

# People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SPRING 2017



## Ciba Salih

### Sharing Resources and Helping Others

Ciba Salih works at Shop Rite of Hillsborough Twp.



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### Advocacy and Engagement

The most important part of advocacy is engagement in what is going on around us. We are currently living in challenging and uncertain times for the disabilities community in our County—proposed cuts to Medicaid; a nationwide DSP staffing crisis; and growing concerns related to special education, employment, housing, transportation, and more. Now, as much as ever, it's important for individuals and families to pay attention, speak up, and take action.

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Ciba Salih works at Shop Rite of Hillsborough Twp.

—Photo by: Rebecca Shavulsky

## 16 DISABILITY POLICY RECOMMENDATIONS FOR THE NEW ADMINISTRATION

### An Overview

The Consortium for Citizens with Disabilities, a coalition of approximately 100 national disability organizations working to influence public policy that impacts individuals with disabilities, recently released a series of recommendations aimed at the Trump administration and the 115th Congress, urging them to consider the impact that their proposed agendas will have on disabled Americans' ability to lead safe, inclusive, and productive lives in our communities. *People & Families* has reviewed these recommendations and provides a detailed analysis for disabilities advocates in New Jersey.

## 20 HOMELESSNESS, POVERTY, AND EDUCATION

### From the NJCDD's *Common Ground Special Education e-Newsletter*

Poverty presents many challenges, but perhaps none is more threatening to a child than attempting to live and go to school without a place to call home. Evidence suggests that homelessness effects a disproportionately high rate of children with disabilities, and creates additional barriers to access appropriate and quality education, mental and physical health services, and other basic needs including nutrition and direct support.

## COVER STORY

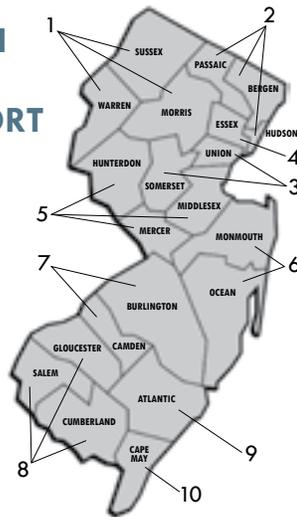
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#### Sharing Resources to Help Others

Ciba Salih, a Hillsborough Twp. resident with traumatic brain injury, holds down a steady job, continues her education, and stays active in her community—all while self-directing all of her support services. Now, she's committed to sharing what she's learned with others so that they too can lead more full and independent lives.



### 28 INFORMATION ABOUT FAMILY SUPPORT



### 30 NEW JERSEY'S STATEWIDE TRANSITION PLAN

#### Finding "CommUnity"

Following a 2014 mandate by the Centers for Medicare & Medicaid Services (CMS), New Jersey was required to develop a Statewide Transition Plan in order to preserve Medicaid funding while shifting to a more community-based system of service for residents with I/DD. After years of writing and rewriting a plan to carry out this transition in a way that best serves our developmental disabilities community, the State has just submitted its finished plan for CMS review.

### 37 A LIVING WAGE FOR DSPS

#### How One Organization Makes It Happen

It has been well documented in *People & Families Magazine* and elsewhere that New Jersey is careening toward an extreme shortage in Direct Support Professionals. Yet, while it has become increasingly difficult to recruit and retain professionals in this critically important field, one disability service organization has developed a business model that is able to provide a robust salary and benefits package.



from the Council Executive Director ■

# ADVOCACY AND ENGAGEMENT

*Positive Changes Within Our System Begin With You*

The single most important function of the New Jersey Council on Developmental Disabilities is advocacy for and about people with intellectual and developmental disabilities (I/DD). And the single most important part of advocacy is engagement in what is going on around us, and in the disability community.

We are living in challenging and uncertain times in our Country. As we've witnessed in recent weeks, a bill was stalled in Congress which would have made drastic and, we think, damaging changes to the Medicaid system, which is the life blood of supports for people with disabilities. Prior to that, a number of staff and Council members went to the 2017 Disability Policy Seminar in Washington, DC, and had the opportunity to express our points of view on the issues involved with New Jersey's Representatives in Congress. As an aside, you would have been very impressed to see the work that Stephanie Pratico, our Chair, and Chris Miller, our vice-Chair did while in Washington. They were both very skilled as we worked with our elected leaders and their staff.

Fortunately, the bill in question was pulled at the last minute because of a lack of support. I believe that through strong advocacy by advocates, family members, and people with I/DD, we were able to have a powerful effect on New Jersey's representatives.

The threat of cuts to Medicaid and other vitally important programs for individuals with I/DD, however, is not gone. We will need to continue to work on proper structure and funding in Medicaid for years to come.

At the same time, we continue to work on the crisis in direct support staffing in our community programs. Families, self-advocates, and providers continue to have a very difficult time finding support staff, primarily because of the very low wages that we pay in community programs. We must continue to work together to ensure that direct

support professionals are able to get a living wage for the work they do. This is a crucial issue, which affects our entire system, and must be solved in order to keep our system in a sound condition.

New Jersey continues to experience wide ranging change in the various systems that support people with developmental disabilities. While much of this change is needed to keep up with funding structures that support the system, self-advocates and families must be actively involved in helping to decide where the system goes, and how it functions. The process of change will continue, and we all need to be actively involved.

The Council also continues to work on a variety of other issues in employment, housing, education, transportation, and health care. There are critical developments all of these areas, and we must strive to be involved as a united disability community.

What draws all of these wide ranging efforts together? Engagement. We must be engaged as a community in all of the critical issues that we face daily. If you don't belong to an advocacy group, join one. If you don't have an advocacy group in your area, start one. If you haven't written your State or Federal representatives recently, sit down and write a letter today. If you haven't expressed your opinion to the people who manage our support systems, sit down and write a letter today.

Our engagement in improving and growing the system of supports for people with disabilities will be a key factor in the future direction of these supports. Get involved, and get involved today.



—Kevin Casey  
Executive Director  
NJ Council on Developmental Disabilities

## What's Your Advocacy? Save The Date for our Next Conference



Over 120 advocates joined us for our first What's Your Advocacy conference on January 21, 2017

On Saturday, January 21, at the Crowne Plaza in Monroe Twp., the NJCDD held its first of a series of developmental disability advocacy seminars entitled "What's Your Advocacy." More than 120 developmental disabilities advocates joined us to learn more about how to effectively speak out for their rights and needs and the rights and needs of their loved ones; as well as to identify the issues and advocacy goals that are most important to people with developmental disabilities in New Jersey.

Here are some of the topics on which advocates would like to focus in the near future:

### **On the National and State Level**

- Living Wages for DSPs
- Special Ed./ The Individuals with Disabilities Education Act (IDEA)
- Healthcare Reform
- Medicaid
- Transportation
- Voting
- Accessibility
- Cultural Awareness
- Closing Institutions

All comments can be sent to the NJCDD's Communications Manager,  
Jonathan Waller, at [jonathan.waller@njcdd.org](mailto:jonathan.waller@njcdd.org)

## On the Local Level

- Inclusive Recreation Programs
- Family-friendly guides to working with DDD/DHS
- Accessible Voting Locations
- High School Transition Plans/Services
- Job/Vocational Training
- Holding Agencies Accountable
- More Advocacy Training
- Anti-Bullying

The NJCDD is now planning our next advocacy training seminar, which will take place on Saturday, August 19 at the Hyatt Regency

Princeton from 8:30am to 3:30pm (registration begins at 8:30am, conference begins at 10am).

For this next event, we'll be partnering with the Alliance Center for Independence and the *Rev UP! New Jersey* campaign to prepare New Jersey residents and their families for voting, speaking up to their elected leaders, and participating more fully in our democracy. This day-long event will feature several guest speakers, fun and informative learning exercises, and more!

Be sure to save the date, and watch out for more details, which will be released in the weeks and months ahead. You may also contact the NJCDD's Disability Specialist, Dennie Todd at [dennie.todd@njcdd.org](mailto:dennie.todd@njcdd.org) for information and to reserve your seat for the conference. We hope to see you this August!

## Franklin School Honored for Recognizing Students With Disabilities

From: The Roxbury Register — March 13, 2017

For the second consecutive year, the grades K-4 Franklin Elementary School has won the Developmental Disability Awareness Bulletin Board Student Contest for the elementary category for Developmental Disability Awareness Month sponsored by the Arc of New Jersey.

Gail LaCosta, guidance counselor, and Alyssa Maksymiv, special education teacher at the school attended a recognition event at the State House in Trenton on Monday, March 6, to formally accept the award for first place in the elementary field, according to a release issued by the K-12 district.

Third and fourth grade students at Franklin were invited to design a bulletin board and/or video that illustrates the students' acceptance of all people with this year's theme of "It Matters to Me".

LaCosta said, "Students were inspired to create the bulletin board because the inclusion of students with all disabilities is very important to all of us at Franklin School."

Franklin has several special education classes and the students and staff do their best to make sure all of the students are included, according to the district.

Students in these programs are included in the general education classroom several times throughout the day.



Accepting the award are guidance counselor Gail LaCosta (left) and special education teacher Alyssa Maksymiv (right)—*Photo courtesy of the Roxbury Register*

“We believe that learning about different disabilities, spreading awareness and acceptance is a huge part for having a fun and safe school for everyone,” shared LaCosta.

All eight classes were given their own developmental disability to discuss and learn about as part of this bulletin board contest. Each class then decorated a balloon with that disability for the bulletin board. The theme was incorporated by using a celebration theme.

“When asking students about ideas for showing something that matters, they expressed that when things matter we celebrate them. Birthdays matter, so we have parties. Holidays matter, so we have parties. When our football team wins, we celebrate. From there we brainstormed ideas and the students and staff came up with the idea of celebrating what students with disabilities can do, so we camouflaged the dis in disabilities. So that at a quick glance our bulletin board says we celebrate abilities”, explained LaCosta.

National Developmental Disabilities Awareness Month is an opportunity to promote respect for people with intellectual and developmental disabilities (I/DD) and to educate others on the spectrum about the abilities people with I/DD possess.

## New Changes for the NJCDD Staff

The NJCDD is happy to announce some changes among our staff. Frank Latham, formerly the Coordinator of our Youth Leadership Project and Lead Presenter for our Anti-Bullying and R-Word Campaigns, has stepped into a new role as Grants Manager. In this new role, Frank will oversee all of the NJCDD’s grant programs and will support the NJCDD Grants Committee as they select new grant recipients each year.

