

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 2, 2022

NEW JERSEY TEAM CHOSEN TO INITIATE SUPPORTED DECISION MAKING



Michael Conrad and Bruce Curless, Founder/Producing Artistic Director of The Ritz Theatre in Oaklyn, on a set at the theatre.

COMMUNITY INNOVATION PROJECTS CIP

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Developmental Disabilities'

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DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

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Gwen Orłowski, Esq., Disability Rights NJ

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

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

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We all must continue to advocate for the health and safety of all individuals living at home and in out of home settings. We must also continue to advocate for increased wages for our direct support professionals who have demanding jobs and are the lifeline to services and supports.



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



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The Center on Youth Voice, Youth Choice (CYVYC), a national resource center for youth with disabilities, has selected five states to join its national Community of Practice to promote alternatives to guardianship for youth ages 14 to 26 with intellectual and developmental disabilities (I/DD). State teams from Indiana, Michigan, New Jersey, Oregon, and South Carolina were chosen.

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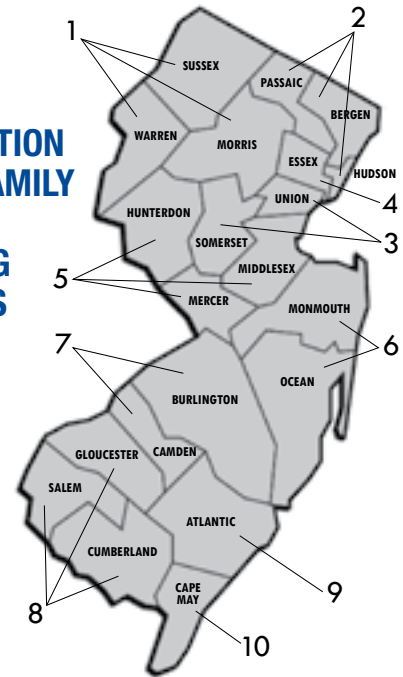
Thousands of people with an intellectual/developmental disability (I/DD) are living longer, fuller lives. As they age, their needs may change over time, and neither the system of supports for people with I/DD, nor the system of supports for those who are aging is ready. And while aging is an inevitable part of life, often, their parents and caregivers are not ready either.



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The 2021 annual report submitted by the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families cites abuse and neglect in community settings in our state. The report includes recommendations including a zero-tolerance policy for abuse and neglect.

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Renewing New Jersey's Commitment to "Employment First"

A new report released by the New Jersey Council on Developmental Disabilities (NJCDD) is calling on the Garden State to improve employment outcomes for individuals with I/DD. The 60-page report, *Advancing New Jersey's Employment First Practices and Policies*, was developed by the John J. Heldrich Center for Workforce Development at Rutgers, The State University of New Jersey, in partnership with the Institute for Community Inclusion at the University of Massachusetts.

from the Executive Director ■

Advocating for Health and Safety

We all must continue to advocate for the health and safety of all individuals living at home and in out of home settings. We must also continue to advocate for increased wages for our direct support professionals who have demanding jobs and are the lifeline to services and supports.

The 2021 annual report submitted by the Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families cites abuse and neglect in community settings in our state. The report includes recommendations including a zero-tolerance policy for abuse and neglect.



At the same time, we must strive for more decision-making power for individuals with intellectual and developmental disabilities (I/DD). In response, we continue to push for better alternatives to guardianship. New Jersey is among five states selected by the Center for Public Representation in conjunction with the Center on Youth Voice Youth Choice (CYVYC), to join its national Community of Practice to promote alternatives to guardianship through supported decision making.

We will develop a statewide plan to promote alternatives to guardianship for youth. Our goal is to raise awareness, engage with youth ambassadors and ultimately enact legislation that provides a legal basis for supported decision making as an alternative to guardianship in New Jersey.

I am also excited and pleased to announce that the Council received a federal grant that will include us as a participant in a five-year national Bridging Aging and Disability Services Community of Practice sponsored by the federal Administration for Community Living.

According to the Division on Developmental Disabilities (DDD) nearly 25% (more than 6,700) of those receiving DDD services are over the age of 50. More than 900 of those are over the age of 70.

Our goal is to build capacity across agencies and systems to support individuals with I/DD and their families to better plan for their future. The project will include our DD Act partners along with fifteen other State Alliance Team members. The NJ Division of Developmental Disabilities and NJ Division of Aging Services will serve as project team leads with the Council.

You can read more about the Ombudsman's report, our efforts around supported decision making and our federal grant in this issue of People & Families magazine.

Warm Regards,

A handwritten signature in cursive script that reads "Mercedes Witowsky". The ink is dark and the signature is written in a fluid, personal style.

Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities



NJCDD COMMITTEE UPDATES

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

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

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

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

The Council's standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee.

Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy Committee. Two new subcommittees, the Diversity Equity and Inclusion (DEI) and the Advocate Advisory, were added. DEI meets under the State Plan Committee and the Advocate Advisory meets under the Executive Committee. The following is a snapshot of some of the committee highlights.

Executive Committee

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

The following are recent Executive Committee activities:

- Nantanee Koppstein has received her formal appointment from the Governor's Office as the newest member of NJCDD. The executive director continues to engage regularly with Governor's Office of Appointments to gain Senate confirmation and formal appointment of the other nominees for membership.

- The Community Building Awards Luncheon has been scheduled on September 22, 2022, at the Estate at Farrington Lake, East Brunswick.
- The executive director is working diligently with the staff to ensure that all funding available to NJCDD is allocated to approved and worthy projects before the funding authorizations expire.
- NJCDD received a federal grant that will include NJCDD as a participant in a five-year national Bridging Aging and Disability Services Community of Practice sponsored by the federal Administration for Community Living. The project will include our DD Act partners along with twelve other State Alliance Team members. The NJ Division of Developmental Disabilities and NJ Division of Aging Services will serve as project team leaders.
- NJCDD is a participant in a national Community of Practice. Disability Rights New Jersey has taken the lead with this project administered by the Center for Public Representation with the Center for Youth Choice Youth Voice. The ultimate goal is to enact legislation in NJ that will provide a legal basis for Supported Decision Making as an alternative to guardianship in New Jersey.
- NJCDD received a \$95,319 Grant from the federal Administration on Community Living grant for Expanding Public Health Workforce, which will run until 9/30/2024. The Executive Director has assembled a coalition of participating organizations to engage in this project.

State Plan Committee

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

- The Planning Committee worked on the 2022-2026 Five-Year Plan for a year and a half, gathering information from public comments, focus groups and in-depth conversations with the Ad Hoc Committee on Equal Access to DD Services. After the draft plan was approved by the Council, it was finalized and submitted to the Administration for Community Living (ACL) last fall. It is pending final approval after

the recent submission to clarify two aspects of the plan.

