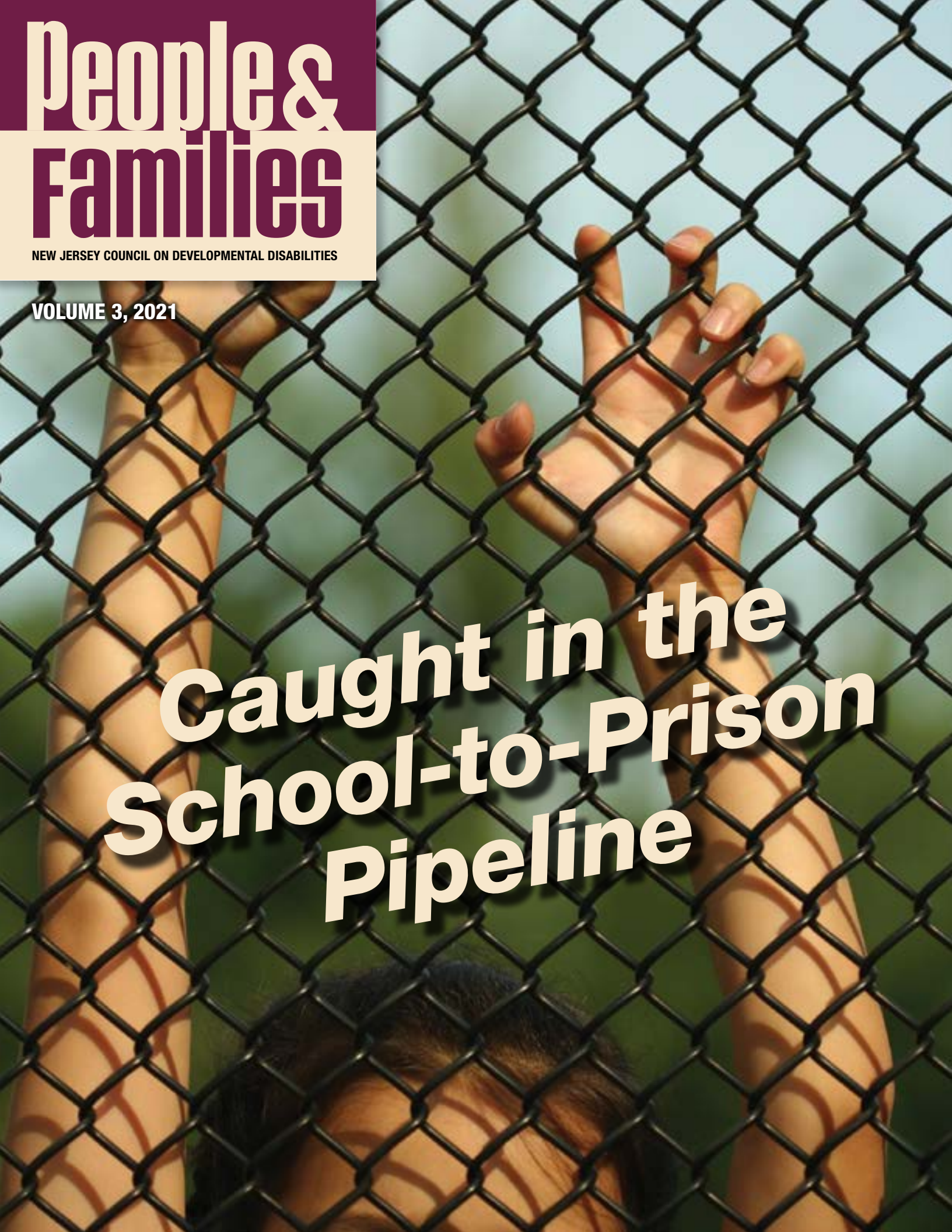


People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

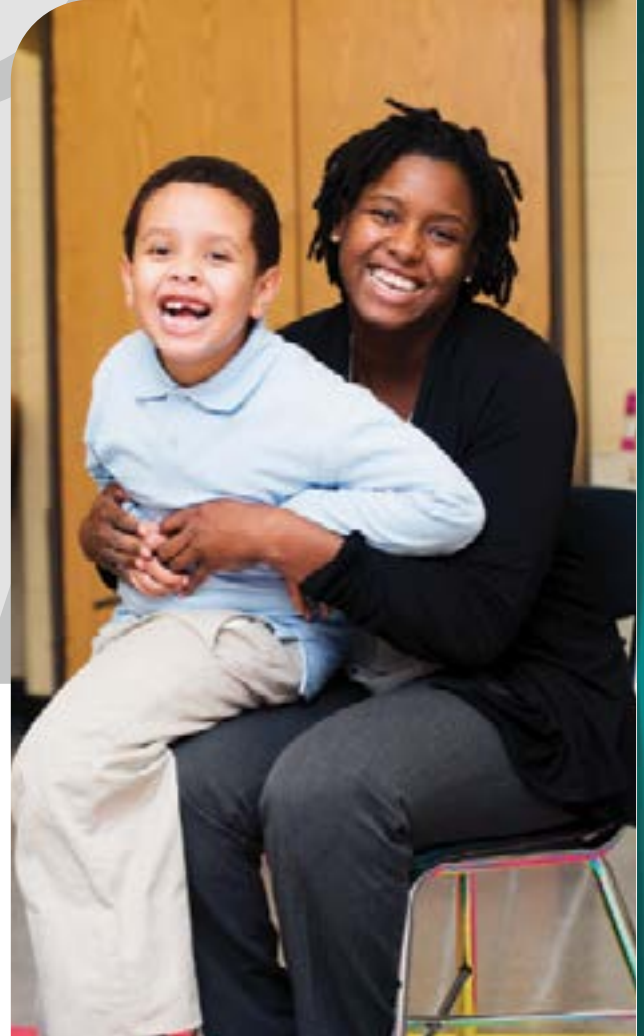
VOLUME 3, 2021

Caught in the School-to-Prison Pipeline



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14 **COVER STORY** STUDENTS WITH DISABILITIES CAUGHT IN THE SCHOOL-TO-PRISON PIPELINE

When a student with disabilities exhibits challenging behavior related to their disabilities, the law says they are supposed to receive special education and related services to address those behaviors. Increasingly, however, schools are taking a reactive, punitive approach to student behavior issues that primarily impact people of color.

18 PRESIDENT BIDEN INTRODUCES PLANS THAT BENEFIT PEOPLE WITH DISABILITIES

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

21 THE HOUSING NAVIGATOR SERIES

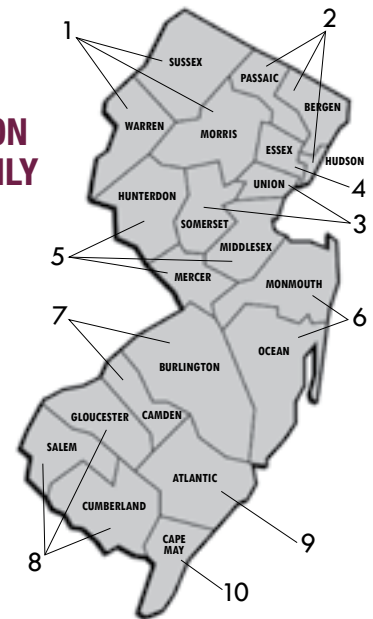
Overcoming these myriad challenges is the mission of the Supportive Housing Association of New Jersey (SHANJ.) And that is why this South Orange-based non-profit launched a program last year to train individuals in becoming “housing navigators” in their own corners of the state.

23 CHARTING THE LIFECOURSE

Developing a Vision for a Higher Quality of Life

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26 INFORMATION ABOUT FAMILY SUPPORT PLANNING COUNCILS



28 PEOPLE WITH DISABILITIES IN THE ENTERTAINMENT INDUSTRY

How unrealistic is it, that producers, directors, writers and film crews turn a blind eye and do not include actual people with disabilities in their work? According to the census of 2000, about two out of every seven families is reported to have a family member with a disability. So why is it that we cannot be seen on the big screen like everyone else? Why is it that people with disabilities are not included in more movies, plays, fashion shows, TV interviews and magazine covers?



from the Executive Director ■

Moving Towards More Culturally-Competent Supports for Individuals and Families

As another year drew to a close the Council entered into a new five-year planning cycle. The Five-Year State Plan lays out broad goals and objectives designed to help us move the system from where it is today to where we want to be in five years. The new plan covers the 2022 -2026 federal fiscal years, which begin on October 1 and end on September 30.

Our current plan has a strong focus on diversity, equity, and inclusion. New goals include objectives that specifically focus on the needs of historically underserved populations.

We are required to develop one objective that addresses identified disparities, over the next five years, NJCDD has multiple objectives which address inequity and disparity experienced New Jerseyans who are Black, Hispanic, Asian, those with limited English proficiency and/or identify as LGBTQ+.

The Council will support projects designed to eliminate the inappropriate use of seclusion, restraint, suspension, and expulsion for Black and Hispanic students with disabilities. We also plan to increase access to information about the Council and the state service system among Black NJ residents with intellectual and developmental disabilities (IDD) and their families.

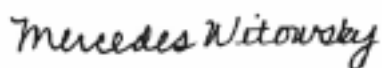
In addition, the Council will support projects to ensure increased levels of diversity, equity, and cultural competency in all aspects of the work carried out by the Council and its staff.

The cover story of this issue sheds some light on how schools are increasingly taking a reactive, punitive approach to student behavior issues that primarily impact students of color. It further exams the long-term effects of the school-to-prison pipeline.

Among other stories, this issue highlights President Biden's plans that benefit people with disabilities. It also features one of our grant-funded programs, the Supportive Housing Association of NJ's Housing Navigator Series.