The NJCDD’s People First New Jersey Coordinator, Jaymes Brill, will now also manage our Youth Leadership Project and will begin to assist Frank in visiting schools and community groups to provide presentations on Anti-Bullying and the R-Word, eventually taking on the role as Lead Presenter for these campaigns.

We hope you’ll join us in congratulating both Frank and Jaymes as they transition into these new roles.

# PBS To Broadcast Autism Documentary

By: Shaun Heasley

From: DisabilityScoop.com — March 10, 2017

The sensory experiences of people on the spectrum take center stage in a new documentary set to air on television.

In what the film’s creators say is a first, “Spectrum: A Story of the Mind” looks at autism through the lens of taste, smell, touch, sight and sound.

“This film goes beyond awareness into acceptance,” said producer Jill Jones.

“Our society often mistakenly views people on the spectrum with fear, as lacking empathy. We explore worlds where lights, sounds, colors

affect behavior hoping to educate and inspire empathy from neurotypical people,” Jones said.

Using live action and animation, the documentary tells the story of autism from the perspective of various people on the spectrum including renowned self-advocate Temple Grandin as well as a nonverbal poet and author, a painter and a martial artist.

The 23-minute film, which premiered in 2015 at the United Nations as part of the International Day of Persons with Disabilities, first aired on April 4 on PBS stations across the country.

New Jersey Council on  
Developmental Disabilities

NJCDD



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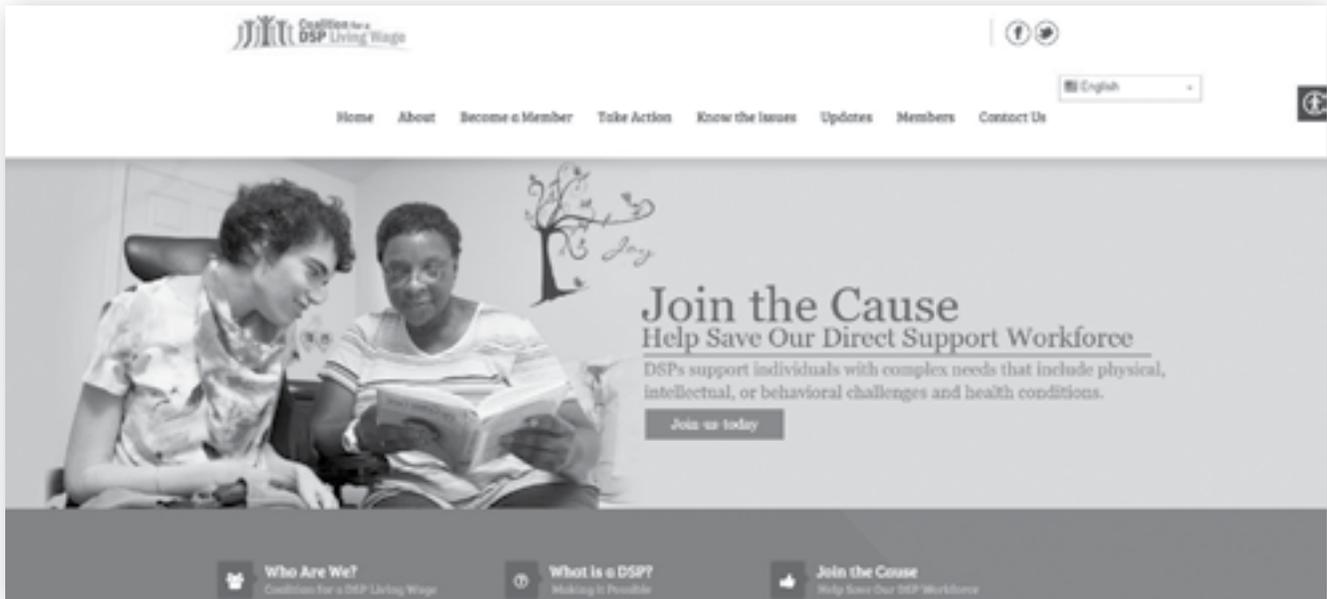


Stay informed on important  
developmental disability news from  
around our state



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

# DSP Coalition Launches New Website



Join with developmental disabilities advocates and organizations to push for a living wage for DSPs. Visit the website at [www.njdspcoalition.org](http://www.njdspcoalition.org).

The NJCDD is proud to be a supporting member of the newly-formed Coalition for a DSP Living Wage. This coalition of developmental disabilities advocacy organizations, individuals with developmental disabilities, and family members is committed to pushing for increased wages for Direct Support Professionals.

The Coalition for a DSP Living Wage is excited to announce the launch of our new website: [www.njdspcoalition.org](http://www.njdspcoalition.org).

What does the website offer?

- Information about the Coalition and the role of a Direct Support Professional in the lives of people with I/DD
- News and updates about our ongoing work and the steps we're taking to promote our cause
- Ways for you to get involved and help us advocate

Please visit the Coalition's website soon to find out how you can join the cause.

## Background Information

Direct Support Professionals assist and support people with intellectual and developmental disabilities. Although they provide critical tasks that allow for community integration, the average starting salary for a DSP is only \$10.50 an hour.

Because of this low wage, provider organizations and families who seek to hire DSPs to care for their loved ones have a very hard time finding and retaining staff. Service provider agencies report a remarkably high turnover rate of approximately 44% and staff vacancy rates of more than 20%.

If nothing is done to address this issue, the workforce shortage will continue and individuals

with I/DD may lose the very important services they rely on.

To ensure that a fully-staffed delivery system for people with I/DD in New Jersey is created and maintained, DSPs must be paid a living wage.

Toward that end, funding must be allotted to raise DSP salaries by \$1.25 per hour every year for five years, starting in Fiscal Year 2018. It is the State's responsibility to assure services are not negatively impacted by a workforce shortage.

With this in mind, we urge the Legislature to add \$36 million to the FY18 Budget, which will trigger matching funds from the federal government via Medicaid, to increase wages to all Direct Support Professionals. This is a necessary step to ensure services continue, without interruption, to those who need them most.

Without a robust and dependable workforce, individuals with intellectual and developmental disabilities and their families may not receive the services they require.

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## Community Care For Disabled Adults to Continue Through Fiscal 2021

By: Lilo H. Stainton

From: NJSpotlight.com — April 6, 2017

The federal government has given New Jersey the go-ahead to expand and reform work it has done over the past 45 years to provide community-based services to adults with serious disabilities to help them avoid institutional living.

Disability advocates welcomed the news that federal funding would continue to pay for critical non-medical services that enable individuals to live independent, productive lives. But they raised concerns about the state's plan to change the way it pays those who provide these critical services, which they fear could lead to gaps in care.

The state's Department of Human Services announced Friday that the federal Centers for Medicare and Medicaid Services had signed off on New Jersey's Community Care Waiver (CCW), renewing the program through June 2021. The program covers services for some 11,000 residents with intellectual or developmental disabilities and

over age 21 and had been operating on a temporary extension since 2013.

Approval of the CCW program, which dates back to 1982, allows the state to continue spending Medicaid dollars on technology, transportation, and other support services that let individuals with significant needs live at home or in community settings, instead of at an institution. Without the waiver, these funds could only be used to help institutionalized individuals.

Although they address similar goals, this waiver is not tied to the larger Comprehensive Medicaid Waiver that the state will soon submit to the CMS for extension. That request seeks permission to spend Medicaid dollars on long-term care for individuals with disabilities or the elderly, supports a shift to managed behavioral care, and streamlines eligibility for NJ FamilyCare, among other changes.

Joe Young, executive director of Disability Rights New Jersey (DRNJ), said both waivers have been essential to helping those with disabilities live, and thrive, outside of institutional settings. It also underscores the importance of protecting Medicaid, he said, which is being eyed for reform by some Republicans in Washington, D.C. as they seek new ways to repeal and replace the Affordable Care Act.

“It is an example of how Medicaid is so much more than just medical services,” Young said. “Any reduction in the Medicaid program seriously threatens the ability of large numbers of individuals with disabilities to have engaged and productive lives in the community.”

New Jersey officials said the CMS decision on the community care program also enables the state to launch payment reform; starting in July, the Division of Developmental Disabilities will begin to reimburse providers, who are now paid through contracts, on a fee-for-service basis.

This change will also allow the division to use Medicaid to cover a wider range of services for this population, which will bring the CCW benefits in line with those offered under the existing comprehensive waiver, officials said. The new options include behavior support; career planning; occupational and physical therapy; and speech, language, and hearing therapy.

“This approval sets in motion New Jersey’s ability to enhance the CCW’s programming, maximize federal funding for additional services, and provide to participants a broader range of opportunities and options that meet their needs,” DHS Acting Commissioner Elizabeth Connolly said.

Assistant Commissioner Elizabeth Shea, who oversees the division, agreed the CCW waiver was good news for those the division serves. “Clients and their families have been awaiting this waiver renewal eagerly and we all look forward to the benefits they will be able to access.”

Governor Chris Christie has championed state efforts to shift individuals with disabilities

and mental illness from state institutions to community centers, and shuttered several state-run facilities in the process. He has anticipated nearly \$550 million in federal Medicaid dollars for the CCW program in fiscal year 2018, which begins in July, some \$40 million more than in the current budget and \$100 million more than was spent in fiscal 2016.

While a shift from state contracts to fee-for-service payments has caused significant concerns for some behavioral health providers, who are involved in their own reform process, the DHS said providers of services to the disabled community are OK with the change. The state has been working with them to help prepare for this transition.

But DRNJ’s Young said advocates and other stakeholders will be watching this payment reform closely to ensure clients aren’t left short. The transition could make the system more precarious,” he said. “While New Jersey should continue to seek to maximize federal participation in cost reimbursement, we are concerned that there could be significant service gaps without access to state funds when needed.”

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# NJ Lawmakers Hear Pleas For Money in Christie Budget As Many Fear Trump Cuts

By: Samantha Marcus

From: NJ Advance Media — March 15, 2017

Under a cloud of concern over anticipated federal spending cuts—to environmental protection, Medicaid payments and women’s health—the Assembly Budget Committee heard appeals from groups for more aid to be included in the next state spending plan.

About a half dozen groups representing people with disabilities, among many others at the Statehouse speaking for schools, women’s health and mental health and addiction services, appeared before the panel to ask for more money in the budget for the fiscal year beginning in July.

Gov. Chris Christie introduced his proposed budget last month, beginning the long march to adoption of a spending plan in June. These groups come before the Senate and Assembly budget committees in a series of hearings in hopes of inspiring lawmakers to take up their cause.