- The plan contains three broad goals in the areas of advocacy, capacity-building and system change. The plan can be found on our website: <https://njcdd.org/njcdd-5-year-planning-2022-2026/>

Grants Committee

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

- NJCDD announced a three-year funding opportunity of up to \$375,000 for three years/ \$125,000 in year one (excluding required 25% match) for a qualified entity to improve access to and the provision of education and transition services that align with Employment First. The Arc of NJ was awarded a contract to begin this work effective June 1, 2022.
- NJCDD announced a multi-year funding opportunity of up to \$250,000 for two years/ \$125,000 in year one (excluding required 25% match) for a qualified entity to plan and implement projects designed to increase the number of individuals with I/DD who are engaged in competitive, integrated employment, including individuals with complex behavioral and medical issues. While a contract was not awarded, NJCDD remains focused and will internally foster activities to meet this objective.

Public Policy Committee

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

- The third meeting of the Legislative Disabilities Caucus this year was held on July 26, 2022. The session was devoted to the DSP issue, including wages, retention of workers, and agency sustainability. Speakers Joe MacBeth, Beverly Roberts, Valerie Sellers and Aaron Fitchner delivered remarks on the need for advocacy in support of DSPs. The next Caucus session will be held on October 25, 2022, on education. Senator Ruiz will chair the session.
- The State Budget was signed by the Governor on June 29th and continues many necessary and beneficial programs for individuals with I/DD and their families as the State slowly recovers from the pandemic. HCBS continues to be a focus at the federal level.
- DDD has announced that it is opening an emergency response center for behavioral issues on the grounds of New Lisbon Developmental Center in the fall of 2022.
- A meeting was held on June 9, 2022, with Senator Vitale's office on the introduced Electronic Monitoring Devices (EMD) bill. The NJCDD position of neither supporting nor opposing the bill was explained along with the possibility of unintended consequences of legislation concerning privacy and violation of federal regulations on HCBS.

Subcommittee on Children and Youth

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

The committee is addressing:

- Improving the system of family support services for those caring for a child under the age of 21
- Access to specialized child health care services
- Special education services, assessments and transition services through COVID
- Racial inequity & disproportionality in special education
- Seclusion, restraint and discipline issues
- School safety drills and school emergency procedures

Subcommittee on Health and Wellness

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

The most recent Health and Wellness Subcommittee meeting was held on July 19, 2022. The Subcommittee is focused on:

- Monitoring funding related to DSP nutritional training.
- Supports for individuals with I/DD through Support Coordination, MCO Care Management, CMO Care Management, transition support, and DSP Core Competencies
- The continuation and expansion of telehealth services.
- Researching screening and early detection resources for the underserved populations of minority access, complex care, and behavioral concerns.
- Continued engagement in next step planning of regulations for newly passed Pediatric Network Adequacy (S3000) legislation.

Diversity, Equity, and Inclusion Subcommittee

The Diversity, Equity, and Inclusion Subcommittee was introduced this year as part of the 2022-2026 Five-Year State Plan. The subcommittee ensures that there is diverse representation within the council and its members, equity in practices, policies, messaging, communication and interactions with people, awareness of environmental impact on family and communities served, as well as openness and accessibility to information and all services provided by the NJCDD are present throughout the plan's goals and objectives.

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

The following are recent subcommittee activities:

- At the June 16, 2022 meeting, Sarah Aziz, chair discussed focusing on systems change in alignment with the 5-year plan with a focus on creating access and awareness in elementary schools. Annette Smith, co-chair further added that a pipeline of information and access is needed from birth to end-of-life. Navigating services prior to school entry is important and some families are still not accessing information or services that could lead to needed diagnosis or support after diagnosis.
- Moving forward, the committee will actively engage in creating strategies to increase awareness and access to services in diverse communities with a culturally competent lens by lending support to current NJCDD grants and projects as well as focusing on how to better connect services at the elementary schools.
- Grantee LeDerick Horne and team including Bill Davis and Dominique Powell updated the subcommittee about their current work with both Piscataway and Asbury Park School districts in helping to provide access to

resources, support, and information to Black students with I/DD and their families.

Self-Advocacy Advisory Subcommittee

The Self-Advocacy Advisory Subcommittee was established under the recently amended bylaws to ensure the voices of advocates are being heard and supported through the Council's goals. Ryan Roy serves as chair. The subcommittee's recent activities include:

- The group held its first meeting on May 2. The group discussed subjects that are most pressing for self-advocates employment, transportation and housing. They also discussed the impact that COVID-19 had on the self-advocate community including some of the lessons learned.
- The subcommittee will plan listening sessions to gather feedback from regional self-advocates regarding strategies gained through lived experience that could help guide Council decision making.
- The subcommittee will also work with the DEI subcommittee on plain language versions of documents and training materials. **P&F**



The banner features the 'common ground' logo on the left, with 'common' in a sans-serif font and 'ground' in a script font, followed by a stylized 'g' icon. To the right, a dark blue speech bubble contains the text 'Common Ground Online' and 'Increasing Dialog Among Stakeholders In New Jersey's Special Education System'. Below the logo and speech bubble is a row of blue icons representing diverse people, including two individuals in wheelchairs. At the bottom, a dark blue bar contains the text 'The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!'. Below this bar are three bullet points: 'Read about current issues in special education', 'Get updates on legal and legislative developments', and 'Find important resources and information'. On the right side, there is a 'Visit' button with the URL 'www.NJCommonGround.org' and the text 'to sign-up for a free online subscription!'.



New Jersey Team Chosen to Initiate Supported Decision Making

By Maryann B. Hunsberger

The Center on Youth Voice, Youth Choice (CYVYC), a national resource center for youth with disabilities, has selected five states to join its national Community of Practice to promote alternatives to guardianship for youth ages 14 to 26 with intellectual and developmental disabilities (I/DD). Twenty-five teams from 21 states and territories applied. State teams from Indiana, Michigan, New Jersey, Oregon, and South Carolina were chosen.

The New Jersey team comprises the Council, the Boggs Center, the Statewide Parent Advocacy Network (SPAN), Disability Rights New Jersey (DRNJ). DRNJ has taken the lead on this initiative. Michael Brower, legal director of DRNJ, said, “We get a good number of calls from individuals saying they don’t want to have a guardian anymore because they disagreed with their guardian, or because they want to make their own decisions. Once a person has a guardian, though, it’s likely they will have a guardian for the rest of their lives. It requires proving to a judge that they no longer meet the legal definition of needing a guardian. Doctors have to tell the judge that the person doesn’t need it.”

For this reason, DRNJ discourages the use of guardians whenever possible. “When we get calls from family members asking for help getting guardianship, we tell them we don’t help with that, as it takes decision making power

from the person with the disability.”

Therefore, the New Jersey team will devise plans to promote alternatives to guardianship for youth. They will also support four youth ambassadors who were recently chosen to join the team and co-lead this work. “We will connect with other states, some of whom are way ahead of New Jersey in terms of changing the system. Some are behind us. We hope to lay out a road-map for New Jersey to improve the system. We come at this from the approach that too many people have guardians. When people tell us they don’t need a guardian anymore, it’s difficult to change, so let’s avoid it in the first place.”

At least 1.5 million adults in the United States are under guardianship. Disability experts such as Brower are shifting away from the overly protective construct of guardianship toward the more rights-focused construct of Supported Decision Making (SDM).

