

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

VOLUME 1, 2022



ADVOCATES PUSH FOR IMPROVEMENTS TO NJ WORKABILITY

Monica Koppstein
with her mother Natanee
at Project Freedom

COMMUNITY INNOVATION PROJECTS CIP

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

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C O N T E N T S

6 LETTER FROM THE EXECUTIVE DIRECTOR Responding to the Need for Competitive Employment



In many respects, our state has fallen short in making competitive employment widely accessible for individuals with intellectual and developmental disabilities (I/DD). In a new report, *Advancing New Jersey's Employment First Practices and Policies*, the Council calls for a renewed commitment to New Jersey's Employment First policy, to improve employment outcomes for individuals with I/DD.

7 NJCDD COMMITTEE REPORT

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



10 COVER STORY ADVOCATES PUSH FOR IMPROVEMENTS TO NJ WORKABILITY

On January 10, 2022, Governor Phil Murphy signed New Jersey Senate Bill 3455/New Jersey Assembly Bill A5262 into law, removing barriers to employment for people with disabilities in New Jersey. The new law expands access to WorkAbility by changing eligibility requirements. Once fully implemented, the new law will completely remove the unearned income limit, allowing more individuals to qualify for WorkAbility.

16 PAYING FOR SPECIAL EDUCATION

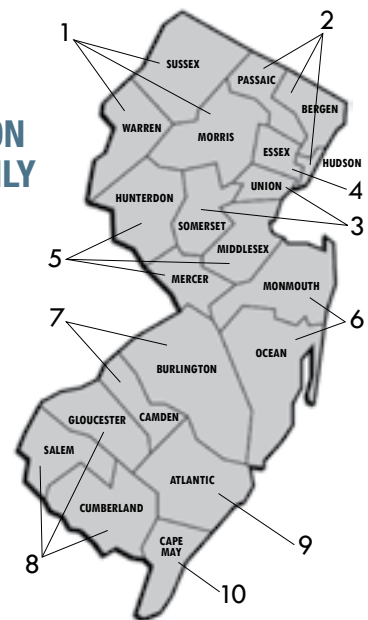
Less than 50 years ago, students in the United States with Down syndrome, autism, cerebral palsy, dyslexia, and other disabilities were routinely turned away from school because of their disabilities. Today, they are entitled to a free and appropriate public education.

24 “ALL” MEANS “ALL” Increasing Diversity, Equity, and Inclusion

Data from a recent NJCDD survey showed that people need better, more culturally and linguistically appropriate information and services. In response, the NJCDD is embarking on a major initiative to improve outreach and expand engagement to a more diverse group of stakeholders.



26 INFORMATION ABOUT FAMILY SUPPORT PLANNING COUNCILS



30 LATINO AND DISABILITY Three Lives and Three Perspectives

Everyone affected by disability also has an ethnic identity and cultural heritage that shapes them. Ethnic identity can be a source of pride, connection, and resilience, but it can also add a layer of challenges to the experience of having a disability. Every person's story is different. Here are three stories of Latinos with disabilities living in New Jersey.

from the Executive Director ■

Responding to the Need for Competitive Employment

I cannot stress enough the importance of supporting the needs of individuals with disabilities and their families. In particular, their need to have their own voice.

Time and time again, individuals have expressed the need for integrated competitive employment. In April 2012, Governor Chris Christie made New Jersey an 'Employment First' state. It means that competitive employment is the first and preferred post-education activity for people with disabilities.

In many respects, our state has fallen short in making competitive employment widely accessible for individuals with intellectual and developmental disabilities

(I/DD). In a new report, *Advancing New Jersey's Employment First Practices and Policies*, the Council calls for a renewed commitment to New Jersey's Employment First policy, to improve employment outcomes for individuals with I/DD.

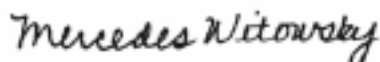
This report was developed by the John J. Heldrich Center for Workforce Development at Rutgers, The State University of New Jersey, in partnership with the Institute for Community Inclusion at the University of Massachusetts. The report's executive summary and action plan include an examination of the current employment landscape with a series of recommendations. NJCDD welcomes a concentrated approach to advance Employment First in New Jersey.

NJCDD applauds Governor Murphy as he signed New Jersey Senate Bill 3455/ New Jersey Assembly Bill A5262 into law on January 10, 2022 to remove barriers to employment for people with disabilities in New Jersey. The new law expands access to WorkAbility by changing eligibility requirements. NJ WorkAbility expands Medicaid eligibility to allow people with I/DD to earn a living and still qualify for Medicaid benefits. You can read more about WorkAbility in this issue of *People & Families* magazine.

Among other stories, this issue takes a comprehensive look at special education funding. While special education may be free to families, it comes at a high cost. This issue also sheds light on the Council's continued work on diversity, equity, and inclusion, with a special commentary on what it is like to be a Latino with a disability.

I sincerely hope you enjoy this issue of *People & Families* magazine and wish you a happy, safe and healthy Spring.

Warm Regards,



Mercedes Witowsky
Executive Director,
New Jersey Council on Developmental Disabilities





NJCDD COMMITTEE UPDATES

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

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

Council members include 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 monitor the Council's Standing and Ad Hoc Committees.

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

Committee. The following is a snapshot of some of the committee highlights.

Executive Committee

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

- The two new Sub-Committees were created under the amended bylaws, the Self-Advocates Advisory Subcommittee and the Diversity, Equity and Inclusion Subcommittee will begin operations during the first quarter of 2022. Council members and interested members of the public were recruited to serve on the subcommittees.
- The Governor's Office of Appointments confirmed one new member. Michael McCarthy, was confirmed during the lame duck legislative session. The Office of Appointments plans to re-submit new nominated candidates for Senate approval during the next legislative session.
- NJCDD is planning a Council retreat on May 11. The May 12 Council meeting will have a hybrid format. Attendees may participate in-person or virtually. All committee and sub-Committee meetings will continue to be conducted virtually.

State Plan Committee

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

- The Planning Committee worked on the 2022-2026 Five-Year Plan for a year and a half, gathering information from public comments, focus groups and in-depth conversations with the Ad Hoc Committee on Equal Access to DD Services. After the draft plan was approved by the Council, it was finalized and submitted to the Administration for Community Living (ACL) last fall 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 role of the Grants Committee is to oversee the development of funding announcements that align with the Council's Five-Year Plan goals, objectives and activities. The Grants Committee reads all responses to funding announcements and makes recommendations to the full Council for funding and continued funding aligned with the Council's Five-year Plan and based on grantee performance. The following are recent committee activities:

- NJCDD announced a three-year funding opportunity of up to \$375,000 for three years/ \$125,000 in year one (excluding required 25% match) for a qualified entity to improve access to and the provision of education and transition services that align with Employment First.
- NJCDD announced a multi-year funding opportunity of up to \$250,000 for two years/ \$125,000 in year one (excluding required 25% match) for a qualified entity to plan and implement projects designed to increase the number of individuals with I/DD who are engaged in competitive, integrated employment, including individuals with complex behavioral and medical issues.

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 first meeting of the Legislative Disabilities Caucus this year was held on January 25, 2022. It included a recap of the 2021 Caucus accomplishments and a video compilation of legislators' remarks on the value and purpose of future meetings. Supporting agencies delivered remarks on the advocacy work and the mission of their agencies. The next Caucus session will be held on April 26, 2022.
- S3000, the "Medicaid Pediatric Care Network Adequacy Act," was signed by the Governor on November 8, 2021. The Committee is monitoring the implementation of the new law.
- Another big win for the disability community was the signing of the WorkAbility bill, S3455/A5262. The bill expands access to NJ WorkAbility. The new law removes a major barrier to employment and career advancement of people with disabilities. The bill received strong support from multiple advocacy organizations and individuals in the past one and a half years.
- S1020 was signed January 2022. The bill requires school districts and charter schools to collect school discipline data on their website and report it to the commissioner of the NJ Department of Education. It also requires NJDOE to establish a database and complete an annual report concerning student discipline.

