

People & Families

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

FALL 2016

WE THE PEOPLE Preparing Students with Disabilities for Civic Engagement

Rianna J., a student at
Westbridge Academy in
Bloomfield, NJ





Advocacy By &
For People with
Disabilities

The international disability advocacy movement has come to New Jersey, fighting for civil rights and equality in our state.

Calling All Advocates



For People First New Jersey to grow and thrive, we're calling on advocates from all over New Jersey to join!

- Make Positive Changes in the Community
 - Speak Your Mind
 - Take Action
- All People with Disabilities Welcome

Want to Make a Difference?



Visit www.njcdd.org, or call
609-292-3745
to find out how to join or start a
People First New Jersey
chapter in your area.



PUBLISHER New Jersey Council on Developmental Disabilities

CHAIR Stephanie A. Pratico

EXECUTIVE DIRECTOR Kevin T. Casey

EDITOR Jonathan Waller

EDITORIAL BOARD MEMBERS

Scott Elliot, Progressive Center for Independent Living

Mike Brill, Public Member

Peg Kinsell, Statewide Parent Advocacy Network

Beverly Roberts, The Arc of New Jersey

Kelly Boyd, NJ Office of Emergency Management

Joseph Amoroso, NJ Division of Disability Services

Rebecca Kasen, Disability Rights New Jersey

DESIGN AND LAYOUT CranCentral Graphics, LLC

CONTRIBUTING WRITERS

Brenda Considine, Maryann B. Hunsberger, Jonathan Jaffe, Robert Titus

PHOTOGRAPHY Rebecca Shavulsky

NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

SELF ADVOCATE MEMBERS

Todd Emmons, Andrew McGeady,
Christopher Miller, Myrta Rosa, Gary Rubin, Kevin Nunez

**PARENT, FAMILY MEMBER,
AND GUARDIAN MEMBERS**

Ellie Byra, Walter Fernandez,
Leah Ziskin, M.D., Safiyah Muhammad,
Tara Montague, Paul A. Blaustein, Margaret Kinsell,
Elizabeth Dalzell, Helen Steinberg

PUBLIC MEMBER

William Testa, The Arc/Morris Chapter

FEDERALLY MANDATED MEMBERS

*Federally mandated members of the Council are mandated to
serve in accordance with the federal
Developmental Disabilities Assistance and Bill of Rights Act*

Joseph M. Amoroso, Division of Disability Services
Elizabeth M. Shea, Division of Developmental Disabilities
Susan Martz, Office of Special Education Programs
Valerie Harr, Division of Medical Assistance
and Health Services
Alice Hunnicut, Division of Vocational Rehabilitation Services
Lisa Asare, Division of Family Health Services
Michael Knox, PhD, The Boggs Center on
Developmental Disabilities at Rutgers University
Joseph Young, Esq., Disability Rights NJ

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

Subscriptions to *People & Families* are free and are available through the Council office or by e-mail at njcdd@njcdd.org. Please include your name and address. Articles may be reprinted without fee by permission. Expressed opinions are not necessarily those of the Council's membership. We welcome your letters and comments. Send them to Jonathan Waller, editor, NJCDD, PO Box 700, Trenton, NJ 08625-0700. Please include your name and town. Letters may be reprinted and edited for space.

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

CONTENTS

6 LETTER FROM THE COUNCIL DIRECTOR AND COUNCIL CHAIRPERSON

In Our American Democracy, Everyone's Voice Matters

One of the most important ways that people with disabilities are able to have their voices heard is by participating in our American Democracy. We urge families and self-advocates to get out and vote this November.

7 NEWS & NOTES

The NJCDD Launches New Website

- UN Panel Calls for Inclusive Education
- NJCDD Announces Family Advisory Council
- Community Options Opens Second Red Ribbon Academy
- Arc of New Jersey and Rutgers University Transportation Research Grant
- Fewer With Disabilities Employed, Data Shows
- Upcoming Events

16 REVUP! NEW JERSEY Let's Vote!

In the last presidential election, only 56.8 percent of citizens with disabilities voted, compared to over 62 percent of non-disabled citizens. As the second largest minority voting group in the US, Americans with disabilities have incredible potential to influence democracy. In this election year, the *RevUp! New Jersey* campaign has encouraged people with disabilities to vote and be heard.



22 NJCDD LEGISLATIVE UPDATE - FALL 2016

24 DECISION 2016 Disability Issues in This Year's Presidential Race

People & Families examines this election year's party platforms and convention coverage to get a sense of where the major candidates stand on the issues important to Americans with disabilities.

Cover Photo
Rianna J., a student at Westbridge Academy
in Bloomfield, NJ
Photo by: Rebecca Shavulsky

30 WORDS OF WISDOM

From One Parent to Another

The best advice often comes from those who have walked in your shoes. With that in mind, the NJCDD's Family Support Councils have launched a new social media campaign which offers newer parents of children with I/DD words of advice from more experienced family advocates.



42

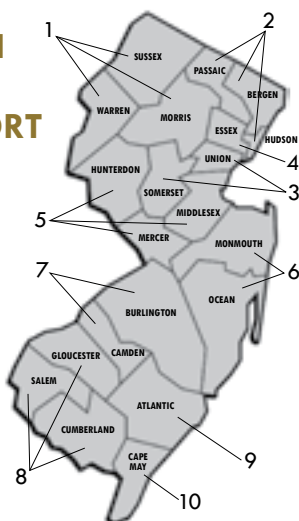
COVER STORY

42 WE THE PEOPLE

Preparing Students with Disabilities for Civic Engagement

Hands-on civic education is essential to sustain our constitutional democracy. We aren't born with an inclination for democracy—we learn it. But, how can we best educate young people with disabilities about civic responsibility?

34 INFORMATION ABOUT FAMILY SUPPORT



36 NEW JERSEY'S DSP CRISIS A Family Perspective

In our continuing coverage of the critical state of the Direct Support Profession in New Jersey, *People and Families* examines the impact this crisis has on family members seeking support for loved ones with developmental disabilities living at home.

48 THE NJCDD 2016 ELECTION QUESTIONNAIRE

Candidates from New Jersey's Congressional Races Weigh in on Disability Issues

Over the summer, the NJCDD contacted the major candidates from each of New Jersey's 12 congressional races in the 2016 election, asking them to consider a questionnaire focusing on several key issues of importance to people with disabilities and their families. Now, we share their responses with you.

from the Executive Director & Council Chairperson ■

In Our American Democracy, Everyone's Voice Matters

Being a good disability advocate is a big job, and there are a lot of things that people with developmental disabilities, their family members, and other allies can do to make our society a better place for *every* American. From speaking up to community leaders and elected officials, to pushing for positive systems changes within government and provider agencies, to cultivating respect and inclusion in our communities, it's important that developmental disability advocates are able to share their views and have a say in our society.

One of the most important ways that people with disabilities are able to have their voices heard is by fully participating in our American democracy. Right now, we are in the midst of an important election season. This year, we are voting for elected positions on both the state and national level, from President of the United States on down to local freeholders. The people that we elect this year will play a key role in the ongoing growth of the supports systems that we have spent so much time building.

It is critical that our elected leaders work to make sure that people with disabilities have a right to work, have a right to a good education, have a right to accessible structures, and have a right to the supports that allow them to live fully in the community.

While the NJCDD does not support or campaign for any specific candidates, we strongly urge people with disabilities and their families to vote on November 8, Election Day. We also believe that it's important to be an educated voter. What positions do the candidates have on disability issues? What are their positions on employment, on education, on support services, or on supporting proper wages for our Direct Support Professionals?

We urge you to visit your polling place prior to the election. Is your polling place convenient and accessible? If not, Disability Rights New Jersey is a phone call away, and is prepared to help you with any problems you may have with voting of with voter accessibility.

The NJCDD, much like the rest of the country, is in an exciting transition period this fall. We're very happy to welcome four new members of the Council, who were recently approved by the New Jersey Senate. Elizabeth Dalzell, Margaret Kinsell, Kevin Nunez, and Helen Steinberg will be joining the Council at our next meeting on October 27. We look forward to working with them as we continue to advocate for people with developmental disabilities.

Our new five-year plan for 2017-2021 was recently submitted to the federal government, and as we await final approval of this plan, we are beginning the process of implementing key goals and objectives. Prior to our October Council meeting, the Grants and Planning Committee will be meeting to discuss the objectives on which we should concentrate first. Part of that plan will be the development and issuing of requests for grant proposals. We will have a discussion of this process at our October 27 Council meeting, and hope to approve new grants this January.

As we continue through the fall in New Jersey, the NJCDD wishes you a pleasant holiday season, and once again urges you to get out and vote on November 8.

—Kevin Casey
Executive Director

—Stephanie A. Pratico
Council Chairperson

The NJ Council on Developmental Disabilities

*NOTE: To find out more about voter accessibility or for assistance in voting, you can visit Disability Rights New Jersey online at www.drnj.org, or call them at 609-292-9742.

NJCDD Launches New Website



The new NJCDD.org features increased accessibility and a beautiful new design

This summer the New Jersey Council on Developmental Disabilities carried out a complete redesign of its website, www.njcdd.org, in an effort to make the site more accessible and user-friendly than ever before.

Now, the Council is happy to share the new website with web visitors, and encourages the public to visit the site to view the new changes. The new website features a beautiful and easier-to-read layout and

design, language options for non-english speaking visitors, text-to-speech features for the visually impaired, and more.

The website's new design also gives the Council room to grow and offer more information and resources for families and self-advocates.

The NJCDD welcomes any comments, questions, or suggestions you might have regarding the new site.

All comments can be sent to the NJCDD's Communications Manager, Jonathan Waller, at jonathan.waller@njcdd.org

UN Panel Calls For Inclusive Education

By Shaun Heasley

From: DisabilityScoop.com—September 7, 2016

Being educated in an inclusive environment is a basic right for students with disabilities, according to a new set of guidelines from the United Nations.

Governments must work together with people who have disabilities and other stakeholders to ensure that schooling is not just integrated, but actually inclusive.

That's the recommendation of a 24-page document known as a "general comment" recently adopted by the UN Committee on the Rights of Persons with Disabilities.

"Despite progress achieved, (the committee) is concerned that profound challenges persist," reads the statement. "Many millions of persons with disabilities continue to be denied a right to education, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision."

Inclusion offers benefits to students with and without disabilities, the committee said. But truly mainstreaming those with varying needs requires much more than just seating them side-by-side with other children.

"Placing students with disabilities in mainstream classes without accompanying

structural changes to, for example, organization, curriculum and teaching and learning strategies, does not constitute inclusion," the guidance states.

In order to make learning truly inclusive, state-run and private school systems must be fully accessible, both physically and in terms of communication and support services, according to the UN panel. This should extend beyond the classroom to include transportation, cafeterias, recreational spaces and other facilities.

"Enabling inclusive education requires an in-depth transformation of education systems in legislation, policy and the way education is financed, administered, designed, taught and monitored. We hope our general comment will guide and aid states toward achieving this goal," said Maria Soledad Cisternas Reyes, chair of the Committee on the Rights of Persons with Disabilities.

The general comment on education serves as guidance for the Convention on the Rights of Persons with Disabilities, a treaty that has been ratified by 166 countries.

The United States signed the convention in 2009, but has not ratified it.



NJCDD Announces New Statewide Family Advisory Council

STATEWIDE – The New Jersey Council on Developmental Disabilities’ (NJCDD) Regional Family Support Planning Councils (RFSPCs) are pleased to announce the formation of a new Statewide Family Advisory Council (FAC). This new advocacy committee has been created with the express intent of delivering the concerns and input of family members of individuals with developmental disabilities across New Jersey directly to officials at the New Jersey Division of Developmental Disabilities (DDD). To learn more about the FAC, and ways to join or provide input, interested family members may contact the NJCDD’s Statewide Family Support Coordinator, Kyoko Coco, at 609-341-3112 or kyoko.coco@njcdd.org

DDD has formally agreed to recognize the FAC as its official advisory group for family members of individuals with developmental disabilities whom they serve. The FAC will facilitate a holistic representation of such families, including all types of disabilities, and across all geographic, cultural, and socioeconomic backgrounds within our state. The FAC will also provide direct input to DDD in all areas of family support, including the Supports Program, Community Care Waiver, and with regard to individuals living both in-home and out-of-home.

Members of the FAC will meet regularly with DDD officials, with the understanding that DDD will take every measure to incorporate input from the FAC in its decision and policymaking.