Amy and Jacob Kiger at Resources for Independent Living in Pennsville NJ.





Michael Conrad at The Ritz Theatre in Oaklyn where he will volunteer

People with I/DD might need assistance making decisions about health care, living arrangements, finances, employment and relationships. Advocates like Brower want youth with I/DD to have the opportunity to confer with others and then choose for themselves. Brower explained that everyone uses supported decision making in their everyday lives. “We take friends shopping with us to help us choose clothes. We ask mechanics if we should buy a certain used car. We discuss with our families whether we should change jobs. We consult with others and then decide on our own.”

The New Jersey State team receives guidance from CYVYC through technical training and support. “We speak to them regularly. They also provide the network for us to connect with other states. New Jersey has a lot of potential to do this

the right way. It’s a good opportunity to formally start this conversation in our state.”

Colleen McLaughlin, associate director of the Boggs Center, said they have been educating the disability community about SDM and alternatives to guardianship through their Developmental Disabilities Lecture Series (DDLs). They have also integrated SDM into the Partners in Policymaking curriculum. The class members learn about SDM and how to advocate for the right to have support in decision making.

McLaughlin said, “New Jersey is at a starting point. We need to work hard so guardianship is not seen as a rite of passage to adulthood. We need to educate people with disabilities and their families from a young age about alternatives to guardianship. We need to empower youth with disabilities to learn to consult with family and

friends and make informed decisions, like everyone else does. We need to educate systems. We're developing an action plan to set the framework for what needs to take place in New Jersey to help SDM come to full fruition."

The UN Rights of Persons with Disabilities conference of 2008 outlawed removing a person's legal capacity to make their own decisions on the basis of disability. The treaty requires countries to modify their legal systems to recognize some form of supported decision making. The US has signed the treaty, but our Senate has never ratified it into law. This means decision making is governed by the states, because there is no uniform law across the US. In some states, the law is on the books. New Jersey does not have a supported decision-making law in place.

The Center for Public Representation, a national public interest law firm, recommends that individuals and their supporters use an SDM agreement form to assure that everyone understands what SDM will mean for the individual and how it will work. A lawyer isn't needed for this.

The individual identifies the areas where he or she needs decision-making assistance and the type of support needed. The individual then chooses trusted supporters.

Molly Lou Conrad of Voorhees does informal supported decision making with her son, Michael, 43. Though they don't use an agreement form, they discuss whatever decisions Michael has to make. Michael lives in a Union County group home. For many years, he has traveled back and forth on his own to New York City to volunteer at an off-Broadway theater. "He's very good with transportation," said Molly. "He takes the train and the subway. He even taught me how to get around on the New York subway."

Michael made the decision to volunteer in the theater with support from his mother. He and his mother have discussed his making a move from Union County to Camden County, closer to home. They located a supported apartment in the area. "He's excited that he will have his own apartment. He will volunteer at the Ritz Theater in Oaklyn. I supported him in making the decision."

Peg Kinsell, policy director of SPAN, stressed that a young person participating in his or her



Jacob Kiger at Resources for Independent Living in Pennsville NJ where his mother Amy works and he attends.

own life is crucial to full growth. "We've advocated for alternatives to guardianship on both state and federal policies. We've opposed bills to make guardianship more restrictive. Alternatives to guardianship should be at the forefront in Trenton and in Washington, DC, and guardianship should be the last resort. This is why we talk to parents and include information about supported decision making in our trainings.

"Schools push parents toward guardianship because they don't know better. It says on the IEP (Individualized Education Program) that parents will lose rights when their child reaches 18. So, the parents think they need guardianship to not lose their parental rights. Service providers also sometimes persuade parents to get guardianship. But, there are alternatives. A school district can provide a simple power of attorney saying that a student wants their parent to share in decision making and be at IEP meetings. There are so many other things to try first that don't take away the civil rights of youth."

Amy Kiger of Quinton does informal SDM with her 23-year-old son, Jacob, so he can share in decision making. They haven't signed an

agreement yet. “I spoke with him about it to explain how it would work. I’d like him to be as independent as he can. He is capable of learning. I just want to provide guidance and support.”

She recently supported him in finding cognitive behavioral therapy. “He decided that he needed therapy. I said, ‘Okay, let’s find it.’ I researched and found a therapist. Whenever he goes to a doctor’s office, he wants me in there to help explain whatever the doctor says. He talks, and if he needs me to fill in, I will. If the doctor examines him, I step out of the room. With therapy, I give suggestions of goals, and then I leave the room to give him privacy. He will do sessions by himself at this point. Once a month, I’ll come in to discuss what progress has been made.”

Quinton said if Jacob wanted to make a decision she disagreed with, she “would explain to make sure he understands the consequences of his decision. As long as he can verbalize what that entails, I’ll let him do it. He will get the final say, as long as it’s not life threatening. You have to let them become as independent as they can.”

Some recent decisions he has made are joining the local volunteer fire department and obtaining a part-time job at an animal shelter. Quinton said Jacob feels independent and self-sufficient making such decisions. “He has a say in what happens. He gets to make a choice. Our job is to teach our kids how to fly. It’s been my goal with him since he was diagnosed. This allows me to guide and teach him informed decisions. I absolutely recommend this to other parents. In some cases, guardianship is necessary, but even if they have guardianship, they should still give their child a choice.”

Mercedes Witowsky, the executive director of the Council, stressed that New Jersey still needs state legislation and definition guidelines to be drawn up and signed by the governor. “That way, the SDM agreement will be accepted by places like hospitals. If a young adult is asked if they want surgery, their opinion might not matter. It can stall medical treatments. With a state decision-making law, a doctor would have to accept the document. We’re nowhere near there yet in New Jersey. We have a desire and willing partners who want to work on this. In the meantime, the New Jersey team will be educating, parents,



Michael Conrad and his mother Molly Lou in Voorhees NJ

teachers, administrators, social workers, hospitals, the public and stakeholders to understand the alternatives to guardianship for people with disabilities.” **P&F**

Center for Public Representation’s SDM Agreement Form: SDM Agreement Form - Supported Decision-Making (supporteddecisions.org)

Center for Public Representation’s Forms for Health Care Proxy, Power of Attorney, Health Care Release Form, School Record Release Form: Getting Started With Supported Decision-Making - Supported Decision-Making (supporteddecisions.org)

The Golden Years

Bridging the Aging and Disabilities Networks

By Brenda Considine

Michelle Murphy was never supposed to grow old.

When she was born in 1973 with Down syndrome, doctors told Michelle's mother, Leone Murphy, that her baby would not live to middle age. At the time, the life expectancy for someone with Down syndrome was only 25 years. Unwilling to accept that grim prediction, Leone, an advanced nurse practitioner, dedicated her life and her work to healthcare equity and access for people with intellectual and developmental disabilities.