Advocate Paul Blaustein told the committee that direct care workers for agencies under contract with the state bathe, dress and feed people with developmental disabilities, but that often their wages are insufficient to support their own families.

Blaustein asked the panel for a \$36 million boost to contracts with agencies providing services to people with developmental disabilities. Those workers earn a starting salary of \$10.50 an hour, and wages have been stagnant for nearly a decade, he said.

“Our most vulnerable persons with developmental disabilities depend upon their direct care workers for personal care 24 hours a day, seven days a week,” said Blaustein, the president of the Family Support Coalition of New Jersey and father of a 39-year-old man with developmental disabilities. “These services are not frills.

Our children’s very existence, their health and well-being, are totally dependent upon direct care workers.”

But flat wages have made it difficult for agencies to recruit and retain support professionals, creating a workforce “crisis,” advocates said. Their request, combined with a \$36 million federal match, would allow agencies to raise wages \$1.25 an hour. Advocates said it’s part of a plan to gradually increase starting pay to \$15 an hour.

But they and Democratic lawmakers expressed concern the GOP-backed proposal to replace the Affordable Care Act would jeopardize the matching funds even if Christie and lawmakers agreed to put up additional money.

Representatives from Planned Parenthood of Northern, Central and Southern New Jersey asked the panel to restore \$7.5 million in grants for women’s clinics he eliminated after taking office in 2010.

Former Supreme Court Chief Justice Deborah Poritz opened the hearing by fighting a \$5 million cut to legal aid services, from \$16.1 million to \$11.1 million.

The nonprofit’s 192 attorneys opened more than 45,000 cases last year on behalf of more than 120,000 clients who otherwise could not afford a lawyer. A \$5 million cut in state funding would translate to 5,000 fewer cases next year.

“These people will have nowhere else to go for help,” she said. “Without lawyers to protect them, people living in poverty cannot stop an improper eviction that will leave their family homeless. They cannot block an illegal foreclosure that stems from a predatory lending practice. They cannot access the protections of New Jersey’s strong statutory shields against domestic violence and sexual assault.” **P&F**

## UPCOMING EVENTS

*The NJCDD, in partnership with the Alliance Center for Independence  
and the RevUP! New Jersey campaign, presents*

### **WHAT'S YOUR ADVOCACY SAVE THE DATE**

**Saturday, August 19, 2017**

**8:30am to 3:30pm**

*(Registration Begins at 8:30am; Conference Begins at 10:00am)*

**Hyatt Regency Princeton  
102 Carnegie Center Drive  
Princeton, NJ 08540**

**This Event Is Free to All Advocates and Families**

*Continental Breakfast and Lunch Provided*

**Information about speakers and activities coming soon**

**Contact NJCDD Disability Specialist Dennie Todd for further information  
and to reserve your spot: [Dennie.todd@njcdd.org](mailto:Dennie.todd@njcdd.org)**

**RSVP Deadline: Monday, August 14, 2017**

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### **NJCDD COUNCIL MEETING**

**Thursday, May 25, 2017**

**10:30am to 2:00pm**

**Hyatt Regency Princeton  
102 Carnegie Center Drive  
Princeton, NJ 08540**

*If accommodations are required, please contact  
the NJCDD offices at 609-292-3745*

**At this meeting, the NJCDD will issue a final vote on Grant projects for FY-2017.  
Successful grantees will be announced on Friday, May 26.**

# Disability Policy Recommendations for the New Administration

## An Overview

By Jonathan Jaffe



## CONSORTIUM FOR CITIZENS WITH DISABILITIES

The Consortium for Citizens with Disabilities (CCD), the largest coalition of national organizations supporting federal policies for 56.7 million Americans with disabilities, has issued its recommended priorities for the new President and Congress.

CCD, headquartered in Washington, D.C. and comprising about 100 professional organizations, is squarely focused on supporting the goals of the *Americans with Disabilities Act* (ADA): equality of opportunity, full participation, independent living, and economic self-sufficiency.

“This transition document was written to convey to the Trump Administration the major issues facing people with disabilities and their families and CCD’s recommended solutions,” explained Kim Musheno, CCD Chair, of the Association of University Centers on Disability in Silver Spring, MD.

“This document is intended as a resource to the Trump transition team and policymakers,” she added. “We encourage you to use it to understand

the policy issues facing people with disabilities and their families.”

CCD envisions a society in which people with disabilities exercise their full rights and responsibilities and are empowered to participate in and contribute to society to the full extent of their abilities.

For the CCD, the focus is community integration. Federal lawmakers should work together to develop new ways to encourage affordable and accessible housing, as well as transportation, enabling people to live independently, as opposed to an institution. Health care, education, job training, and supported employment are also integral to the ultimate goal of full inclusion.

There is plenty for Washington lawmakers to talk about. As the Trump Administration works to enact its agenda and receive approvals from Congress, CCD has detailed key issues:

- **Maintain and expand vital programs:** CCD opposes any attempts to cut benefits, funding, eligibility, insurance coverage, or supports and

services under any of the vital programs that provide supports to people with disabilities and their families. CCD is also against any attempts to weaken or undermine the laws that guarantee the civil rights of people with disabilities.

- **Don't cut funding to federal programs:**

CCD believes the *Affordable Care Act* and the current financing structures of Medicaid and Medicare must be maintained. No changes should be made to eligibility requirements for Social Security Disability Insurance and Supplemental Security Income programs.

- **Presidential appointees should have a disability perspective, especially in the Office of Public Engagement and Domestic Policy Council:** These individuals should embrace national policy that calls for full inclusion, independence, empowerment, and integration of children and adults with disabilities into every sector of our society. Moreover, these constituents should be actively recruited for leadership positions, including appointments to Cabinet, Secretarial, and judicial positions.

CCD also urges the Trump Administration to have a designated disability liaison in the White House Office of Public Engagement and to appoint a disability policy advisor to the Domestic Policy Council.

The CCD drills down into many key areas in its transition report, including:

## EDUCATION

Providing students with disabilities inclusive educational opportunities with high expectations and access to rigorous coursework is directly linked to better employment. There is obvious work to do: In the 2013-2014 school year, the graduation rate for all students reached an all-time, new high of 82 percent nationally. The graduation rate for students with disabilities, however, was 64 percent.

## EMPLOYMENT & TRAINING

According to the CCD, people with disabilities want to be able to work and become taxpayers to achieve the American dream just like anyone else, but face many barriers in getting and keeping employment. Unfortunately, only two out of

10 adults with disabilities have jobs in the U.S., according to the transition document. The new Administration must work to educate, encourage, and assist employers to hire people with disabilities, while making the federal government a model employer.

## FINANCIAL SECURITY

In 2014, people with disabilities were more likely to be without bank accounts, unable to cover monthly expenses, and dependent on non-banks for borrowing, further increasing debt, reports the National Disability Institute. Moreover, one in three Americans with a disability lives in poverty and many have difficulty navigating federal disability programs. Asset limits in programs such as Medicaid and Supplemental Security Income (SSI) further constrain people's ability to save and plan for the future.

CCD is calling to strengthen SSI and adoption of the *ABLE Age Adjustment Act*. Many individuals now prevented from participating in ABLE programs due to the age of onset of their disability had devoted years of advocacy to pass the law. Under the program, people with disabilities can establish special accounts where they can save up money without jeopardizing Social Security and other government benefits.

## FISCAL POLICY

The CCD is calling for the federal budget to be balanced without detriment to people with disabilities, for whom government services and supports are vital to remain healthy, employed, educated, and independent in their communities. The coalition also urges the Administration to oppose a Constitutionally-balanced budget amendment and other proposals that would adversely affect funding for programs for people with disabilities.

Changes in entitlement programs on which people with disabilities depend for their health, long-term supports, and income security as their lifeline, such as Medicaid, Medicare, Social Security, Supplemental Security Income, and veterans' disability compensation and pension benefits, must not result in reduced access to needed services.

## HEALTH

People with disabilities have diverse, complex health care needs that make access to health care imperative. The government must protect Medicaid from drastic cuts and structural changes, and expand the Medicare benefit to include all necessary services. The Children's Health Insurance Program (CHIP) must continue, with full implementation of the mandated Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. CCD also wants to maintain and build on the success of the *Affordable Care Act*, as well as other health care access laws.

## HOUSING

People with disabilities have historically faced a severe crisis in the availability of decent, safe, affordable, and accessible housing. Today many still live in large congregate facilities or other inappropriate, expensive places, like institutions.

According to *Priced Out* in 2014, the 4.9 million non-elderly, non-institutionalized Americans with disabilities who rely on monthly Supplemental Security Income (SSI) averaging \$750 for their basic needs would be required to pay up to 104 percent of their SSI benefit if they wanted to rent a modest one-bedroom apartment. This finding confirms that, in 2014, it was virtually impossible for an adult receiving SSI to obtain decent and safe housing in the community without some type of rental help.

CCD is calling for vigorous enforcement of all fair housing and civil rights laws, as well as increased funding for Section 8 Housing Choice Vouchers targeted to non-elderly individuals with disabilities, among other initiatives to allow all people to live affordably in the community.

## LONG-TERM SERVICES AND SUPPORTS (LTSS)

LTSS encompasses a broad and complex range of medical care and assistance with activities of daily living for people with disabilities. Medicaid, as the nation's largest public funder of LTSS, helps millions of individuals with disabilities and

## ABOUT CCD

The Consortium for Citizens with Disabilities is a Coalition of national consumer, advocacy, provider, and professional organizations headquartered in Washington, D.C. Since 1973, the CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

## VISION

The Consortium for Citizens with Disabilities (CCD) envisions an American society in which all individuals, aided by an enabling government, have the freedom and opportunity to exercise individual decisions concerning their own lives, welfare, and personal dignity.

CCD envisions a society in which communities are fully accessible to all individuals with disabilities and their families, where they are included and fully participate in all aspects of community life.

In CCD's vision of society, individuals with disabilities exercise their full rights and responsibilities.

## MISSION

To achieve this vision the CCD engages in advocacy efforts for national public policy that:

- Ensure the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society
- Enhance the civil rights and quality of life of all people with disabilities and their families
- Reflect the values of the *Americans with Disabilities Act*

seniors. Further cuts would force people with disabilities into institutions and increase the unnecessary use of expensive emergency room care, CCD states.

## RIGHTS

Ensuring that people with disabilities have access to legal representation to protect their rights is critical. The federally mandated Protection and Advocacy Systems and the Client Assistance Program network are the largest providers of legal advocacy services to people with disabilities in the United States and must be preserved.