You can read more including our comprehensive Five-Year State planning process in this issue of *People and Families* magazine. Stayed tuned for more information about how we as a Council will continue to advance our ambitious goals.

Thank you for reading and for your active engagement all year. Wishing you and your loved ones a wonderful New Year!



Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities





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

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

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

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

The Council's standing committees consist of the State Plan Committee, Grants Committee, and Public Policy Committee. Sub-Committees on Children and Youth and Health and Wellness meet under the Public Policy Committee. The 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 committee activities:

- The executive director presented a tentative 2022 schedule for Council, committee and sub-committee meetings. We hope to commence hybrid (in-person and virtual) Council meetings in the second quarter of 2022. Committee and sub-committee meetings will continue to be conducted virtually. Hybrid Council meetings will accommodate Council members and public attendees who prefer the in-person experience, while allowing virtual participation for those who prefer to remain remote participants.
- The executive director provided an update from the Governor's Office of Appointments regarding their proposed timeline for the confirmation of new Council Members. The Office of Appointments planned to submit all nominated candidates for Senate approval during the lame duck legislative session in November.

- The amended Council bylaws that were approved by the Council will be implemented on January 1. This will create two new Sub-Committees: the Advocates Advisory Subcommittee and the Diversity, Equity and Inclusion Subcommittee. We will recruit Council members and interested members of the public to serve on these two new subcommittees.
- The Council has received conditional approval of the 2022-2026 Five Year Plan from the federal Administration for Community Living, which will allow NJCDD to begin committing FY 2022 funding for Council projects and grants. Our FY2019 funding has been completely allocated and we are awaiting a final decision on the deadlines for committing FY2020 and FY2021 funding.
- The NJ Division of Medical Assistance and Health Services released their draft Amended Reapplication for the 1115 Comprehensive Waiver. The document is available on the DHS website. DMAHS has solicited public comments. The state's amended application will be submitted to the Center for Medicare and Medicaid Services (CMS). CMS will post NJ's application for a federal public comment period, before considering it for approval.

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. The draft plan was approved by the Council in May. It finalized and submitted to the Administration for Community Living (ACL) this fall and is pending final approval.
- 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 Council is on the verge of starting a new chapter to represent people with disabilities and their families across the state of New Jersey. As we begin a new Five-Year Plan, all of the upcoming grants will relate to the goals and objectives of the new 2022-2026 Five-Year Plan. The following are summaries of the first three issued requests for proposals. While the application is closed and review of proposals are underway, we encourage stakeholders to stay tuned as additional requests for proposals are announced. Throughout this process, the Council will learn and grow in order to better meet the needs of its constituency. For more information, please visit the Council website.

- NJCDD accepted proposals to develop, design, and deliver the project(s) that will build a new generation of self-advocates and create leadership and training opportunities for people with I/DD. The work must be managed and led by people with I/DD to the maximum extent.
- NJCDD accepted proposals to increase access to information about NJCDD, its DD Act Partners, and all developmental disabilities systems among Black New Jersey residents with I/DD and their families, and how to access the full range of supports and services available through New Jersey's system of services and supports.
- NJCDD accepted proposals to support projects and engage in outreach designed to ensure increased levels of diversity, equity, cultural competency, and linguistic responsiveness in all aspects of the work carried out by the Council and its staff.

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 fourth meeting of the Legislative Disabilities Caucus took place on October 26, 2021, with the topic focus on transportation. Steve Cook, executive director of The Arc of Mercer, presented a comprehensive analysis of the transportation system for people with disabilities and a framework for improvement. More than 150 people participated including legislators, advocates and family members.
- Division of Medical Assistance and Health Services (DMAHS) proposed changes for state usage of federal funding allocated through the American Rescue Plan. The combined state and federal investment of \$634m, prioritized “independence, community options and person-centered care” according to Acting DHS Commissioner Sarah Adelman. NJCDD continues its input.
- The Centers for Medicare and Medicaid Services (CMS) 1115 Waiver for NJ, designed to direct individuals from institutional care to community living and maintain home and community-based services, is in the process of being renewed for 2022. DMAHS submitted a plan for public comment in September and NJCDD provided comments and suggestions to benefit people with I/DD.
- NJCDD participated in The National Association of Councils on Developmental Disabilities (NACDD) August 2021 Effecting Change Conference. Participants hosted a discussion on the passage of the extended school year for special education students through federal pandemic recovery funding. Public Policy Committee Member and NJSPAN director Peg Kinsell; Rebecca Span of the Education Law Center Advisory Board; Subha Bolisetty, parent and advocate; and Bob Titus, parent and NJCDD staff member presented.

Subcommittee on Children and Youth

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

- 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.
- School safety issues.
- Access to special education services, assessments and transition services throughout the COVID pandemic.
- Seclusion, restraint, suspension and expulsion in special education, with an emphasis on disproportionality.

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.

Within the 2022-2026 Five Year Plan, the H&W Subcommittee has identified the overarching goal of collaborative care, with an emphasis on the three main objectives of underserved populations, telehealth, and supports:

- Underserved populations as defined by minority access, I/DD with co-occurring mental health concerns, complex care, behavioral concerns, dental concerns, and aging individuals with I/DD.
- The continuation and expansion of telehealth services
- Supports for individuals with I/DD through Support Coordination, MCO Care Management, CMO Care Management, transition support, and DSP Core Competencies **P&F**



Mapping a Plan for the Future

The Five-Year State Planning Process

By Brenda Considine

When it comes to supports and services for people with developmental disabilities and their families, the needs are great, and the resources are limited. How then, does the New Jersey Council on Developmental Disabilities (NJCDD) make decisions about what to do?

Each of the 56 Councils across the United States and its territories, including New Jersey, fulfills its federal mission by engaging in advocacy, capacity-building, and systemic change efforts. The Council, whose volunteer members are appointed by the governor, seeks to assure that individuals with intellectual/developmental disabilities (I/DD) and their families participate in the design of—and have access to—needed community services, individualized supports, and other forms of assistance. The Council works to promote self-determination, independence, productivity, integration, and inclusion in all facets of life through culturally-competent programs.

The day-to-day work of the NJCDD is rooted in its Five-Year State Plan. The Five-Year State Plan lays out broad goals and objectives designed to help move the system from where it is today to where we want to be in five years. Based on that plan, an annual work plan details specific activities and projects that will implement those goals and objectives.

Every five years, NJCDD engages in a robust strategic planning process, inviting the public to help make decisions about priorities, goals, and objectives. The previous Five-Year State Plan

ended on September 30, 2021, so a new Five-Year State Plan must be in place. The new plan will cover the 2022, 2023, 2024, 2025, and 2026 federal fiscal years, which begin on October 1 and end on September 30.

The Year of the Pandemic

In late 2019, as NJCDD was gearing up for its outreach and planning to develop the new plan, the COVID-19 virus was still unknown to most, but slowly making its way across the globe. Many of the anticipated processes—in-person town hall meetings, public meetings, face-to-face focus groups, and live strategic planning—would be rendered impossible.

“Our planning process began long before any of us could have imagined a global pandemic, so we had to regroup,” said Helen Steinberg, a parent member of the NJDCC and chairperson of the State Plan Committee. “COVID certainly changed the ways in which we did things, but it did not change our commitment to engage the Council or members of the public. We just had to shift gears and reimagine how we would do it.”

Council staff quickly pivoted to create virtual events that would allow input.

Asking Questions and Listening

“A major part of the process was asking questions and listening,” said Mercedes Witowsky, executive director. “Our task was to identify the needs, service gaps, and community priorities. We did this

through collecting data and by asking questions.”

In the spring of 2020, NJCDD issued a comprehensive survey for families, self-advocates, providers, and other stakeholders. The survey asked about their experiences with the system, unmet needs, and priorities. More than 1,000 individuals responded. The survey was offered in English, Spanish, Chinese and Portuguese, the four most common languages in New Jersey.

The NJCDD wanted to ensure that a broad range of stakeholders had a chance to participate, and that historically underserved communities would have a voice. Working with leaders from diverse communities, and with input from Council members, NJCDD developed custom outreach lists in an effort to reach community churches, civic centers, and neighborhood providers. In addition, NJCDD hosted five virtual public forums, including one in Spanish, as well as two focus groups in Spanish. More than 230 people registered for these events.

Among other things, stakeholder input showed significant differences in the ways in which services are available, and deep divides in service access, particularly for those with complex medical and behavioral needs.

One of the important themes that emerged through the public input process was the urgent need to “be in the room” where the decisions are made. Through the surveys and public town hall meetings, NJCDD heard:

“Parents need to have a seat at the table to give input to DDD and lawmakers. It is abundantly clear that the folks at the top who are making policy decisions are completely clueless about the needs of individuals and their families. They may be well intended but are CLUELESS.”

—a parent

“Individuals and families need to be at the table BEFORE one more policy is changed, BEFORE another form is amended at DDD for support coordination (creating yet another barrier to services).”

—a parent

The input process also identified the need for system change, more advocates, better inter-agency coordination, and system simplification:

“It’s a maze, too many people and nobody really understands the whole picture.”

—a self-advocate

“State agencies need to work together.”

—a self-advocate

“[The system is] very complex, not easy to understand. Hard to figure out where to go for more information or help.”

—a parent

And the NJCDD heard about the need for broader engagement from a more diverse group of stakeholders—geographic, linguistic, racial and ethnic, sexual and gender identity, and disability identity:

“Language (Spanish) is a big barrier—we make mistakes because we do not understand.”

—a parent

“In our part of the state (Cumberland County) there is very little in the way of crisis or behavioral support.”