Today, the average life expectancy of a person with Down syndrome is 60 years and continues to climb. At 48, Michelle is healthy, active, and still working her "dream job" at Banana Republic, a position she has held for 18 years. She lives at home with her parents in Monmouth County, as she has done her entire life. But she is slowing down. She is enrolled in a research study looking at the development of dementia, a condition



Michelle Murphy with her puppy Paisley

that affects about half of all older in adults with Down syndrome.

In Michelle's story, there is both good news and bad news.

The good news is that thousands of people with an intellectual/developmental disability (I/DD) are living longer, fuller lives. The bad news is that as they age, their needs may change over time, and neither the system of supports for people with I/DD, nor the system of supports for those who are aging is ready. And while aging is an inevitable part of life, often, their parents and caregivers are not ready either.

A Tidal Wave on the Horizon

The National Association of Councils on Developmental Disabilities estimates that nearly one million American families include an adult with I/DD living with aging caregivers. About two-thirds of these families do not have advanced care plans, and most are not receiving formal services through their state's I/DD agency. More

than half (54%) of family caregivers do not have a plan for the future, and worry about what will happen when they are no longer able to care for their family member.

Here in New Jersey, the Division on Developmental Disabilities (DDD) data show that nearly 25%—more than 6,700—of those receiving DDD services are over the age of 50. More than 900 of those are over the age of 70.

The Challenges: Changing Needs and Two Systems

Like other senior citizens, adults with I/DD want to enjoy their golden years. But as they age, their needs and abilities may change. They will retire. They may need more specialized medical, housing, transportation, personal care, or other services. And there are complex questions about care, dignity, and end-of-life decisions that must be considered.

Unfortunately, most disability-based organizations have not planned for the challenges faced by older people with I/DD. And most community-based services for senior citizens are not prepared to meet the special needs of older adults with I/DD.

“In addition to the lack of coordinated systemic supports, we see family caregivers who lack information about and access to resources they might need to plan ahead,” said Mercedes Witowsky, executive director of the NJCDD. “Old age is another developmental milestone, but many families are not ready for it.”

National Attention

In September 2021, the Administration on Community Living at the US Department of Health and Human Services awarded nearly \$4M a year over five years for new Projects of National Significance called “Bridging the Aging and Disabilities Networks.” The funding went to the National Association of Councils on Developmental Disabilities (NACDD) to develop a Community of Practice.

“The goal is to build capacity across agencies and systems to support individuals with I/DD and their families to better plan for their future across

Diverse Perspectives

New Jersey's application for the federal project emphasized diversity, equity, and inclusion.

“New Jersey is one of the most culturally diverse states in the country, and our systems are struggling to keep up with its cultural growth. Research shows that improving cultural competence reduces health disparity for those with disabilities. There is a clear need for increased cultural competency across all settings, most especially in aging and disability populations where health disparities already exist,” said Witowsky.

The New Jersey State Alliance Team consists of diverse voices and perspectives by design.

the lifespan,” said Andrew Morris, MPD, project manager/consultant for NACDD.

This spring, New Jersey was among five states selected through a competitive grants process (the other states are Connecticut, Washington, DC, Florida, and Hawaii). Over the next three years, ten more states will be chosen to take part in the five-year-long Community of Practice.

According to Morris, the national project seeks to strengthen collaboration in the states among aging and disability programs by building coordinated services that address care needs of both aging caregivers and individuals with disabilities. Grantees will plan, sustain, and replicate emerging policies that support the needs of individuals with disabilities and their families that can be replicated across the states and territories.

Efforts Underway in New Jersey, but More Planning and Support is Vital

The Department of Human Services, which houses both DDD and the Division on Aging Services, is already engaged in efforts to better serve and support aging residents with I/DD.

With state savings realized from participating in federal programs, DDD has been able to fund new initiatives, including accessibility modifications of group homes so that individuals with I/DD can age in place. Recently, the Division of Aging Services received federal grant funds to provide infrastructure to sustain the home care workforce for residents—including those with I/DD—who are transitioning from a nursing facility to the community.

Most programs administered by the Division on Aging and the 21 county-based Area Agencies on Aging (AAAs) provide information and referral regardless of the age or disability status. In addition, Individuals with I/DD age 60 and older are eligible for the same OAA, state and locally-supported services as their senior peers.

But more must be done, and New Jersey leaders agree that the timing of the project is important.

“We need to bring together aging and disability resources to address historical shortfalls and generate real system change,” said Witowsky.

Last year, the Council completed a five-year strategic planning process. One of the goals is to ensure that all New Jersey residents with I/DD and their families will have increased information and support to access the services and supports they need to live, work, and learn in the community with independence. This includes older adults and their caregivers whose needs have not been addressed in any systemic or meaningful way. Witowsky and others believe that this project is particularly important to New Jersey at this time, given recent nursing home crises. It is estimated that at least 800 people with I/DD are currently living in nursing facilities in New Jersey.

New Jersey leaders hope the efforts will allow the state to build on its current work with the

Q: *What is Charting the LifeCourse®?*

A: The Charting the LifeCourse® framework was developed by families to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. The framework is the keystone for supporting a community of learning that champions transformational change through knowledge exchange, capacity building, and collaborative engagement. The framework is human-centric, meaning the principles are designed to reflect the needs of people. The key principles were initially developed to drive person-centered change for people with developmental disabilities and their families, but it became clear very quickly that the LifeCourse framework and tools applied to everyone and that they could be used to also drive transformational change in practices, organizations, policies, and communities.

(Source: <http://www.lifecoursetools.com>)

National Community of Practice for Supporting Families to infuse the Charting the LifeCourse®. In 2019, New Jersey joined as a member state in the Community of Practice for supporting families and was recently acknowledged for its success in family outreach.

Guiding the Work

New Jersey will rely on a State Alliance Team (SAT) to create a work plan to drive systematic changes and strengthen the partnership among the agencies, so that people can be best supported in their communities as they move through the various stages of life. The SAT will be co-led by the NJCDD and the DDD, in partnership with the New Jersey Division of Aging Services (NJ DoAS).

“The direct leadership and support of all three organizations is key to a successful project. It demonstrates the joint commitment that the

State Alliance Team members will experience as they proceed in developing and implementing New Jersey's Work Plan," added Witowsky.

Tom Hester, communications director at the Department of Human Services believes the grant will help stakeholders plan coordinated services to address the care needs of both older individuals with disabilities and their aging caregivers.

"Stakeholders will develop a work plan to educate individuals with disabilities and their families on services and supports available as people age across the lifespan. We will also be educating the people who provide aging services on services and supports available to those who are eligible through the Division of Developmental Disabilities (DDD)," he said.

Fourteen organizations, including County Offices on Aging from Warren and Cumberland Counties, have each signed a memorandum of understanding, committing to be part of the effort through the SAT.

One of those SAT members is Leone Murphy. Three years ago, she started a support group for families of a person with Down syndrome who is aging. It quickly grew to more than 90 families, without any advertisement. Many members are not parents—they are siblings. Leone will serve as a liaison between her group and the SAT, allowing family members



Michelle Murphy with sisters Cheryl and Karen

to have direct input and function as one of the SAT's many sounding boards.