Subcommittee on Children and Youth

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

The committee is addressing:

- The important role of non-attorney advocates in special education
- Improving the system of family support services for those caring for a child under the age of 21
- Access to specialized child health care services
- Special education services, assessments and transition services through COVID
- Racial inequity & disproportionality in special education

Subcommittee on Health and Wellness

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

The most recent Health and Wellness Subcommittee meeting was held on January 18, 2022. The Subcommittee is currently focused on:

- Engaging in next step planning of regulations for newly passed Pediatric Network Adequacy (S3000) legislation.
- Wrapping up project funding addressing vaccine hesitancy in individuals with I/DD and their caregivers.
- Continuing to participate in activities promoting increased oral health in individuals with I/DD across the lifespan.
- Monitoring updates on the newly passed Telehealth (S2559) legislation and ensuring the voice of individuals with I/DD is included in planning.
- Discussing plans to address additional areas of concern such as obesity, individuals dually diagnosed with I/DD and mental health disorders, and systemic barriers to quality health care for individuals with I/DD.

Diversity, Equity, and Inclusion Subcommittee

The Diversity, Equity, and Inclusion Subcommittee was established under the recently amended Council bylaws. Sarah Aziz serves as chair and Annette

Smith serves as co-chair. The DEI subcommittee is comprised of Council members, members of the I/DD community as well as family members, advocates, and state agency representatives.

The subcommittee's role is to:

- Advise the Council on matters involving diversity, equity and inclusion involving individuals with I/DD and their families.
- Advise the Council regarding internal and external policies, activities and any other areas affecting individuals with I/DD and their families as it relates to diversity, equity and inclusion.
- Review materials and other Council materials to evaluate and make recommendations regarding diversity, equity and inclusion approaches.
- Work in conjunction with other committees regarding issues concerning diversity, equity and inclusion.

The first meeting was held on March 17, 2022. The subcommittee will meet quarterly.

Self-Advocacy Advisory Subcommittee

The Self-Advocacy Advisory Subcommittee was established under the recently amended bylaws to ensure the voices of advocates are being heard and supported through the Council's goals. Ryan Roy will serve as chair. Ryan is a newly-appointed Council member. The subcommittee's role is to:

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

The subcommittee will meet quarterly beginning May 2, 2022. **P&F**

Advocates Push for Improvements to NJ WorkAbility

By Maryann B. Hunsberger

Steve Gruzlovic of Robbinsville is a busy man. He advocates for appropriate job accommodations for people with intellectual and developmental disabilities (I/DD) through the Employment First Initiative. This helps people attain and maintain competitive employment.

He serves as transportation chair for the Statewide Independent Living Council (SILC). He is board president for the Progressive Center for Independent Living in Hamilton, helping families with a multitude of needs so they can transition to their most independent life. He just wants to get paid for his work and keep his Medicaid. “I already work as an advocate for people with disabilities, consulting for businesses and for families navigating the NJ developmental disabilities system, but I do it for free. I don’t make money.”

A program called NJ WorkAbility (WorkAbility) would allow Gruzlovic, 32, to work, since it expands Medicaid eligibility to allow people with I/DD to earn a living and still qualify for Medicaid benefits. But, as an adult dependent, when his father started receiving Social Security benefits, it increased Gruzlovic’s Social Security Disability Insurance (SSDI). “It brought it to over \$1,133 per month, which disqualified me from WorkAbility.”

Anytime an individual with disabilities’ parent dies or begins collecting retirement or disability



Steve Gruzlovic, Advocate, working at his computer where he lives at Project Freedom.

benefits, the individual may receive SSDI based on the parent’s work record in an amount that exceeds the 2022 threshold amount of \$1,133 per month, thereby making the disabled adult child ineligible for WorkAbility. This is because income from the parent’s work record is viewed as unearned income. Paid leave, unemployment benefits and child support received by adult disabled children from divorced parents also count as unearned income.

Besides requiring that unearned income be equal to or less than 100 percent of the Federal Poverty Level (FPL), earned income also presents a problem. Earned income must be equal to or less than 250 percent of the FPL, which comes to \$65,196 per year/\$5,433 per month for an individual.

In addition, individuals over age 65 are ineligible to participate in WorkAbility.

However, on January 10, 2022, Governor Phil Murphy signed New Jersey Senate Bill 3455/New Jersey Assembly Bill A5262 into law, removing barriers to employment for people with disabilities in New Jersey. The new law expands access to WorkAbility by changing eligibility requirements.

Unearned Income

Once fully implemented, the new law will completely remove the unearned income limit, allowing more individuals to qualify for WorkAbility.

Earned Income

The legislation also removes the earned income limit. This means that WorkAbility enrollees can work, receive job promotions or obtain better paying jobs and still keep their Medicaid. “We needed the legislation so more people could remain employed and keep their Medicaid, allowing them to receive services from DDD and other Medicaid-funded programs,” said Gruzlovic.

Continuation of Coverage

Previously, if employment ended for WorkAbility enrollees, their Medicaid coverage could have been quickly terminated. Medicaid coverage through WorkAbility will now continue for one year after a job loss. This allows unemployed WorkAbility enrollees to focus on job searching and their return to work.

Disregard of spousal income

Spousal income and assets will be completely disregarded in financial eligibility determination of the individual.

Upper-age limit

The bill will remove the upper-age limit for WorkAbility enrollees. Previously, if a person with I/DD

was employed and in the WorkAbility program, their Medicaid was terminated at age 65.

The upper-age limit is where the legislation gets especially complicated. Specifically, removal of the upper-age limit requires that the Division of Medical Assistance and Health Services (DMAHS) submit a State Plan Amendment (SPA) to the Centers for Medicare and Medicaid Services (CMS) to add the Balanced Budget Act of 1997, which has no upper age limit, to the existing federal authority of the Ticket to Work Incentives Improvement Act of 1999.

The starting point for this bill was when Nantanee Koppstein, a parent advocate from Princeton Junction, researched and found a paper that was written in January 2015 and published by the National Council on Disability (NCD) about Medicaid buy-in programs. “It was an eye-opener for me,” said the Princeton Junction resident. “If an individual loses Medicaid, it’s huge. It requires so much paperwork. It’s an administrative churning when people go in and out of different waivers. So, I compiled a simple table of what 20 other states have done. Some had no earned or unearned income limit. They continue Medicaid coverage after someone stops working. I saw that other states could do this, so why couldn’t we?”

Koppstein worked with the late Rebekah Novemsky of the Council. Together, they put WorkAbility on their agenda. Koppstein wrote a paper on the benefits of changes to the law, and that paper became the basis of their advocacy. “We came up with the five changes that needed be made to WorkAbility’s financial eligibility requirements to remove barriers to employment and career advancement of people with disabilities in NJ. Kevin Nunez, the Council’s vice chair, took it to State Assembly member Carol Murphy, who was the champion for this legislation.”

SILC also played a crucial role in the WorkAbility law changes. “Expanding access to WorkAbility through legislative reform was discussed at every monthly SILC meeting from the start of our advocacy. New Jersey’s independent living community which includes the SILC and Centers for Independent Living (CIL) was front

and center in the support of WorkAbility bills as introduced. Individual SILC members and CIL directors and advocates submitted public comments for legislative hearings. SILC members, including Steve Gruzlovic and Norman Smith, the SILC chair, had meetings with legislators throughout our advocacy,” said Koppstein.

Also, “the NJ Disability Action Committee, a cross-disability advocacy group, was instrumental in ‘getting the word out’ before the bills got their green lights.”