—a provider

“Our (Black) sons are suspended and expelled from school, and then they enter the ‘school to prison’ pipeline. They need education, not discipline.”

—a parent

Council Member Engagement

Throughout the process, NJCDD sought to fully engage Council members.

The Federal Developmental Disabilities Act (DD Act), which established the State Councils in Developmental Disabilities, empowers Council members to be the driving force behind the State Plan. As such, NJCDD held scores of committee meetings, workgroups, and sub-committee

meetings, all with strategies in place to support Council members in providing input and decision-making as it related to developing the State Plan.

In addition to quarterly Council meetings, and monthly meetings of the State Plan Committee, topic-focused work groups met for more than 12 hours over the course of several days to go over state data and review survey results. They discussed important issues around housing, employment, health care, family and individual supports, advocacy and leadership, education, recreation, transportation, and more.

“The planning committee and all members of the Council worked very hard throughout the last year and a half. This robust and ongoing process helped us shape goals and objectives that really capture needs and priorities,” said Steinberg.

The work culminated in January of 2021 with a strategic planning retreat, at which time each draft goal and objective was carefully considered, word by word.

“While the remote Zoom event was not what we had planned initially, there was a silver lining: nearly every Council member was able to attend, and we did not have to worry about winter weather,” added Witowsky.

Prior to the retreat, a consumer caucus comprising self-advocates on the NJCDD met to go over the draft goals and objectives, and prepare any questions or comments.

Collaboration with Developmental Disabilities Act partners (The Boggs Center on Developmental Disabilities, New Jersey’s University Center for Excellence; and Disability Rights New Jersey, New Jersey’s state Protection and Advocacy agency), is an important and required component of the process. As such, the Council worked to ensure that planning included leaders from both agencies.

“We are privileged to have had active participation on the part of our DD Act partners on our State Plan Committee. Key staff from those agencies participated actively in more than two dozen meetings over the course of the past 18 months,” said Witowsky.

Diversity and Equity

“This year, there was a strong focus on diversity, equity, and inclusion,” said Paul Blaustein, Council Chairperson. “Many new goals include objectives that specifically focus on the needs of historically underserved communities.”

While state councils are required to develop an objective that addresses identified disparities, this year, NJCDD has two such objectives. Both aim at addressing inequity and disparity experienced by Black and Hispanic New Jersey residents. The Council plans to support projects designed to eliminate the inappropriate use of seclusion, restraint, suspension, and expulsion for Black and Hispanic students with disabilities. They also plan to increase access to information about the Council and the state service system among Black NJ residents with Intellectual and Developmental Disabilities (IDD) and their families. In addition, the Council will support projects to ensure increased levels of diversity, equity, and cultural competency in all aspects of the work carried out by the Council and its staff.

“Our survey work, our data collection, and input from Council members and stakeholders in the community pointed us toward this important area. Because New Jersey is such a diverse state, we wanted to be more ambitious in tackling some of the historical and ongoing challenges,” Blaustein said.

In August of 2020, Blaustein appointed Council member Safiyya Muhammad to chair an ad hoc subcommittee of the Planning Committee—the Ad Hoc Committee on Equal Access to DD Services—to identify unmet needs, and to provide focused feedback on the draft plan prior to its adoption by the full Council. The group met remotely throughout the fall of 2020 and winter of 2021.

The Plan

At its February meeting, the NJCDD voted to approve the draft plan, at which time it was put out to the public for comment. Again, a robust campaign to invite input was launched.

“From the very start, the goals and objectives were rooted in data and input from the public, but the public comment period allowed us to fine tune the language, and ensure that the plan is comprehensive and clear,” said Steinberg.

Based on public feedback and input from the Ad Hoc Committee on Equal Access, the Council agreed on the need to simplify some of the terms in the plan to reduce jargon. They also heard from advocates about the need to specifically address the unmet needs of the LGBTQ+ communities.

The Council adopted the plan at its May 2021 meeting. It includes three broad goals in the areas of advocacy, systems change, and capacity-building, with four to six objectives each in the areas of self-advocacy, leadership development, healthcare, housing, employment, transition, special education, formal and informal support, and community capacity-building.

Goal 1: Advocacy

Data and public input show that people with I/DD and their families need information, skills, support, and access in order to advocate for themselves and others, and to educate policy makers on their unmet needs. Goal #1 in the area of advocacy seeks to address that.

“All New Jersey residents with intellectual and developmental disabilities (I/DD) and their family members, from an early age and throughout the lifespan, will have increased access to information in order to learn and strengthen the advocacy and leadership skills they need to be self-directed, manage supports and services, and engage as active citizens with control and choice over their own lives.”

Goal 2: System Change

Data and public input show that the service system in New Jersey is highly fragmented and siloed. Families and advocates report a lack of service coordination, and a lack of interagency collaboration, particularly at times of transition and crisis. Often, generic community programs

created for the general public fall short of meeting the needs of people with I/DD and their families. Goal #2 in the area of systems change addresses this issue.

“All New Jersey residents with I/DD, their families, and stakeholders will have increased ability to improve the design and delivery of the services intended to support and benefit them.”

Goal 3: Capacity-Building

Data and public input show that people with I/DD and their families need greater and easier access to information and support services promoting independence and access in order to live happy, productive lives in the community. Goal #3 in the area of capacity-building addresses this.

“All New Jersey residents with I/DD and their families will have increased information and support they need to access the services and supports they need to live, work, and learn in the community with independence.”

“NJCDD can be proud, not only of the plan itself, but of the planning process. More so than in any year in recent memory, the public and the Council were actively engaged in shaping the plan, and carefully considered each and every word to ensure that the plan will have a positive impact, and produce change that New Jersey stakeholders need,” said Blaustein. “I commend Helen for leading this process through such uncharted waters, and Safiyyah for her steadfast commitment to making diversity, equity, full inclusion and equal access such a high profile part of our plan.”

Witowsky is equally thankful to the Council members and especially to those who participated in the process.

“We could not have done this without full participation from everyone. The Five Year State Plan is ambitious, comprehensive, and achievable.

Now the real work begins,” Witowsky concluded. **P&F**



Students with Disabilities Caught in the School-to-Prison Pipeline

By Brenda Considine

CN: Trauma; Incarceration

- Local police handcuff and arrest a second-grader. Video footage shows the boy sobbing as an officer announces, “You’re going to jail.” Three officers are called to the scene—an elementary special education classroom—where they arrest the 8-year old with disabilities on charges of felony battery.
- Police arrest a 6-year-old girl following a disability-related tantrum at school. She is taken into custody and fingerprinted, and her mugshot is taken.
- A school resource officer handcuffs a 10-year-old boy with autism and pins him to the ground for arguing with his teacher and hiding in a classroom closet.
- A school safety officer removes a third-grader from his class and closes him in a staff bathroom. Bodycam footage shows the officer telling the child to “stop crying like a little girl.” The boy’s crime? He refused to leave his art class.

How Does This Happen?

When a student with disabilities exhibits challenging behavior related to their disabilities, the law says they are supposed to receive special education and related services to address those behaviors. There are legal protections to prevent

A NATIONAL PERSPECTIVE

- During the 2017–18 school year, students in the United States were referred to law enforcement nearly 230,000 times. A study by the Center for Public Integrity found that school policing disproportionately affects students with disabilities and Black children: they are referred to law enforcement at nearly twice the rate of others.
- According to data from the U.S. Department of Education, 2015–2016 Civil Rights Data Collection, students with disabilities were arrested and physically harmed by school police at higher rates than non-disabled students. Data from the American Civil Liberties Union (ACLU) show that students with disabilities were nearly three times more likely to be arrested than students without disabilities, and the risk is multiplied at schools with police.
- Research by the National Survey of Children’s Health showed that 5.4 percent of young children with disabilities had been suspended or expelled, compared to 1.2 percent of children without disabilities. Younger children with attention deficit disorder, attention deficit hyperactivity disorder, or related behavioral challenges were also more likely to experience exclusionary practices.

inappropriate disciplinary actions like suspension and expulsion from school.

Increasingly, however, schools are taking a reactive, punitive approach to student behavior issues. According to advocates, the growing use of resource officers and police in schools is making the problem worse.

“Resource officers and police in schools cannot replace counselors, effective behavior plans, or appropriate mental health supports,” said Peg Kinsell, chairperson of the NJCDD subcommittee on Children and Youth, and policy director at SPAN Advocacy.

Long-Term Effects: Pipeline to Prison

Disciplinary action that removes a student from the school building or the classroom increases the chance that a student will repeat a grade, drop out, or end up in the criminal justice system, according to a report issued by the U.S. Commission on Civil Rights, *Beyond Suspensions: Examining School Discipline Policies and Connections to the School-to-Prison Pipeline for Students of Color with Disabilities*.

Researchers from Boston University, the University of Colorado Boulder, and Harvard University have found that punishment of behavior at school when a child is young is linked to increases in adult crime. Students who attended a stricter middle school are more likely to have been arrested and incarcerated as adults. They were also more likely to drop out of high school and less likely to attend a four-year college.

More Counselors, Fewer Cops

According to a report by the American Civil Liberties Union, there is not strong evidence that police in schools improve safety, educational outcomes, or mental health. In fact, evidence suggests that the presence of school resource officers (SROs) actually *harms* students. They report on a 2018 study that looked at the impact of school police in Texas on 2.5 million students. It showed a 6 percent increase in middle school discipline rates, a 2.5 percent decrease in high school graduation rates, and a 4 percent decrease in college enrollment rates. Another 2018 study found that adding more police in New York City schools hurt the test scores of Black male students.