Besides the *Americans with Disabilities Act*, CCD also wants to preserve the *Rehabilitation Act of 1973*, which, in part, requires affirmative measures to employ people with disabilities—by the federal government and by large federal contractors. The federal government plays a key role in implementing and enforcing these obligations, which are critical to improving the employment rates for people with disabilities. Currently, the employment rate for people with disabilities is less than half of that for people without disabilities, CCD notes.

## SOCIAL SECURITY

Social Security disability and SSI cash benefits, along with the related Medicaid and Medicare benefits, are the means of survival for millions of people with severe disabilities.

These are programs of last resort with extremely strict eligibility rules. But they allow people with the most significant impairments to live independent lives with a measure of economic security. Social Security benefits are modest by most standards, but play an important role in reducing poverty among people with disabilities and their families.

CCD wants to ensure the impact on people with disabilities is considered in the ongoing Social Security and SSI policy debates on Capitol Hill. Moreover, the Social Security Administration (SSA) must have sufficient funding to make disability decisions in a timely manner and to carry out other critical workloads.

The CCD urges the Trump Administration to oppose proposals to cut Social Security or SSI benefit; to restrict eligibility; to narrow who is insured for Social Security; or to privatize, block grant, or otherwise alter the basic structure of these essential systems.

## TECHNOLOGY AND TELECOMMUNICATIONS

As more of American civic and economic life is served online and through technological means, the ADA dictates individuals with disabilities must have equal opportunity to participate in all aspects of society. That includes equal access to the Internet.

The CCD believes numerous statutes that include technology provisions for people with disabilities have not been fully implemented, or need revision and updating in light of new technologies or medical coding practices.

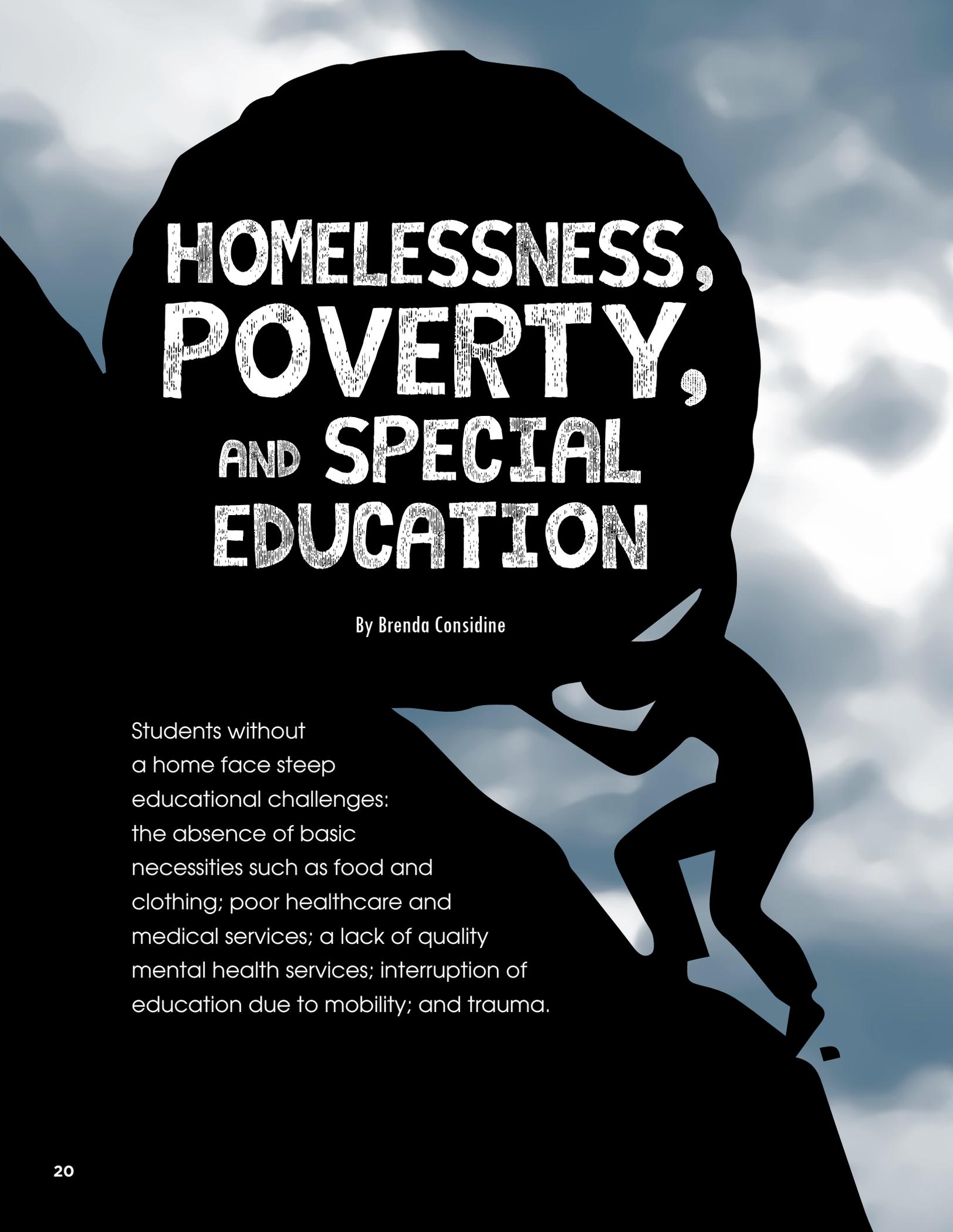
## TRANSPORTATION

The CCD supports continued funding for enhanced transit, which also allows many people with disabilities to be mobile and maintain their independence. Although all public transit programs are important, programs supporting rural and smaller communities are greatly needed to allow access to public transit for people with disabilities.

In many communities in America, there remains a lack of emergency management planning for the safe removal and first aid for people with disabilities in public transportation. Other suggestions: Bike sharing, promotion of self-driving cars, and ensuring the Transportation Security Administration works with disability advocates to improve policies at airports and on flights.

Organizational members of CCD include self-advocacy groups as well as consumer, provider, advocacy, and professional organizations. CCD has advocated on behalf of people of all ages with physical, mental, and sensory disabilities and their families since 1973. To download the full report, or to learn more about the CCD, please visit:

[www.c-c-d.org/fichiers/CCD-Transition-Memo.pdf](http://www.c-c-d.org/fichiers/CCD-Transition-Memo.pdf) **P&F**



# HOMELESSNESS, POVERTY, AND SPECIAL EDUCATION

By Brenda Considine

Students without a home face steep educational challenges: the absence of basic necessities such as food and clothing; poor healthcare and medical services; a lack of quality mental health services; interruption of education due to mobility; and trauma.

Poverty presents many challenges, but perhaps none is more threatening to a child than attempting to live and go to school without a place to call home. According to data from the U.S. Department of Education and the U.S. Census, 2.5 million children were homeless in 2013—one in every 30 children in the country. In New Jersey, the National Center on Family Homelessness counted nearly 17,000 homeless children during the 2012-13 school year, a 78% increase from the previous year. While shocking, the report's numbers rank New Jersey as second in the nation, ahead of 48 other states.

American children had rarely been homeless in significant numbers, other than during the Great Depression. Things changed in the mid-1980s as child homelessness began to garner attention as a major social problem. While progress has been made to reduce homelessness among single adults and military veterans, the number of homeless children has been growing steadily by roughly 8% a year and is now at its highest level ever.

Students without a home face steep educational challenges: the absence of basic necessities such as food and clothing; poor healthcare and medical services; a lack of quality mental health services; interruption of education due to mobility; and trauma. *Disabled World*, an online resource, reports that nearly 20% of these children do not attend school, and suffer higher rates of acute illness, causing them to miss school.

Evidence suggests that homeless children experience a disproportionately high rate of disabilities. When compared to children who are not homeless, twice as many students with learning disabilities and three times the number of students with behavioral and emotional problems are homeless.

The first challenge is identification. The effects of homelessness can mirror challenges faced by students with learning disabilities, intellectual

disabilities, autism, emotional disturbances, behavioral disabilities, and speech or language impairments.

Once identified, homeless students with disabilities still face added barriers. They may not be diagnosed in a timely manner due to mobility and other stressors; they struggle with a lack of continuity of services due to school transfers and may lack timely or efficient records transfer when enrolling in a new school. Some may face language barriers. And often, these children lack an available parent or surrogate to advocate on their behalf.

According to a 2014 report issued by the National Center on Family Homelessness, 24% to 40% of homeless school-aged children were found to have mental health problems requiring clinical evaluation—two to four times the rate of other low-income children. Children who are homeless are found to need special education services at two or three times the usual rate.

Like homelessness, poverty is also tied to higher rates of disability. Nationwide, roughly 15 million children live in poverty. In New Jersey, that number is 308,000, or 16% of all children. But even children in families above the federal poverty threshold suffer adverse affects of poverty. In 2014, 31% of New Jersey's children—more than one in three—were living in households considered low income, a family of four living on less than \$48,000.

These data have important implications for special education. Students with the highest needs are often living in the poorest communities, many of which lack robust school-based services. A report issued by the U.S. Department of Education found that low-quality schools are disproportionately located in low-income areas, where quality special education services and supports may not be readily available.

With all the pressures facing schools in low-income communities, educators need to reach out



**Like homelessness, poverty is also tied to higher rates of disability. Nationwide, roughly 15 million children live in poverty. In New Jersey, that number is 308,000, or 16% of all children.**

for resources and assistance from agencies and community-based services.

The *McKinney-Vento Act*, a federal law which focuses on homeless children, and the *Individuals with Disabilities Education Act* (IDEA) lay out procedures that schools must follow to ensure that homeless children and those with disabilities are provided an appropriate education that meets their individual needs. The Child Find provisions of the *McKinney-Vento Act* require states to ensure that homeless children with disabilities are identified, located, and evaluated.

Each school district in New Jersey is required to have a homeless education liaison to track and advocate for students experiencing homelessness. That can be complicated because children and youth experiencing homelessness move a lot, and may try to keep their circumstances secret. The liaison is responsible for assisting homeless students and their parents or guardians with enrolling in school and accessing school services; obtaining immunizations or medical records;

informing parents, school personnel, and others of the rights of homeless students; working with school staff to make sure that homeless students are immediately enrolled in school pending resolution of disputes that might arise over school enrollment or placement; and helping to coordinate transportation services for homeless students. Translation services, if necessary, must be provided.