How to Become a Member of the Family Advisory Council

In order to serve on the statewide Family Advisory Council, interested family advocates MUST FIRST become active members of their RFSPC. To find your Regional Family Support Planning Council, please visit www.njcdd.org and view our information about the Regional Family Support Planning Councils.

The Statewide Chair and Vice Chair of the Family Support Planning Councils will be permanent members of the FAC. Chairs of each

of New Jersey’s ten RFSPCs can nominate one or more of their Council members to serve on the FAC, with voting being done by Council members.

The FAC may have up to 12 active members, each having one alternative member. Each member of the FAC may serve for up to two years.

The Role of the Division of Developmental Disabilities in the FAC

In recognizing the RFSPCs’ Family Advisory Council, DDD agrees to the following:

- Refer all family members of individuals with developmental disabilities to their local RFSPC based on where a family member resides in New Jersey
- Recognize the FAC as the official stakeholder input group to DDD policies and procedures
- Meet regularly with the FAC to solicit input to all policies and procedures affecting family members and individuals with developmental disabilities
- Obtain direct input from the FAC before proposing or adopting new or revised DDD policies and procedures. Provide feedback to all FAC recommendations, whether or not they are adopted by DDD, with justification and/or explanation

- Appoint DDD staff liaisons to meet with the FAC on a regular basis. The purpose of these meetings is to maintain open communication before any decisions are made

Background

In accordance with the 1993 *Family Support Act* The New Jersey Council on Developmental Disabilities established the Regional Family Support Planning Councils (RFSPCs) to provide a way for family members caring for people with developmental disabilities to participate in the design of needed community services to care for someone at home, as well as provide input on how to make such services more accessible. RFSPC members also partner with the state Division of Developmental Disabilities (DDD) and the Department of Children and Families to

provide input on budget and policy decisions that directly impact individuals with developmental disabilities living at home with their families.

For the benefit of all families in their region, members provide input to local officials and state legislators about issues that affect systems and supports for individuals with developmental disabilities living with their family, and stress the importance of services and supports that promote self-determination, independence, productivity, and inclusion in all aspects of community life.

RFSPC members, through their regional councils, organize and conduct events within their communities where families can learn about available services from local provider agencies as well as township and county-based services. RFSPCs educate families by hosting public forums with informed speakers and by distributing literature.

common ground 

Common Ground Online
Increasing Dialog Among Stakeholders in
New Jersey's Special Education System

The NJCDD's publication for educators, parents, and other special education professionals and policy makers is available online!

- Read about current issues in special education
- Get updates on legal and legislative developments
- Find important resources and information

Visit
www.NJCommonGround.org
to sign-up for a free online subscription!

Community Options Opens Second Ribbon Red Academy in New Jersey



Community Options staff, board members, and advocates celebrate the opening of their second Red Ribbon Academy at a ceremony in Hillsborough —Photo courtesy of Community Options, Inc.

PRINCETON, NJ— On September 8, Community Options opened its second Red Ribbon Academy, located at 2230 Camplain Road in Hillsborough, NJ. The Red Ribbon Academy is a state-of-the-art medical special needs adult day program with a combination of tender loving care, therapy integration and fun, adapted activities. The program provides quality medical, therapeutic, and recreational support to medically fragile adults with developmental disabilities.

“This represents where we started from and the journey we endured to get to the next level,” said Ayesha Patrick, Executive Director of the Red Ribbon Academy. “Community Options Enterprises (COE) broke down doors and boundaries and has stepped out of the traditional program/ medical day program model and created a quality, state-of-the-art program that is being duplicated within COE in accordance with the overall mission and in continuing to make a difference in the life of

medically fragile individuals.”

Originally launched in 2013, the first Red Ribbon Academy in Wayne, NJ quickly became a model day-program that garnered significant media attention and numerous awards for its barrier-free design and advanced therapy rooms with special sensory environments for people with profound intellectual disabilities and medical needs. A wide array of therapeutic experts and advanced recreational programs also are available to maintain and increase the participants’ mental acuity and maximize their physical ability.

16 individuals are currently enrolled in the Hillsborough program for its opening. The Red Ribbon Academy is open to anyone who qualifies for services under the NJ Division for Developmental Disabilities with transportation provided to and from the Academy.

For more information about the Red Ribbon Academy, please visit: <http://www.comop.org/celebrating-two-years-of-making-a-difference/>

The Arc of New Jersey Partners with Rutgers University To Conduct Study on Transportation Issues And Obstacles Facing NJ Residents With Developmental Disabilities



Photo courtesy of the US Dept. of Transportation

The Arc of New Jersey has partnered with the Alan M. Voorhees Transportation Center at Rutgers University to reach out to New Jersey residents with intellectual and developmental disabilities (I/DD) to conduct research on transportation and how it affects the lives of individuals in this community.

Funded through a grant from the New Jersey Council on Developmental Disabilities, the research team is using a vast and diverse network of self-advocacy groups and community connections to get in touch with as wide a population of individuals as possible, attempting to include:

- Statewide Coverage
- Urban, suburban, and rural locations, plus those living in developmental centers
- A diversity of economic, racial, and ethnic backgrounds
- A diversity of disabilities, including different levels of support needs
- A diversity of reasons an individual might use transportation (employment, community involvement, recreation, independent living, etc.)

Research will be in the form of direct and in-person interviews with people with I/DD, with interviews taking place in the most convenient location for the individual. The Arc of New Jersey is taking the lead in capturing the personal stories of people with I/DD related to transportation by using an oral history interview format modeled after the Works Progress Administration (WPA) efforts of the 1930s, and

more recently by the successful NPR program *StoryCorps*.

After collecting this broad variety of interviews, Rutgers University will analyze them and develop a report identifying trends and themes, as well as recommendations for state transportation officials. Recommendations will focus on both practical systemic issues as well as broader advocacy issues.

The full project team will produce a final summary report that will include real-life examples and personal stories, which will put a

“face” on the transportation issues encountered by New Jersey residents with I/DD. The team will develop both a written and audio summary which can be used together or separately to highlight the compelling stories that have been collected.

All self-advocates living in New Jersey are encouraged to participate in this research project. For more information about the project, and to find out how to participate, contact The Arc of New Jersey’s NJ Self-Advocacy Project at NJSAP@ArcNJ.org or call 732-749-8514.

The New Jersey Council on Developmental Disabilities

Want to Become a Council Member?

To recommend yourself or someone else to be a member of the Council, follow the steps below:

On the website: www.state.nj.us

- On the top, blue tab, choose → Government
- On the left hand side, choose → Governor's Office
- On the top, red tab, choose → Administration
- On the top, blue tab, choose → Boards, Commissions & Authority

Follow the instructions for submitting the required information, and be sure to include that you are interested in becoming a member of the New Jersey Council on Developmental Disabilities.

Or contact the Governor's Appointments Office:
 Phone: 609-777-0251 Fax: 609-777-0331

Council Members are appointed by the Governor. Membership is open to New Jersey residents who have a developmental disability or are immediate family members of someone with a developmental disability.

Council members review the state's service systems for people with developmental disabilities, advise policy makers on the best ways to change those systems to better serve the population, and promote the goals of the federal Developmental Disabilities Assistance and Bill of Rights Act. Members review and award grants to spark innovative projects throughout New Jersey. The Council and its individual members also advocate for people with developmental disabilities and their families on an on-going basis.

For more information about the Council visit our web site: www.njcdd.org

Fewer With Disabilities Employed, Data Shows

By Shaun Heasley

From: DisabilityScoop.com—September 6, 2016

The unemployment rate for Americans with disabilities is edging up as less people in this population actively seek work, according to new data from the US Department of Labor.

Figures released just before Labor Day show that the jobless rate for those with disabilities hit 11.3 percent in August, up slightly from 11.1 percent the month prior.

The shift appears to be due at least in part to more individuals with disabilities giving up on the job market altogether.

Meanwhile, the economy added 151,000 jobs in August and the unemployment rate for the general population was unchanged at 4.9 percent.

Federal officials began tracking employment among people with disabilities in October 2008. There is not yet enough data compiled to establish seasonal trends among this population, so statistics for this group are not seasonally adjusted.

Data on people with disabilities covers those over the age of 16 who do not live in institutions. The first employment report specific to this population was made available in February 2009. Now, reports are released monthly. **P&F**



Connect with Us on Social Media



“Like Us” on Facebook
www.facebook.com/NJCDD



Follow us on
 Twitter@theNJCDD



Subscribe to
 Our YouTube Channel
www.youtube.com/theNJCDD

UPCOMING EVENTS

NJCDD COUNCIL MEETING

Thursday, October 27, 2016

10:30am to 2:00pm

Hyatt Regency Princeton
102 Carnegie Center
Princeton, NJ 08540

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

ELECTION DAY

Tuesday, November 8, 2016

To find your local polling station, how to vote by mail, and whether you are registered to vote, visit the New Jersey Division of Elections at

<http://www.njelections.org/voting-information.html>

THE REGIONAL FAMILY SUPPORT PLANNING COUNCIL #3 PRESENTS

A PUBLIC FORUM & PROVIDERS FAIR FOR SOMERSET AND UNION COUNTIES

Tuesday, November 15, 2016

7:00pm to 9:00pm

The Arc Kohler School
(Back Entrance)
1137Globe Avenue
Mountainside, NJ 07092

Guest Speakers

Beverly Robert, The Arc of New Jersey Mainstreaming Medical Care Program

Darlene Yannetta, Division of Developmental Disabilities

Come learn about:

Determination of Medicaid eligibility at age 18, the Support Program, the new Fee-for-Service system, Support Coordination, and Person-Centered Planning

Bring your questions/experiences!

Contact rfspc3@gmail.com for additional information
and to ensure space is available



REV UP!
NEW JERSEY
LET'S VOTE!

By Maryann Hunsberger

On a swelteringly hot and sunny afternoon on July 25 of this year, a small crowd of disability advocates gathered together in front of the New Jersey State House in Trenton to send a message. And the message was loud and clear—“We’re people with Disabilities, and we vote!”

The crowd of advocates were gathered to kick off a statewide campaign to reach out to New Jersey residents with disabilities and urge them to make their voices heard on election day by registering to vote and casting their ballots. The campaign is called *REV Up! New Jersey*.

REV UP! New Jersey is part of a larger movement, *REV UP!* (Register, Educate, Vote and Use your Power), aimed at bringing more people with disabilities to the polls. The Alliance Center for Independence (ACI) of Edison, supported by a grant from the New Jersey Council on Developmental Disabilities (NJCDD), organized the kickoff event, which featured live music, exhibit tables, and guest speakers. The crowd of over 30 people, including Assemblyman Eric Houghtailing from Monmouth County, gathered in 108 degree heat to make others aware about disability rights and voting.

Bob Kafka sent a message from National Adapt reminding people of the words of disability rights pioneer Justin Dart, who said, “Vote like your life depends on it, because it does!” Carole Tonks, Executive Director, Alliance Center for Independence, stressed that people with disabilities were the second largest minority voting bloc in the 2012 elections, but had a lower turnout. Chris Miller from Disability Rights NJ, and Vice-Chair of the NJCDD, pointed out that

people with disabilities need to get involved in the political process as politics directly affects their lives.

Eulanda Brooks of Somerset spoke about the history of voting rights, saying, “Just as disability rights are civil rights, voting is a civil right and a responsibility. Many died just so we can enjoy the right to vote for whom we choose. It is easy to sit back and complain that things are the way they are, but it is our individual duty. Change only comes about when we each do what we can

to make change. I can do very little, but that very little I’m going to do.”


Brooks further explained that her mother and grandfather, born in the south, weren’t allowed to vote in the past due to their race. Such injustices sparked her passion for voting.

A History of the Struggle to Vote

The Fifteenth Amendment to the United States Constitution, adopted in 1870, stipulated that all American men could vote, regardless of race. Yet, many people still couldn’t vote. Women didn’t gain the right to vote until 1920. Chinese Americans weren’t made voting citizens until 1943. Asian Indians followed in 1946, and other Asian Americans in 1952. Though the *Indian Citizenship Act* passed in 1924, the last state to allow Native Americans to vote was Utah in 1956. Jim Crow laws, including literacy tests and poll taxes, kept some African Americans from voting until the *Voting Rights Act* passed in 1965.

