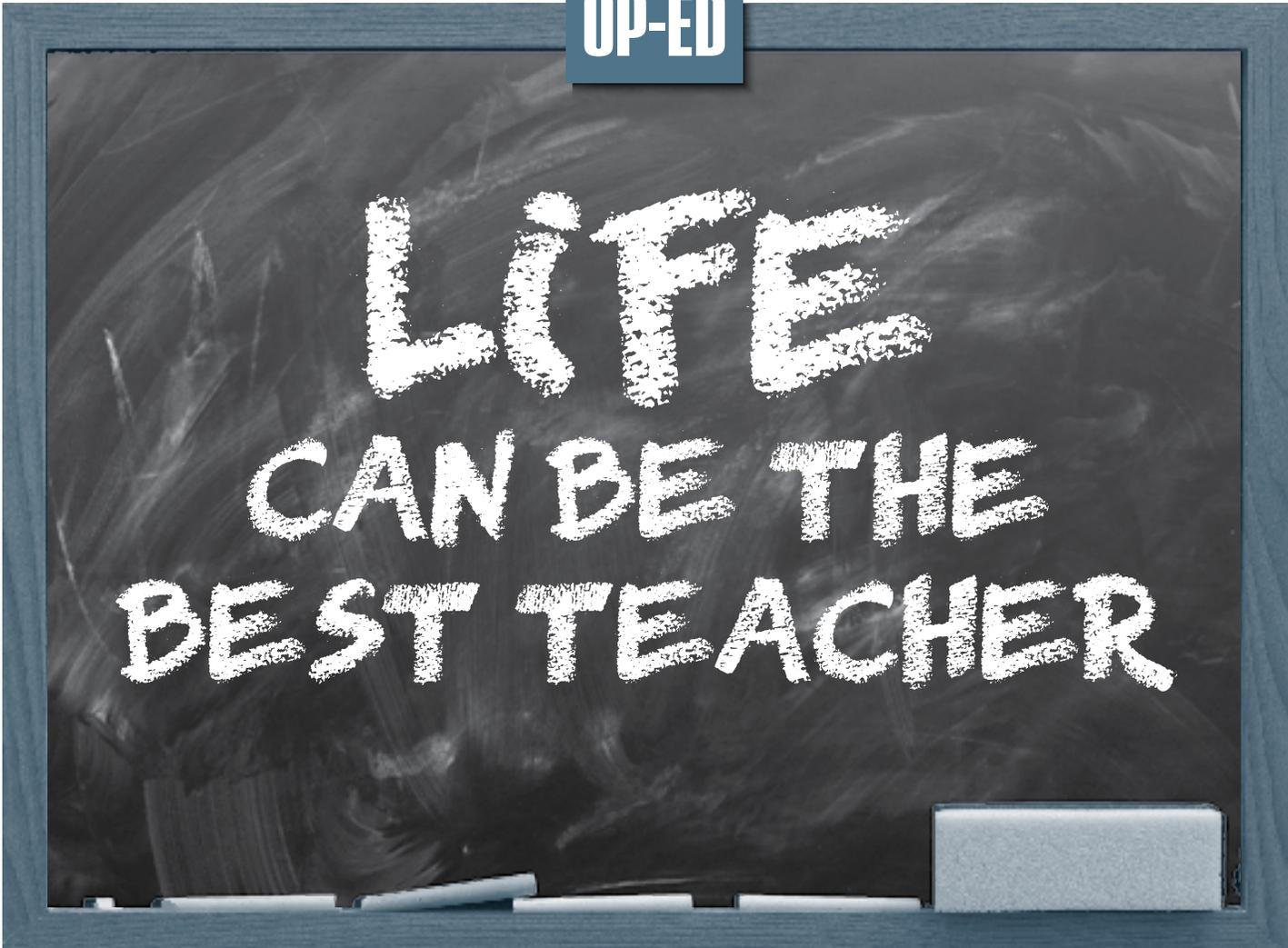
<http://www.state.nj.us/humanservices/ddd/resources/njcat.html>

### **Webinar on How to Complete the NJCAT**

<https://www.youtube.com/watch?v=nluCSO5kFWk&feature=youtu.be>

### **How to file an appeal with DDD**

<http://www.state.nj.us/humanservices/ddd/documents/ddd%20web%20current/CIRCULARS/DC37.pdf>



# LIFE CAN BE THE BEST TEACHER

By Marianne Valls

**E**ducating children is one of the most important jobs a society has, and youngsters with disabilities must be included. However, when it comes to teaching children with disabilities, society sometimes has far lower expectations on what these children can and should learn. And this goes beyond the usual “Book Learning”. Key skills like self-reliance, independence, grit, and responsibility are vital for a successful adulthood.