"Many families, including my own, did not have guardianship and have never considered our own wishes or the wishes of our family member on end-of-life decision-making," said Murphy. "More families need to have these discussions and be prepared. It is not a matter of if, it is a matter of when."

Murphy is hopeful that the new state project will shine a light on the issue of aging for people with I/DD and help more families engage in planning.

"There is so much work to be done and families need so much information. I think the new grant is a wonderful start," she concluded. **P&F**

RESOURCES

CL - Strengthening the Aging and Disability Networks

<https://acl.gov/programs/strengthening-aging-and-disability-networks>

Charting the LifeCourse®

<http://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/>

NJ Statewide Respite Program

www.state.nj.us/humanservices/doas/services/srcp

NJ Aging and Disability Resource Connection

1-877-222-3737

Ombudsman Report Cites Continued Abuse in Group Homes

By Jonathan Jaffe

On Christmas of last year, a group home in Bayville dropped Brandon Quesada off at the Community Medical Center in Toms River.

According to his mother, Priscilla, her son, now 23, had been eating the kitchen's spices and hitting a window with his hand, prompting the group home to "abandon" him at the hospital, where he ultimately stayed for 76 days, she said.

Since that time, the mom has been taking care of Brandon at her Egg Harbor Township home, as he requires extensive care for autism and a bipolar disorder. Of the six group homes Brandon has lived in since age 14, Quesada claims he has been abused at five and abandoned on Christmas at the sixth.

"He's been strangled. He's endured a smashed left eye. He has had bruises and lots of rug burns over his face and body," the mother said.

"Group homes just don't have the trained staff to work with autistic people who can't express themselves verbally. If he hits them, they can't hit him. It isn't fair."

Quesada said she is done with group homes and will now be self-directing the care of her son at a home near her, where she can supervise his care under cameras.

"All of us parents are afraid to die because we don't know what the hell will happen to our kids," Quesada said. "It's scary. It's all about the money in group homes and there's no accountability."

Quesada has sought the help of Paul Aronsohn, who says she is just one of the regular

calls he receives from families reporting abuse and neglect.

As the state ombudsman for individuals with intellectual or developmental disabilities and their families, Aronsohn hears from desperate people every day who claim their need is immediate and a matter of basic health and safety.

"I have a haunting feeling that many adults who need supports and services are effectively being shut out of the system," said Aronsohn, in his 2021 annual report to the governor and state legislature. He cites cultural, language and socio-economic barriers.

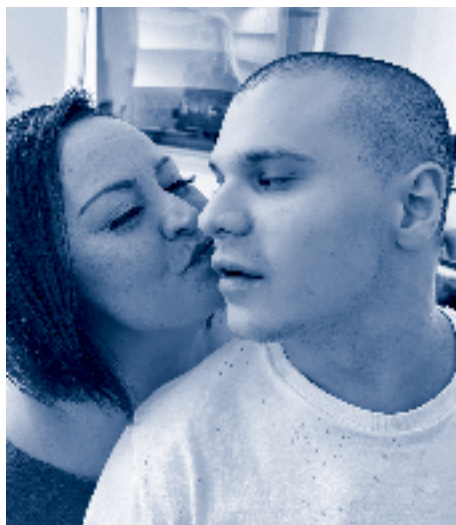
And he also cites ongoing abuse and neglect in group homes.

"Families share horrifying pictures and stories with us on a regular basis," Aronsohn said. "Sometimes it is in the form of physical injuries. Sometimes it is in the form of locked bedroom doors, with-

held food, incorrect medication administration, unsanitary conditions or some other inhumane treatment. Sometimes it is verbal and psychological, expressing itself in demeaning and degrading behavior toward an individual."

The ombudsman was quick to note the Murphy Administration takes such allegations "very seriously" and key steps to prevent it. He cited, for example, the Komninos Law, implemented in 2018 to further protect people with intellectual or developmental disabilities.

Stephen Komninos, 22, died Oct. 8, 2007 from choking on a bagel that he ate while unsupervised. The law doubles annual unannounced



Brandon Quesada with his mother, Priscilla
—Photo Courtesy of Priscilla Quesada

inspections, requires employees to undergo drug tests and mandates that group home operators disclose injuries within two to eight hours, depending upon the severity and circumstances.

“That said, there is clearly a disconnect here. Despite all of the good faith efforts, the abuse and neglect persists,” the ombudsman said. “Despite all of the information brought to light over the past couple of year—through legislative hearings, news stories and personal pleas from families—I am not aware of any new proactive initiatives to reduce, if not eliminate, abuse and neglect.”

Aronsohn said he has not seen any new transparency measures to shine a bright light on abuse and neglect. And except for a very recent effort to develop “core competencies,” there has been no new effort to meaningfully enhance compensation and training for direct service professionals (DSPs), he said.

In the ombudsman’s report, he quotes a hospital psychiatric evaluation for an 18-year-old group home resident, dated December 2021: “I have the impression that this patient has been physically and mentally declining deconditioning (sic) probably related with poor care in her group home.”

The report pulls another quote from a parent of a child who died last year in a group home. The parent is quoted in March as saying, “I don’t know why I didn’t push more. Actually, I do know why. I was afraid of retaliation. The agency was very spiteful. But if I had pushed more, maybe he would still be here.”

The ombudsman suggests four action items:

- The Administration should lead an open and frank discussion about abuse and neglect with individuals, families, advocates, providers and legislators.
- The state should enact a zero-tolerance policy with no excuses or second chances
- It should be easier for individuals and families to report abuse and neglect, perhaps through one single, central phone number or portal.
- There should be an increase in the salary, training and expectations of direct support professionals.

In response to the report, a spokesman for the state Department of Human Services

provided a written statement: “We appreciate the Ombudsman’s efforts to be a resource for families and are reviewing his report as we are always interested in feedback that may further strengthen our service system for individuals with intellectual and developmental disabilities.

State officials added: “Human Services remains steadfast in its commitment to helping individuals with intellectual and developmental disabilities thrive in their communities and to continuing a strong partnership with families. The Department demands the best from the providers and caregivers that support the individuals we serve, and our top priority is always the health and safety of individuals with intellectual and developmental disabilities.

The statement concludes here: “All complaints are taken seriously and investigated thoroughly by a robust system of oversight and monitoring critical to helping ensure the health, safety and wellbeing of individuals receiving services and supports.”

Aronsohn’s 30-page report also looks into other areas of concern, such as the state’s highest-in-the-nation autism rates, challenges with limited housing options and an appeals process that appears weighted against the families.

Thomas Baffuto, executive director of The Arc of New Jersey, said he is “deeply troubled” by allegations of abuse and neglect in the report. “It pains us when we see this, but the issue is not as rampant as claimed,” he said.

Baffuto said such allegations drag down hard-working DSPs, painting the entire system with the same soiled brush.

“We need to identify and eliminate bad apples, with zero tolerance for abuse and neglect,” he said. “But the truth is a lot of families of residents in group homes are not having this problem. It is not consistent with what I am hearing from families. But that does not mean we shouldn’t take this report seriously.”