Throughout all of this, people with disabilities were continually disenfranchised. Most with intellectual and developmental disabilities had been forced into institutions, where they were





**“Just as
disability rights
are civil rights,
voting is a civil
right and a
responsibility”**

—Eulanda Brooks,
of the Alliance Center for Independence

unable to vote. Then, when institution residents began leaving to live in the community, they found that most polling places were inaccessible. Finally, the *Voting Accessibility for the Elderly and Handicapped Act* of 1984 required polling places to ensure accessibility for all people with disabilities during federal elections. Still, inaccessibility remained a problem, and the law didn't even pertain to state, county, and municipal elections.

The *Americans with Disabilities Act* of 1990 created the most significant change by calling for accessibility within polling stations. Still, in 1992, the Federal Election Commission reported that more than 20,000 polling places across the nation were inaccessible, depriving people with disabilities of their fundamental right to vote. Since voter registration of people with disabilities and minorities was still low, the *National Voter Registration Act* of 1993 required both federal and state agencies to assist in voter registration procedures. The *Help America Vote Act* of 2002 required each polling station to have at least one

disability-accessible voting machine per federal election.

An Ongoing History of Injustice

Despite these legislative actions, according to *USA Today*, in the 2012 United States presidential election only 56.8 percent of people with disabilities reported voting, compared to the 62.5 percent of eligible citizens without disabilities. Physical barriers still existed in the form of improper signage, steep or broken wheelchair ramps, narrow entranceways, inoperative doorbells, heavy doors, and inaccessible voting machines.

Brooks likens the struggle for accessibility at the polls to the civil rights movement. “As long as it took to get the civil rights for minorities to vote, it's even harder for people with disabilities. Even today, if you go into a polling place, they still might not be able to vote if they can't reach the machines. It still hasn't been resolved. It's mind boggling.”

A 2012 article in *The Atlantic* explains that court-ordered voting restrictions can apply to

people judged mentally incompetent due to disabilities such as Down syndrome or autism. About 30 states and the District of Columbia have laws in their constitutions that can limit people with intellectual disabilities from voting if they have been ruled mentally incapacitated or incompetent by a court.

Mark Salzer, a Temple University professor and chairman of the school's Department of Rehabilitation Sciences, said voting rights for people with such disabilities haven't been viewed as being important. "They think that if you have a mental illness—and they use the term broadly—then your rationality is impaired and

you shouldn't be able to vote. It's just plain wrong. It too easily disenfranchises voters. It takes away people's citizenship rights. They label people and perpetuate stigma and discrimination."

What Can We Do About It?

People with disabilities can create change by voting. Charles "CJ" Dodge of Garwood, who took part in the *REV UP! New Jersey* kickoff, stressed the significance of this. "It's important for individuals with disabilities to vote because many programs that affect our lives, such as education and healthcare, are run by the government. We as a community need the skills to be employable.



Dozens of disability advocates gathered at the New Jersey State House to spread the word about the importance of voting.



At the RevUP! New Jersey kickoff event, people with disabilities were able to fill out voter registration forms, and pledged to get out and vote this November

To become active, productive members of the community, we need employment programs. We must make sure that the services we need are important to our representatives.”

REV UP! New Jersey is doing exactly that and also registering people with disabilities to vote, holding statewide voter education workshops and gathering information about the candidates’ positions on issues important to people with disabilities. “Knowledge of the candidates’ positions on disability issues is crucial to making educated choices on voting day,” said Tonks.

Christine Hines of Edison, who attended the kickoff, feels this knowledge is especially important. “I like that REV UP! New Jersey is educating voters on the candidates’ stances on issues that affect us. People with disabilities are an under-represented population. We must learn which candidates in each election are aware of issues impacting people with disabilities.”

Lindsay Truman of Essex, who was part of the planning committee for the July event,

likes that REV UP! New Jersey educates people on voting and the election process in general. She pointed out that when she first voted, she couldn’t reach the levers in the voting booth. “Nobody there knew how to lower the booth to wheelchair height. I hung around a bit until I saw someone I knew, and she figured it out.” Since that time, she checks her polling place ahead of time to be sure the entrance and the booths are accessible. “I definitely recommend doing this. Everyone should check out their polling places in advance and ask questions. If there are problems that aren’t resolved, they can contact their local Center for Independent Living, Disability Rights NJ, and the local Board of Elections.”

Dodge points out, “We show what is important to us by voting. We need to speak up to create change. Nothing will be done if we don’t speak up. It’s important for our representatives to continue to support our ultimate goal of being



Norman Smith, who spoke at the RevUP! kickoff event in July, was joined by his son Joshua



Chris Miller, Advocate at Disability Rights New Jersey and Vice Chair for the NJ Council on Developmental Disabilities, encouraged people with disabilities to get involved in the political process

a completely inclusive society. We are well along our way to being there, but things still need to be done.”

Assemblyman Houghtaling believes our state is at its best when we listen to the voices of all our residents. “This is why it is so important to encourage those with disabilities to make their voices heard, and to make participating in the voting process easier for people with disabilities. I hope the rally was just the beginning of a movement that will bring more attention to the rights of New Jersey residents with disabilities, and it’s a movement I’m proud to be a part of.”

Tonks stressed, “*REV UP! New Jersey* uses the chant, ‘nothing about us without us.’ That won’t happen if people with disabilities don’t go out and vote. We can’t be complacent. We have to be a part of the process and we have to be seen. *REV UP! New Jersey* won’t be done after the election. We won’t stop until every last person with a disability is out there voting.” **P&F**

Resources for Voting

Look up your assigned polling place here:

<https://voter.njsvrs.com/PublicAccess/jsp/PollPlace/PollPlaceSearch.jsp>

Voter Report Form for Polling Place Accessibility Concerns:

<http://www.state.nj.us/state/elections/voting-access-feedback-form.html>

Register to Vote Online:

<https://register2.rockthevote.com/registrants/map/?partner=34861>

Anyone who missed receiving a copy of the booklet *Voting: It’s Your Right* at the July kickoff, can obtain a free copy from Disability Rights NJ at **1-800-922-7233**, or read it online at http://www.salemcountynj.gov/?wpfb_dl=1041.

Each NJ County should have a Voting Advisory Accessibility Committee with at least one person with a disability serving.

To find the local county committee, go to:

<http://www.state.nj.us/state/elections/voting-information-voter-rights.html>

NJCDD Legislative Update

Fall 2016

By Robert Titus,
NJCDD Public Policy Coordinator

With the State embroiled in issues of funding for transportation infrastructure, public employee pensions, casino expansion, and education, it can seem that very little legislation is being discussed concerning intellectual and developmental disabilities (I/DD). In fact, there are currently several dozen bills in the legislature that would address some of the issues important to the I/DD community. What is also apparent is that some of the most crucial unmet needs are still pending legislative attention: bills have not even been written for them!

Who are the advocates that were successful in the current legislative session? As the NJCDD's public policy coordinator, I participate in many committee meetings and public hearings at the State House and other places. Advocacy is a passion and a mission for agencies like The Arc of New Jersey, the Alliance for the Betterment of Citizens with Disabilities (ABCD), the New Jersey Association of Community Providers (NJACP), Autism New Jersey, the Statewide Parent Advocacy Network (SPAN), and Disability Rights New Jersey (DRNJ). The self-advocates and professionals who testify on behalf of enlightened change use very limited resources to effectively influence policy. Family members were greatly responsible for historic change when the "Return Home NJ" program for residential out-of-state placements was largely discontinued in 2015. An overlooked source and support of advocacy are legislators themselves, who honor and respect their constituents by the introduction of bills in response to legitimate needs. Then there is the executive branch of government that has (more

often than not) worked to ultimately sign this legislation into law.

Some valuable results were achieved by advocacy in 2015-2016. Bills to upgrade services for people and families affected by I/DD were signed into law, including NJ's version of the *Achieving a Better Life Experience (ABLE) Act*, establishment of an "MVP" Emergency Alert System, starting an ombudsman program for Special Education issues, and requirements for state departments to follow practices when notification for terminations of services to people with developmental disabilities does occur. A bill to create a NJ Caregiver Task Force to evaluate and provide recommendations on caregiver support services was passed by the legislature but unfortunately "pocket vetoed" by the Governor.

The most comprehensive and most controversial bill for the I/DD community is probably A2963, the *Protection for Individuals with Developmental Disabilities in Institutional and Community Settings Act*. Two of the primary sponsors are the influential chairs of the Assembly Human Services Committee (Valerie Vainieri Huttel) and of the Assembly Budget Committee (Gary Schaer) respectively. While no action has been taken since the bill's introduction in February, 2016, the 21-page bill is certain to be scrutinized and modified as critical discussion begins with the next legislative session this fall. According to the bill's "Statement" it "is designed to provide protections for individuals with developmental disabilities residing in community residences for the developmentally disabled, developmental centers, private licensed facilities, and nursing

homes.” The Departments of Health and of Human Services would be required to submit plans to correct deficiencies and providers of services could be fined and their licenses revoked for non-conformances to listed standards; sections of the provision include monitoring of adult day programs. Service providers’ staff would be required to prove competence and to attend continuing education programs, and physicians and chief executive officers of hospitals could be fined for failure to correctly oversee their staff members. While the bill’s sponsors undoubtedly felt that punitive measures would enhance compliance on health-related issues, providers’ associations have received unfavorable reactions from their members. Clearly, there will be language and other changes if the bill is to go forward.

Other bills already introduced include A1449: it has cleared committee and is ready for a vote in the Assembly. The bill “Requires DHS to develop (a) timeline for use by individuals with developmental disabilities to gain benefit of State and federal programs; requires posting timelines on DHS, DCF, and DOE websites.” The NJCDD is scheduled to petition the sponsors to add the Department of Health to the legislation, in recognition of their role in the Early Intervention program. One of the most helpful bills in terms of stabilizing resources within the I/DD community is A2488, which would direct certain recoveries of federal funds for services to persons with developmental disabilities be used for grants to support community infrastructure purposes. Similarly, affordable housing needs would be boosted under A2506: Certain motor vehicle surcharge revenues would be dedicated to the Special Needs Housing Trust Fund. The Fund has been unfunded for almost ten years. Both of these bills, however, will likely meet strong opposition from the Administration since they would 1) limit state control of revenue and 2) introduce a new tax. Advocacy and compromise offer the best possibility for advancement.

Being New Jersey, nothing is to be assumed, but several bills have a great chance of passing—they are so basic in their intent that some wonder why they are even needed! For example,

A1472 requires the Division of Developmental Disabilities (DDD) to make a comprehensive list of its programs available to the public. This would seemingly be covered with the “Timeline” bill or be considered part of the mission of the Agency. A3026 requires DHS to verify the level of severity of reports received about incidents involving individuals with developmental disabilities. S2387 requires training of certain staff and health care professionals in interacting with individuals with developmental disabilities. It must be pointed out, however, that bills are often developed in response to the concerns of constituents, and legislators can only act with...legislation. Also, legislators do not always coordinate their efforts, especially with members of the opposition political party.

We must, as advocates and policy shapers, see that some of the most challenging and system-threatening issues are hardly addressed or worse, not addressed **at all** by current State legislation. The encompassing problem of Direct Support Staffing Issues is not a pleasant discussion, nor a new conversation, but it is faced by the entire I/DD community: providers, individuals, families, the direct support professionals (DSPs) themselves, and state departments and agencies too. Will it take a cataclysmic collapse of services to make legislators and the executive branch aware that systematic and comprehensive reform is long overdue? The solutions will include legislation, and advocates must take the lead. No one will be served by downplaying or ignoring a discussion, let alone displaying ignorance that decisions must be made. Similar arguments can be made for issues related to housing, employment, transportation, and health and wellness. Our State is lacking for neither ideas nor informed and motivated advocates. The work does not end, but begins anew: welcome to the frustration and reward of advocacy! It is never boring and always necessary. **P&F**

NJCDD’s Public Policy Committee meets at every Board meeting. See the NJCDD website for more information and contact Robert Titus, Public Policy Coordinator, with your proposals on developing new legislative initiatives. (robert.titus@njcdd.org)

DECISION 2016

Disability Issues in This Year's Presidential Race

By Jonathan Jaffe



Non-partisan political pundits in the disability community are using this summer's national political conventions to gauge how the next President of the United States will address pressing issues among people with developmental disabilities.

Traditional journalists, as well as content providers for blogs and social media, combed through the party platforms and carefully tracked how often speakers at both conventions referred to people with disabilities. Also, it was quickly noted when a speaker would approach the podium who happened to have a disability.