COPS, NOT COUNSELORS

- 1.7 million students are in schools with police but no counselors.
- 3 million students are in schools with police but no nurses.
- 6 million students are in schools with police but no school psychologists.
- 10 million students are in schools with police but no social workers.
- 14 million students are in schools with police but no counselor, nurse, psychologist, or social worker.

—(ACLU)

“The data are clear. The presence of police in schools shifts the focus from learning and supporting students to over-disciplining and criminalizing them. They get removed from classes, subjected to physical restraint, interrogation, and other risks,” added Kinsell.

In many districts, school counselors, nurses, social workers, and psychologists are the first to see students when they are stressed or traumatized. Data show that schools with adequate support services not only have lower rates of suspension and expulsion, they also have improved attendance rates, better academic achievement, and higher graduation rates. Under-resourced schools can become a pipeline to prison when they rely on police rather than educators and counselors to manage behavior and discipline issues. School resource officers who patrol school hallways often have little or no training in working with youth. Students in these schools are more likely to be subject to school-based arrests, most of which are for non-violent offenses, such as disruptive behavior.

Greatest Impact on Black Male Youth with Disabilities

Students with disabilities represent a quarter of students arrested and referred to law enforcement, and Black male youth with disabilities are most vulnerable to being propelled along the school-to-prison pipeline. Research shows they are disciplined more harshly, and more frequently referred to law enforcement, subject to school-

based arrest, and incarcerated. Over 13 percent of students with disabilities receive out-of-school suspension, compared with 6 percent of students without disabilities. For Black male high school students with disabilities, approximately one-third are subjected to school discipline.

The higher rate of school discipline does not reflect a higher rate of misbehavior, but reflects instead the impact of school policies, practices, and leadership. Each suspension increases a student's likelihood of becoming delinquent, abusing substances, getting involved with gangs, and getting caught up in the juvenile justice system.

"These data, while discouraging, should come as no surprise. When kids do not feel supported by their school community and are literally sent away, they do not learn the skills they need to graduate and be successful," added Kinsell.

Jails and Detention Centers

Youth with disabilities are especially vulnerable to the impact of secure confinement. The rate of suicide in juvenile justice facilities is approximately four times greater than in the general population. Juvenile incarceration greatly increases the likelihood of further involvement with the criminal justice system.

Youth in the juvenile justice system are often denied procedural protections and often are not assigned a court-appointed lawyer. Students who commit even minor offences may end up in secured detention if they violate probation conditions such as missing school or disobeying teachers.

Through a unique program at The Arc of New Jersey, Robyn Holt, MA, works with the courts to find alternatives to incarceration for adults with intellectual and developmental disabilities

KNOW YOUR RIGHTS

Short-term suspension

A school may suspend a student with a disability for up to 10 consecutive school days, as long as the suspension doesn't constitute a "change in placement." School staff decides whether a "change in placement" occurred. In making this decision, they consider:

- whether the series of suspensions total more than 10 school days in a school year,
- whether the student's behavior is similar to her behavior in previous incidents that resulted in the series of suspensions, and
- additional factors such as the length of each suspension, the total amount of suspension time, and the proximity of the suspensions to one another.

If school staff determines suspension is a change in placement, long-term suspension rules apply.

Long-term suspension

A school may impose a long-term suspension of more than 10 consecutive days on a student with a disability if:

- the student's IEP does not provide otherwise, and
- the student's conduct is determined not to be a "manifestation" of the child's disability

What is a manifestation determination?

The district must hold a meeting within 10 school days from the date of suspension to determine whether the student's conduct was a manifestation of the student's disability.

- If conduct is not a manifestation, the student may be suspended more than 10 days.
- If conduct is a manifestation, the student must return to school placement immediately, unless the 45-day exception applies. The school must also conduct a functional behavioral assessment. This assessment identifies the causes of a student's problem behavior(s), and helps the school develop a plan to address those causes.

What is the 45-day exception?

A school may place a student with a disability in an alternative educational setting for 45 days, even when the behavior was a manifestation of the student's disability, for the following behaviors:

- possession of a weapon
- knowing possession or use of illegal drugs
- infliction of serious bodily injury upon another person

from: https://edlawcenter.org/assets/files/pdfs/publications/Student_discipline_manual.pdf

who have become involved in the criminal justice system. She sees plenty of evidence of a “school-to-prison” pipeline.

“Quite often those we serve have a history of issues that started in school,” she said.

While her program serves adults 21 and over, Holt often gets calls from terrified parents who have a child with disabilities being charged with a crime due to behavior that occurred in school. From her perspective, schools are overly harsh and pursue consequences that do not fully consider the student’s disability.

“Parents feel really left in the dark after their child has an incident that results in criminal charges. Even when the student’s disability is well-documented, and is being addressed through the IEP [Individualized Education Program], it seems like it is fully disregarded if the student does something; the disability considerations just seem to go out the window,” she noted.

In 2020, Disability Rights New Jersey received a grant from the Ford Foundation to prevent youth with disabilities from entering the juvenile justice system. Through the Special Education and Juvenile Justice Project in Mercer County, they work closely with the Public Defender, representing youth involved in the juvenile justice system who need special education services and supports. The goal is to get the student back in school with educational services and supports in place and also, when the charge is based on an incident that occurred in school, to get the delinquency charge reduced or dismissed.

The New Jersey Council on Developmental Disabilities has also identified this issue as a priority and has included it in its 5-Year State plan submitted to the Administration on Intellectual and Developmental Disabilities in Washington, DC. The Council will support projects using best practices designed to eliminate the inappropriate use of seclusion, restraint, suspension, and expulsion for Black and Hispanic students with disabilities in schools and districts with high rates of seclusion, restraint, suspension, or expulsion, and/or high rates of referral to law enforcement.

“Through our work in this area, we hope to change the conversation—and the outcomes—for all students with disabilities, but especially for Black and Hispanic students. They are often

subject to life-altering disciplinary actions when what they need, and are legally entitled to, is instruction and support,” said Mercedes Witowsky, executive director of the NJCDD.

Re-Entry

Students with disabilities face major barriers after they leave the justice system and work toward school re-entry. Unfortunately, many never graduate from high school.

In Newark, Donnell Hill leads the Urban Youth Reentry Program. This social justice effort at the Urban League of Essex County aims to put a dent in the school-to-prison pipeline. Through a grant from the National Urban League, the program focuses on helping young adults who have been involved with the justice system get jobs and an education and get on track for self-sufficiency.

Like Holt, Hill works with youth who had an IEP in the school system and then encountered a lack of effective support within the probation and parole system. He believes that many people working in the probation and parole system do not know how to help people who have disabilities or who have experienced trauma.

“These young people do not get a list of places to go for help and support, but may still need help with mobility, anxiety, planning, and life-skills in general. The probation system is just not supportive of them,” he said.

“Our goal is to completely cut off that recidivism pipeline. We want to offer a new pathway, a different direction,” he concluded. **P&F**

RESOURCES

If you believe that a student has been subject to inappropriate disciplinary action, or disciplined in a way that violated their rights, help is available:

Advocates for Children of NJ: 973-643-3876

Disability Rights New Jersey: 800-922-7233

Education Law Center: 973-624-1815

Legal Services of NJ: 1-888-576-5529

SPAN Advocacy: 973-642-8100

President Biden Introduces Plans that Benefit People with Disabilities

by Maryann B. Hunsberger

President Joe Biden made good on his campaign promise to name a disability policy director, Kimberly Knackstedt, to sit on its Domestic Policy Council and to assure that the government is giving priority to the needs of Americans with disabilities. Knackstedt, who has a Ph.D. in special education and policy, told Time magazine, "One of my key goals is making sure that we are putting people with disabilities at the beginning of our policy development, not as the afterthought, which I think has happened so often."

Lauren Agoratus, state coordinator of Family Voices NJ, stressed the importance of this position. "It is essential to include people with disabilities in policy development. Diverse community engagement will include all relevant stakeholders, including those with disabilities and underserved populations. This will help address disparities that were exacerbated due to the pandemic. Diverse representation, including disability and race and ethnicity, will help create equitable policies both nationally and in NJ."

Before the pandemic, roughly 60 million people had disabilities. With studies estimating that between 10 and 30 percent of people who contract COVID-19 will experience symptoms that can last for months after being infected, many more people could join the disabled ranks.

Expanding Home and Community-Based Services

This year is the 30th anniversary of the passage of the Americans with Disabilities Act (ADA), and President Biden has introduced plans that would benefit people with disabilities, including the American Rescue Plan. The federal government has approved NJ Department of Human Services' plans to invest \$634 million over the next three years to expand Medicaid Home and Community-Based Services for individuals with disabilities. The plan will bring in \$329 million in federal funding, for a total investment

of \$634 million. The plan will use federal matching dollars through Biden's American Rescue Plan to expand and bolster Home and Community-Based Services under the state's Medicaid program known as NJ FamilyCare.

"We are prioritizing independence, community options and person-centered care," Acting NJ Human Services Commissioner Sarah Adelman said. "Importantly, this plan was devised with significant public input gathered during group calls, a public listening session and emails. It was vital that we listen and take advantage of this opportunity to make New Jersey a stronger and more resilient place to live. This plan reflects that goal, and we're thrilled by the approval."

Increasing Social Security Funding

In addition, President Biden's 2022 budget includes an increase of up to \$1.3 billion or 9.7 percent in annual Social Security funding. This would mean a raise in Social Security Administration (SSA) monthly income checks amounting to a total of \$1.2 trillion in both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) paychecks in 2022. The proposed increase is the amount SSA expects to pay to more than 74 million recipients in 2022.