Koppstein has a personal reason for her WorkAbility advocacy—her daughter, Monica, who is a WorkAbility participant. Monica, 34, has worked for ten years while retaining her Medicaid through WorkAbility. “If one of us passes away, as a disabled adult child, Monica would receive 75 percent of the late parent’s Social Security benefits. This would most likely disqualify her without the new WorkAbility law. This new law will keep her eligible for Medicaid through WorkAbility.”

Koppstein explained why working is so crucial for her daughter. “It is the best rehabilitation because she is constantly interacting with other human beings. Monica requires a lot of support and has a job coach. It’s difficult, but with support and planning, she has done okay. It’s important for her physical and mental health.”

Advocates are enthusiastic to see full implementation happen. Tom Baffuto, executive director of The Arc of New Jersey, said, “The Arc of NJ strongly supported this bill which will improve the provisions of the WorkAbility Program. We applaud the legislative sponsors who helped to shepherd this bill over the finish line and we are



Monica Koppstein is on NJ Workability and works full time.

grateful to the governor for signing S3455/A5262 into law. We are eager for the implementation of the changes, as it will open doors to individuals with I/DD who were previously excluded from the program because of ‘unearned’ income provisions and it will give these individuals a pathway to have Medicaid and DDD services, while also being employed.”

Koppstein said, “I am confident that Jennifer Langer Jacobs, the assistant commissioner of DMAHS, is doing the best she can to ensure that internal operational logistics are in place while getting federal approval. The latter is likely to make the changes retroactive to January 10,

2022. Prompt implementation allows more eligible New Jerseyans with disabilities to work at their full potential, thereby benefiting the state and local economies. Another fiscal rationale for prompt implementation is to enable eligible individuals ages 65 and older who are currently utilizing Personal Care Assistance services through the state-funded Personal Assistance Service Program (PASP) to become eligible for WorkAbility which is partially funded by federal dollars.”

Assistant Commissioner Langer Jacobs said that DMAHS is currently working with federal partners at the Centers for Medicare & Medicaid Services (CMS) to identify and request additional federal approvals that are required to implement the income and age eligibility changes required under the new law. “While that process is ongoing, we are simultaneously working internally to determine additional operational and systems changes that may be needed in order to ensure all

eligible individuals get enrolled and/or maintain their coverage in the WorkAbility program,” said Langer Jacobs.

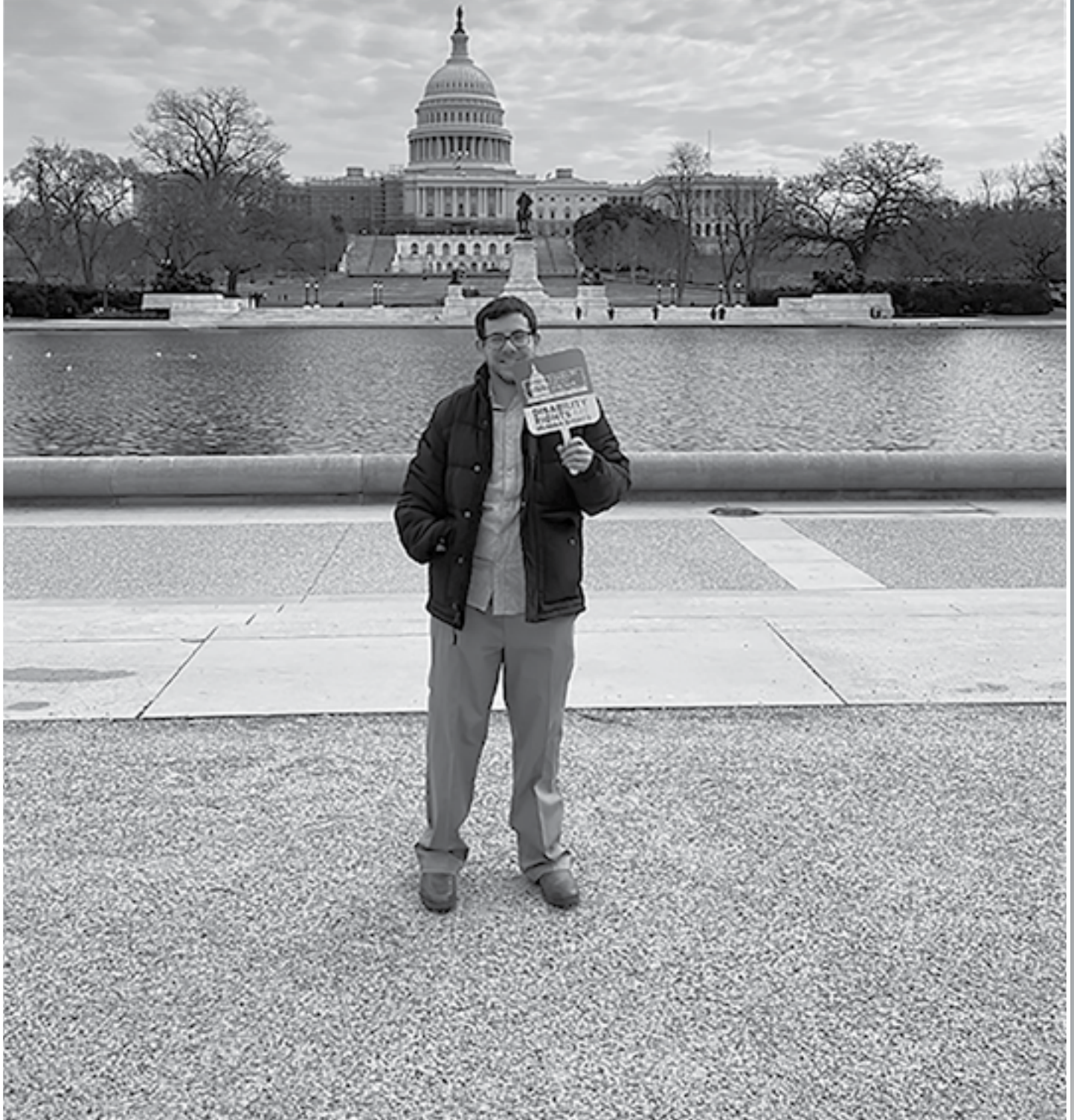
“Full implementation will occur after the state receives the necessary approvals and authorizations from CMS and operational changes are made. While we are committed to implementing this legislation as soon as feasible, we note that some of the operational and systems changes required are significant and will take time to implement. Once we have a more detailed timeline for implementation we will share it with the public and stakeholders.”

Koppstein said, “This has been more than a group effort. It’s not a village, but a state-wide effort. This landmark legislation is not just for people with disabilities. It’s a win-win for everyone: the state, the individual and the families. I can volunteer and work because my daughter works. It has made such a big difference all around.” **P&F**

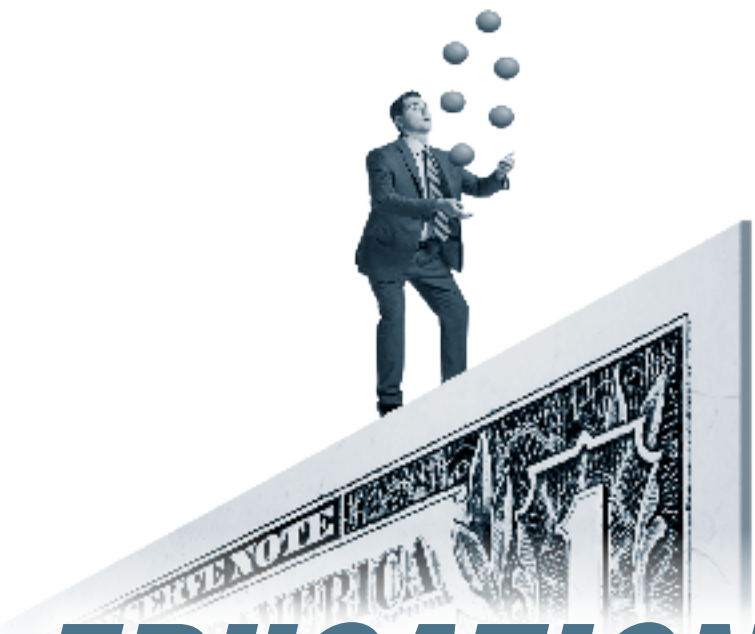


The banner features a dark blue background with a large white speech bubble on the left containing the text "Disability in Focus". To the right of the speech bubble is the logo for "The New Jersey Council on Developmental Disabilities". Below the logo are three rounded rectangular buttons: "Presenting Facts", "Sharing Views", and "Starting Conversations". The main text of the banner reads: "Visit the NJCDD's Blog, **Disability in Focus** to get the latest news and views from around the state and across the country about our developmental disabilities communities. Join the conversation by sharing your own views on topics we discuss." At the bottom, there is a call to action: "We Can't Wait to Hear From You! Visit us at www.njcdd.org". An illustration at the bottom left shows several hands raised, with one hand holding a megaphone.