For example, the Republicans opened their convention with a moving rendition of The Star Spangled Banner from Marlana VanHoose, who is blind and has cerebral palsy. Meanwhile, the Democrats had Senator Tom Harkin highlight the anniversary of the *Americans with Disabilities Act* during his primetime speech on the second night of their convention.

But, cutting through the four-day infomercials that political conventions have become, the question remains: which party is better positioned to serve America's disability community?

Superficially, the Democratic Platform mentions disability, in some way, 35 times; the Republican Platform, 21 times. This is based on a simple word search of the documents using: "disability," "disabilities," "disabled," "special needs," and "handicapped."

"Although most disability activists lean Democratic, disability issues don't all fit neatly into one particular ideology," said Andrew Pulrang of Plattsburgh, NY, a disability blogger and co-coordinator of #CripTheVote, a nonpartisan campaign to engage both voters and politicians in a productive discussion about disability issues. "Overall, it seems like the Democratic Party platform gets more specific and takes stronger, less equivocal, stands on disability issues than the Republican Platform.

"From a practical standpoint, the most impactful thing the Democratic Platform is calling for is ending sub minimum wage, which might be traumatic for some in the short term, but in the long term would be a positive move," he added. "In the Republican Platform, it's

probably the idea of block granting Medicaid, which as I said, could put almost all developmental disability services into disarray, with little prospect of better services emerging from the chaos, since the whole point of block granting is to spend less money."

So, while the Republican Platform isn't as condescending or sentimental about disability as I thought it might be," Pulrang said, "the Democratic Platform seems to have a better grip—though not perfect—on the broad scope of issues faced by people with disabilities, including those with developmental disabilities."

RespectAbility, a nonprofit, nonpartisan organization working to enable people with disabilities to have a better life, tries to gain clarity through a 16-point questionnaire. Last winter, it gave all major candidates the document, which asks their positions on disability rights and equal opportunity for all.

The questionnaire was premised on the fact that one-in-five Americans has a disability. Although African Americans, Hispanics, women, and other groups have made important progress in the last decades, almost 70 percent of the 22 million working-age Americans with disabilities don't have jobs. This leads to poverty, prison, and poor health outcomes, according to RespectAbility.

Each year more than 300,000 young people with disabilities reach the age to enter the workforce. Despite polls showing that most of these youth want to work, they often are unsuccessful because of failed policies and negative stigmas, the group adds.

According to word searches compiled by *The New York Times*, the word disability barely even registered on the word clouds during the 2012 conventions by either party. The word "disability" hardly was mentioned at town halls or debates.

"Disability is an issue that is really still in the shadows," RespectAbility President Jennifer Laszlo Mizrahi said. "There's so much stigma around disability that people don't really talk



about it publicly. I am especially pleased to see that employment for people with disabilities made it into both the Democratic platform and the Republican platform [in 2016].”

RespectAbility remains eager to learn the candidate’s positions on disability issues. Hillary Clinton provided answers to the questionnaire; Donald Trump had yet to respond by press time for this issue of *People and Families*. On his campaign website, by press time, Trump had also not provided specific policy positions on disability issues, or suggestions on how he would create jobs for this significant factor of the American population.

RespectAbility had nine reporters in New Hampshire and Iowa during the primary season to interview the candidates and to urge them to fill out the questionnaire. Jeb Bush filled it out entirely, while John Kasich, New Jersey Governor Chris Christie, and Ben Carson provided additional responses from the GOP side. When RespectAbility asked Trump when he would fill out the questionnaire, his response was, “We are going to have a plan and you are gonna love it,” Mizrahi recalled. “We have since spoken to the campaign multiple times and there is no plan.”

In contrast, during her acceptance speech at the convention, Clinton spoke at length about her early exposure to people with intellectual and developmental disabilities while working with the Children’s Defense Fund, “going door to door... on behalf of children with disabilities who were denied the chance to go to school.”

Meanwhile, Trump did not focus on people with disabilities in his speech. But

his son, Eric, said the candidate is running for “families with special needs children.” The word “disability” was not used a single time throughout the Republican National Convention on the main stage at prime time, RespectAbility notes.

“To single mothers, to families with special needs children, to middle class families who no longer can afford medical benefits sufficient to cover their everyday needs, my father is running for you,” Eric Trump said.

Below are reports from both conventions, highlighting the roles of people with disabilities in the process:

REPUBLICAN NATIONAL CONVENTION July 18-21 — Cleveland, Ohio

Besides VanHoose, the Republicans invited Margo Hudson, who has a learning disability, to recite the Pledge of Allegiance, while Brock Mealer, who has a spinal cord injury, spoke the



Margo Hudson, who has a learning disability, stands with RNC Chairman Rance Priebus and recites the Pledge of Allegiance at the 2016 Republican National Convention.— Photo Credit: J. Scott Applewhite/AP Photo

final night of the convention, when Trump accepted the party's nomination.

RespectAbility had reporters in the crowd, asking the party faithful to discuss Trump's position on people with disabilities. Reactions ranged from excited to lukewarm, it was reported.

"The one thing coming from New York, he respects disabilities," said Amanda Downing of Louisiana. "Every single building, he was one of the first people to recognize that people with disabilities need help. He corrected a failing ice skating rink; it was all disability accessible. He is very, very respectful of disabilities."

Lonnie LuAnderson of Oklahoma told RespectAbility she was optimistic about changes Trump could make for people with disabilities.

"They're willing to give more money and more accommodations for people that don't live here in America that aren't US citizens, and that's gotta change," she said of Democrats. "And with Trump I think that will change. I know with Hillary it won't. We don't really know what Trump's gonna do. Well, he's not a politician, which is good."

Mark McKinnon, founder of the bipartisan center No Labels and media advisor to President George W. Bush responded to RespectAbility's question of whether Trump could lead the charge to create opportunity and eliminate barriers for people with disabilities.

"I think that the Republican Party's message is to create freedom and opportunity for everybody, and that should include everybody in the disability community," he said. "I have a brother who is paralyzed and uses a wheelchair. When we were teenagers, we had to fight the school board to even let him back into the public school where he was hurt. So I have a lot of sympathy and understanding for the fights that people with



Donald Trump, the 2016 Republican nominee, delivers his speech at the Republican National Convention in Cleveland, OH.

—Photo Credit: Jeff J. Mitchell/Getty Images

disabilities face. So if the Republican Party is true to its word, as you create opportunity, you eliminate barriers for everybody."

Mizrahi noted: "2012 Republican presidential nominee Mitt Romney did not reach out to voters with disabilities at all, which became a contributing factor to his loss. As Donald Trump and down ballot Republicans look toward the general election, reaching out to the disability community can mean the difference between winning or not."

Another co-coordinator of #CripTheVote, Gregg Beratan, said Trump's positions on his website regarding healthcare and reforming the VA are "of great concern" to the disability community.

"But interestingly enough, the only real reference to disability is a very vague promise to improve care for veterans with PTSD (Post Traumatic Stress Disorder) & TBI (Traumatic Brain Injury)," said Beratan, an educational consultant and disability rights activist. "Other than that, he has implied that he would be great for the disability community because he made all buildings ADA compliant, a legal requirement.

The 2016 Republican platform strongly supports the *Americans with Disabilities Act* (ADA), specifically mentioning the importance of employment of people with disabilities.

DEMOCRATIC NATIONAL CONVENTION

July 25-28 — Philadelphia, Pa.

People and Families had the opportunity to cover the convention for the New Jersey Council on Developmental Disabilities, in which Anastasia Somoza, a young woman with cerebral palsy delivered a speech on the opening night. There was also Senator Harkin celebrating the ADA and former Representative Gabby Giffords discussing mental illness.

While she has touted her work with the Children’s Defense Fund on countless occasions, Clinton recalled: “I remember meeting a young girl in a wheelchair on the small back porch of her house. She told me how badly she wanted to go to school—it just didn’t seem possible.”



Democratic Presidential Nominee Hillary Clinton addresses attendees of the 2016 Democratic National Convention in Philadelphia, PA.
—Photo Credit: John Locher/AP Photo



Anastasia Somoza, a young woman with cerebral palsy, delivers a speech at the opening night of the 2016 Democratic National Convention.
—Photo Credit: Aaron P. Bernstein/Getty Images

Her focus was on a child with the disability, rather than a parent or another surrogate. “It’s a big idea, isn’t it? Every kid with a disability has the right to go to school!” Clinton added, to cheers.

The Democratic platform has 35 mentions of disability, up from 17 in an earlier draft. People with disabilities are included in numerous sections, from employment, community integration, minimum wage, and housing to technology, education, and voting rights—and not just segregated in its own section.

The platform also includes support of the *Disability Integration Act* (DIA), which would ensure that people in need of long-term services and supports such as personal care attendants can receive these services while living at home or in the community instead of in developmental centers.

While the Democratic platform still doesn't mention the DIA specifically, it now includes wording and sentiment that support the act:

"We will protect and expand the right of Americans with disabilities to get the accommodations and support they need to live in integrated community settings ... Programs that emphasize independence rather than institutionalization must be better structured to support them," the platform states. "Democrats

will take steps to strengthen and expand the home care workforce, give seniors and people with disabilities access to quality, affordable long-term care, services, and supports, and ensure that all of these resources are readily available at home or in the community."

The DNC platform also reaffirms the ADA and the need to "improve access to meaningful and gainful employment for people with disabilities." **P&F**



WHAT BOTH SIDES ARE MISSING



Alice Wong, who is another co-coordinator of #CripTheVote, is also the Founder and Project Coordinator for the Disability Visibility Project™ (DVP), a community partnership with *StoryCorps* and an online community dedicated to recording, amplifying, and sharing disability stories and culture that started in 2014. Wong is Staff Research Associate for the Community Living Policy Center at the University of California in San Francisco, a Rehabilitation Research and Training Center funded by the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), and the Administration for Community Living.

People & Families asked Wong what she believes are some key issues that neither political party is discussing this campaign season.

"Disability rights have seemingly only just begun to enter the periphery of the vision of mainstream American politics, so there are many issues we see being omitted," Wong said. She points to four key issues:

Violence. "We live in a world where women with disabilities are more likely to encounter domestic violence and 19 people in Japan were murdered because they were disabled. We live in a country where many people of color who are killed, profiled, brutalized, or harassed by police are also disabled people of color."

Community Living: "The campaigns need to focus on funding of Medicaid Long Term Services and Supports (LTSS). These services allow people with disabilities to live in the community independently. Not all states offer community-based LTSS and

many people are on waiting lists for years or are forced to live in nursing homes. The *Disability Integration Act* (DIA) of 2015 will establish a federal law that will make states and insurance providers offer community-based LTSS. The DIA also requires states and insurance providers to pay competitive rates for the caregiving workforce (a major concern that affects the Baby Boomer generation). It also requires states to provide more affordable and accessible housing for people with disabilities."

Employment: "We need to have a serious discussion about why the unemployment rate for people with disabilities is consistently more than twice that of non-disabled people. The current administration has been aggressive about going after disability discrimination, but clearly much more needs to be done."

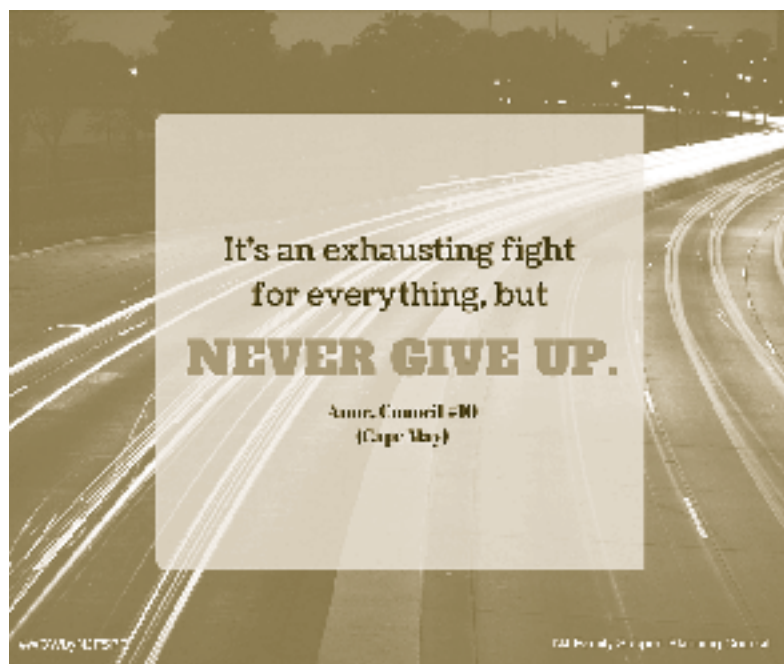
Education: "We have also heard very little on education in this election cycle. Public Education is failing students with disabilities and has been for some time. Students with disabilities are more likely to be targeted by school discipline measures, more likely to not complete schooling (the graduation rate for students with disabilities is 60% compared with 80% for non-disabled). Students with disabilities are still the only students who can legally be segregated in the country."