Education staff focused on children with disabilities need to work closely with homeless education liaisons in order to get to know newcomers and identify students in need of special education services. Often, the homeless liaisons can be included in IEP meetings for special education students. And because low-income families move twice as often as other families, school officials need to cultivate positive working relationships with other districts in order to exchange information.

On enrolling a new student who is homeless, school staff might get a better handle on whether that child has an IEP, 504 plan, or needs special education services with questions such as:

- “Did your child receive special instruction in the other school?”
- “Was your child in a class with just a few other students?”

Responses should indicate whether it might be appropriate to involve the school’s homeless liaison or special education coordinator.

Working with children in families who are homeless or live in poverty is one of many educators’ toughest challenges. The needs are great as schools work harder to collaborate with many stakeholders. By looking closely and getting to know individual needs early, dedicated professionals can help change the fates of some of New Jersey’s most vulnerable children.

*Editor’s Note: This article first appeared in the NJCDD’s Common Ground online newsletter, which highlights issues of importance relating to special education in New Jersey. Subscription to this valuable resource for parents, educators, and other special education professionals is free, and can be found at [www.njcommonground.org](http://www.njcommonground.org). P&F*

## RESOURCES

### **Excessive Stress Disrupts the Architecture of the Developing Brain.**

This working paper from the National Scientific Council on the Developing Child defines the concept of “toxic stress”—what happens when children experience severe, prolonged adversity without adult support.

[http://developingchild.harvard.edu/resources/reports\\_and\\_working\\_papers/working\\_papers/wp3/](http://developingchild.harvard.edu/resources/reports_and_working_papers/working_papers/wp3/)

### **From The National Center for Homeless Education (NHCE)**

Homeless Liaison Toolkit: the essentials that local liaisons must know in order to carry out their responsibilities. Seventeen chapters on topics essential to implementing the *McKinney-Vento Act*.

[http://center.serve.org/nche/pr/liaison\\_toolkit.php](http://center.serve.org/nche/pr/liaison_toolkit.php)

### **School Help for Homeless Children with Disabilities: Information for Parents**

[http://center.serve.org/nche/downloads/briefs/idea\\_parents.pdf](http://center.serve.org/nche/downloads/briefs/idea_parents.pdf)

### **Best Practices in Homeless Education Brief Series**

Navigating the Intersections of the *McKinney-Vento Act* and *Individuals with Disabilities Education Act*: Coordination to Help Homeless Children and Youth with Disabilities

[http://center.serve.org/nche/downloads/briefs/nav\\_idea\\_mv.pdf](http://center.serve.org/nche/downloads/briefs/nav_idea_mv.pdf)

### **Determining Eligibility for Rights and Services Under the *McKinney-Vento Act***

[http://center.serve.org/nche/downloads/briefs/det\\_elig.pdf](http://center.serve.org/nche/downloads/briefs/det_elig.pdf)

### **Prompt and Proper Placement: Enrolling Students without Records**

<http://center.serve.org/nche/downloads/briefs/assessment.pdf>

### **McKinney-Vento Law into Practice Brief Series**

Children and Youth Experiencing Homelessness: An Introduction to the Issues

<http://center.serve.org/nche/downloads/briefs/introduction.pdf>

### **Identifying Children and Youth in Homeless Situations**

<http://center.serve.org/nche/downloads/briefs/identification.pdf>

### **Supporting Homeless Children and Youth with Disabilities: Legislative Provisions in the *McKinney-Vento Act* and the *Individuals with Disabilities Education Act***

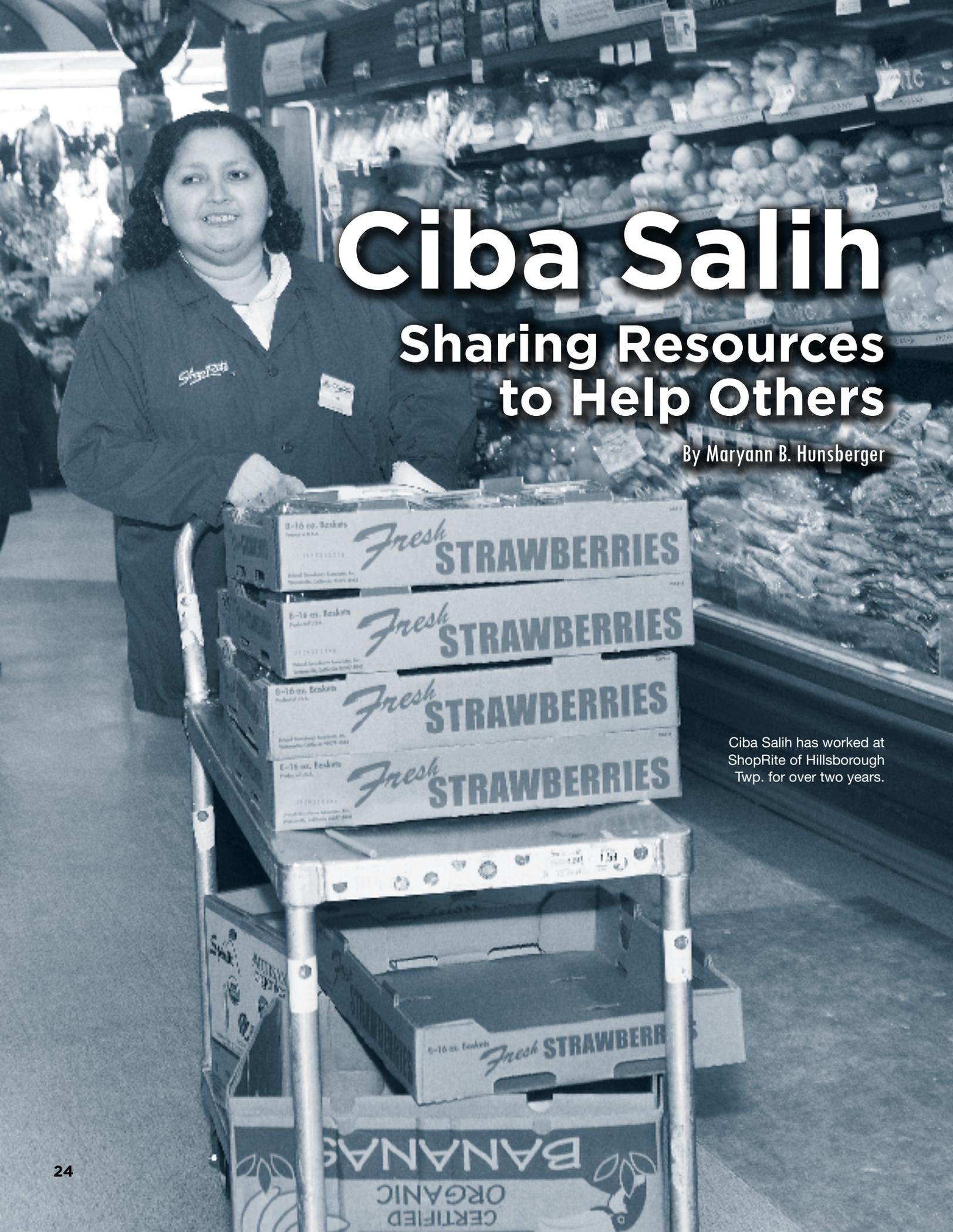
<http://center.serve.org/nche/downloads/briefs/idea.pdf>

### **From The National Law Center on Homelessness & Poverty**

Connecting Homeless Students to Special Education Services:

A Guide to Rights and Resources

<http://www.azed.gov/wp-content/uploads/PDF/ConnectingHomelessStudentstoSPEDServices.pdf>



# Ciba Salih

## Sharing Resources to Help Others

By Maryann B. Hunsberger

Ciba Salih has worked at ShopRite of Hillsborough Twp. for over two years.

**A**s Ciba Salih does her job at ShopRite of Hillsborough Township, customers and coworkers often notice her rotating the fruits and vegetables single-handedly. Inevitably, questions arise about why she doesn't use both hands. She tells people that during surgery to remove a brain tumor at age 5, she had a stroke that paralyzed her left hand. Salih has answered this question so many times that she decided to put her story into writing. As the years continue, she adds to her story when new things happen. She enjoys sharing her story with other people as a way of helping people to learn about life with a traumatic brain injury.

Salih gladly shared her story with *People & Families Magazine* so people with disabilities and their families can learn about the various supports she uses and perhaps find resources for themselves.

Salih, 31, lives in Hillsborough with her parents and sister. She attended special education classes at Hillsborough High School and remains friends with some of her classmates, even working with two of them at ShopRite. Whether at ShopRite or elsewhere in the community, she meets people with disabilities who need help. Her friends sometimes need assistance, too. "I help them find which agencies to call, what to ask for, what kind of services they need and what kind of services an agency can provide."

Salih has learned about available supports and resources from her own experience. She recounts with pride how she self-directs all of her services. Through research and perseverance, she has become involved with the Division of Developmental Disabilities (DDD) and the Division of Vocational Rehabilitation Services (DVRS). DDD found her eligible for self-directed services, which pays for her membership at the Hillsborough YMCA and continuing education classes at Raritan Valley Community College (RVCC). She has taken classes in painting, floral design, cooking, and accounting. She also earned a certification in Microsoft Office.

**RESOURCE:** Self-direction expands individual choice and control over services and supports needed in the community. Individuals who are eligible for self-direction will:

- Manage their services and supports
- Be assigned a budget based on their individual needs
- Be assigned a support coordinator to assist them
- Identify the members of their planning team
- Develop their own Individualized Service Plan (ISP)
- Work with a fiscal intermediary to manage their budget
- Hire, fire, and supervise their support staff
- Choose individualized services and supports based on their needs

For more information, individuals and their families should contact their DDD case managers.

Direct support professionals assist Salih in doing the activities she chooses to participate in. She currently has two assistants who take her out two days each week to run errands, to work out at the YMCA, to eat at restaurants, and to shop.

Christine Clause from Neighbours, Inc. serves as Salih's support coordinator. Clause has worked with Salih for six years, guiding her and empowering her to make her own decisions with input from Clause. Salih contacted Neighbours, Inc. on her own because she needed a case manager for her self-directed services. Salih has served as a peer mentor through the agency in the past, and Clause hopes to start a peer support group led by Salih and one of her assistants. Clause said in this way, Salih could talk to individuals, assist them in finding resources, and help them to advocate, while her assistant could handle the work



requiring good organizational and memory skills, such as invoicing and staff time sheets. “We help Ciba to work out her life as a whole. She loves to talk and is an amazing young lady. She is very persistent. If she wants something, she won’t stop until she gets it. She will call and email until she gets an answer. She is phenomenal with that. So, we want to help her to have more purpose to her life and improve her self-esteem.”