Advocates Attended the Disability Policy Seminar in Washington D.C. from March 28-March 30







Paying for **SPECIAL EDUCATION**

By Brenda Considine

Less than 50 years ago, students in the United States with Down syndrome, autism, cerebral palsy, dyslexia, and other disabilities were routinely turned away from school because of their disabilities. Today, they are entitled to a free and appropriate public education.

New Jersey was a pioneer. As early as 1911, New Jersey lawmakers required local public schools to provide special classes and equipment for students who had fallen behind. The law required the local board of education to pay for it, but a year later, in 1912, the state added a budget item to help districts cover the cost. In 1959, the Beadleston Act further protected New Jersey students with disabilities by guaranteeing their right to special education. It is regarded as the predecessor to the federal legislation that would follow.

In 1974, the Education for All Handicapped Children's Act (now, the Individuals with Disabilities Education Act, or IDEA) was signed into law. IDEA guarantees all children with disabilities the right to a "Free Appropriate Public

Education." Local school districts must identify students who need special education, provide an assessment, develop an individualized plan to meet their needs, and provide necessary services and supports, all at no cost to parents.

While special education may be free to families, it is certainly not free. Of all areas of school funding, special education is perhaps the most vexing. It can also be divisive, in part because the costs can be high.

Because funding is so opaque and fragmented, it is poorly understood. Very few stakeholders and government leaders have a full understanding of the systems. Most understand only the aspects that are relevant to their constituents.

Federal Funding: A History of Unkept Promises

When IDEA was enacted, the federal government promised to pay 40 percent of the excess cost of special education (that is, the cost above what it costs to educate a student without a disability). Unfortunately, that never happened. Today, nearly half a century later, the federal government is still covering less than 15 percent of the excess cost.

IDEA is one of the largest programs overseen by the U.S. Department of Education. The 2022 federal budget funds \$15.5 billion for services to students with disabilities under IDEA. This represents a \$2.6 billion (19 percent) increase—the first in eight years.

States receive federal funding in the form of a state grant, but in order to get that money, they must demonstrate compliance with key areas of IDEA. Some of the money in the state grant is used by NJ Department of Education (NJDOE) to administer and oversee the program, but the majority of the funds are “passed through” to local school districts. In 2019, New Jersey received more than \$381.8M in federal funds for IDEA.

In addition to IDEA funding, Medicaid is another source of federal funding that can be used to pay for special education services for qualifying students. The Special Education Medicaid Initiative (SEMI) funds school districts providing health-related services. SEMI is separate and unique from other Medicaid programs because it is limited to services provided in an educational setting. New Jersey law requires school districts to maximize their participation in SEMI. Districts must apply for the funds on a student-by-student basis, and carefully track the delivery of services. Districts receive 35 percent of the Medicaid revenue generated, while the rest goes to the state. The paperwork and bookkeeping are seen as onerous by many districts, and some claim it costs more to administer the program than they receive in reimbursement.

But federal funding is only a small part of the puzzle. State, local, and sometimes county tax dollars make up the bulk of special education funding in New Jersey.

State Funding: A Balancing Act

The School Funding Reform Act of 2008 (SFRA) established a new way of distributing state education aid to local school districts. The new formula also dramatically changed the ways in which special education dollars are allocated.

“While special education is free to families, it is certainly not free.”

Prior to 2008, special education students in New Jersey were funded based on their level of need through the Comprehensive Educational Improvement and Financing Act (CEIFA). Each student was counted and placed into one of four “funding tiers,” with higher levels of state aid for students with greater needs. For example, a student with severe autism would generate more state aid than a student with dyslexia. Districts received state aid based on the actual number of students they served in each tier. But a 2003 study by the Center for Special Education Finance showed that New Jersey had higher per pupil spending for special education than the national average. It recommended switching to census-based special education funding

to help the state control spending.

SFRA’s “census approach” to special education funding was supposed to discourage “over-classification”—that is, districts identifying students as eligible for special education in order to collect state funds. Under SFRA, state special education aid to districts is not based on the number of special education students in a district. Instead,

Using Funding to Shape Policy and Practice

IDEA-funded grants are also used to drive policy and advance best practices. In 2020, NJDOE funded a 5½-year, \$8M initiative to promote the inclusion of students with disabilities into Pre-K through 12th grade general education classrooms in local public schools. In recent years, NJDOE has also used federal funds for grants to advance practices around the effective use of positive behavioral supports, effective transition planning for integrated employment, and improving parent engagement of children with disabilities in schools.

the formula uses a statewide average rate of classification (currently calculated to be 15.9 percent) regardless of how many special education students a district actually serves.

The amount of special education aid is also based on a “statewide average” excess cost, which is calculated annually (\$19,524 in the 2023 NJ State budget). Unlike the system of tiers in CEIFA, SFRA funds a student with severe autism at the same level as a student with dyslexia.

In practice, this funding scheme has not worked to decrease classification rates, nor has it held down costs. Since SFRA was enacted in 2009, the statewide average classification rate has increased, and the statewide average excess cost for special education is up 44 percent. The full cost per pupil for special education services has increased 67 percent, from \$19,519 in 2009 to \$32,674 in 2023.

SFRA is also not equitable. Classification rates vary widely from district to district. Some of New Jersey’s 600+ school districts identify fewer than 10 percent of their student population as having a disability, while others identify nearly 30 percent as having a disability. A handful of districts reported no special education students at all. Districts who “under identify” (that is, serve less than the statewide average) may be “overfunded,” while those who “over identify” (serve more than the statewide average) may be “underfunded.” County vocational districts also receive census special education funding, but have an average classification rate of just 10.4 percent.

Once a district’s state special education aid has been calculated, there is still another step: wealth equalization. Two-thirds of the aid is adjusted for local wealth, with poorer districts getting all of the aid or a large percentage, and wealthier districts getting less, or none at all. The remaining one-third of the aid is provided to all districts in the form of special education categorical aid. This ensures that every district in New Jersey receives some level of state aid for special education.

While state special education aid may be called “categorical,” it is not “dedicated,” which means districts are free to spend the funds as they wish.

Another area of inequity is SFRA’s assumption that using the “average excess cost of special education” is fair to districts. In practice, costs vary widely. For example, districts with a well-respected autism program or progressive transition program can have much higher costs per student than other districts offering fewer intensive services. And for a very small district with a few “high need/high cost” students, the effect on the local budget can be significant.

“Extraordinary Aid” in Special Education

Extraordinary Aid for special education was first provided in New Jersey in 1996 through CEIFA. The popular program was preserved when the funding formula was revised in 2008 under SFRA. Extraordinary Aid allows New Jersey school districts to be reimbursed by the state for a portion

Understanding Extraordinary Aid		
Placement Type	Cost Threshold	Percentage of cost above the threshold that can be reimbursed
In-district public-school program with non-disabled peers, whether run by a public school or by a private school	\$40,000 for direct instructional and support services	90%
Separate public school program for students with disabilities	\$40,000 for direct instructional and support services	75%
Separate private school for students with disabilities	\$55,000 for tuition costs	75%

of high cost/high intensity special education services. The program has complex cost thresholds, along with a list of intensive services that must be in a child's IEP in order for the district to qualify.