For a stronger sense of what the disability community's policy priorities are, please see a poll that #CripTheVote ran during the primary season. View the results here:

<https://www.surveymonkey.com/results/SM-VYKHSXWW/>

WORDS OF WISDOM: FROM ONE PARENT TO ANOTHER

By Brenda Considine



The best advice often comes from those who have walked in your shoes.

With that thought in mind, the New Jersey Council on Developmental Disabilities' (NJCDD) Statewide Family Support Planning Council launched a new Facebook campaign. The campaign is called "Words of Wisdom" or WOW. WOW is a burst of short, effective information and encouragement to families, from families. It is designed to support parents and to recruit younger parents to join the Regional Family Support Planning Councils (RFSPCs).

Many of the parent volunteers on the RFSPCs have been part of the movement for years and now have adult children. The committee wants to reach out to parents of younger children. They are hoping a social media campaign might help.

The idea came from the RFSPC Public Relations Strategies Committee - Gabrielle Bohon, Margaret Hefferle, Eileen Hurley, and Jennifer Owens. Together with Kyoko Coco, the NJCDD's Statewide Family Support Coordinator, they invited parents to share ideas and strategies with other parents on Facebook.

A New Era in Parent Support

Parent-to-parent support is nothing new, but using social media to build connections and to increase engagement is. For decades, parents have

sought advice and guidance from other parents who share experiences through support groups.

Margaret Hefferle lives in Lincoln Park. She is chairperson of the RFSPC #1. That council monitors family support services in Morris, Sussex, and Warren Counties. Margaret has a 27-year old son with autism. She is part of the team who came up with the idea for WOW.

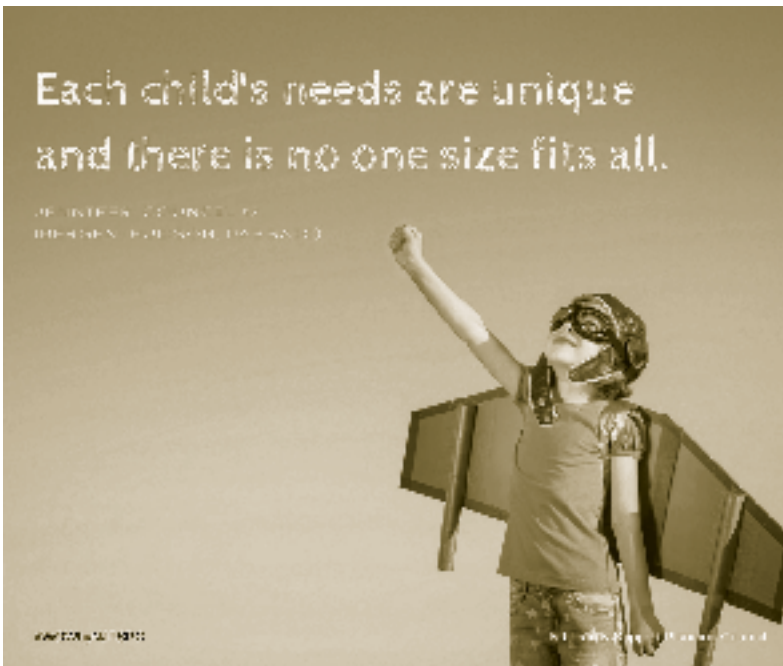
For nearly 20 years, Margaret had been part of a support group for parents of children with autism. The group, called ARISE, met once a month on a Friday night.

"When the meetings were over, a group of us would stand in the church parking lot till midnight, just talking," she recalled.

Eventually, the support group ended due to funding cuts, but Margaret and others continued to meet informally. Their needs had changed and their children were older, but they felt a very strong connection.

"We just understood each other. We all have children and they are all different, as are we. When we get together, we share our common experiences. We laugh out loud, a lot," she said.

She hopes that the WOW campaign can re-create that sense of connection and camaraderie.



Stories and words of encouragement are shared by family advocates on the Family Support Councils' Facebook Page

Advice that is Useful, Honest... and Funny

The group asked members of each RFSPC to submit “Words of Wisdom” within several general themes:

- **Your Support System:** You need people who ‘get it!’ How did you meet your support system? How did you cultivate it?
- **Preparation:** What’s always in your bag of tricks? What do you wish you had known when you started this journey?
- **“The Chosen People:”** How do you handle well-meaning friends, who think you were just perfect for your “role”?
- **Dealing With Sibling Rivalry:** It isn’t really a fair fight.
- **Favorite Quotes:** Share where your inspiration came from.
- **Funniest Thing My Child Did:** Humor can be therapeutic.
- **The Most Memorable Thing You Heard:** Appreciation from your own child? Validation you needed? Biased comments you proved wrong?

The committee wants the advice to be real, useful, and upbeat.

Eileen Hurley is the chairperson of the committee. For the last 18 months, she has

served on RFSPC #4, which represents Essex County. She admits that every family has a nightmare story, but that is not the purpose of WOW.

“We are trying to keep things very positive and offer help,” she said.

Margaret agrees.

“In the news, we hear so many bad stories. We want to create a place for good stories. Facebook is full of advice and stories. As parents of children with disabilities, we have many of our own good stories and anecdotes to share,” she said.

Gabrielle Bohon’s 17-year old daughter has Down syndrome. Gabrielle knows how important it is for the tips and ideas to be real. That might mean they are also funny.

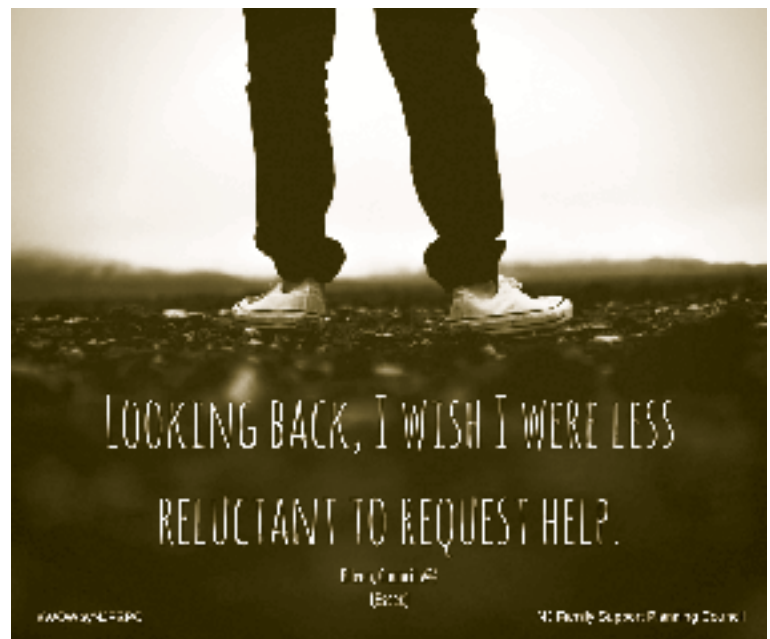
“It is not all challenges and difficulties. Some of the stories are funny. We are just like any other parent. Our kids do funny things and make us laugh. You have to find the humor in everyday life,” said Gabrielle.

Building Engagement

The outreach effort has been building for months. Eileen, a public relations professional by training, wanted more parents to know about the RFSPCs so she started the Public Relations Strategies committee. The group meets by phone about once a month.



Shared by Artea, RFSPC #5
(Hunterdon, Middlesex, and Mercer Counties)



Shared by Eileen, RFSPC #4
(Essex County)

The New Jersey Family Support Planning Council started its Facebook page about eight months ago. Today the page has more than 340 “likes” and it is growing. Kyoko wants the page to become a dialogue and a way to build awareness among families about the RFSPCs.

Jennifer Owens is a member of the committee and serves on RFSPC #2. Like many of the parents who are part of the RFSPC, Jennifer’s son is now in his 20s. She wants to see parents of younger children more engaged.

“There are programs and benefits available, but parents with younger children may be under the impression that those programs were always there, and will always be available,” said Jennifer.

“We must continue to advocate for the programs we have, and at the same time, continue to push for new and better programs. There’s lots of work to be done. We need parents of younger children to join in the fight to push to increase the availability of family support service for the families and people with disabilities,” said Jennifer.

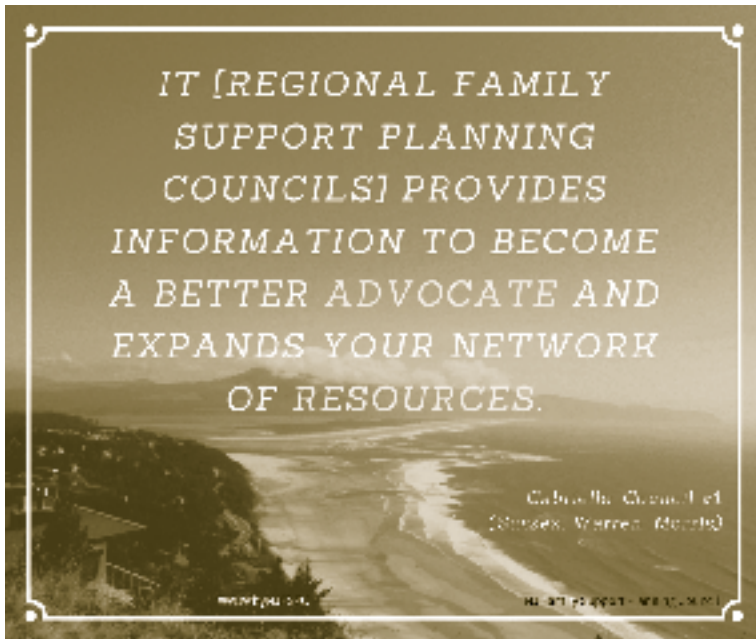
So far, more than 100 comments and tips have come back as part of the WOW campaign. Kyoko has posted WOW comments to the Facebook page every day since mid-July. The effort will continue through the late fall.

Eileen’s son with autism is non-verbal. He just turned 25. She wants parents of younger children to know about *all* of the good things that the Council does.

In 2015, she graduated from the NJCDD’s *Partners in Policy-Making* program. It is an eight-month leadership education program for adults with disabilities and family members. The goal of the project is to prepare disability advocates to work for meaningful change in laws and policies. She said that program changed the way she looks at things, and helped her see more positive aspects of raising her son.

Eileen contributed to the WOW campaign. Here is her advice:

“I always pack my patience. Keeping a positive outlook among adversity is paramount. Looking back I wish I were less reluctant to request help. There is a natural inclination to be a martyr. To save your child on your own. The best-case scenario is a dynamic, energetic parent who can adapt to ongoing challenges. It takes a village to raise our children. Do not be afraid to relinquish control. There are unique and talented people who can impact the progress of your loved one in a positive way.” **P&F**



Shared by Gabrielle, RFSPC #1 (Sussex, Warren, and Morris Counties)



Shared by Annie, RFSPC #10 (Cape May County)

About the Regional Family Support Planning Councils

The *Family Support Act* of 1993 established the Regional Family Support Planning Councils (RFSPCs) to provide a way for parents and family members of people with developmental disabilities to come together to exchange knowledge and information about family support services. New Jersey was the first state with family support legislation that places family members in such a significant role in this process.

They advocate for families and individuals with developmental disabilities at the local and state level on issues that directly impact their lives. They also work with the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) on how to better serve individuals and their families.

There are 10 Regional Councils. Members of each council monitor and evaluate family support programs, inform families about current family support

issues, provide information to policymakers, partner with DDD and DCF, and advocate to local officials and state legislators about the needs of those who support a family member with Intellectual/Developmental Disabilities at home.

New Jersey Regional Family Support Planning Councils consist of family members. The main goal is to create, monitor and improve the Family Support Service system in the State of New Jersey.