**RESOURCE:** Eligible individuals who want DDD-funded services must either select or be assigned to a support coordination agency. The support coordination agency assigns a support coordinator to work with the individual and family to ensure completion of the person-centered planning tool and to develop the Individualized Service Plan (ISP).

For more information, go to: [http://www.nj.gov/humanservices/ddd/services/support\\_coordination.html](http://www.nj.gov/humanservices/ddd/services/support_coordination.html)

Clause reached out to the Brain Injury Alliance of New Jersey (BIANJ) to request their help in teaching Ciba to self-direct. Joy Melendez, Director of Education and Outreach, has worked with Salih. “She came here and connected with our support coordination services. She is very independent, a self-starter, and a good self-advocate. She created her own resources and her own plan for her life.”

Melendez said Salih has been active in BIANJ’s vocational program at JFK Medical Center, learning skills to make her marketable. Salih enjoyed learning office skills at the vocational classes. “I tried to find office work, as it’s what I really wanted to do, but I got the job at ShopRite instead.”

Melendez explained that Salih continually empowers herself. For instance, she had always



Ciba learned to paint while attending Raritan Valley Community College. She’s taken what she’s learned and developed a steady hobby, painting flowers, nature, and birds.

been afraid of water, so she began taking swim lessons at the Hillsborough YMCA to overcome her fear. “She has conquered that fear now, and remains physically active through her swimming and working out at the Y. And she never forgets to give back by doing things like participating in our annual walk.”

Salih said her assistant walked with her that day. “It was so much fun to participate. It was on a Saturday morning, and I normally don’t like to wake up early on Saturday. But, I wanted to do this. I met some really cool people there. We had breakfast afterward. It was my first walk, and I’d like to do it again.”



She is hoping that Neighbours, Inc. will start the peer support group soon and is excited about the possibility of leading it with her assistant, Allison. The duo attended an advocacy conference held by the NJCDD in January, 2017 so Salih could learn how to be a better self-advocate and help more people in need of information about services.

Salih used DVRS’s job coaching services and then found her job at ShopRite through a friend. Her manager, Tim Stone, said she has worked there longer than he has. In the two years he has known her, she has proven to be an excellent employee. “I give her a task to do and she completes it. She is very customer oriented, always answering customer questions. She helps people pick out the best produce and helps them to find things. She’s great to have working here.”

She still uses the painting skills she acquired at college. “I paint flowers, nature and birds and bedazzle them as a hobby. I have painted on several surfaces, including wood. I’ve done this for several years. I painted this whole past weekend. I also paint whenever I am bored.” Her assistant takes her to Walmart to buy canvases and paint. As a special gift for her birthday, her sister paid for them to take a one-evening painting class together.

Melendez enjoys continuing to work with Salih. “It’s challenging with a brain injury, but her relationship with BIANJ helps her to live independently with a brain injury instead of looking at it as a setback in her life.” **P&F**

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Ciba works with several other people with disabilities, including Tom (pictured).

**RESOURCE:** Eligible individuals can obtain job coaching, skills training, and other services from DVRS. For more information, go to: [http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational\\_rehabilitation\\_services.shtml](http://careerconnections.nj.gov/careerconnections/plan/foryou/disable/vocational_rehabilitation_services.shtml)

Living with a brain injury affects Salih’s memory, but she finds that following a routine helps. Working out is part of that routine. “I like to keep physically active for my health and so I won’t be stuck at home every day. The trainer stretches my back out when it hurts.” She and her personal trainer use the machines and go for walks, concentrating on exercising her legs and her good arm. She also enjoys using her new aquatic skills by regularly swimming to the deep end and back.

She also goes to physical therapy for knee pain, taking Medicaid medical transport to ride there and back. She uses the exercise bike, weights, and stretches her leg.



# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

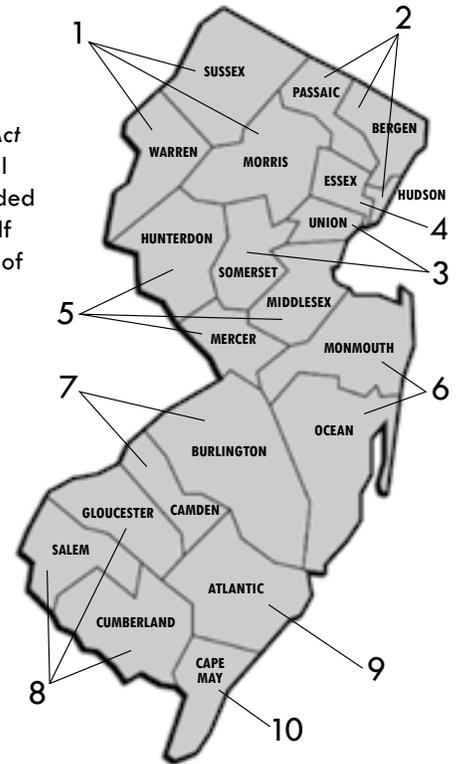
#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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

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

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

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



**For more information, Call the Statewide Family Support Coordinator Kyoko Coco at 609-341-3112 or email her at [kyoko.coco@njcdd.org](mailto:kyoko.coco@njcdd.org) Or visit our website at [www.njcdd.org](http://www.njcdd.org) and follow the link to Family Support.**

#### THE FAMILY SUPPORT ACT OF 1993

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

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

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

Visit the NJ Council on Developmental Disabilities' web site at: [www.njcdd.org](http://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**  
**PO Box 12**  
**Pompton Plains, NJ 07444**  
**e-mail: [rfspc1@gmail.com](mailto:rfspc1@gmail.com)**  
**Chair: Margaret Hefferle**

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

## 2 BERGEN, HUDSON, PASSAIC

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

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

## 3 SOMERSET, UNION

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

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

## 4 ESSEX

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

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

## 5 HUNTERDON, MIDDLESEX, MERCER

**RFSPC #5**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [rfspc5nj@gmail.com](mailto:rfspc5nj@gmail.com)**  
**Co-Chairs: Paul Blaustein, Cheryl Crick**

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

## 6 MONMOUTH, OCEAN

**RFSPC #6**  
**PO Box 76**  
**Lakewood, NJ 08701**  
**e-mail: [rfspc6-chair@excite.com](mailto:rfspc6-chair@excite.com)**  
**Chair: Mike Brill**

Meets the second Thursday of each month  
Lakewood Municipal Bldg.  
231 Third St., 2nd floor  
Lakewood, NJ 08701  
7:30 p.m.—9:30 p.m.

## 7 BURLINGTON, CAMDEN

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

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

## 8 CUMBERLAND, SALEM, GLOUCESTER

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

Meeting dates posted at [njcdd.org](http://njcdd.org)  
River Winds Community Center  
1000 Riverwinds Dr.  
West Deptford, NJ 08086  
6:00 p.m.-7:30 p.m.

## 9 ATLANTIC

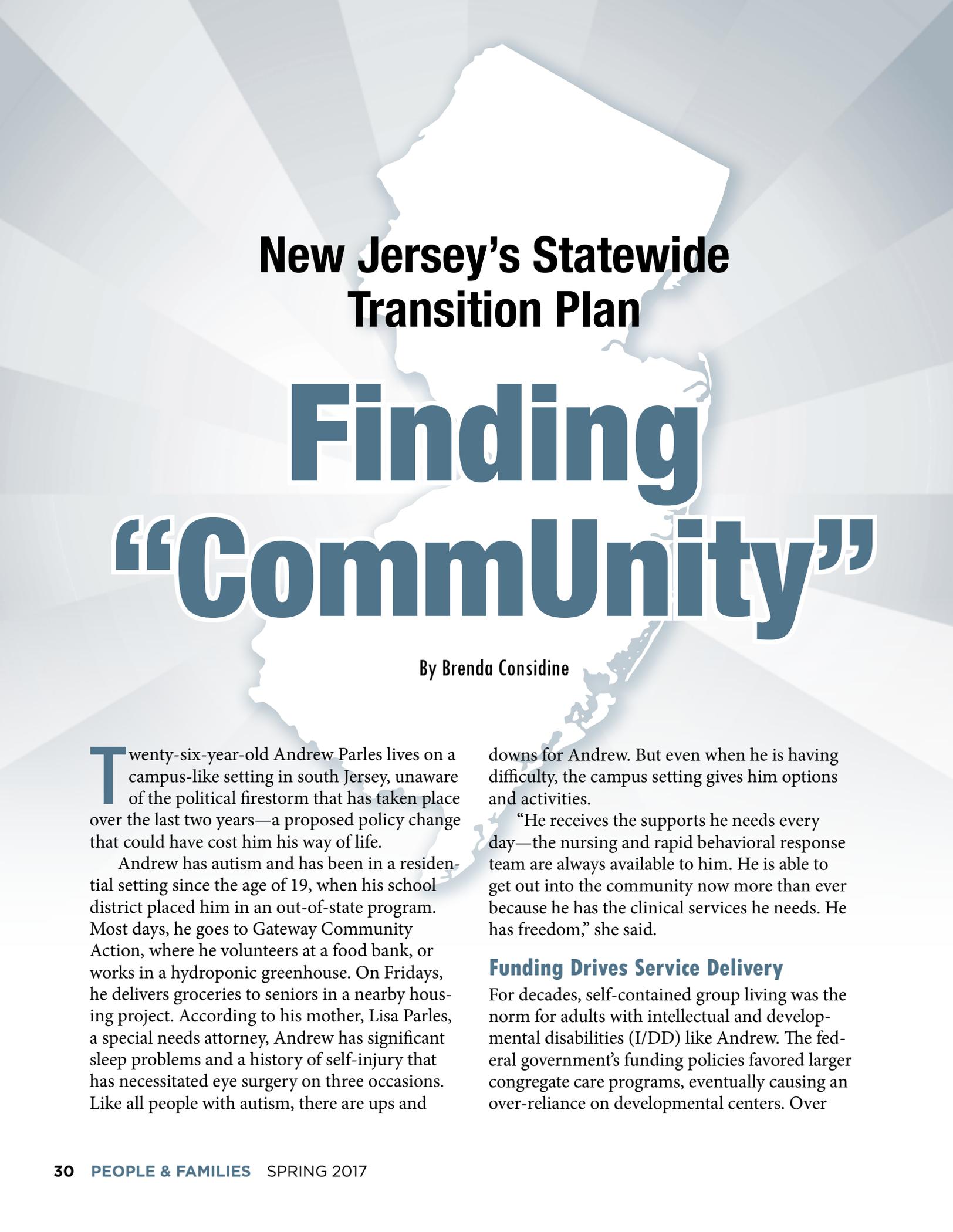
**RFSPC #9**  
**PO Box 700**  
**Trenton, NJ 08625**  
**e-mail: [RFSPC9@yahoo.com](mailto:RFSPC9@yahoo.com)**  
**Chair: Mary Ann Philippi**

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

## 10 CAPE MAY

**RFSPC #10**  
**PO Box 199**  
**South Dennis, NJ 08245**  
**e-mail: [RFSPC10@yahoo.com](mailto:RFSPC10@yahoo.com)**  
**chair: Anne Borger**

Meets the third Thursday of the month  
except for July, August, December,  
and January  
Cape May Special Services School  
148 Crest Haven Dr.  
Cape May Court House, NJ 08223  
Meeting times TBD



# New Jersey's Statewide Transition Plan

# Finding “CommUnity”

By Brenda Considine

**T**wenty-six-year-old Andrew Parles lives on a campus-like setting in south Jersey, unaware of the political firestorm that has taken place over the last two years—a proposed policy change that could have cost him his way of life.