The cost threshold is *not* placement neutral, meaning that certain placements will generate more state reimbursement. In addition, for each placement type, a different set of costs counts toward the threshold. The state reimburses only for costs **above** the threshold; the district is responsible for all costs under the threshold. But much like the federal aid promised for special education, this provision in the law has never been fully funded, so districts only get a percentage of the aid to which they are entitled.

The program has grown dramatically. In 2009, approximately 4.4 percent of the students classified for special education met the threshold for reimbursement under extraordinary costs. By 2020, the percentage nearly doubled to 8.25 percent.

County Funding

In New Jersey, there are eight county-based Special Services School Districts serving roughly 3,900 students with disabilities in specialized public schools. These programs also provide shared services to local school districts, bringing expertise to help them serve students locally. County freeholders allocate nearly \$3M in county tax dollars to support these programs, offsetting tuition rates they charge to local school districts.

Local Taxpayer Role

The local school district is ultimately responsible for braiding together the federal, state, and local funds to pay for the services each eligible child needs. They are expected to spend at least the same amount they are spending on general education, plus whatever else is needed to

Paying for Out-of-District Placements

When the IEP team agrees that a student's needs cannot be met in the local program, that student has the right to placement in a specialized out-of-district program. These public and private schools charge tuition to the local sending school district—often more than \$70,000 per student. But the tuition rate does not tell the whole story. A private school's tuition rate reflects all costs. But in public programs, costs associated with pension, social security, health care benefits for retirees, and other items are paid by state tax dollars. This allows public programs to set a tuition rate that is lower than their actual costs.

In addition, county-based Special Services School Districts are subsidized by more than \$30M in county taxes, which helps to offset the tuition that the local district must pay. These two accounting practices create a funding incentive for districts to place students in public programs.

According to John Mulholland, executive director of ASAH, a statewide association of private special education schools, the result is unfair to local school districts and to students.

"The funding and accounting system for all placements, public and private, should be the same and it should be placement neutral. That way, IEP teams can make decisions about what is right for a student, not what is right for the local budget," said Mulholland. "The current accounting system for tuition setting is inherently unfair to local boards of education when they have a student who needs a private school."

implement each student's individual education program (IEP).

Often, special education is a large portion of the local school budget. A single student with high cost needs can cost more than \$90,000, plus transportation. Even after school district budgets have the stamp of approval from local taxpayers, a child may move in who needs high cost services, throwing the budget into turmoil.

Betsy Ginsberg is the executive director of the Garden State Coalition of Schools (GSCS), a statewide, grassroots, volunteer-based association that represents roughly 100 New Jersey school districts and their communities.

“Year to year, or even month to month, districts don’t know what their special education costs will be. It is hard to plan. This presents hardships not only for districts, but also, inevitably, for families too,” she said.

“Anything that can help to relieve the tension on all sides would be helpful, and that usually means more resources,” she said.

Advocating for Adequacy, Efficiency, and Equity

In February 2022, the New Jersey Senate Education Committee approved legislation (S-354) to establish a task force to study, evaluate, and suggest changes to SFRA. Special education funding is of particular interest to the bill’s sponsor, Senator Vin Gopal, who chairs the Senate Education Committee. In a press statement, Gopal noted, “Districts get the same aid whether they have large populations of students with disabilities or not, and regardless of whether they are spending as much as they should or providing the special education their students need.”

In 2015, a special education task force recommended that New Jersey reevaluate the school funding formula with a particular focus on special education. They suggested a new funding formula that stabilizes general and special education funding, and ensures that state aid follows students eligible for special education and related services as well as general education students. This was never done.

In a 2011 report commissioned by the NJDOE, school finance experts found clear differences in the types and costs of special education classifications among districts, mostly along the lines of local district wealth. They advised the state to consider funding special education based on actual enrollment, differentiating funding levels by disability categories, and examining whether the

special education funding system is fair and equitable. This has not been done.

Since 1996, the New Jersey Coalition for Special Education Funding Reform has been advocating for a state funding formula that is adequate, efficient, equitable, predictable, flexible, transparent, fully placement-neutral, and accountable for both spending and student outcomes. The Coalition, a broad-based group of 13 advocacy and provider organizations, has recommended that New Jersey conduct a scientifically-validated, longitudinal

outcomes study to examine the lives of adults who, as students, received special education services in New Jersey.

Peg Kinsell, a founding member of the Coalition, serves as chairperson of the New Jersey Council on Developmental Disabilities’ subcommittee on Children and Youth, and is director of Public Policy at SPAN Advocacy.

“We invest millions of dollars in educating students with disabilities, but objective data on these students in adult life is absent,” said Kinsell. “We need a study to identify variables that affect positive outcomes in order to make

informed decisions about education policy and funding.”

Mulholland, whose group is also a founding member of the Coalition, says his organization also urges an outcomes study, along with a cost study to look at the full excess cost of special education.

Many advocates and education stakeholder groups agree that the current formula needs reform.

John Burns, Esq. is senior legislative council for the New Jersey School Boards’ Association (NJSBA). He notes that a good starting point for reform would simply be to fund the current formulas at the federal and state levels. In 2007, NJSBA sponsored a study that found that local school districts supported 57 percent of the costs, with the

“Revisiting the special education census formula must be a central focus of such an analysis. To continue to fund districts under the false pretense that the incidence and cost of disabilities are evenly distributed across the state is unfair and harmful to all students.”

—Danielle Farrie, PhD, research director, Education Law Center



remainder coming from state funds (34 percent) and federal aid (9 percent).

“The verbal commitments are far larger than the money we [the state of New Jersey and the Federal Government] have been willing to put behind it. And we are asking our local districts to do more,” noted Burns.

Burns believes that New Jersey does more for students with disabilities than most states, but funding is “stacked against districts that do a good job in special education.”

“The formula assumes a certain percentage of classified students, but if your district has a good reputation and serves more students than that, funding is inadequate,” said Burns.

One of the leading voices for change is Education Law Center (ELC). Widely recognized for groundbreaking court rulings on behalf of at-risk students, ELC promotes educational equity. According to Danielle Farrie, PhD, ELC’s research director, New Jersey has had many opportunities to examine and revise the special education funding

system, but has failed to do so. Under SFRA, the governor must issue an Education Adequacy Report (EAR) to the Legislature every three years, with recommendations for updating certain elements included in the formula. The most recent report was issued in March of 2022, but ELC and other groups have urged a more comprehensive analysis.

“Revisiting the special education census formula must be a central focus of such an analysis. To continue to fund districts under the false pretense that the incidence and cost of disabilities are evenly distributed across the state is unfair and harmful to all students,” said Farrie.

Ginsberg from Garden State Coalition of Schools agrees.

“To say that every district has the same percentage (of special education students) is ridiculous. It needs to be reevaluated,” said Ginsberg.

There is also broad agreement among stakeholders that a comprehensive cost study is needed before funding reform can occur.

Jonathan Pushman, director, government relations at New Jersey School Boards Association believes an independent cost study would be “an appropriate next step.”

“When the challenge of how to fund special education comes up, there is often a task force, but they don’t necessarily have the data they need. Without data, how can you figure out how to fund it or how much you need? This is one area where there is a lot of consensus in the education community,” he concluded.

“Whenever we try to change this flawed formula, the objection [from government] has always been that it will cost more money. But maybe special education DOES cost more,” said Ginsberg.