Visit the Family Support Facebook page and read the Words of Wisdom from families across New Jersey at: www.facebook.com/NJFSPC/

Find out more about the Family Support Councils and how to get involved:

Kyoko Coco
 Statewide Family Support Coordinator
 Kyoko.coco@njcdd.org
 609-341-3112

FAMILY SUPPORT

STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

WANTED

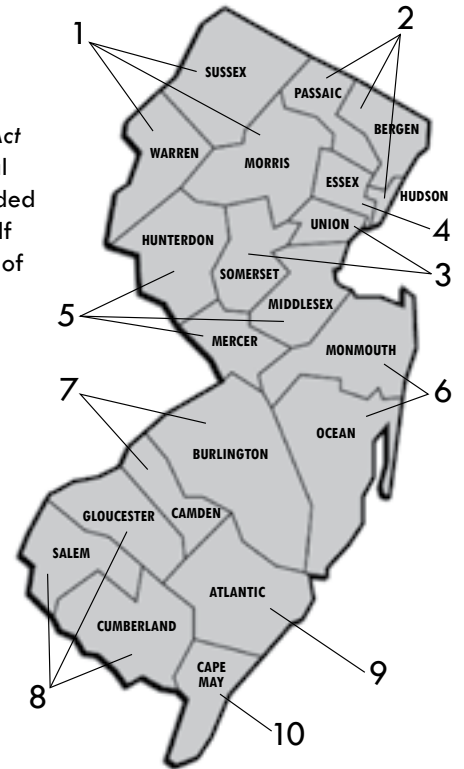
NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

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 Or visit our website at 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,
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
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
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
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
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
e-mail: 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
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 641
Mt. Laurel, NJ 08054
e-mail: 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
Co-Chairs: Sandra Backensto,
Lisa Parles

Meeting dates posted at 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
Co-Chairs: Larry Farber,
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
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



Gail Frizzell with her daughter Lauren at Lauren's home in Franklin, NJ

New Jersey's DSP Crisis

A Family Perspective

By Jonathan Jaffe

As people and families cope with the growing lack of Direct Support Professionals (DSPs) in New Jersey, and try to shore up the profession with qualified individuals before this shortage crisis worsens, there is a coalition desperate to bring the issue to the forefront.

Last October, a group of ten members from the Family Support Coalition formed the Direct Support Workforce Crisis Workgroup, comprising parents and others throughout New Jersey who are eager to share their stories about the critical need for well-trained, experienced, and compassionate DSPs in the ongoing care of their

loved ones. Many are concerned by the shrinking pool of DSPs across New Jersey and the nation, and what it all means to those with a lifetime of significant disabilities.

This workgroup considers the low pay of the profession a vital issue and will be working with the newly-formed Coalition for a DSP Living Wage this fall to hopefully secure additional state funding to boost salaries. The workgroup also has established a website—<http://directsupportcrisis.org/>—to educate the public and to encourage action.

Gail Frizzell of Wantage, who chaired the Direct Support Workforce Crisis Workgroup,

is balancing her time between this important advocacy work and caring for her 30-year-old daughter, Lauren. Securing qualified DSPs, and providing the necessary training, is an endless task.

Frizzell knows all about the budget limitations that plague the state year after year. But the need for better paid DSPs is too great to ignore. While asking for more money from the state coffers is a thankless task, it must be a necessary focus in the upcoming months, she says.

Life has been an ongoing juggling act for Frizzell. In June of this year, she lost a live-in caregiver who retired and had covered two shifts of her daughter's care. An advocate for 30 years on the state level, Frizzell says her daughter's disability and the necessary advocacy work is a full-time job, with endless nights and weekends.

"For four months, I searched on my own for a qualified DSP. Then I started working with a home health care agency—who couldn't find DSPs either," she says. "Fortunately, someone started on June 27 for one shift. Then, it took a few more weeks to find someone for the other shift, with the help of this agency."

"We have an ongoing vacancy to help with the weekend shift which I have been trying to find for two years," she adds. "I asked the agency to help. But the job is under a different funding stream and the reimbursement rate is low, so the agency won't consider taking us. Other agencies won't even come into Sussex County, where I live. So, our weekend coverage goes weekend by weekend. We never know."

Five years ago, Lauren moved from her parent's house to her own home about 20 minutes away in Franklin, NJ, where there is 24-hour staffing. Frizzell, who is 60, and her husband, who is 80, recognize there are physical limitations in how they can care for Lauren, after spending so many decades tending to a daughter with a rare disorder, multiple disabilities, seizures, and an inability to walk, talk, or feed herself.

Frizzell says many of the DSPs begin with wages of around \$9 an hour, adding it is unfair to ask them to handle the toileting, feeding, diapering, and ongoing care of a full-sized adult while working at such a low wage. "If we were able to pay more money to DSPs, we would be tapping into a broader pool of caregivers and recognizing the level of skill and responsibility needed for this work," she says.

The state Department of Human Services (DHS) contracts with about 300 agencies and organizations to provide residential and community services/programs to more than 40,000 people with developmental disabilities in New Jersey, says Nicole Brossoie, DHS assistant commissioner for public affairs.

"We need to elevate DSPs to the level where the work is respected and acknowledged as lifeline for families."

— Lorraine D'Sylva-Lee

These agencies engage in recruitment efforts, as needed, to promote and expand the services they offer. They also determine the rate at which their employees are paid. The state does not dictate their employee pay scales, she adds.

It is important to note, however, that the state *does* set reimbursement rates that provider agencies receive.

A "Perfect Storm"

Last year, the New Jersey Association of Community Providers (NJACP) conducted a survey about DSP wages, aimed at determining the disparity between what positions are paid in the community with comparable positions in the developmental centers, as well as what the salaries averaged for large, medium, and small agencies. Benefits were also considered.



Lauren Frizzell and her DSP Cheryl Nance. Cheryl has been working with Lauren for six years. DSPs help people with disabilities, like Lauren, with much more than their physical needs. They provide emotional and behavioral support and companionship, and make it possible for many people with disabilities to lead full lives in our communities.

The average salary for a DSP in the community was \$24,257, (Federal poverty level for a family of four is \$24,250), while the same position in the state run developmental centers averaged \$40,350. Those salaries are governed by title, longevity, and duties, as prescribed by union contracts, Brossoie says.

About half of DSPs in New Jersey require some form of federal assistance, such as Medicaid and food stamps, to make ends meet, NJACP reports.

There are other important issues, such as the fact that only about half of the agencies are able to provide paid holidays, sick days, personnel days, and vacation days.

Agencies have also had to deal with no contractual revenue increases from the state in eight years, with any and all surplus required

to be given back to the state Division of Developmental Disabilities, NJACP reports.

NJACP considers the DSP shortage a “perfect storm,” as none of these five glaring issues appear to have a solution:

- Unlike home health aides or personal care assistants, DSPs may serve individuals with complex intellectual and behavioral health conditions whose challenges in navigating everyday life are far more than physical.
- DSPs must understand and act upon behavioral health plans developed by Masters and PhD level professionals, providing education and habilitation services to allow individuals with I/DD to further develop knowledge and master daily life skills.

- DSPs must complete extensive training to ensure a knowledgeable and competent workforce.
- DSPs must understand and comply with a significant number of complex regulations.
- DSPs are continually at risk of job-related injuries due to behavioral and mental health challenges of some of the individuals they serve.

Life with DSPs

Tom and Carol Hopkins have spent years working with DSPs, who have come and gone from their Bridgewater home. Some stay a few years, some stay a few months, some may even be around for just a few weeks.

They help care for the couple's 45-year-old son, Bobby, who has cerebral palsy and functions at the same level as a nine-month-old baby. Bobby has seizures, is non-ambulatory, non-verbal, and requires 24-hour-a-day care.

Carol Hopkins says her son has been involved in the Real Life Choices program for 10 years, in which the family manages his budget, hires staff, and handles his care—often challenging because of his uncontrolled seizures. Through the program, Bobby is able to remain living with his parents, with special bedding and a fully accessible house. Moreover, his living situation allows him to be involved in a day program run through the Somerset Arc.

Hopkins says the family is given a budget through Real Life Choices to support Bobby at home. The mother, who is a retired banker, likens the relationship to running a business. Sometimes, she interviews part-time DSPs through agencies, sometimes she finds them on her own. But the Hopkins family is responsible for coordinating scheduling and ensuring the DSPs are best qualified to handle her son, who she describes as being on the most profound end of the disability spectrum.

“Many DSPs want to work with clients who they can take to the mall or to the park,” she says. “But, with Bobby, we need DSPs who are willing to spend the day inside, at our home. He can sit up, but he's non-verbal. So, any DSP would focus on feeding him, diapering him, and bathing him. It is a certain type of DSP who would want to do that work.”

Hopkins says she has not really dealt with the common concerns of DSPs, such as the industry's low pay or lack of career advancement. The struggle, she says, is to find trained DSPs who are prepared to work with Bobby. She says the training for such work could be four to six months and that limits the pool of candidates that she can consider.

“The state is encouraging more and more families to be innovative in the approach to providing services. ...We need to be more proactive, but there are no supports in the system to help families do that. We shouldn't be left to flounder on our own.”

— Lorraine D'Sylva-Lee

Lorraine D'Sylva-Lee has been directing her daughter's care since 1998. Aaliya D'sylva has five DSPs; two full-time and three part-time, who come to the condo in Phillipsburg where the 33-year-old woman has lived since 2012.

“We have opted to self-hire our DSPs, which means that I end up the supervisor, the CEO, the trainer, the time-sheet keeper, and handler of all the needs associated with supporting my daughter,” D'Sylva-Lee says. “There is a very specific reason why Aaliya lives in Phillipsburg; it is where there is a large concentration of potential DSPs that we can recruit. It is 20 minutes from our home in Changewater; the urban area of Warren County.”

D'Sylva-Lee says she has been very strategic in securing DSPs, while remaining vigilant on



Lauren Frizzell and Julie McMichael, another one of her DSPs, who has been working with Lauren full time for over two months

state polices and legislation that could affect her daughter's care. She recognizes that only a precious few families are in her position to have such laser focus, and has empathy for many parents around New Jersey who she contends are completely lost in the system.

"The state is encouraging more and more families to be innovative in the approach to providing services," D'Sylva-Lee says. "We can't bury our heads in the sand and hope the system will somehow take care of us. We need to be more proactive, but there are no supports in the system to help families do that. We shouldn't be left to flounder on our own."

Rutgers University conducted a wage and salary study last year of DSPs, showing a 44 percent turnover rate in the industry. That equated to lost agency revenue of \$6,500 to \$8,000 per person being trained. The costs come from overtime for training personnel, background checks, fingerprinting, and physicals, NJACP reports.

Rutgers University conducted a wage and salary study last year of DSPs, showing a 44 percent turnover rate in the industry. That equated to lost agency revenue of \$6,500 to \$8,000 per person being trained. The costs come from overtime for training personnel, background checks, fingerprinting, and physicals, NJACP reports.

Training and workforce development for DSPs is provided through the College of Direct Support (CDS), an internet-based educational program for professionals that provides more than 30 competency-based online courses about disabilities, Brossoie says.

All private service providers that receive funding through the New Jersey Medicaid Community Care Waiver have been given access to the CDS programs and have been provided with technical assistance by the Elizabeth Boggs Center on Developmental Disabilities at Rutgers University in New Brunswick on the use of this curriculum as well as the online management system to record and track courses taken by staff members, she adds.

Through coordination by The Boggs Center, the voluntary “Career Path” program uses the College of Direct Support (CDS) in combination with onsite mentors to enhance professionals’ skills, the state official notes.

While the CDS is a highly valuable tool for the training and development of qualified DSPs, issues do persist, particularly for individuals and families who seek to hire staff themselves. Many individuals and families do not have as much time to train their self-hired staff as provider agencies would. Particularly for those with barriers to computer access, literacy, or language, the ability to fully utilize CDS training materials can be problematic. Especially when they don’t have existing DSP staff to provide care while new staff is trained.

The Future

DSPs have their struggles; so do the agencies that provide them. NJACP says there are changes to federal regulations that can negatively impact providers. There is concern that many agencies will close shop or remove essential services from people with disabilities who rely on them. Of paramount concern:

- The Department of Labor is increasing the current threshold for the overtime exemption from \$23,660 to \$47,476, costing providers millions in overtime expenses. The threshold will be updated every three years based on the national salary averages in the lowest census region in the US, which is the south.
- There is no commensurate increase in the Medicaid reimbursement to cover additional overtime expenses.
- There are increased costs to comply with Home and Community Based (HCBS) Final Rule and New Jersey’s State Plan.
- There are additional costs associated with the State Transition Plan; providers must now absorb the cost of assuming responsibility as landlords resulting in more administration/regulatory requirements.