The SSA closed most field offices during the pandemic, worsening the wait for those applying for SSDI and SSI. The backlog of pending cases rose from 593,944 in 2019 to 763,747 last year, an increase of 30 percent. Processing times for claims increased by 11 days, so the average application took 131 days to process. SSDI claims are likely to continue increasing as more individuals face long-term disabilities as a result of COVID-19, which will likely increase wait times even more.

The President is calling for \$14.2 billion in total for SSA for fiscal year 2022. Biden's proposed funding could help alleviate these administrative problems,

as the money would also go toward improvement in customer service, such as appointment policies, backlogs, wait times, community outreach to populations and technology upgrades for better services by the SSA. It would also support bringing the administration's IT infrastructure up to date.

"The President's budget will support our efforts to improve service and our customers' experience. These improvements will provide the public with additional service options that do not require them to visit a field office or call our national 800 number. By providing more convenient online options for people who can use them, we can focus on the more complex cases and individuals who need in-person help," said SSA Commissioner Andrew Saul, in the agency's budget overview. Saul pointed out that SSA has used virtual meetings and online services amid the pandemic, and stated that some of those changes could continue.

\$96 million of that money would also go toward additional outreach for SSI benefits with a goal of contacting vulnerable people who are eligible for benefits, such as adults and children with disabilities.

The plan would include nominating judges who support disability rights and reflect the diversity of the country. It would ensure that child welfare agencies and family courts do not violate the rights of parents with disabilities, and that they have appropriate training to fairly assess parental capacity in a nondiscriminatory manner. It would promote efforts to provide people with disabilities viable alternatives to guardianship if they need decision-making assistance, including supported decision making. And it seeks to update SSDI and SSI's employment rules to allow people with disabilities to work, earn, save money and marry without losing benefits.

Biden's SSDI plan for 2022 includes efforts to guarantee access to high-quality affordable physical and mental healthcare and expansion of Home and Community-Based Services through the Affordable Care Act. These services would enable people with disabilities to live at home and avoid congregate care.

According to National Public Radio (NPR), home-based services can include home visits from nurses or occupational therapists; assistance with personal care such as eating or bathing; help from case managers; attendance at adult day centers; help

with cooking, cleaning and other chores; transportation; and home repairs and modifications. It can also help pay for durable medical equipment such as wheelchairs or oxygen tanks.

Adhering to the Olmstead Decision

The President would also work with Congress to pass legislation ensuring adherence to the US Supreme Court's Olmstead decision. The Olmstead decision requires that government programs provide people with disabilities the choice to live, work, and receive services in integrated settings appropriate to their needs.

This is important because about one in 12 people who live in long-term-care facilities have died of COVID-19 nationally, as confirmed by the COVID Tracking Project. The figure is nearly one in 10 for nursing homes. The deaths of so many congregate care residents from COVID-19 in our state underscore the importance of people receiving the support needed to live at home. NPR says that half of the states spend twice as much on institutional care as they do on community-based care. And 41 states have waiting lists for Home and Community-Based Services, totaling nearly 820,000 people, with an average wait of 39 months.

Increasing Home and Community-Based Services means more caregivers will be needed. Therefore, President Biden introduced the American Jobs Plan, which will boost the caregiving workforce and the number of people served. As part of this, Congress has introduced the Better Care Better Jobs Act (H.R. 4131/S.2210) to functionalize and develop President Biden's proposal to spend \$400 billion over eight years on the Medicaid Home and Community-Based Services (HCBS) program with the goal of taking people with disabilities off waiting lists. It would also increase pay and benefits for direct-care staff to remedy the direct support professional (DSP) workforce crisis.

Addressing Wages for Direct Support Professionals

Sharon Levine, director of governmental affairs and communications at The Arc of New Jersey, said, "The President's plan for HCBS, outlined in the Better Care Better Jobs Act, would greatly benefit people with intellectual and developmental disabilities living in New Jersey. The plan and the related funding would help move people off waiting lists

and assist them as they transition out of institutional settings and into the community.

“Additionally, the plan addresses direct support professional wages so that individuals with intellectual and developmental disabilities (I/DD) will have a robust and dependable workforce. In New Jersey, we continue to struggle to hire and retain DSPs. The plan put forward by the President would raise wages and create more direct-care jobs. This would help cut down on turnover, which in turn creates consistency of care and support for people with I/DD. Overall, the President’s plan would give individuals with I/DD in New Jersey the tools and assistance they need to lead full lives in the community. It would also give families the supports they need to help their loved one thrive and pursue their unique and individual life goals.”

Agoratus feels HCBS is probably the most important topic for self-advocates and their families. “Improving pay and jobs would increase the workforce supporting people with disabilities and alleviate the national shortage of home-care workers. As a healthcare advocate, I see benefits for people with disabilities in our state by expanding HCBS for people with disabilities. This helps more individuals with disabilities to stay in their communities with appropriate supports and services. It eliminates the

institutional bias of Medicaid in keeping with the Olmstead Act.”

The White House said research suggests that increasing pay for direct-care staff leads to better quality care, greater productivity, fewer health violations and helps prevent deaths. They also said, “these investments will help hundreds of thousands of Americans finally obtain the long-term services and support they need, while creating new jobs and offering caregiving workers a long-overdue raise, stronger benefits, and an opportunity to organize or join a union and collectively bargain.”

Rep. Frank Pallone, Jr., representing New Jersey’s 6th congressional district, said, “HCBS allows seniors and people living with disabilities to receive the high-quality care they need in their communities and in close proximity to their friends and families. However, far too many people are unable to receive HCBS care because of long waitlists and chronic underinvestment in care workers. The Better Care Better Jobs Act makes a historic investment that will allow millions of Americans to access home and community-based care while giving a much-deserved raise to the workers who provide care to our loved ones.”

It is up to Congress to approve the funding Biden has requested. **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 speech bubble contains the text 'Common Ground Online' and 'Increasing Dialog Among Stakeholders In New Jersey's Special Education System'. Below the logo is a row of colorful stick figures holding hands, including two figures in wheelchairs. A dark horizontal bar below the figures contains the text 'The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!'. At the bottom left, three bullet points with circular icons list: 'Read about current issues in special education', 'Get updates on legal and legislative developments', and 'Find important resources and information'. At the bottom right, a dark button with the word 'Visit' is positioned above a dark banner with the URL 'www.NJCommonGround.org', which is above another dark button with the text 'to sign-up for a free online subscription!'.



The Housing Navigator Series

By Jonathan Jaffe

Finding the right housing for people with developmental disabilities has been a constant challenge in New Jersey. Beyond the issues of limited supply, accessibility and access to local transportation, the state has some of the most expensive real estate in the country.

All too often, cost is the prevailing factor that prevents many people with disabilities from living where they truly want to be—near family, friends and their jobs.

Overcoming these myriad challenges is the mission of the Supportive Housing Association of New Jersey (SHANJ.) And that is why this South Orange-based non-profit launched a program last year to train individuals in becoming “housing navigators” in their own corners of the state.

The Housing Navigator series was funded by the New Jersey Council on Developmental Disabilities (NJCDD). “I applaud SHANJ’s comprehensive approach to strengthening the skill level of trainees while providing comprehensive housing navigation resources,” said Mercedes Witowsky, NJCDD’s executive director.

“Finding housing is a huge problem,” said Diane Riley, executive director of the SHANJ. “People with intellectual or developmental disabilities don’t know where to begin and really need help looking. The housing navigators have been specially trained in overcoming challenges and can provide different ideas to help in the search. They can also make sure people get the appropriate service through a housing voucher and other supports.”

There were 33 individuals who participated in this free, eight-week program, comprising 30 hours of training served up in two-hour chunks on Zoom. The training was done through interactive video, with leading experts in New Jersey and New York providing unique insight on how best to connect people with developmental disabilities with the ideal living situations.

“We taught the navigators to better understand how the system plugs together,” Riley explained. “The journey is not always easy to find apartments for those who want to live near their support system; there are not always openings. There are a lot of questions between the type of housing that people want and the type of housing they can find. There’s a gap.”

Mary Kneuer, who provides technical assistance for Neighbours, Inc. in Princeton, said the course provided her with valuable person-centered approaches to housing.

“I would much rather see someone in their own home, self-directing their services and supports,” she said. “Staff relationships can be maintained longer, staff wages are usually higher which tends to lead to staff longevity and much more consistent supports.”

The training was overseen by Riley and Deborah Wehrlen, an experienced special needs housing consultant based in Brick.

The navigators were briefed about state entities that can assist with housing, as well as explanations of the various roles that the different state divisions play in serving people who require support.

Topics were far-reaching, from Social Security benefits to financial planning, from assistive technology to the latest in affordable housing policy. Navigators dove into issues regarding direct support professionals, as well as other support staff, while also reaching into areas of credit history, individual budgets, waivers and how earnings from employment factor into subsidized housing.

There are two ways in which navigators can help. They can help an individual find a group home or supervised apartment, while connecting with the providers to ensure a right fit. Navigators can also help people who want to live more independently to link with companies that can find the most appropriate affordable housing.

“Affordability is a huge issue, as well as finding what is available,” said Bill England, president of Disability Services and Advocacy, Inc. of South River, who was trained as a navigator. “Meeting the affordability guidelines through the government is not often easy. And the wait lists for affordable housing are long. Not for an opening; just to get on the waiting lists.”

“That’s why this navigator program is so important,” he said. “It’s giving us the tools so that we can help.”

Seminars offered robust discussions about how some families choose to set up their own group homes and use state funding to pay for all expenses as well as staffing. These families are seeking more control, and hope for creating better outcomes.

There were also reviews of state websites and other resources that provide various housing options, England said. There were also discussions of financial considerations with each choice, as well as forms and documents that need to be used as part of the process toward securing a place to live.