Regardless of disability, every child comes with their own set of talents and struggles. It may be challenging for parents of a child with impairments to see where their abilities and talents shine. But they are there and must be found and encouraged.

Overcoming common misconceptions about people with disabilities is everybody’s business. Historically, textbooks have painted an ableist picture of people with disabilities, making us seem more fragile and in need of constant care than is oftentimes really the case. Each of us, including those of us with disabilities, must rid ourselves of these views. The road to independence and self-reliance starts in childhood, and it is the job of parents and educators to set children with disabilities on their way.

Maybe it’s just that today’s “experts” in child rearing read too many books. I was born with cerebral palsy in 1945. Back then, little was known about my disability—and that may have

actually been a bit of a good thing. When I was a child, my parents had little knowledge of what my lifelong limitations might be. Therefore, there were fewer deviations in the way I was raised versus my typically developing peers. I was expected to behave, learn, and do chores to the best of my ability. These are all good disciplines for a child to grow, regardless of physical or intellectual disability.

When I was young, still living with my mother, my regular chore was to clean our bathroom. My lack of hand coordination made the job time-consuming. Although it often took me a half an hour or more to complete this chore that she could do in 15 minutes, my mother knew that one day I would need to be able to clean a home of my own.

One other important skill my mother taught me was how to be “social”. Relating to people and making genuine connections is not learned by reading a book or solving complex math equations. In work, school, and life in general, people thrive by networking; by exchanging ideas; and by making contacts within our communities.

In all aspects of life, people with disabilities must learn to be their own advocates whenever possible. While I don’t want to discourage parents, friends, co-workers, or anyone else from offering to help a person with a disability who is struggling, I also think it does no favor to that child or young adult with a disability to always have someone else step in do anything that they themselves can do alone. Even if a child has difficulty doing a task on their own, they should be allowed to try and try again, so that they can have a higher level of self-reliance in adulthood.

Nowadays, many people with disabilities are able to live independently with the help of home health aides and direct support professionals, and we should all hope that we can strengthen and maintain this system. But an in-home support worker can only do so much for an individual if the individual isn’t practiced in speaking up for themselves and communicating their needs. These skills also begin in childhood.

The Americans with Disabilities Act (ADA) is one of the most important laws guaranteeing people with disabilities have full access to all areas of our society. But the full benefits of this law—making it easier for people to live fully in their communities—can’t be realized if people with disabilities are brought up without the skills necessary to take advantage of it.

Regardless of how resourceful and independent a person with disabilities may be, there will likely always be barriers limiting their access to things that non-disabled people enjoy. This is why laws like the ADA need to be protected and strengthened. But the most important factor in ensuring the effectiveness of the ADA is for people with disabilities to speak up for themselves and communicate their experiences. Only people whose everyday experiences include disability can point out the barriers that still exist in our society. People who encounter obstacles in the environment are less likely to contribute to the society. Everybody pays for barriers that block disabled individuals’ productivity and independence.

Children must learn to communicate that they are entitled to live independent and self-directed lives. They need to learn that they are valuable human beings who can contribute to their homes, their communities, and beyond. Emphasizing a child’s abilities rather than their disabilities can lead to a successful adulthood. Talents encouraged in childhood often lead to employment and self-sufficiency later in life. A good piece of advice for parents or guardians of young people with disabilities is to seek out adults with disabilities who have found success and independence—Centers for Independent Living or Self-Advocacy groups are a good place to start the search.

Life is a game everyone must play, regardless of their level of ability. But a person has a better chance of winning if they have a voice and the resources to excel. The path to charting one’s own direction and finding one’s voice begins in childhood. **P&F**



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Mira and Daniel Szyper at their kitchen table in Kendall Park, NJ