Valerie Sellers, CEO of the New Jersey Association of Community Providers, notes that Aronsohn’s annual report consistently includes complaints from families who call him with allegations of neglect, abuse and exploitation within the state system.

“We are talking about human behavior that we are trying to control through education and training,” said Sellers, whose association includes 67 providers in New Jersey. “Sometimes you have bad players. But until we start providing the appropriate salary for DSPs, we will not be able to recruit more qualified individuals.”

Sellers said an average starting salary for a DSP in New Jersey is about \$14.25 an hour, an annual salary of about \$30,000 per year, and just north of the \$13 minimum wage in the state.

“Meanwhile, Target is paying \$24 an hour, Chick-fil-A is at \$19 an hour and Amazon is paying \$21 an hour,” she said. “Serving as a DSP is a hard, 24/7 job. Many people with disabilities can’t communicate, or have severe behavioral issues or become violent. DSPs need to prepare food, do feedings, change diapers, administer medication and take people to the doctor.”

Sellers said it is “appalling” that the lowest-paid professions in New Jersey involve taking care of seniors, people with disabilities and children.

To reduce cases of alleged abuse or neglect, Sellers said, her association is planning to develop training videos to serve as visual guides for how best to care for people, noting training manuals or computer modules are just not as effective.

“We need to show, for example, the most appropriate way to guide someone into a van that does not require pulling an arm,” Sellers said. “One might say that is abuse. We need to visually show DSPs the proper way. And that can’t easily be done on a computer screen.”

For those who question the validity of his report, Aronsohn replied: “It breaks my heart that anyone would downplay or dismiss the fact that abuse and neglect are realities for many folks within our system.”



Brandon Quesada showing injuries that his family claims occurred in his group home

—Photo Courtesy of Priscilla Quesada

A critical issue is staffing. The state does not have a mandated ratio of staff to residents in group homes, the ombudsman said, noting that some facilities may just have one employee to handle a myriad of issues overnight.

“Understaffed houses allow for abuse and neglect,” Aronsohn said. “It can take many forms, such as someone locked in a room because there is no one to take them outside. It could be about poor nutrition, like getting served a box of macaroni and cheese for dinner. Or having no air conditioning for a prolonged period of time. Or living in a dirty house. Or being berated by a staff member,

who suggests taking the issue outside.”

His recommendations in the 2021 report mimic those from his 2020 report, in which he also expressed grave concerns about abuse and neglect in group homes.

Aronsohn wrote in 2020: “People may disagree about the prevalence of abuse or neglect, but there is absolutely no denying it exists. The New Jersey State Assembly Human Services Committee held two hearings that made that painfully clear.”

In his report, Aronsohn agreed that DSPs need to be paid as professionals, as well as provided with better training and other supports.

“We can’t think for a second that paying a DSP \$16 an hour is enough,” he said. “How could such an important job be worth so little? If we paid people a realistic professional salary, there would be better outcomes and life experiences. And there would also be less staff turnover and less staff depending on Medicaid, food assistance and housing assistance. And there would be less trips to the ER.”

Those with concerns about abuse, neglect or exploitation are urged to contact the state Division of Developmental Disabilities Abuse and Neglect Hotline at 1-800-832-9173. Every case is handled anonymously. **P&F**

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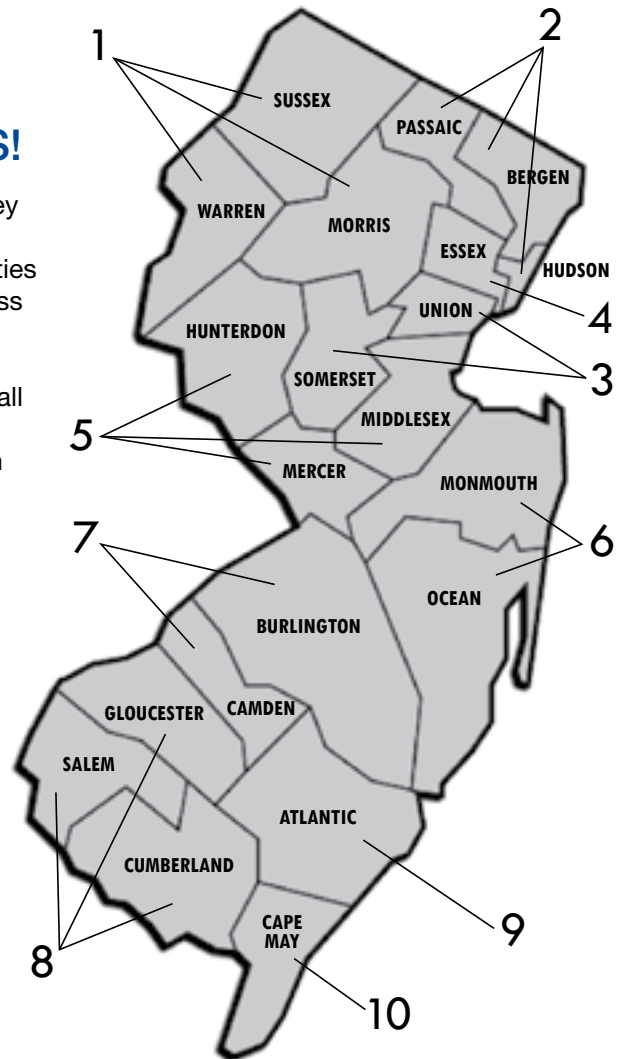
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

The councils work in partnership with the state's Division of Developmental Disabilities and Children's System of Care to advise on policy decisions that affect people with developmental disabilities. Councils sponsor events where individuals and their families can learn about the services available in the area, as well as host public forums to solicit feedback from the community. In addition, councils regularly distribute literature with important information for people with developmental disabilities and their families.

Family members of people with developmental disabilities can volunteer to serve on their regional planning council. Council members assist and advise the Division of Developmental Disabilities and Children's System of Care as to how resources can best meet the needs of families and individuals living in their region.

Councils meet regularly—usually once a month; each Council may have up to 11 members. Council members are volunteers but will be reimbursed for reasonable transportation, child care, and other costs related to serving on the council.



For more information, Call the Statewide Family Support Coordinator Kyoko Coco at 609-341-3112 or email her at kyoko.coco@njcdd.org

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

THE FAMILY SUPPORT ACT OF 1993

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

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

1 SUSSEX, WARREN, MORRIS

RFSPC #1
e-mail: rfspc1@gmail.com
Chair: Margaret Hefferle

Meets the third Tuesday
of each month
Wegmans Market Cafe
34 Sylvan Way
Hanover, NJ 07054
7:00 p.m.– 8:30 p.m.