“There were very good and very extensive presentations on how to work with architects that specialize in working in accessible housing,” said England, whose company works with about 1,200 clients. “There was talk of funding for development companies to initiate projects and examples of a couple of providers, such as the United Way, that help set up housing for people with developmental disabilities. Again, it was all quite extensive.”

Riley explained the navigator program followed a curriculum offered through a similar program in New York, in which hundreds of navigators have been trained. “We looked at what they did and made it appropriate for New Jersey,” she said.

A key was to provide the navigators with broader exposure as to the services offered. Riley noted that some advocates don’t always look beyond a certain state department or agency for resources. “They only know so much by looking in that sphere,” she said. “We wanted them to be trained in a more broader sense.”

Jenn Brown, founder and CEO of Eiros Group of Tewksbury, also attended the housing navigator program as part of her commitment to providing housing to people with developmental disabilities. “I’m a housing geek,” she said, with a laugh. “So this program was like Christmas, New Year’s, my anniversary and my birthday all wrapped into one.”

Brown said the program was ideal for people who have tremendous passion in finding homes for people with developmental disabilities. “Everything I have learned over the past 15 years, giving my blood, sweat and tears, was covered in just eight weeks of Zoom calls.”

Brown said she continually refers to the printed material she collected from the program, noting some of the important information is included on a corkboard just an arm’s reach from her desk. She lauded the SHANJ as the “perfect partner,” with a shared commitment and passion.

“The byproduct of this program is that there is now a network of housing navigators throughout New Jersey,” she said. “We regularly talk to each other and refer to each other and have built a strong group with similar passions. Having this resource and network in which to bounce questions is very, very valuable for all of us.”

The SHANJ also provides its own “housing hub” on its website as a resource to individuals and families looking to establish a home that promotes the utmost independence. The search tool, supported by a grant from the New Jersey Council on Developmental Disabilities, is free for those seeking a home. Searches are based on county, municipality and availability of supportive services. Listings are available here: shanj.org/listings/ **P&F**

Charting the LifeCourse

Developing a Vision for a Higher Quality of Life

by Maryann B. Hunsberger

New Jersey is among the 21 states that have joined the National Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities. This national initiative develops support systems for families across the lifespan of their loved ones. Essential to this initiative are Charting the LifeCourse (CtLC) tools and framework.

Patricia Brennan, director of waiting list and special projects at the Division of Developmental Disabilities (DDD), serves as the state facilitator of CtLC and a certified CtLC ambassador. She said, “As CtLC is a framework for helping individuals and families of all abilities and ages develop a vision for a high quality of life, DDD has set a series of goals designed to help accomplish that vision and to help professionals act on strategies. Helping individuals achieve a high quality of life has always been our goal, and this framework helps boost our efforts.”

Brennan said DDD wants individuals to live their lives to the fullest and to have providers build their models of support around this concept. “DDD works with other agencies on this concept to help people plan earlier, with the goal being to have self-direction increase and self-determination realized. The information obtained through this vision and planning is used throughout all life stages. Individuals and families are using the CtLC concepts to share what they want for their lives, and professionals and providers are listening and thinking in the same context.”

The New Jersey Council on Developmental Disabilities (the Council), the New Jersey Division of Developmental Disabilities (DDD) and the Boggs Center on Developmental Disabilities are collaborating to increase awareness of CtLC. As part of this, leaders from the Regional Family Support Planning Councils (RFSPC) are supporting families in implementing CtLC framework and tools.

New Jersey’s CtLC leadership team, made up of certified CtLC ambassadors, is currently developing a welcome packet that will be sent from DDD to new families. Kyoko Coco, NJCDD’s family support coordinator, is the RFSPC state-wide liaison and a certified CtLC ambassador. She explained, “We are targeting families newly coming into DDD so we can help them understand person-centered thinking. We want to know what they want to accomplish and what the good life looks like for their loved one. We don’t want people to just ask which services we have so a person can try to fit into the existing system. They shouldn’t have to change their lives to fit in.”

She said, “CtLC allows providers, family members and individuals to consider all the different aspects of the individual’s life, understand what they may need to know or do based on their current life stage, begin planning for an upcoming transition, and explore the variety of supports that currently exist, or that they may need, to help achieve their vision.”

Brennan said that CtLC framework will also be used as people are reached on the priority waiting list, at annual New Jersey Individualized Service Plan (NJISP) meetings, and throughout the system as people, families, support coordinators, providers and other stakeholders are made aware of the tools and concepts and the value that they hold in helping people achieve outcomes.

One family member using CtLC is Cathy Tamburello of Verona. She used the CtLC domain tool and trajectory tool to support her 36-year-old son, Michael. The tools helped Tamburello and her daughter, Jenna, 31, to put their vision for Michael on paper to share with those who support him. “The domain tool was really helpful when Michael was changing day programs. It asks you to look at what you want for your child in all different life domains that make for a good quality

of life, such as employment, community living, safety, social and spirituality. This helped me figure out how to complete the trajectory tool. It helped us to understand which outcome we want for him, which things help him get close to that vision, and which things don't," said Tamburello.

Coco said each of the 10 RFSPCs has a Family Action Group liaison who will use the tools to assist families in finding supports and services to help their loved ones achieve the lives they desire. She said it's common for families to not know how to explain what they need, so the tools are important for this. "How do I get a friend for my daughter? How do I get my child included in the sports team? It gives parents a way to ask questions."

As the co-chair of the RFSPC #4 in Essex County, the Family Action Group liaison for RFSPC #4, and the Intellectual and Developmental Disabilities (IDD) consultant for the Family Support Organization of Essex County, Tamburello frequently uses the tools to support families. She said, "When I'm working with a family who is having an Individualized Education Program (IEP) issue, I have a conversation around the tools so the school system and family can have a common vision and move the child toward that."

The tools can be used through the lifespan. Tamburello has used them to support families with young children. "A mother of a 5 year old was looking at goals for when their child becomes an adult. I told her to look at goals for when their child comes out of kindergarten instead, so the



Cathy and Michael Tamburello, Princeton, NJ

child can succeed in elementary school. I also spoke to a family who is concerned about middle school for their 10 year old. We looked at which supports and services their child needs for the here and now, and what needs to be prioritized, so the next journey in life will be successful."

Coco said the tools are also a great conversation starter between parents and older children. "One mother used the trajectory tool with her teen and brought the answers to the IEP meeting. It helped her to know what her child wants to accomplish and how to achieve that in a safe way."

Tamburello said parents of adult children could use the tools with anyone who is involved in the life of the individual, including their support coordinator, their family, job coaches, day program staff, employers and recreation program staff. "Again, it should always start with what will make a good life for that person, and what kinds of services and supports we need to achieve that."

Coco said the integrated supports star tool can be used this way to expand people's thinking about supports in five areas: personal strengths and assets; relationships; eligibility specific services; community-based places and services available to everyone with and without disabilities; and technology.

"It shows you other areas beyond eligibility-based supports. You might not realize the supports you could have in the community. It forces you to think about non-disability related supports. It could be a barber who speaks their language, so

WHERE TO FIND THE TOOLS

The tools mentioned in this article can be found online at:

Domain Tool:

https://www.lifecoursetools.com/wp-content/uploads/2020/05/CtLC-VisionTool-Set_2020_FamilyPerspective.jpg

Trajectory Tool:

https://www.lifecoursetools.com/wp-content/uploads/2020/07/CtLC_LifeTrajectory_Family_Perspective_Planning_2020.jpg

Integrated Support Star:

Integrated Supports Star – LifeCourse Nexus (lifecoursetools.com)

the person feels comfortable going to that barber. It could be anyone you have a relationship with in the community. If the person wants friends, we use tools to help figure out how to make that happen. Maybe they like baseball and they would like a baseball fan club or meet up group. It helps to develop a vision for a good life, to think about what they need to know and do, how to find or develop supports, and discover what it takes to live the lives they want to live.”

Tamburello has experienced this with her son. “My son loves pizza and the employees at a nearby pizzeria love Michael. They are incredibly nice people who all make a point of interacting with him. Michael can’t eat the pizza if it’s too hot, but he can’t explain that, so I told them. They bring the pizza out at just the right temperature. He goes to the same table every time. He knows the drill. He feels like he belongs and fits in. It’s a social connection for him.”

Brennan said DDD is working to continue integrating this framework into intake practices, communications with stakeholders, development of guides for people and families, and outreach to people as they transition to the adult system from school services. “So far, we are pleased with the success.”

Brennan said DDD staff have been fully embracing these concepts and are eager to learn best practices in implementation and infusion of these tools. “CtLC ambassadors are working with staff throughout DDD. As we enter the third year as a member state for CtLC, more DDD staff are educated in the tools and are beginning to use them in every-day work.

“The core belief is that ‘all people have the right to live, love, work, play and pursue their life aspirations in their community,’ so interagency cooperation on CtLC is an integral piece. All people need to be collaborating so that we remain true to the principles.” **P&F**

CHARTING the LifeCourse

What is the Charting the LifeCourse?

Charting the LifeCourse is a framework that was developed to help individuals and families of all abilities and ages in Age of Life develop a vision for a good life, think about what they need to know and do, think how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and needs at the time but may also find it helpful to not spend too much thinking about life experiences now that will be pursued later as an individual, student, or in the future. The framework is designed to help any person think about their life, not just individuals known by the service system.

Even though the framework was initially developed for people with intellectual disabilities, it can be used by any family thinking about their future, whether they have a member with a disability or not.