Andrew has autism and has been in a residential setting since the age of 19, when his school district placed him in an out-of-state program. Most days, he goes to Gateway Community Action, where he volunteers at a food bank, or works in a hydroponic greenhouse. On Fridays, he delivers groceries to seniors in a nearby housing project. According to his mother, Lisa Parles, a special needs attorney, Andrew has significant sleep problems and a history of self-injury that has necessitated eye surgery on three occasions. Like all people with autism, there are ups and

downs for Andrew. But even when he is having difficulty, the campus setting gives him options and activities.

“He receives the supports he needs every day—the nursing and rapid behavioral response team are always available to him. He is able to get out into the community now more than ever because he has the clinical services he needs. He has freedom,” she said.

## Funding Drives Service Delivery

For decades, self-contained group living was the norm for adults with intellectual and developmental disabilities (I/DD) like Andrew. The federal government's funding policies favored larger congregate care programs, eventually causing an over-reliance on developmental centers. Over

the past 30 years—and pushed by the courts in response to substandard services, poor living conditions, and civil rights issues—federal funding rules have shifted, and now states are required to provide services and supports in smaller facilities and through programs that meet certain standards of care. Group homes, supervised apartments, and smaller community-based supports have become the norm.

In 2014, the Centers for Medicare & Medicaid Services (CMS) issued new rules for their Home and Community-based Care Waiver requiring services in the most integrated settings. The rules and guidelines discourage settings deemed to be isolating, such as disability-specific gated communities, farmsteads, residential schools, campus-like settings, and “intentional communities” where people can live, work, and play on the same property. In fact, CMS will not give pre-approval of new housing projects that fall into these categories unless they are fully operational.



Andrew Parles lives in a campus-like setting in South Jersey. There, he participates in the community while receiving supports for a number of significant care needs. His mother, Lisa, feels that a smaller group home would not be appropriate for her son.

## The Terms You Need to Know

**Centers for Medicare & Medicaid Services (CMS)**—CMS is the federal agency in Washington, DC that administers Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP).

**Medicaid**—The nation’s single largest source of health insurance, Medicaid is a joint federal and state program that provides health coverage to over 72.5 million children, pregnant women, parents, seniors, and individuals with disabilities. All individuals who receive services from the Division of Developmental Disabilities (DDD) in New Jersey must be Medicaid-eligible.

**Medicaid Expansion**—An option under the *Affordable Care Act* (ACA), the federal government pays a large percentage of the

cost of those added to the program. Opting in to this program has saved New Jersey \$500 million a year, according to New Jersey Policy Perspective.

**Statewide Transition Plan (STP)**—Required by the CMS, the STP describes how state systems of care will shift services and supports in order to comply with new Medicaid rules for Home and Community Based Services (HCBS).

**Home and Community-Based Services (HCBS)**—A waiver to Medicaid rules that allow beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs—more than 300 nationwide—serve a variety of targeted population groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.

## New Jersey's Statewide Transition Plan —The First Draft

In order to preserve Medicaid funding under the new rules, states are required to develop a Statewide Transition Plan (STP) to map the shift to a more community-based system of service. But in 2015, when the New Jersey Department of Human Services (NJ DHS) first released its STP for public comment, parents and providers reacted with panic and opposition. The plan was so extreme that housing advocate Tom Toronto, president of Bergen County's United Way, called it a "misguided social experiment."

According to Desiree Kameka, an advocate with the Coalition for Community Choice (CCC), New Jersey was one of the few states that opted to add more regulations than were required, and concluded that "the plan would have limited choices unnecessarily for citizens with disabilities."

New Jersey's STP initially focused on the concept of "density" by limiting group homes to no more than four people—under special circumstances, six; prohibiting funding for a person with disabilities living in a facility, farm, or campus for those with I/DD, or an apartment setting if more than 25 percent of the tenants already living there have disabilities. The plan withheld funding for recreational, vocational, and job support if the individual spent more than an hour or two each day—25 percent of their time—in a facility for people with disabilities.

### Community Response: Group Housing Is Not Institutional Living

Andrew's mother, Lisa Parles, was one of the first and most vocal opponents; her biggest concern was for those with more complex service needs. She and other advocates wrote letters, attended public hearings, created petitions, leveraged social media, and lobbied lawmakers in efforts to educate families and consumers about the issue. She argued that traditional four-person group homes cannot safely and successfully serve people on the autism spectrum who have more significant needs.

"Smaller group homes are inefficient and have staffing patterns that cannot always be responsive to challenging behavior issues. You have to consider the clinical needs of the person you are planning for. For someone [with the eating disorder, pica] who is eating plastic, direct line-of-sight supervision and staffing is not 'an invasion of privacy,' it is lifesaving!"

"Without a doubt, we have had a history in New Jersey of too many people living in developmental centers—people who wanted to get out. But now, we are swinging in the other direction," she said.

Toronto agrees.

"There is a wide space to operate that includes more dense housing projects without coming even remotely close the conditions of a developmental center," he said.

### Promoting Choice by Limiting Choices?

The fulcrum of the debate centered on the concept of "settings that isolate," and what that means in the lives of people with I/DD. CMS guidance suggested that "settings that isolate" are those that are designed specifically for people with disabilities, where the individuals served are primarily or exclusively people with disabilities. The guidance specifically discouraged settings designed to serve people with disabilities through an array of on-site services and activities: housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.

The CMS rules reflect an odd tension. They were, on one hand, limiting choice, and on the other, emphasizing choice, rights and protections, and person-centered planning.

"The definition of 'community' is a qualitative one, not a quantitative one," said Suzanne Buchanan, PsyD, BCBA-D, Executive Director of Autism New Jersey. "Someone living in an apartment in the community could be far more isolated than someone living in a group setting or in a planned community. It is such a value judgment."

"The aspect of choice in the new CMS guidelines is essential. If someone with autism wants to live with five other people who have autism, who are we to tell them that that is not OK?" she asked.

## Who Is Isolated and Lonely?

Data from the National Core Indicators reveal that feelings of loneliness among individuals with I/DD can occur in any setting. Surprisingly, those living in I/DD-specific institutional settings report the least loneliness (37 percent) while those in foster homes report the most (51 percent). Among those living in other settings, such as group homes, independent home/apartment, and family home, reports of loneliness hover between 40 and 43 percent.

“Concepts like ‘inclusion’ and ‘community’ are not about the setting—they are about the services and the supports—the way of life. There are a lot of qualitative issues that were left out of the equation in the first version of the STP,” concluded Buchanan.

Stephanie Pratico, the chairperson of the New Jersey Council on Developmental Disabilities wants choice and a range of options for all people, including her two children, both of whom have Trisomy 21.

“I would like to be able to honor my children’s choices in how they envision their adult life. Although my children have the same primary diagnosis, they are two very unique individuals with very different support needs as well as desires for adult life. This just goes to support the need for choice. I don’t think that a [limited] menu of choices can be developed,” she concluded.

While the NJCDD remains steadfast in advocating for the continued move toward full community inclusion in housing—as opposed to farmsteads or other campus-like settings—it cannot be denied that there are families and individuals who find these settings to be the most beneficial at the present time.

## Unintended Barriers

According to a paper published by the Coalition for Community Choice (CCC), a national organization promoting choice and expansion of housing options for people with I/DD, “*The state and federal government are using non-regulatory enforcement to restrict the use of one’s essential life supports and, in turn, limit housing options for individuals with I/DD.*” CCC suggests that new policy trends “unintentionally create barriers to innovative supportive housing options.”

One of those barriers is cost as it relates to both service delivery and expansion of affordable housing.

“We have seen decades of very limited financial resources—providers have gone ten years without an increase and staff vacancy rates are through the roof,” said Thomas Baffuto, Executive Director of The Arc of New Jersey. The Arc has been a firm supporter of an increase in wages for direct support professionals and has launched a campaign to highlight the need.

“Where was the cost perspective in all of this? Providers are trying to reduce costs. When you remove economy of scale, you further pinch providers,” said Parles.

Then, there is the cost of the housing itself. Even with a paid job in the community, market rate rent is unaffordable to most people with I/DD. According to a 2015 report by the National Low Income Housing Coalition, one needs to earn more than \$25 an hour to afford a two-bedroom apartment in the Garden State. With housing costs in New Jersey among the highest in the nation, and the Special Needs Trust Fund now empty, Toronto sees the state’s preoccupation with density as sadly ironic.

“We are using tax credits and other programs that require a certain number of units be built—sometimes 50 or more. The finance regulations are in direct conflict with the density requirements that were proposed. It reflects public policies at odds with each other,” he stated.

“We now have municipalities looking for successful models to build affordable housing, but either they cannot finance it or the density issues come into play, paralyzing the process. Developers



The development of New Jersey's State Transition Plan has been a years-long process, and has involved collaboration between lawmakers, advocates, families, and disability experts.

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and communities need density and larger projects in order to keep it affordable," he said.

The fact that CMS will not approve certain types of settings unless they are fully operational leads CCC to conclude that the process *"limits housing options to wealthy families who can afford to private pay up-front, and halts the development of emerging housing communities that rely on financing because most lenders will not risk lending money to a neighborhood development that might be restricted from the potential residents they aim to serve."*

"We have a life-threatening housing crisis right now, so we do not need roadblocks on projects that can save lives," said Parles.