2 BERGEN, HUDSON, PASSAIC

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

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

3 SOMERSET, UNION

RFSPC#3
e-mail: rfspc3@gmail.com
Chair: John Brewer

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

4 ESSEX

RFSPC#4
e-mail: rfspc4@yahoo.com
Chair: Yolanda Smith

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

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5
e-mail: rfspc5nj@gmail.com
Chair: Paul Blaustein

Meets second Saturday
of each month
South Brunswick Library,
110 Kingston Ln.
Monmouth Junction, NJ 08852
10:00 a.m.–12:00 noon

6 MONMOUTH, OCEAN

RFSPC #6
PO Box 76
Lakewood, NJ 08701
e-mail: rfspc6-chair@excite.com
Chair: Mike Brill

Meets the second Thursday
of each month
The Arc of Ocean
815 Cedar Bridge Ave
Lakewood, NJ 08701
6:00 p.m.–7:30 p.m.

7 BURLINGTON, CAMDEN

RFSPC #7
e-mail: rfspc7@gmail.com
**Co-Chairs: Laura Kelly,
Lisa Weissbach-Effrat**

Meets the second Thursday
of the month
Wegmans (Cherry Hill, NJ)
2nd Floor Cafe
2100 RT-70W
Cherry Hill, NJ 08002
Even months: 7:00 p.m.– 8:30 p.m.
Odd months: 12:00p.m.-1:30p.m.

8 CUMBERLAND, SALEM, GLOUCESTER

RFSPC #8
e-mail: RFSPC8@gmail.com
**Co-Chairs: Amy Kiger,
Elena Gardner**

Meets second Thursday
of each month

9 ATLANTIC

RFSPC #9
e-mail: RFSPC9@yahoo.com
Chair: Mary Ann Philippi

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

10 CAPE MAY

RFSPC #10
PO Box 199
South Dennis, NJ 08245
e-mail: RFSPC10@yahoo.com
Chair: Anne Borger

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

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Real Jobs, Real Wages

Renewing New Jersey's
Commitment to
"Employment First"

By Brenda Considine

"We work to become, not to acquire."

—Elbert Hubbard, American writer and philosopher

José Flores, a student at The Forum School, spends part of his school day learning job skills at Eppley Building & Design, a fine cabinetry and architectural woodworking firm in Hawthorne, NJ —PHOTO CREDIT: The Forum School

José Flores knows what he wants to do when he graduates next spring, and feels ready for the job of his dreams. The 20 year-old Hudson County resident attends The Forum School in Waldwick, New Jersey, a private special education school serving students with autism and related challenges.

Through innovative career counseling and job sampling, José has developed an interest in woodworking and carpentry. He spends part of his school day learning skills at Eppley Building & Design, a fine cabinetry and architectural woodworking firm in Hawthorne, NJ.

“We offer students diverse opportunities to learn job skills, both on campus and in the local community,” said Brian Detlefsen, director of The Forum School. “While we value all of our community partnerships, we try to look beyond the traditional types of jobs in food service and retail, to make sure the

student enjoys their work, and that it is connected to their interests and longer term goals. We believe every student should have the chance to develop the skills and community connections needed for competitive, integrated employment.”

But not every graduate with disabilities in the Garden State is that fortunate. Many young adults with intellectual and developmental disabilities (I/DD) like José leave school and “transition” into a state-funded day program or sheltered employment situation. And once there, it is hard to get out. According to the most recent data available from the National Survey of State Intellectual and Developmental Disabilities Agencies’ Employment and Day Services, fewer than 1,800 of the nearly 12,000 NJ individuals in DDD-funded day and employment services were either working or receiving services to assist them to become employed in the community.

José Flores takes part in The Forum School’s E.L.I.T.E. (Education Leading Individuals Toward Employment) Program, which prepares students ages 18 through 21 to join the workforce.

In addition to spending time each week at his Work-Based Learning Experiences (WBLs or job placements), José learns skills like scheduling, time management, personal finance, and budgeting, along with academics, like reading and writing. Staff teach José vital executive function skills, social skills, and other “soft skills” for the workplace, in this case, Eppley Building & Design.

With support from staff from The Forum School, José answered some questions about his work plans. He tried other jobs before he found his carpentry, and learned what he likes and dislikes.

“A good job keeps you busy,” said José. “I didn’t like repetitive work.”

As José began to develop a preference for his work at Eppley Building & Design, the school increased the time there. This

year, José will also learn to use public transportation to get back and forth to work.

Through staff, José said he likes this job “because they teach me to be responsible and all about different kinds of wood. They are nice people. They treat me well,” he said.

According to José the staff at The Forum School help him with “grammar, formal etiquette and how to look with my clothes.”

Families are supported through the program as well, to ensure that necessary linkages are in place after graduation. Through a Spanish language interpreter, José’s mother, Teodora Briones shared that her dream for her son is “to keep progressing. I am very proud of him. He has improved a lot thanks to his teachers,” she wrote.

With the values and principles of Employment First front and center, plans are in place for José to work in the community after he graduates.

“We strive to limit gaps in service once the student turns 21. Our goal for José and for every student is always a seamless transition,” said Detlefsen.

A new report released by the New Jersey Council on Developmental Disabilities (NJCDD) is calling on the Garden State to improve employment outcomes for individuals with I/DD. The 60-page report, *Advancing New Jersey's Employment First Practices and Policies*, was developed by the John J. Heldrich Center for Workforce Development at Rutgers, The State University of New Jersey, in partnership with the Institute for Community Inclusion at the University of Massachusetts.

“Employment First” in New Jersey

Many states have formally committed to the Employment First framework through executive proclamation or legislative action. In 2012, New Jersey officially joined the growing national

movement to deliver meaningful employment, competitive wages, and career ladder opportunities for people with disabilities. In so doing, state leaders promised to take proactive steps to promote competitive employment in the general workforce for people with any type of disability, but in the years since that promise, little has changed.

“In spite of this important policy shift a decade ago, the mainstream labor force participation rate for individuals with intellectual and developmental disabilities (I/DD) in New Jersey has not significantly increased and continues to lag behind national trends,” said Mercedes Witowsky, executive director of the NJCDD.

To address this deficit, the NJCDD commissioned the John J. Heldrich Center for Workforce Development to evaluate New Jersey's

Employment First policies and practices, and develop recommendations and an advocacy plan to increase meaningful competitive employment. The work was done in partnership with the Institute for Community Inclusion (ICI) at the University of Massachusetts, Boston.

“We wanted to better understand the strengths, challenges, and opportunities New Jersey faces in implementing its Employment First policy, and to identify strategies to support more New Jersey residents with I/DD to succeed in integrated employment,” Witowsky added.

This project used a range of approaches to understand the experiences, barriers, and opportunities related to integrated employment in New Jersey, and to ensure that New Jersey stakeholders had opportunities to participate. Information was collected through key informant interviews, virtual stakeholder forums, policy and document review, analysis of secondary data, and an online survey offered in English and Spanish.

Building on New Jersey's Strengths

Investigators identified a solid foundation of support for employment for individuals with I/DD, including efforts from the New Jersey Division of Developmental Disabilities (DDD) and the New Jersey

Q: What is Employment First?