D’Sylva-Lee says DSPs must no longer be devalued in society. Families should no longer have to compete with the likes of Walmart or McDonald’s in recruiting low-income people to serve as caregivers. “There are no efforts in New Jersey to recruit people for this type of career,” she says. “We need to work with community colleges. We need to help families recruit. We need to raise the hourly wage!”

“We need to elevate DSPs to the level where the work is respected and acknowledged as lifeline for families,” she says. “This is not babysitting. This is not glamorous work. But DSPs give my daughter a life of dignity, filled with humanity. They deserve so much more.” **P&F**

The Direct Support Workforce Crisis Workgroup website:

<http://directsupportcrisis.org/>



WE THE PEOPLE

At the Midland school, all students are encouraged to vote in their student government elections. Students as young as five can cast their ballots and have their voices heard

Preparing Students with Disabilities for Civic Engagement

By Brenda Considine

It is Friday afternoon and the class has earned an ice cream party. Will it be chocolate or vanilla? Lets take a vote!

Democracy can be expressed in ways that are simple and concrete, but no matter how it happens, hands-on civic education is essential to sustain our constitutional democracy. We are not born with a natural inclination for democracy—we learn it.

According to the Center for Civics Education, schools must go beyond teaching basic knowledge about democracy and the role of citizens in that democracy. Students must learn and use civics skills. They must learn how to participate in group discussions and decision-making. They must learn about and develop a ‘civics disposition’—character traits essential to building and improving democracy.

Researchers have looked at outcomes of recognized civics curriculums and found that students who take part score significantly higher than other students in six important measures:

- 1) respect for the rule of law;
- 2) political attentiveness;
- 3) civic duty;
- 4) community involvement;
- 5) commitment to government service; and
- 6) the norms of political efficacy and political tolerance.

Few studies have looked at citizenship skills among students with disabilities, but those that have show that students with disabilities do not do as well as general education peers on tests of basic civic competence. They need more.

Civic Education In Action

From small acts of kindness to community-wide projects, civics education through service learning teaches students to “pay it forward.”

In Haworth, NJ, the Bergen Center for Child Development was the nation’s first special education school to form a Rotary Interact Club. Sponsored by the Rotary Club of Northern Valley,

the Bergen Center’s Rotary Interact Club encourages students to give back to their communities as part of a worldwide network of students their own age. The school has focused its service on Pascack Valley Meals on Wheels, making emergency kits for seniors, and projects at local nursing homes.

“We know that civic engagement needs to start in our own back yard,” said

Susan Raymond, school principal.

“Through the Rotary Interact Club, our students—many of whom have received so much—learn that they have a lot to give to others,” she added.

“The program helps our students meet community leaders who see them as contributing citizens. This can lead to jobs,” she concluded.

The non-profit school, which serves students ages 5-21 with developmental and intellectual disabilities, also has an active Student Council, giving students a chance to learn about democracy in a hands-on way as they make decisions about school-wide issues.

Preparing Leaders for Tomorrow

For many students with disabilities, civic engagement can lay the foundation for self-advocacy skills.

From small acts of kindness to community-wide projects, civics education through service learning teaches students to “pay it forward.”



Sponsored by the Rotary Club of Northern Valley, the Bergen Center for Child Development's Rotary Interact Club encourages students to give back to their communities

Frank Latham is the founder and program director for the Youth Leadership Project, which has been offered by the New Jersey Council on Developmental Disabilities for nearly a decade. Working with schools and community groups, the program teaches eight units designed to build transferrable leadership skills in young people with disabilities.

Latham sees civics education, civic engagement, and leadership skills as the foundation for self-advocacy. Whether through participation in formal student government or simply learning how to ask for a new menu item at school lunch, students with disabilities need to learn the character traits of good leaders and have the opportunity to model leadership skills.

“Young people need to get involved, either at school or in their own town. By taking action around something that matters to them, they develop their own beliefs as advocates, as citizens, and as voters,” said Latham.

Latham believes that the single best practice for educators is to provide ways for students to get directly involved in making change.

“Students learn by doing. Once you give students the foundation, not only are they better students of government, they understand the process and are more ready to make civic decisions,” he concluded.

The Peer Leadership Program at New Road School in Ocean County is preparing students for citizenship by training them to be young leaders.

Students apply to be part of the program and—like a candidate seeking to be on the ballot—must get signatures to support their application. Once selected, they meet with school staff monthly to plan events and activities.

“We focus on what it means to be a leader, qualities of leaders, and the importance of community service,” said Diane O’Donnell, Director of New Road of Ocean County.

Peer leaders are assigned as greeters at public events. Last year, they planned and managed a “Random Acts of Kindness” campaign—including an assembly—to encourage fellow students to show kindness and support.

“The Peer Leadership Program prepares them to be good citizens and good neighbors because it invites them to look outside of themselves at their own communities to see who needs their support,” concluded O’Donnell.

Student Government: “Of the people, by the people, for the people”

Student government plays a vital role in providing hands-on knowledge of and practice in the democratic process. At The Midland School in Branchburg, the student council functions like any student government. Participants are elected by the entire student body—children as young as 5 can vote. The voting process requires students to register, and there is a campaign complete with an assembly, speeches, and posters.

Those elected to serve on student council develop leadership skills while providing service

Benefits of Joining Student Government

Networking: Meet other students with similar interests.

Social & Communication Skills: Learn how to talk to other people and solve problems.

Leadership Skills: Hands-on training will teach good leadership skills.

Community Connections: Student organizations are often connected to community leaders. This can help students with job searches and mentoring.

Friendships and Fun: meet people and build lasting friendships.

Adapted from the NASC



At the Midland School in Branchburg, candidates for student government give speeches and campaign to their fellow classmates.

to the school and the larger community.

Comprised of about a dozen representatives from each high school homeroom, the council meets once a month to discuss student concerns, determine themes for dances and events, organize school spirit days, and plan service projects.

Student council has been part of The Midland School for more than two decades.

Francine Giorello, special education teacher and student council advisor, knows that while only a handful of students are elected to lead, the student council engages the whole student body.

“All the students get a copy of the agenda and minutes of the meetings, which is discussed throughout the day. They can also get involved in council-led activities,” she said.

The Midland School offers all students the chance to petition for change with a “Suggestions

Box” near the main office. Students have successfully lobbied for more hot lunches in the cafeteria, additional overnight respite outings, and changes to the playground.

The experience exposes all of The Midland School’s students to the democratic process.

“They learn to put forth an idea and help make change happen as a result. It is very empowering,” concluded Giorello. “They learn the process and how to use the proper channels.”

“Student council shows students that their voice matters. They can take action and make a difference,” added Robin Casucci, a speech language therapist who serves as assistant advisor to the Student Council.

Character Education

Researchers know that there is a strong relationship between civics education and character education. At Westbridge Academy, character education is the foundation of all instruction and learning. The school, located in Bloomfield, NJ, serves students with learning, social, and behavioral disabilities. There, staff teach the six pillars of character: trustworthiness,

Teachers: What Can YOU Do To Build Civic Engagement in Students

- Encourage Students to Develop and Express Opinions
- Encourage Students to Vote on Classroom Decisions
- Consider a Student Newspaper
- Work to Make Community Service part of Your Lesson Plan
- Take Part in School-wide and Community-based Donation Drives
- Invite students to discuss Current Events—Local, State, National and International Issues

respect, responsibility, fairness, caring, and citizenship.

“We want our students to be global citizens—to be able to advocate for themselves and also to learn how to be part of a democracy,” said Dr. Viviana Litovsky, the school’s executive director.

While only a handful of students are elected, the Midland School student council engages the whole student body.



“We have found that through character education, our students grow beyond ‘tolerance’ to a true appreciation of diversity,” she added.

Many Westbridge students go on to take part in the New Jersey Department of Education’s annual Dare to Dream Student Leadership Conference, both as participants and as presenters.

“We teach our students how to take self-advocacy to the next level by bringing their skills and knowledge to others,” she concluded.

Character, civic engagement, and self-advocacy are deeply intertwined. Each requires learning skills that build a foundation for meaningful citizenship in a complex democracy. It gets down to the belief that change is possible!

“The opportunity to affect change is very powerful and exciting,” said Latham. “Young people need the chance to decide what matters to them and learn to speak up and organize for change. It is how our country was built.”

Latham is sure to tell young people an important message:



The Peer Leadership Program at New Road School in Ocean County is preparing students for citizenship by training them to be young leaders.

“You have the keys to the planet much sooner than you realize. There are things that seem insignificant to you now, but once you have these skills, they appeal not only to teachers and employers, but to friends as well. It is exciting to be around leaders. And anyone can learn how to grow as a leader—no matter who you are,” Latham concluded. **P&F**

RESOURCES

New Jersey Association of Student Councils

<http://www.njasc.org/index.html>

Center for Civic Education

<http://www.civiced.org/>

National Constitution Center

<http://constitutioncenter.org/learn/educational-resources>

American Student Government Association

<http://www.asgaonline.com>

National Association of Student Councils

<https://www.nasc.us/?SSO=true>

NEW JERSEY

2016

CONGRESSIONAL RACES



The NJCDD 2016 Election Questionnaire

Candidates from New Jersey's Congressional Races Weigh in on Disability Issues

Much of the news coverage around this year's election centers around our major candidates for President of the United States. However, Election Day (which, this year, will be held on Tuesday, November 8) will also give New Jersey voters an opportunity to elect legislators to represent us in the US House of Representatives. This year, each of our state's 12 Representatives will be decided upon by voters. With that in mind, it's very important for us to be informed on the issues that matter most to us and our families.

Over the summer, *People & Families* Magazine repeatedly contacted the campaign offices of New Jersey's Republican and Democratic candidates for the US House of Representatives, and presented each of them with a list of six questions that address major

issues of importance for New Jersey residents with developmental disabilities and their family members.

Of the 24 candidates contacted for this survey, six have submitted their responses in time for the publication of this magazine. Any additional candidate responses received after the publication of this magazine will be listed on the NJ Council on Developmental Disabilities' website at www.njcdd.org.

The topics addressed in the survey include Social Security and Medicaid funding, Direct Support Provider wages, restraints and seclusion, employment, and transportation. Below is a complete list of the questions asked. Following that are the full and unedited responses for each of the candidates invited to participate in this survey.

The NJCDD 2016 Election Questionnaire

QUESTION 1: Federal Funding for Disability Support

Federal funding sources such as SSI, SSDI, and Medicaid are a common way in which individuals with intellectual and developmental disabilities (I/DD) secure critical support services that allow them to lead meaningful and productive lives within our communities. In your view, how should such programs be modified to ensure that individuals with I/DD are able to receive the support services they need in community-based settings?

QUESTION 2: Direct Support Provider Wages

Home Health Aides and Direct Support Professionals (DSPs) provide the kind of vital day-to-day support for individuals with I/DD that makes it possible for such individuals to live successfully in our communities, and America's need for workers in these professions is projected to increase dramatically in the coming years. However, current funding models keep DSP wages at very low levels – around just 10 dollars an hour, on average in New Jersey – and prevent these professionals from securing full-time work or benefits. As a result, the turnover rate in this field is staggering, with support provider agencies struggling to retain qualified staff. How would you work to address this issue to ensure that qualified DSPs are able to stay within this profession?

QUESTION 3: The Use of Restraints and Seclusion in our Schools

Research shows that both physical and chemical restraints and seclusion practices in schools are used disproportionately on children with disabilities, frequently resulting in trauma, injury, and even death. The federal *Keeping All Students Safe Act* (KASSA) would allow the use of restraints and seclusion only in extreme emergency circumstances. Thus far, only two US Representatives from New Jersey have co-sponsored the bill. How would you act to ensure that children with I/DD are kept safe in New Jersey's schools?

QUESTION 4: Employment First

Many New Jersey residents with developmental disabilities have expressed either an increased desire or an outright expectation for having a steady job that pays a competitive wage. In April of 2012, Governor Chris Christie declared New Jersey to be an "Employment First" state. What does that distinction mean to you, and how would you work to create an environment where employers are not only willing, but eager to hire people with disabilities for paid positions?

QUESTION 5: Transportation

Adequate and easily accessible transportation options play a critical role in ensuring that individuals with I/DD are able to live, work, play, and exercise their rights as citizens as included members of our communities. However, in New Jersey, many individuals with I/DD find traveling throughout our state and beyond to be a considerable challenge. How would you address our state's need for increased accessible transportation options?