Foundation of the LifeCourse Framework

- Core Belief:** All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community.
- All People:** All people, regardless of age, ability or family role, are considered in our vision, values, principles, services for supporting and supporting families. All families have choices and supports supported by need, whenever they are known to the disability service system or not.
- Family System and Cycle:** People live and live together and take turns with in a family system, which adjusts as the individual members change and age. Individuals and families need supports that address all levels of life and adjust as needs and needs of all family members change as they age through the family cycle.
- Life Outcomes:** Individuals and families focus on life experiences that lead the trajectory toward a good quality of life. Based on current supports or services that focus on the life goals (education, career, social capital and economic well-being), the emphasis is on planning the life outcomes, not just services.
- Life Complex:** People live within the meaning of one life, connected, and integral life domains, which is important to a good quality of life, including daily living, safety and security, community living, healthy lifestyle, social well-being, and education and advocacy.
- Life Stages and Trajectory:** Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences in past and influence life trajectory. It is essential to have a vision for a good quality life, and need opportunities, experiences and supports to enter the life trajectory in a positive direction.
- Individual and Family Supports:** Supports address all facets of life and adjust as the needs and needs of family members change. Types of support might include advisory and navigation information, assistive technology, social networking and connecting (peer support), and general and specialized living and financial supports.
- Integrated Delivery of Supports:** Individuals and families utilize an array of individual supports to achieve the envisioned good life, including those that are public and privately funded and based on eligibility, community supports that are available to anyone, relationship based supports, technology, and that also are available to people of all ages of the individual and family.
- Policy and Systemic:** Individuals and families see systemically created policies making so that they influence housing, policy, implementation, evaluation and metrics of the program that affect their lives, program, and policies, systems and policy makers that a way to think about the person in the context of family.

Connect with the LifeCourse framework and materials at lifecoursetools.com.

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

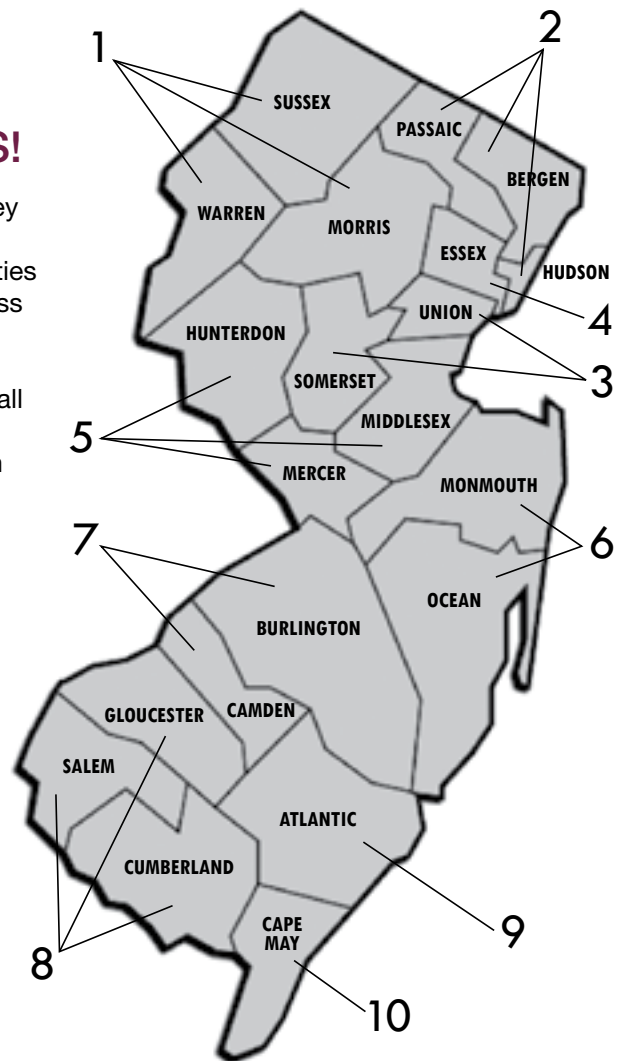
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

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

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

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



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

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

THE FAMILY SUPPORT ACT OF 1993

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

Visit the NJ Council on Developmental Disabilities' web site at: www.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.

DURING THE PUBLIC HEALTH EMERGENCY, ALL MEETINGS ARE HELD VIRTUALLY. If you are interested in attending, please contact a chair to request a meeting link.

People with Disabilities in the Entertainment Industry

By Elizabeth Ortiz

A friendly and realistic reminder to society and the entertainment industry, people living with a disability are still people. We are people with dreams, goals and aspirations, who just happen to have a disability that accompanies us on that journey.

Visual representation of differently-abled people will help to destigmatize negative and one-dimensional perceptions. We should see people living with disabilities as simply unique in the bigger scope of the human race.

I have a strong passion for this platform and for total inclusion in this field. I am a New Jersey resident who has a passion for speaking up about the lack of inclusion in the entertainment industry, particularly in the form of acting and modeling, especially when it comes to the portrayal of people with disabilities.

How unrealistic is it, that producers, directors, writers and film crews turn a blind eye and do not include actual people with disabilities in their work? According to the census of 2000, about two out of every seven families is reported to have a family member with a disability. I'm sure we are your neighbors, your friends, your co-workers, your sisters, your brothers, your uncles, your aunts, your fathers, your mothers or someone you may see on a daily basis, living life as usual. So why is it that we cannot be seen on the big screen like everyone else? Why is it that people with disabilities are not included in more movies, plays, fashion shows, TV interviews and magazine covers? Let that resonate for a while.

The few parts that are out there for persons with a disability in movies are given to able-bodied actors or actresses. This is equivalent to a person who is White playing an African American person and painting their face Black. So why can't people with disabilities play their own parts? This is a double standard.

One of the first movies that portrayed a real life disabled person was Helen Keller, who was blind, deaf, and mute. Another was the Elephant man, the story of a man who was terribly disfigured. Since then, several shows and movies have in fact realistically depicted individuals with disabilities. At this point in time, one would think that the disabled population should be included more in the entertainment industry. Instead, we still continue to lurk in the shadows only to be seen every so often.

I personally know this firsthand as I've been trying to get into modeling and acting with no success.

My Story

As a child I was diagnosed with Progressive Spinal Atrophy which is one a form of Muscular Dystrophy. As a result, I use a power wheelchair to get around. I am one of nine siblings, and honestly never felt different from them, neither did my siblings. They never treated me any different. I pretty much did everything they did except climb a tree and that was because I couldn't figure out how to do it.

Since I can remember I've always been very conscious of the way I dressed and what I wore. Appearance was always very important to me. I was always fascinated with fashion, I would buy fashion magazines and collect them to see the different styles and even hoped to see someone like myself, but sadly enough it never happened. As I got into my teens and twenties I would take numerous pictures in my different outfits. I always considered myself a fashionista and somehow, some day a model or actress in the making. That has always been my dream.

During the 90s I attended an acting school in New York. I also did some local modeling and some print ads for a few companies. I even tried out for a play called "Julie's Song" where I landed

a role. In 1999 and 2000, I entered the Miss Wheelchair New Jersey pageant. I did not win the title but it certainly was a great experience and one that I will never forget.

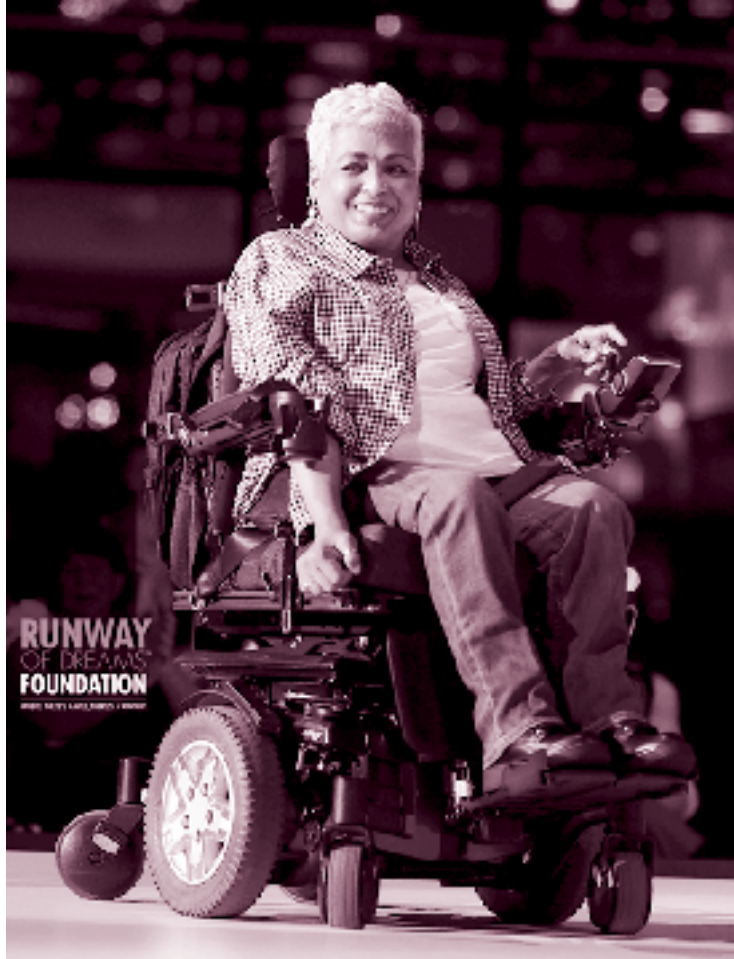
In 2019 I came across a modeling contest run by Zappos and decided to enter it. To my disbelief, I won. What a feeling that was to win something that I had been dreaming about for so long. In January of 2019, I flew with my sister to Las Vegas for three days for a photo shoot. The photoshoot was held at Zappos headquarters. It included a personal assistant who picked out my clothes for the photo shoot, a hairdresser to do my hair and another young lady to do my makeup. I truly felt like a celebrity.