*“Whatever and whenever reform happens, it is going to be a Herculean task. We cannot design an effective funding system until we know the **REAL** costs. We need **REAL** numbers, for a **REAL** funding system, and for **REAL** solutions.”*

—Betsy Ginsberg, Director,
Garden State Coalition of Schools (GSCS)



SUGGESTED READING

New Jersey State Education Aid – Education Adequacy Report (2023)

<https://www.nj.gov/education/stateaid/2223/EAR2023.pdf>

School-based Medicaid

https://www.nj.gov/treasury/administration/semi-mac/pdf/SEMIPProviderHandbook_FY22.pdf

New Jersey Coalition for Special Education Funding Reform

<https://specialedfundingnj.org/>

IDEA Series – Broken Promises: The Underfunding of IDEA (2018)

https://ncd.gov/sites/default/files/NCD_BrokenPromises_508.pdf

New Jersey School Boards Association – Task Force on Special Education Report (2014)

<https://www.njsba.org/news-information/research/njsba-task-force-on-special-education-report-2014/>

School Funding in New Jersey: A Fair Future for All

<https://www.njpp.org/publications/report/school-funding-in-new-jersey-a-fair-future-for-all/>

New Jersey Task Force on Improving Special Education for Public School Students (2015) Final Report

<https://www.nj.gov/education/specialed/highlights/TaskForceReport.pdf>

FAQ Special Education Extraordinary Aid (NJ) (2021)

<https://homeroom.state.nj.us/exaid/doc/FAQEXAID.pdf>

Analysis of New Jersey’s Census-Based Special Education Funding System (2011)

<https://www.nj.gov/education/sff/sereport.pdf>

Now Available

for download <https://bit.ly/3lZJ5lg>

AN ENHANCED

FAMILY SUPPORT CRISIS HANDBOOK

A Behavioral Health Wellness Toolkit

Promoting voice and choice for New Jerseyans of all ages with intellectual and developmental disabilities, and all stakeholders who support them.



“All” Means “ALL”

Increasing Diversity, Equity, and Inclusion

By Brenda Considine

The vision of New Jersey Council on Developmental Disabilities (NJCDD) is to ensure that all individuals with intellectual and developmental disabilities (I/DD) are participating, as included members, in their communities, make real choices and have control over their own lives, and have the same rights, privileges, responsibilities, and opportunities of citizenship as any other New Jersey resident.

But like so many businesses and organizations in our state and nation, NJCDD is falling short when it comes to reaching and engaging *ALL*. Data from a recent NJCDD survey showed that people need better, more culturally and linguistically appropriate information and services.

“Our recent five-year planning process sought to engage a diverse community of stakeholders; we did that, but not to the degree that represents the diversity here in New Jersey,” said Mercedes Witowsky, executive director, NJCDD. “We looked at the data and knew we could do better.”

Under her direction, the NJCDD is embarking on a major initiative to improve outreach and expand engagement to a more diverse group of stakeholders.

“Our state service systems need to be designed and delivered such that they are accessible to everyone who needs them, and that means getting input and participation from a broader range of stakeholders,” she said.

Intersectionality

We are all many things, and when it comes to disability, that is especially true. People identify in different ways, whether it’s with their disability, race, religion, culture, language, gender, and/or sexuality.

“Within the disability community, we are not a homogeneous group. Everyone needs something different and deserves to be viewed as an individual whose views and perspectives are important,” said Sarah Aziz, a member of the NJCDD who has recently been appointed to chair a new subcommittee on Diversity, Equity, and Inclusion.

Even language around disability is individualized and evolving. It used to be that advocates, agencies, journalists and policy-makers pushed for “person first” language (i.e., “person with a disability,” vs “disabled person”), but self-advocates are taking a fresh look at that and are claiming disability as part of their identity.

“I identify as a Black, non-binary, trans autistic woman,” said Cory S. “I am not a person with autism any more than I am a person with blackness. I do not have autism... I AM autistic.”

A New State Plan for NJCDD

As part of a federally-mandated strategic planning process, Developmental Disabilities Councils nationwide must identify disparities affecting

unserved or underserved populations and include work in their state plan to address a “targeted disparity.”

New Jersey’s Council went beyond that minimal requirement to create a state plan that addresses disparity in every area. Within each goal, there are specific objectives that directly engage historically-underserved communities, including urban, rural, Black, Hispanic, Asian,

those with limited English proficiency, and LGBTQ+.

New Jersey’s plan identifies not one but two specific targeted disparity objectives. In the area of advocacy, the NJCDD has committed to work each year to increase access to information about NJCDD, its DD Act Partners, and all developmental disability systems, and how to access the full range of supports and services available

DATA: Disability and...

Within intersectionality, there is information. Data from numerous sources suggest that some communities of people with disabilities have been overlooked, and may be experiencing a lack of services, supports, and favorable outcomes.

The National LGBTQ Task Force, together with the Center for American Progress, estimate that 3-5 million LGBTQ people have disabilities.

- According to data from the National Disability Institute, 40 percent of Black Americans with disabilities live in poverty compared to 22 percent of Blacks without disabilities.
- According to Cornell University’s Disability Statistics project, 28 percent of working-age Black Americans with disabilities are employed compared to 72 percent of working-age Black Americans without disabilities.
- According to the National Center on Disability and Journalism, Black Americans with disabilities who need medical treatment face barriers that range from negative stereotypes on the part of practitioners to a lack of transportation to get to a doctor’s office.
- According to classification data from the USDOE, in the last decade, the percentage of Hispanic and/or Latino students with disabilities receiving special education under IDEA Part B increased from 21.8 to 27.2 percent.
- According to classification data from the New Jersey Department of Education, in 2019, Asian children ages 5-21 represented 9.5 percent of the student population, but just 4.5 percent of the students served in special education.
- According to classification data from the New Jersey Department of Education, in 2019, Black children ages 5-21 represented 13.7 percent of the student population, but 16.4 percent of the students served in special education.
- According to graduation data from USDOE, nationwide, 72.6 percent of all students with a disability graduated with a diploma. During the same period, 65 percent of Black students with disabilities graduated with a diploma; 69 percent of Hispanic/Latino students with disabilities graduated with a diploma.
- According to the 42nd Annual Report to Congress on IDEA, in the 2019-2020 school year, 16.4 percent of Black students with a disability were placed in the general education classroom less than 40 percent of the day, compared to 12.8 percent of all students with disabilities.
- According to data from the National Center for Learning Disabilities, in 2019, one in five Black, American Indians, and multi-racial male students with disabilities were suspended from school.

through New Jersey’s public and private system. In the area of capacity building, the NJCDD will facilitate government and community partnerships, and improve interagency coordination through collaborations and coalitions designed to reduce barriers to service access and delivery. The emphasis will be on reducing inequities experienced by historically underserved populations, including individuals who are Black, Hispanic, or Asian, have limited English proficiency, and/or identify as LGBTQ+.

Paul Blaustein, chair of the NJCDD, recognizes that information is power.

“People who know about the services get the services,” he said.

There are many families who are outside the system simply because they are not aware that the system even exists. Council member Sarah Aziz knows firsthand that the people who need the most help are the ones who may not even be involved or who have experienced isolation. Aziz, who identifies as a Muslim, is the mother of three children; her oldest, 13-year old Leah, has autism.

“When your kids are toddlers, or you are working full time—when you are struggling with meltdowns, or diapering, you are juggling every day. You are desperate. You don’t have time for this advocacy work. You don’t have time to research services,” she said.

“We will need to do more outreach to identify families earlier in the process, and focus on communities that are underserved and underrepresented in our work,” she concluded.

The other key area of disparity is in the area of special education. By 2026, and in collaboration with educators and stakeholders, NJCDD 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.

Internal Focus: Building Capacity

For each year of the plan, NJCDD committed to supporting projects and engaging in outreach designed to increase diversity, equity, cultural



Jade Pollock focuses on developing and maintaining diverse community and stakeholder relationships at NJCDD.

competency, and linguistic responsiveness in the work carried out by the Council and its staff.