A: Employment First is a national systems-change framework centered on the premise that all individuals—including people with the most significant disabilities—are capable of full participation in Competitive Integrated Employment (CIE) and community life. Under this approach, publicly-financed systems align policies, regulatory guidance, and reimbursement structures to commit to CIE as the priority option with respect to the use of publicly-financed day and employment services for youth and adults with significant disabilities. Embedded in this system change framework are the core beliefs that:

- Competitive employment in the general workforce is the first and preferred post-education outcome for people with any type of disability.
- People with disabilities are “ready” to work as soon as they express an interest in doing so.
- All people with disabilities can and should work.

Q: What is Competitive Integrated Employment (CEI)?

A: CEI is work that is performed on a full-time or part-time basis for which an individual with disabilities is:

- Compensated at or above minimum wage and comparable to the customary rate paid by the employer to employees without disabilities performing similar duties and with similar training and experience;
- Receiving the same level of benefits provided to other employees without disabilities in similar positions;
- At a location where the employee interacts with other individuals without disabilities; and,
- Presented opportunities for advancement similar to other employees without disabilities in similar positions.

Division of Vocational Rehabilitation Services (DVRS). Both agencies have undertaken a series of policy changes over the past several years to advance employment of individuals with I/DD.

They also found strong support on the part of key stakeholders, including the state legislature, the business community, and disability advocacy groups. Even the federal government, through actions by Congress and federal agencies, has placed increased emphasis over the past decade on integrated employment, while encouraging the reduction in use of facility-based services (such as sheltered workshops). The report underscores that this federal landscape provides opportunities for New Jersey to leverage, in order to increase integrated employment.

The Challenges Are Real

One of the most obvious challenges facing New Jersey is that its strong public policy has not translated into practice or system change. In fact, the report points out that “while New Jersey has policies that are highly supportive of integrated employment, the reality is quite different. Families and individuals report an inability to access necessary services and supports, and often indifference or active discouragement by professionals in terms of pursuing employment in the community.”

Investigators also found inconsistency in the overall agency culture of support for integrated employment, with a lack of commitment on the part of many people in the system to the values that are the foundation of Employment First.

Another major challenge is that New Jersey’s service systems are highly “siloeed.” The report underscores the need for significant improvement in the “relationships and partnerships between public systems like DDD, DVRS, [and the] New Jersey Department of Education,” and found a need for those agencies to work in cooperation in order to eliminate administrative hurdles for people accessing services from multiple agencies. There are also inconsistencies among systems, and major challenges in accessing funding and services across systems.

And while transition programs like the one offered at The Forum School hold hope, there is a lack of consistency statewide. The report found that New Jersey has pockets of excellence in terms of transition from school to employment,

but too often youth with I/DD leave school with little work experience, and are unprepared for the workplace as adults.

In the area of financing, the report suggests that funding be “rebalanced” and increased over time to prioritize employment. It found a need to revise rate structures and reimbursement rates for providers, as current rates force service providers to operate employment services at a loss.

The report also underscores the need to meet the needs of New Jersey’s diverse residents.

“As part of overall efforts to address diversity, equity, and inclusion, steps must be undertaken to build employment services and supports within underserved communities,” said Witowsky.

Moving the Needle

While the challenge may seem overwhelming, the report provides a national framework for comprehensive, sustainable change. It also lays out 20 specific strategies for improving employment outcomes in seven key areas: leadership and values; interagency collaboration; policy and goals; financing; capacity development/training and technical assistance; outcome data; and service innovation.

The first recommendation is to establish an Employment First Commission comprising a broad range of stakeholders to oversee ongoing efforts to improve employment for individuals with I/DD, a strategy supported by The New Jersey Association of People Supporting Employment First (APSE) and others.

Next Steps and Community Reaction

This report laid out a comprehensive set of issues and recommendations regarding increasing employment of individuals with I/DD in New Jersey. The task ahead can seem overwhelming and there are no simple quick fixes.

“Given the lack of progress regarding integrated employment, accepting the status quo because the problem seems too difficult or presuming that “we’re doing the best we can” is unacceptable: unacceptable for individuals with I/DD, for their families, and for the state of New Jersey as a whole.”

—From *Advancing New Jersey’s Employment First Practices and Policies*



Monica Koppstein is a full time employee at Costco, where she receives full benefits. —PHOTO CREDIT: Nantanee Koppstein

The report was met with enthusiasm from families and advocates. In a prepared statement, NJAPSE Board President Stefanie Rinaldi wrote: “... our membership of providers, professionals, family members, and self-advocates have reported to our board these same challenges of poor access to state systems, the siloed nature of supports, groups, and legislators supporting sheltered work and subminimum wages, lack of quality programs, and more.

“The NJCDD report’s recommendations to realize Employment First in NJ are clear but will require commitment from many entities to effect impactful change. In particular, New Jersey can’t be seen as a leader in Employment First without ensuring individuals in sheltered work and earning subminimum wages can successfully transition to meaningful careers with competitive pay...”

Nantanee Koppstein, a board member of NJAPSE, parent, and long-time advocate for the principles and values of Employment First, read the report cover to cover. Even with decades of advocacy work behind her, Koppstein found the report—and especially the comments from families and stakeholders—“eye opening.”

She believes the system and complex rules of state agencies, and the level of effort required by families is “beyond burdensome... it is nearly impossible for families to navigate.” She knows this first hand, having advocated for her 34-year old daughter Monica who now works full time at Costco. Monica receives full benefits, including paid vacation, sick time, and a 401K, and is able to keep her vital Medicaid benefits through a special waiver program.

“Families are swamped with day-to-day issues, especially when their child has aged out.

I can understand why they would simply give up the goals of finding a job. Day programs and sheltered workshops seem to provide stability, and they seem safe. Families feel vulnerable,” she noted.

For that reason, Koppstein believes that families and individuals with I/DD need to be “front and center,” in the discussions about systems changes. She believes that in order to make Employment First a reality, system changes need to focus on those individuals with the highest support needs.

“We need to ensure that underserved and unserved populations have their needs met. They cannot be an ‘add-on.’ Their needs must be embedded in everything we do,” she said.

Next Steps

The report is unique in that it included an action plan for implementation—and it is already under way. NJCDD began its “call to action” by circulating the report widely among policymakers, legislators, public agencies, service providers, business leaders, advocacy organizations, individuals with I/DD, and their families. The Council has also created short summary documents regarding the report’s findings in both English and Spanish, and plans to host a series of community forums to share the findings.

The report itself is honest about the task ahead: “Realizing the vision of Employment First will require a commitment by the full range of stakeholders to work together, measure progress, hold themselves mutually accountable, and diligently make changes over time.”

“There is a great deal of hope that this report will not just sit on a shelf, but rather act as a roadmap for change. Advocates and families are ready to roll up their sleeves, and they know it will take work,” concluded Witowsky.

Advocates are ready, but acknowledge that change will not be quick or easy.

“Reports like this one help NJAPSE and our allies continue our work to push the needle forward for competitive, integrated employment for all,” wrote Rinaldi.

“There is a lot of work to be done, and a lot of trust to be built. This is not a sprint. It is a marathon,” concluded Koppstein. **P&F**

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Michael Conrad who is moving to Voorhees NJ from Union.