This was a great experience for me as this was the first time that I had flown in quite a while. Also, the reality of having my dream come true was definitely mind blowing. I still can't wrap my head around or believe that I achieved those accomplishments in my life. As the saying goes "when one door closes another opens", and that cannot be further from the truth for me.

After doing the photoshoot for Zappos I was introduced to Mindy Scheier of Runway of Dreams. In September of the same year, I was in Mindy's fashion show for New York Fashion Week at Cipriani's. What an exciting time and a true dream come true. I would love to continue modeling and doing other work in the industry, but it comes with changes that could hurt my healthcare.

There are limits that are put on us by the state and government and other agencies that do not allow us to earn a living like anyone else. This is due to the high cost of healthcare and the equipment that we need on a daily basis. If you get a job in this industry and make more than you are allowed, you could lose your benefits.

So, if you do not get a steady job that brings you the income and insurance you need. This could cause hardship for someone like me. It can also cause all kinds of problems. So where does that leave someone like me? Where do I turn to get the answers? Personally, I think this is something that the state and government need to work on as part of employment for persons with disabilities. There are a lot of changes that yet need serious revamping in this system from its prehistoric status



Elizabeth Ortiz at New York Fashion Week Runway of Dreams

to bring it to today's reality. So, between Hollywood and the government there is a lot of work to be done. I honestly believe they know this but continue dragging their feet on these issues.

People with Disabilities in the Spotlight

More people with disabilities are visible in the media - some commercials and some movies but, it is still not enough. There is more work to be done in this industry. The media, networks and Hollywood especially, have an enormous potential to change the way people view individuals with disabilities. They can have a positive impact by simply focusing on the person rather than their disability.

Let me brag a little bit about some individuals who are paving the way for the rest of us. First, Zack Gottsagen. He's definitely a real inspiration to the disability population as a breakthrough entertainer who has made it onto the big screen numerous times. Zack is an actor with Down Syndrome known for the movies, "The Peanut Butter Falcon" (2019), "Best Summer Ever"

(2020), "At Last" (2020 short) and "Becoming Bulletproof" (2012). He also plays on "Boynnton Beach" on ABC. On February 9, 2020, Zack made history by being the first presenter with a disability at the Oscars along with Shia LaBeouf.

Chelsie Hill is a wheelchair user, who was in a drunk driving accident that left her lower extremities paralyzed. Chelsie had big dreams of being a dancer. She did not let that dream die. Chelsie did become a professional dancer, content creator, model, actress, advocate and the founder and CEO of Rollettes; an LA-based wheelchair dance team committed to educating, and empowering females with disabilities. Chelsie has been on numerous talk shows and news outlets. She also appeared in a TV commercial and in "Push Girls" a reality show about four young ladies who are all wheelchair users. It focused on how they navigated through their lives. She is definitely making a difference in our community.

Jillian Mercado is a model and actress who has Muscular Dystrophy. She has modeled for Diesel, Tommy Hilfiger Adaptive, Oil of Olay and numerous other brands. She also appears on "The Lword: Generation Q", a television drama, as an attorney.

Laura "Lolo" Spencer is another model and actress who is making a difference in the modeling world. Lolo was diagnosed with Lou Gehrig's Disease at the age of 14. She's a model, public speaker and content creator and has her own YouTube channel called "Sitting Pretty". "Sitting Pretty" is a series she created to showcase her life as a woman who uses a wheelchair. Lolo appeared in an independent film, "Give Me Liberty" and was nominated for Best Supporting Female. She also appeared in, "The Sex Lives of College Girls" (2021) and "The eZWay" (2020).

Stephanie Aiello was in a car accident that left her unable to walk and now uses a wheelchair. Stephanie is an Instagram star who rose to fame through her passion for makeup artistry. Her career began when she started uploading videos to her YouTube channel in 2012. Steph is now the first disabled model, to represent Ulta cosmetics. She is truly beautiful and a real inspiration.

Sammi Haney is a 9-year-old actress who has Osteogenesis Imperfecta (brittle bone disease).

She plays Esperanza, a wheelchair user on the Netflix series "Raising Dion". Esperanza is a bright classmate of Dion's. She is a brilliant artist who is wise beyond her years. Dion grows to realize she is his best friend.

Wesley Hamilton is a wheelchair user due to a gunshot that left him with a spinal cord injury. Wes turned his disability into a positive path. He found, his foundation named "Disabled But Not Really" which is an adaptive athletic program for people with disabilities. Wes is a very positive young man, at his gym he encourages other to get fit and live a healthy positive life. He pushes independence and empowerment, to those attending his gym. Wes is also a motivational speaker, disability advocate, model and a community activist.

These individuals encourage others to not be afraid to step outside of their comfort zone and live their dreams. Our lives and desires are as normal as anyone's. These are only a handful of people who have been able to make a name for themselves in the industry. Hollywood and the entertainment industry have their work cut out for them and therefore should start implementing this into practice as of yesteryears. We're in the 21st century and things should definitely be further along than they are.

On September 9, 2021, I was once again asked to model for New York Fashion Week Runway of Dreams. I modeled, Target brand. What a blessing it was to be able to stroll the runway once again in the big apple. The fashion show was held at the Glasshouse, such a beautiful venue, near Chelsea Pier. There were about 50 of us modeling accessible clothing for individuals with disabilities for Target, Tommy Hilfiger, Kohl's, Stride Rite, and Zappos Adaptive.

I met so many people that evening, some were social media friends, others from the companies that helped with the show. I even got to meet Nyle DiMarco, who is an American model, actor and a deaf activist. He appeared in "America's Next Top Model" in season 22, becoming the second male winner and first deaf winner. He was also the Mirror Ball winner on "Dancing with the Stars." DiMarco also produced the 2018 Broadway production of *Children of a Lesser God*.

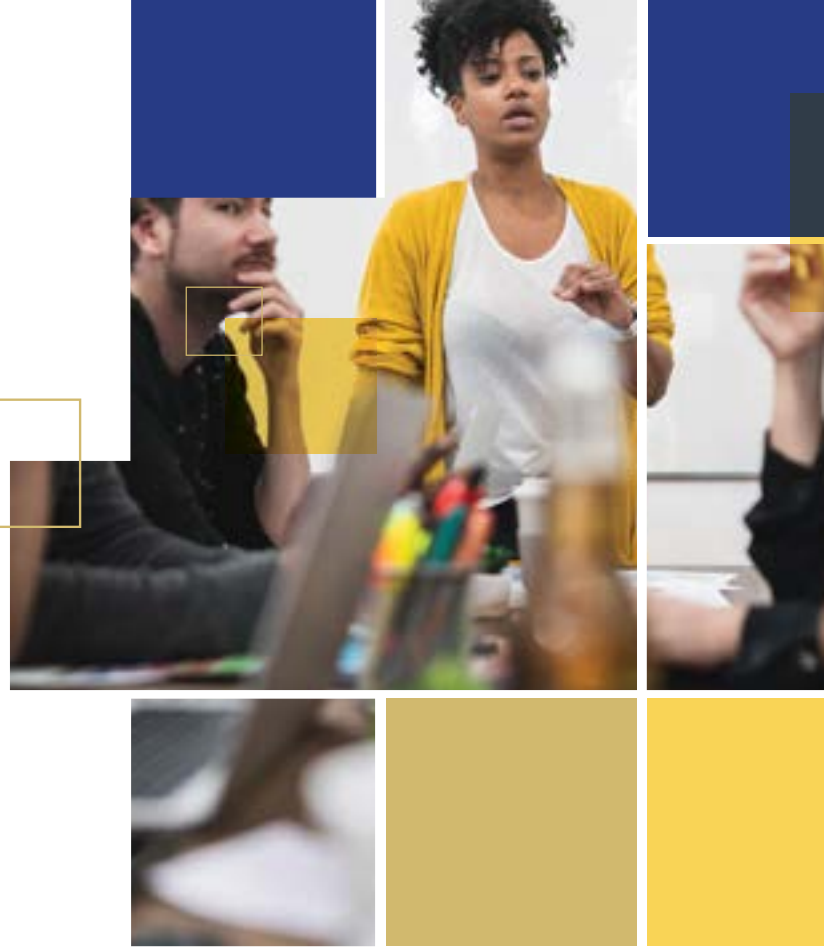
What an evening it was. **P&F**

COMMUNITY INNOVATION PROJECTS CIP

The New Jersey Council on
Developmental Disabilities'

Community Innovation Projects (CIP)

encourage new and innovative activity
designed to bring about meaningful
local change.



Primary Goals




The primary goal of Council-funded activities is to produce short and/or long-term system change. Ideas that can be shared and replicated.

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

COMMUNITY INNOVATION PROJECTS REQUIREMENTS

- Relate to the Council's 5-Year Plan.
- Focus on advocacy, local capacity building, systems change, social change, equal access, community competence, or education of families and self-advocates.
- Create and strengthen relationships with local associations and groups.
- Position people with developmental disabilities and/or their family members as active and engaged participants who influence the work and participate directly.
- Have a plan for sharing successful practices.
- Reflect the values, preferences, languages, and cultures of the communities they engage.

ACTIVITIES CAN INCLUDE

-  An innovative approach to a systemic challenge OR;
-  An activity that addresses a systemic problem that is being overlooked, OR;
-  An innovative project or pilot project related to the 5-Year plan that demonstrates a best practice.

To apply, fill out our
letter of interest found at
<https://bit.ly/2ZUVnNB>
and email the form to
grants@njcdd.org



*Cathy Tamburello and her son Michael at his favorite spot, Alfonso's Pizzeria in Princeton.
Center is Kim Borredon, Proprietor.*