The Council wasted no time. Immediately following the successful submission of the State Plan, NJCDD hired Jade Pollock, a consultant whose work focuses on developing and maintaining diverse community and stakeholder relationships. In addition to her professional experience, Jade is also the mom to two sons on the spectrum one of which is diagnosed with autism.

“This is not only a professional endeavor, but also a personal journey for me,” said Pollock, who has spent the past 16 years working on issues within the social service field on race, equity, and diversity. “When advocating in a space that directly impacts you, it feels so different. It is very fulfilling because I live this.”

Pollock knows that outreach and engagement will require investment. “Together with NJCDD staff, we are looking at a multi-layered outreach strategy using public and private agencies,” she said.

“In order for NJCDD to move forward, we need to share a definition of culture, diversity, equity, and inclusion. Even as a nation, we have not addressed this yet, so there is a lot of work to be done,” added Pollock.

The first step was taken in January 2022 with a grant awarded to SPAN Advocacy, a New Jersey based nationwide non-profit. They will be working

with NJCDD to define terms, and to review policies and practices to support NJCDD as it moves forward in actionable, measurable ways.

Grants Process: A New Emphasis

As part of a comprehensive internal review process, the NJCDD has placed increased focus on ensuring that its grants process invites a more diverse range of applicants and serves a more diverse group of stakeholders.

“Beginning with direct outreach to a growing number of multicultural agencies and providers, the changes to the grants process reflects our commitment to getting more people to the table,” said Witowsky.

The grant application itself was revised to require applicants to demonstrate cultural competency and the ability to reach and support diverse and historically-underserved communities.

Applicants must also describe how they will reach a culturally and linguistically diverse population in their proposed work. The grant scoring process will look at an applicant’s history and their ability to carry out work in ways that align with the Five-Year State Plan.

Depending on the grant, NJCDD is also requiring that work specifically include serving those in urban and rural areas, and must include another group of people whose needs are often unmet: those with complex needs such as medical and/or behavioral challenges.

One of the first grants issued in NJCDD’s new five-year cycle went to a Black-owned firm with a CEO who has disabilities. LeDerick Horne Speaks, LLC is a new grantee that will be working on a project designed to increase access to information for Black NJ residents. Diagnosed with dyslexia and the grandson of a civil rights leader, LeDerick Horne has a strong track record of building bridges between communities.

His firm’s approach will expand the range and comprehensiveness of the Council’s ability to empower Black communities by providing information that enhances access to information and services. They will develop and facilitate the NJ Black I/DD Consortium including members from organizations, school districts and local advocates. The Consortium will guide the

development of strategies to access information that maximizes academic, employment and quality life outcomes for Black NJ residents with I/DD and their families.

Bylaw Change and New Subcommittee

In developing the State Plan, the NJCDD established an ad hoc committee to examine equal access to DD services. That group went to great lengths to review the draft of the state plan and provided critical input. Its work inspired the Council to include a recommendation in its review and proposed revision to its bylaws that adds a Subcommittee on Diversity, Equity, and Inclusion.

The new 12-member subcommittee, the largest of any Council subcommittee, includes five members of the general public and seven members of the NJCDD: Sarah Aziz, Kevin Nuñez, Myrta Rosa, Safiyah Muhammad, Helen Steinberg, Paul Blaustein, and Phyllis Menendez.

Pollock, Aziz, and Blaustein underscore that the subcommittee is looking beyond race to explore the concept of “diversity” to address age, gender, religion, sexual orientation and gender identity, language, national origin, socioeconomic status, immigration status, and culture.

“We know there are many barriers to accessing vital public services. We want remove the stigma, and we can only do that with more voices at the table,” Pollock said.

“The folks on the subcommittee are an amazing group of people. They opened up and showed bravery and acceptance. Building cultural competence requires that we do not make assumptions or judgments about people,” concluded Pollock.

“This is more than a subcommittee and objectives in our 5-year plan. This is our mission. This is our commitment,” Blaustein concluded.

Blaustein is proud of the forward movement and the pace of change at NJCDD, but he quickly admits that “this is work for the disability community that should have been done a long, long time ago.”

“Developmental disability services are funded by government and are intended for all residents. There is no excuse for any resident of New Jersey not to have access. Everyone has a right to those services,” he concluded. **P&F**

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

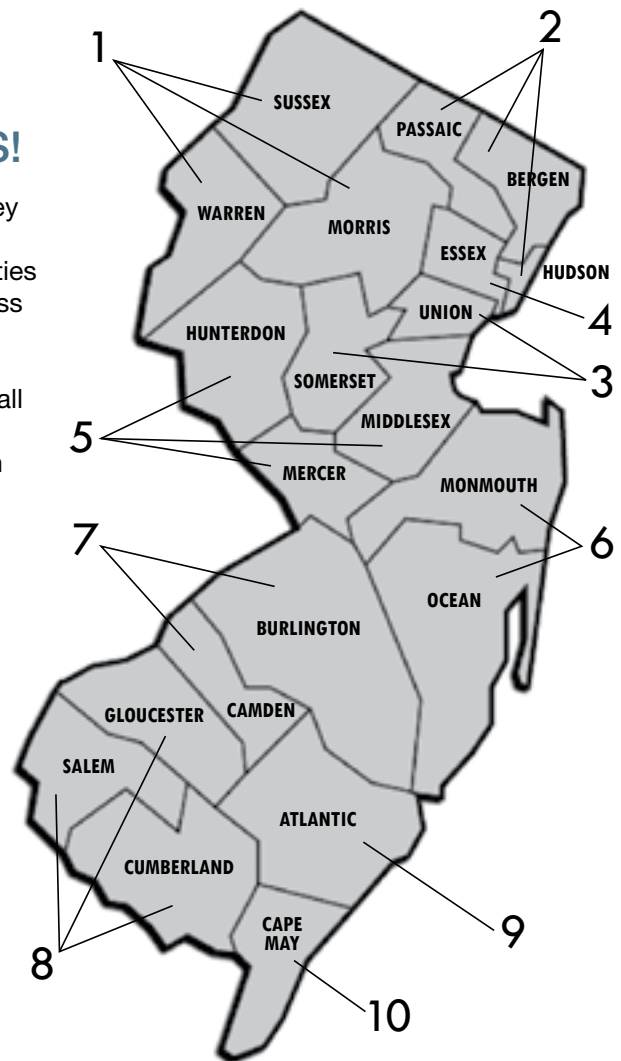
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

The councils work in partnership with the state's Division of Developmental Disabilities and Children's System of Care to advise on policy decisions that affect people with developmental disabilities. 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: RFSP1@gmail.com
Chair: Margaret Hefferle

Meets the third Tuesday
of each month
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
7:00 p.m.–8:30 p.m.

3 SOMERSET, UNION

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

Meets the third Tuesday
of each month
7:00 p.m.–9:00 p.m.

4 ESSEX

RFSPC#4
e-mail: RFSPC4.Essex@gmail.com
Chair: Yolanda Smith

Meets the first Wednesday
of each month
7:00 p.m.– 8:30 p.m.

5 HUNTERDON, MIDDLESEX, MERCER

RFSPC #5
e-mail: RFSPC5@gmail.com
Chair: Paul Blaustein

Meets second Saturday
of each month
10:00 a.m.–12:00 noon

6 MONMOUTH, OCEAN

RFSPC #6
PO Box 76
Lakewood, NJ 08701
e-mail: RFSPC6@gmail.com
Chair: Mike Brill

Meets the second Thursday
of each month
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
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

Evenings: TBD

9 ATLANTIC

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

Meeting times and dates TBD

10 CAPE MAY

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

Meets the third Thursday
of the month
except January, April, July,
August, and December
6:30 p.m. – 8:00 p.m

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

Latino and Disability

Three Lives and Three Perspectives

By Elizabeth Ortiz

Disability does not exist in a vacuum.