### **State Transition Plan— The Final Version**

Parents, advocates, providers, developers—and eventually lawmakers—pressed NJDHS to rethink their approach. After a heated two-year battle marked by public hearings and "listening sessions," NJDHS submitted a plan to Washington that was considerably more flexible. In December 2016, NJDHS issued an addendum that eliminated a rigid, quantitative approach to

measuring "density" and replaced it with a more flexible "community integration review" process. The review will look at individual experience in determining whether a setting is truly "home-and-community-based," noting, *"While the size of a setting is certainly one of the factors considered in the evaluation, it will not be the only factor."*

On the issue of day programs, NJDHS shifted as well. Rather than requiring individuals to spend a "majority" of their day in the community, the plan now calls for providers to demonstrate their commitment to person-centered planning with an emphasis on community integration.

Buchanan believes that the end result is a good one. "The new STP will encourage community integration, but is also responsive to the treatment and housing needs of people with disabilities," she said.

Pratico believes that the final STP reflects the advocacy efforts of the I/DD community

"The primary focus is supporting people in community living," she concluded.

Pratico, who has likened the transition to 'trying to turn the Titanic,' is cautiously optimistic.

"We have a large population of individuals with I/DD in New Jersey who receive services,

so the magnitude of this transition in itself is a challenge. The larger the population, the greater diversity of need, and so it will take tremendous effort to build capacity to address all the needs.”

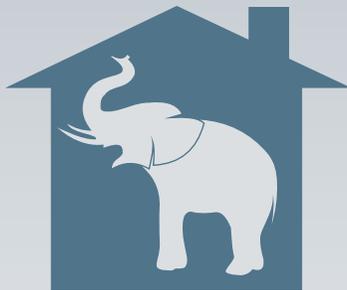
NJDHS submitted the final plan to Washington in early January and as *People & Families* goes to press, approval is still pending.

## The Elephant in the Room

The growing threat of Medicaid block grants at the federal level lingers in the minds of many. According to the Center on Budget and Policies (CBP), a non-partisan research and policy think tank, Medicaid block grants would eliminate the guarantee that everyone who’s eligible and applies for its benefits would receive them, and would give states authority to restrict eligibility, cut benefits, and make it harder to enroll. In addition, data show block grants would lead to draconian cuts to benefits and provider payment rates, further stressing an already stretched system.

“It would be a giant step backward,” said Diane Riley, Executive Director of the Supportive Housing Association of New Jersey, a statewide, nonprofit organization founded nearly 20 years ago, whose mission is to promote and maintain a strong supportive housing industry in New Jersey serving people with special needs. “In the past, block grants have not translated into better supports for people.” Riley also believes a certain amount of federal oversight is necessary for a more uniform and planned approach.

“We are all holding our breath a little; block grants would mean a huge loss of federal funds for New Jersey,” she added.



## Difficult Process, Good Results

In spite of the challenges in getting to New Jersey’s final STP, advocates believe that the process was important and produced good results. Many believe that the review process itself increased awareness that people with disabilities belong in the community and moved the needle on inclusiveness.

“Even before these rules take effect, folks are looking at their programs and asking how they can make adjustments. So the system is already more inclusive. Providers have been proactive and are stepping up their game to get individuals out in the community even more,” said Baffuto.

Riley is also encouraged.

“The new STP will open doors. It takes the chains off to make it more flexible for developers to create housing in communities. Developers and providers need to know that projects are approved before they build—the new plan lets them,” she said.

Parles believes it has galvanized the community and brought out perspectives that had been silent.

“This mobilized a constituency of parents and advocates—it made people come together to say they wanted choice. I am feeling hopeful again,” she said.

Parles, Baffuto, Buchanan, Kameka, and many others credit Assistant Commissioner Liz Shea and Acting Commission Elizabeth Connolly with opening up the conversation in ways that bring about a better service system.

In a letter to stakeholders, Acting Commissioner Elizabeth Connolly noted just that:

*“The Department and its state partners appreciate the time, attention, and input of everyone who participated in the public hearings and stakeholder meetings. The STP is better for it, and New Jersey’s residents will be better served because of it.”*



At the beginning of this year, disability advocates met with lawmakers at the NJ State House to work out final details of the Statewide Transition Plan before it was sent to Washington. (from left to right: Tom Baffuto, Exec. Dir. of the Arc of NJ; NJ Senate Pres. Steven Sweeney; Gail Levinson, former Exec. Dir. of SHA NJ; Suzanne Buchanan, Exec. Dir. of Autism NJ)

## RESOURCES

**Autism New Jersey • 609-588-8200 • [autismnj.org](http://autismnj.org)**

Website features section on Statewide Transition Plan and a timeline of activity

**Coalition for Community Choice • [coalitionforcommunitychoice.org](http://coalitionforcommunitychoice.org)**

Website features information, stories, public policy updates, and resources related to housing and employment choices for those with I/DD

**NJ Citizens for Choice in DD Housing and Services  
[facebook.com/NoToNJStatewideTransitionalPlan/](https://facebook.com/NoToNJStatewideTransitionalPlan/)**

Facebook page with frequent posts about the NJ STP

**NJ Department of Human Services  
[state.nj.us/humanservices/dmahs/info/hcbs\\_trans.html](http://state.nj.us/humanservices/dmahs/info/hcbs_trans.html)**

Website has Statewide Transition Plan

**Supportive Housing Association of New Jersey • 908-931-1131 • [shanj.org](http://shanj.org)**

Website features “The Journey to Community Housing with Supports: A Road Map for Individuals and Their Families in New Jersey”

**The Center on Budget and Policy Priorities • [Cbpp.org](http://Cbpp.org) **P&F****

# A Living Wage for DSPs

## How One Organization Makes it Happen

By Jonathan Jaffe

It has been well documented that New Jersey is careening toward an extreme shortage in Direct Support Professionals (DSPs), as the state has a growing population of seniors and people with developmental disabilities.

It has become increasingly difficult to recruit and retain professionals willing to work in people's home, often during non-traditional hours and holidays, providing an intensive level of care that makes the difference between life or death.

The reasons for the shortage are many. But the prevailing are low salaries and limited opportunities for growth. Many DSPs can spend entire careers in the industry and earn less than \$14 an hour, forcing them to take second jobs elsewhere or to live in dual-income households.

As the industry demands the state provide well-deserved raises, and that the federal government finally contribute more Medicaid dollars to make that happen, there are some examples of private companies that are able to retain DSPs, pay them higher salaries, and keep them engaged in what is commonly a very challenging job.

One example is Brett DiNovi & Associates LLC, with offices in Cherry Hill and Mount Laurel, NJ. The company does not provide the level of care that some DSPs are required to do, such as toileting, bathing, and feeding their clients. But staff at DiNovi work with children who have severe behavioral issues, including high levels of autism, requiring detailed attention, patience, and specialized knowledge to help students achieve.

A typical day for a DiNovi staff member has him or her assigned to a public elementary school, spending the day with one or more children with developmental disabilities. Once the



DSPs at Brett DiNovi & Associates work with children with developmental disabilities at school and in the home.

recess bell rings, these staff members then do visits with children at their homes, providing applied behavior analysis and therapy.

A typical workday for a staff member could be 10 to 12 hours. The day often goes from 8 am to 3 pm in a school, followed by an estimated three hours in the homes of children, working with the entire family on methods for success.

Brett DiNovi, CEO of the company, said the staff has now ballooned to 300 employees, who fan out among 80 school districts in New Jersey and eastern Pennsylvania, as well as providing at-home services. The company also does consultation with children worldwide through video and Skype services. He says his company is the largest of its type on the East Coast.

DiNovi is especially proud that turnover is very low, at an estimated 3 percent, because the company offers higher salaries and plenty of incentives to keep employees engaged. DiNovi



The company owns two limousines, which it uses to transport children and families to community activities while working on social skills.

also estimated the industry turnover for similar work can be upwards of 40 or even 50 percent.

He said DiNovi offers higher wages. Other agencies, he says, pay \$11-\$16 an hour. His staff is paid \$17 to \$30 an hour, averaging about \$25 an hour for direct care.

He explained his company can pay more money because it is not as tethered to government funding. Rather, the company is paid by school districts, private health insurance, and private pay clients. DiNovi describes it as “funding diversity.”

While this model may not work for other service providers—particularly those who serve children and adults with complex needs who require intensive care at home and in the community—who rely on more significant funding for state and federal government, the low staff turnover rate at Brett DiNovi & Associates gives direct evidence that providing DSPs with a living wage and benefits yields dramatically positive outcomes in the recruitment and retention of workers in this vitally important field.

With more money to work with, DiNovi said he is able to also provide full health benefits for all employees who work more than 30 hours a week. There is also profit sharing as well as a 401(k) with an employer match.

For Blake Kilvington of Audubon, a clinical coordinator who has worked for DiNovi for three years, the company does plenty more to keep the staff engaged and happy. There are weekly surveys so the company can easily monitor and rectify

any issues. There is also a mentoring program. Kilvington is assigned a mentor; he is currently mentoring three other staff members.

“If there is a problem, I’ll just reach out to Brett and he will give someone a call and help them out,” said Kilvington, 28. “He is very hands-on and is always there when we need him.”

The company is also the owner of two stretch limousines, which it uses to transport children and their family members to various community activities while working on social skills among peers in the limo.

The staff is encouraged to post on an internal social media program, where there are plenty of photos of kids and staff in the limos. There are also contests that reward employees who get a lot of comments on their social media posts.

Higher wages and other encouragements make work a lot easier for Kilvington, who spends every school day, from 7 am to 2:30 pm with one fifth grader enrolled in Burlington County Special Services, an 11-year-old boy who has emotional challenges and autism. From there, he oversees client outcomes in the company’s home-based services.

Alex Carter, another clinical coordinator who works in the Florence schools for DiNovi, said he typically puts in a 10-hour day. The work, for this 27-year-old Marlton man, is fulfilling and worth it.

“I like to see the change in the individuals I work with,” said Carter, noting he works with students with autism attending a grades K-3 school. “I want parents to know they are no alone in the struggles of their children. I use the same principles of motivate the children as Brett uses to motivate us. He always wants us to go above and beyond. He is a terrific motivator.”

Carter said DiNovi is always devising new ways to create excitement. He notes there is a contest for a trip to the Caribbean, as well as generous bonuses and the trips in the limo. Even clinical staff meetings the third Wednesday of the month at the Mount Laurel office can be fun, as DiNovi raffles off \$100 bills.

“The company has its own techniques to recruit people, who are dedicated to providing better services than what is typically offered by a school district,” Carter said. “It’s a major reason why the company keeps growing and growing.” **P&F**



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