Everyone affected by disability also has an ethnic identity and cultural heritage that shapes them. Ethnic identity can be a source of pride, connection, and resilience, but it can also add a layer of challenges to the experience of having a disability.

Research suggests that Latinos have a strong family foundation—“familismo”—which can provide an intergenerational source of loyalty, support, and interdependence. At the same time, Latinos with disabilities may face added obstacles to receiving services such as language barriers, immigration status, discrimination, and self-acceptance.

Every person’s story is different. Here are three stories of Latinos with disabilities living in New Jersey:

My Own Story:

I am a Latina with a disability, born in Puerto Rico to Puerto Rican parents. I became sick in Puerto Rico as a child, which left me with a developmental disability. When I was a little girl my parents moved our family to New Jersey for a better life, economically and medically. As a teenager, I was diagnosed with muscular dystrophy.

Here in New Jersey, my dad started working so my mom could care for me and my three

siblings. My parents did not speak English when we moved to New Jersey. In many ways, I feel the system failed me, because of the language barrier, and the lack of knowledge of my disability.

I know that my parents took me to a lot of doctor appointments. We had a social worker, but I don't think it worked out too well because my mother was not given any help as far as an aide to help her with me. She had to care for me on her own.

When I started school, my mom got me up in the morning, and did my morning care, from washing up, to getting me down stairs to catch the bus. In between, she had to feed us and get everyone ready for school. We lived in an apartment that was not accessible—there were seven steps. If my parents spoke the language and were better informed of services, they could have spoken to someone to see what could be done to make our home accessible. Every morning, I had to be taken down those seven steps in my wheelchair, and then back up those same steps when I returned from school.

This was a two-person job and dangerous, so my mom always had to look for someone to help her. Once I entered high school, I was given an electric wheelchair so I could get around school. That meant bringing a very heavy electric wheelchair down those seven steps, then bringing me



Elizabeth Ortiz

down in my manual wheelchair. My mom had to physically lift me up and transfer me out of the manual chair, into my electric wheelchair, then take the manual wheelchair upstairs. That was a lot of work, but my mom did it twice a day, every day, with no complaints.

that I attended did not teach too high of an academic level like they should have.

I truly believe that because of the language barrier and lack of disability information, society has failed me in many areas. I am beyond happy and ecstatic that the generations of today do

“I believe if there wasn’t a language barrier, I would have been better off medically than I am today.”

—Elizabeth Ortiz

When I was younger, I had a manual wheelchair but the chair was for an adult not a child. I’m not sure why, but I certainly was not given proper medical care. From being in that chair that was not properly fitted for me, I wound up developing a secondary disability, scoliosis, which made my primary disability worse. I believe if there wasn’t a language barrier, I would have been better off medically than I am today.

When it was time for me to go to school I was put in a special school for disabled children. The grade level went up to 8th grade, but at a lower teaching grade level. After I graduated from grammar school, I went to high school.

I could not go to the same high school as my sisters and brothers near our apartment, because that school was not accessible. Instead, I attended Arts High School in Newark because it had an industrial elevator. When I started classes at the high school I ran into some problems. It felt like I went from 8th grade to 10th grade. I was smart, but the grammar school

not have similar problems as I had. They are able to go further with their endeavors and aspirations. In addition, the medical field has advanced so much that the children of today with a disability have a greater chance at a life of, what some would call "normalcy" than I did. Not to say that I never overcame a lot of those things, because I have achieved many of my goals and beyond what doctors' expectations of me were. I thank my parents for being the great parents that they were. They never discouraged me from doing anything I wanted to do.

I encourage anyone and everyone with a disability to never allow anyone to steal your dreams, or tell you that you cannot do what you want to do. Today, I say: "I can, because I did," and "the glass ceiling of yesterday today is my runway".

Myrta Rosa's Story:

Myrta is a Latina of Puerto Rican descent, who was diagnosed with cerebral palsy. She was born in Puerto Rico. When she was 5, she immigrated with her family to the United States, moving to Perth Amboy, NJ. After her parents died in 1998, she moved to Woodbridge Developmental Center where she lived for 12 years. A 2007 graduate of Partners in Policymaking, she is active in the self-advocacy movement in New Jersey and the nation. She is also member of the New Jersey Council on Developmental Disabilities.

"Make sure your voice is heard and never give up. Never let people tell you what to do... be your own person and don't let your disability define you."

—Myrta Rosa



Myrta Rosa

Myrta said she has experienced negativity due to her disability, but never due to her Latina background.

"People have always made fun of me because of the way I walk due to my disability and sometimes the way I speak," she said. Even today she says she gets ridiculed.

Myrta says she never had any problems with being Latina and having a disability as far as services, education, and medical care. She feels she always had support and help with whatever she needed. In fact, she thinks her Latina background has helped others. Myrta became an interpreter

for the school she attended in Edison. She was the only bi-lingual person in the school. Myrta would translate for the teachers and staff whenever Spanish-speaking visitors needed information. "I was the translator," Myrta said.

Myrta's advice to people with disabilities who are Latino is to find people who can assist them and understand them. This means finding helpers who will take their time and find out all the information regarding what your needs are.

She also urges people to get involved in advocacy. "It will help them to speak up for yourself and know your rights," she said. "Make sure your voice is heard and never give up. Never let people tell you what to do...be your own person and don't let your disability define you. Realize that no one can defend you as you would yourself, so it is vital to be heard, and respected the way you want to be," she concluded.

Myrta's advice to people with disabilities who are Latino is to find people who can assist them and understand them. This means finding helpers who will take their time and find out all the information regarding what your needs are.

Myrta believes that by advocating for yourself, you let other people know to treat you- the same way they would treat an individual without a disability. Lastly, she suggests that people research agencies that care about you as a person and your needs.

"As for myself I found, Community Access Unlimited," she said. "The agency has been there for me and has supported me to this present day."

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Keven Nuñez's Story:

Kevin was born in Rio Pierda, Puerto Rico. He and his twin brother, Abner, were diagnosed with cerebral palsy at birth. Today, Kevin lives in Burlington County with his father and brother, and serves as vice-chairperson of the NJCDD. Also a 2007 graduate of Partners in Policy Making, he is a disability advocate, blogger, podcaster and published author.

“[Moving from Puerto Rico to NJ] was not an easy decision, but one of necessity, one that [my parents] had to make the sacrifice for.”

—Kevin Nuñez

When he and Abner were just four years old, his parents relocated to New Jersey due to the lack of infrastructure in Puerto Rico, and a lack of services and accessibility.

“Being that Puerto Rico is a territory and not a state, there were a lot of things that the US has that Puerto Rico lacks in general,” Kevin said.

Kevin believes that the transition from Puerto Rico to New Jersey was harder on his parents than it was for him and his brother. “This was not an easy decision, but one of necessity, one that they had to make the sacrifice for,” he said.

After moving to New Jersey, Kevin and his family would visit Puerto Rico every summer. As he got older, he realized that his parents made the right choice to leave the island that had been their home for generations.

“The services we would need just did not exist for people with disabilities,” he noted.

Kevin says he has experienced negativity due to his disability: navigating the system, and general lack of knowledge from the non-disabled population.



Kevin Nuñez

The language barrier was also a challenge because he had to learn English. His parents did not believe in ESL, (English as a second language) so he had to learn it the hard way. He attended Bridgewater-Raritan High School for grammar school all the way to high school. He recalled that as a fair-skinned Latino, some people took him to be Caucasian, until they heard him speak. While at medical appointments, the staff would learn that he spoke Spanish, and would use him as an interpreter.

Kevin's advice for those who are Latino and have disabilities is simple: Be patient and learn.

“Learn the language, and get familiar with all three cultures...your ethnic heritage, your disability culture and your American connection. And especially if you're young, never lose your roots. In the end you will benefit from your experiences,” he concluded. **P&F**

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Steve Gruzlovic is an advocate who wants to work for pay through Workability