QUESTION 6: Vision for the Future

In your view, what do you see as the most ideal future for people with developmental disabilities in our communities? How would you work toward achieving that ideal?

Candidate Responses

US HOUSE OF REPRESENTATIVES

DISTRICT 1

(Republican) Bob Patterson

As of press time, no responses have been submitted by the candidate

(Democrat) US Congressman Donald Norcross



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT: Social Security, Medicare, and Medicaid have been the cornerstones upon which disability policy have been built over the last quarter century.

It is important not only to preserve these programs for future generations, but also ensure they work better for current generations. Earlier this year, I introduced legislation that would change how cost of living adjustments (COLA) are calculated for people on SSI and SSDI to better align their COLAs with the increases in goods and services that beneficiaries are actually purchasing. For example, this new formula would weight increases in the cost of health care services more heavily, given that individuals with disabilities are high utilizers of health care services.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES: Home Health Aides and DSPs play critical roles in the continuum of care and constantly face new challenges as they serve the needs of the burgeoning home health care market. Earlier this year, I introduced a bill that would raise the minimum wage for all Americans to \$15, including home health aides. Raising the minimum wage would help boost all American's wages and ultimately allow home health aides to remain focused on the important work of delivering care, without being

worried about whether they are going to be able to pay their bills.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS: I am proud to be one of the two cosponsors from New Jersey of the *Keeping All Students Safe Act* (HR 927). Restraints and seclusion should only be used in extreme emergency circumstances and should not be ordinarily employed as a condition of a child's education. Furthermore, any use of restraints or seclusion should be wholly transparent and reported to parents promptly and comprehensively.

QUESTION 4—EMPLOYMENT FIRST: New Jersey is fortunate to have some of the best rehabilitation programs in the country. An "Employment First" State means to me that integrated employment should be our State's goal for all of its residents, and more specifically that individuals applying for jobs should be judged upon their ability to discharge the duties of a job, not based upon an employer's preconceived notion of a person with a disability. I support employment for people with disabilities in the most integrated setting possible, as well as creative employment options for the most severely disabled individuals, including rehabilitation therapy.

QUESTION 5—TRANSPORTATION: Access to transportation is a critical part of ensuring that individuals with disabilities in New Jersey are able to reach their full potential. I was proud to support the passage of the *FAST Act* this past Fall, that included more than a 10% increase in formula grants for the enhanced mobility of seniors and individuals with disabilities. While a 10% increase is a good start, it is not nearly enough. I support increasing access to public transportation for all Americans and people in New Jersey, including the construction of a Camden-Glassboro light rail line,

The NJCDD 2016 Election Questionnaire

which would have the added benefit of increasing the ease of transportation and independence of individuals with disabilities.

QUESTION 6—VISION FOR THE FUTURE: The ideal future that I envision for individuals with developmental disabilities entails ensuring that all Americans are able to reach their full potential and includes two specific goals. First, we must continue to modify laws/programs comprehensively to ensure that all venues/opportunities are open to any American, with or without a disability, who are capable of performing the task. As discussed above, barriers to meeting that goal can include discriminatory employment policies, lack of access to high quality rehabilitation and medical services, and even issues with transportation. The second goal is to increase our understanding of the science behind developmental disabilities and invest in ways medical advancements that ameliorate or eliminate those disabilities. During my time in Congress, I have been proud to support and sponsor legislative efforts to increase funding for the NIH and CDC dramatically, so that they might be able to pursue new breakthroughs in a variety of questions that have evaded researchers for decades.

DISTRICT 2

(Republican) US Congressman Frank LoBiondo

As of press time, no responses have been submitted by the candidate

(Democrat) Dave Cole

As of press time, no responses have been submitted by the candidate

DISTRICT 3

(Republican) US Congressman Tom MacArthur

As of press time, no responses have been submitted by the candidate

(Democrat) Frederick John LaVergne

As of press time, no responses have been submitted by the candidate

DISTRICT 4

(Republican) US Congressman Chris Smith

As of press time, no responses have been submitted by the candidate

(Democrat) Lorna Phillipson



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT:

There has been a reduction of benefits through SSI, SSDI, and Medicare over the years and this needs to be corrected. The government should be providing better care, not less. We can enable the disabled to live within their community, just like able-bodied people. We should be providing a better support system to the families, rather than leaving them on their own. Charitable groups are essential, but government subsidies and direct support for caregiving, transportation, healthcare, and education can provide the missing piece. With increased autism in children and other developmentally challenged children becoming adults, we need to expand care and training.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES:

Wages in general are too low. We cannot expect workers to struggle with poverty level salaries. The Living Wage in NJ is over \$20/hr. No doubt, better pay, benefits, and working conditions would reduce the turnover for DSPs. Recognition for their hard work and dedication also helps. Assistance with training might be useful.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS:

I have been appalled at the excessive use of restraints and seclusion. We hear way too many stories about children abused in

The NJCDD 2016 Election Questionnaire

these ways at public and private schools. Training teachers, aides, and caregivers better methods to deal with developmentally disabled children is necessary. Greater understanding by administrators, the police, first responders, and others is essential. New legislation can provide better support for the children and adults in their care.

QUESTION 4—EMPLOYMENT FIRST: Remind employers that a disability does not mean “incapable”. Encourage companies to hire people with disabilities through subsidies, if necessary. Even veterans with brain injuries want to have opportunities to stay in a productive society. The government can and should legislate to encourage employers to hire the developmentally disabled.

QUESTION 5—TRANSPORTATION: There has been minimal effort to address transportation issues and the state can and should add funding to remedy the situation. Many of us recognize the problem when we become temporarily disabled from injuries. I have lived in other countries and noted how little has been done in other countries, but am extremely critical of the situation in the US. I am well aware of the challenges because of memory loss in my elderly parents, my friends who have mentally challenged and autistic children, my friends who have brain injuries from accidents, illnesses, or war.

Frequently, people will recognize the physically disabled but fail to notice the mentally disabled and developmentally challenged. Society as a whole needs to be better informed. The government in coordination with nonprofits can bring this information to the public at large.

I know several families dealing with autism and other developmentally disabled children. Several are now adults, which brings another dimension to the needs and challenges.

Recently, a caregiver was shot, because the police officer felt threatened by the autistic adult in his care. (He was aiming for the autistic person

and hit the caregiver instead!) Shocking, but the lack of training has created this situation.

Airlines and security lines at the airports have been slow to recognize the situation for developmentally disabled children and adults. Again, staff require additional training to recognize the disabled and they need to listen to the caregiver with the person.

I am very sympathetic about the lack of transportation, lack of access to stores, restaurants, hotels, community access to parks, beaches and recreation, and much more. These can and must be improved. I applaud places that make improvements, like my local theater with special showings for people who prefer lights on and lower sound levels. I wholeheartedly agree that much more needs to be done.

QUESTION 6—VISION FOR THE FUTURE: I would be happy to champion the various accessibility issues (as I know it), but would greatly appreciate the guidance from groups who are working with the disabled.

DISTRICT 5

(Republican) US Congressman Scott Garrett

As of press time, no responses have been submitted by the candidate

(Democrat) Josh Gottheimer



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT: I promise

to protect Social Security and Medicare for future generations and will oppose any attempt to privatize or cut the benefits of these essential programs. Efforts to privatize the

system endanger too many who need the system's support. Instead, we should make our current programs sustainable for future generations through a strategic bipartisan approach. Social Security and

The NJCDD 2016 Election Questionnaire

Medicare are foundational for many Americans' retirement plans and individuals with I/DD; those programs should be a guarantee—not a gamble.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES: Our elected leaders in Washington need to make sure that we are supporting those who work hard for a living. Throughout my campaign, I have enjoyed the support of hard-working people who understand the need for wage growth in our economy. To me, a living wage is one that would ensure that an American working full time can avoid the edges of poverty and food insecurity that plague too many. Direct support professionals provide a critical lifeline between communities and individuals with I/DD, and they should be given financial security for doing such important work.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS: I believe that restraints should only be used in emergencies when a child is at risk of harming themselves or others.

QUESTION 4—EMPLOYMENT FIRST: I believe that we can form public private partnerships that match individuals with I/DD and positions in which they can flourish. Meaningful employment and the opportunity to contribute and earn a salary is something that is beneficial for both employers and employees.

QUESTION 5—TRANSPORTATION: Fixing our broken transportation and infrastructure is one of my top priorities. I believe we need public transportation that is reliable, robust, and easily accessible for everyone.

QUESTION 6—VISION FOR THE FUTURE: Ultimately, the most important thing we can do is make the tools that can help individuals with I/DD succeed available to them and make them feel

empowered to achieve whatever they dream to be possible. My role in that is to be an ally to this community, to listen and to craft legislation that allows those possibilities to become realities.

DISTRICT 6

(Republican) Brent Sonnek-Schmelz



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT: These programs act as lifelines for people in need to allow them to live normal lives and operate independently without risk of becoming destitute.

As a society, we have an obligation to provide a basic level of income to those in need, and those that cannot adequately provide for themselves. Through SSI, SSDI and Medicaid, I/DD can access and pay for care as they need it. But the programs are not perfect. Often accessing these programs can be complex, as are most federal programs. By simplifying access, we can ensure that more people can access benefits they deserve and remain productive members of their communities.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES: Direct Support Professionals are the lifelines for developmentally disabled and elderly care around the country and help their patients lead longer, happier, more fulfilling lives. It is an inevitable reality that, as the baby-boomers population ages, the number of Americans needing assistance from DSPs is going to skyrocket.

According to the Department of Health and Human Services, the number of DSPs needed for long term services and support is expected to more than double, from 12 million in 2010 to 27 million in 2050. Additionally, the CBO estimates the need for DSPs is expected to increase by 48 percent in the next decade alone. But as a result of low salary and uncompetitive benefit packages,

The NJCDD 2016 Election Questionnaire

the DSP workforce has been plagued for decades by turnover rates ranging from 40-50%, a rate far exceeding most other industries. Meeting this looming need will be extremely difficult to achieve without a committed, stable and well-compensated DSP workforce.

That is why I support many of the efforts to increase the overall wages of Direct Support Professionals, including exploring new payment mechanisms under Medicaid, providing meaningful cost of living adjustments to offset inflation, and requiring that states develop and implement a plan to address reimbursement rates, high turnover, and inadequate training.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS:

Restraint and seclusion are antiquated forms of punishment and are counterproductive to the health and wellbeing of all children, but especially those with developmental disabilities. As the GAO has found, there have been thousands of cases where children have been injured or even killed because of these tactics, and they must be abolished from our schools. Furthermore, it is clear from the evidence that the use of restraint and seclusion can often exacerbate the behaviors that staff are trying to eliminate. It is immoral and unjust to allow these practices to continue in the place of more constructive and safe practices, and I would proudly co-sponsor the *Keeping All Students Safe Act*.

QUESTION 4—EMPLOYMENT FIRST:

‘Employment First’ acknowledges that the preferred outcome for an adult in society to find fulfilling and worthwhile employment, and that this is no different for adults with disabilities. I would agree that having a good paying job is a key tenant to living the American Dream, and that the ability to be a productive, self-determining, and employed member of society is beneficial for the developmentally disabled by increasing self-esteem, instilling a sense of personal fulfillment,

and increasing their social networks. It also reduces poverty and expands the tax base, shrinks enrollment in entitlement programs, creates a more diverse community for everyone, and eases demand on social service agencies.

In practice, we should create opportunities for community employment by examining policies, practices, and roles that currently exist in government to determine where competitive employment for these individuals is possible. We should also identify community needs, address program sustainability, and emphasize best practices to identify and promote successes or quickly address failures.

Finally, there are many benefits for a business to consider hiring a person with a developmental disability, and I would work to ensure these positive attributes are well known and encourage the business community to participate in the program.

Research suggests that 92% of the American public view companies that hire people with disabilities more favorably than those who do not. And, 87% of the public would prefer to give their business to companies that hire people with disabilities. Additionally, it can reduce turnover costs as people with disabilities tend to keep their jobs longer, as 62% of employees with a disability have been at the same job three years or longer. Industry reports consistently rate workers with disabilities as average or above average in performance, quality and quantity of work, flexibility to demands, attendance and safety.

QUESTION 5—TRANSPORTATION:

New Jersey is renowned for its poor job of funding transportation projects. It’s even more unfortunate when you couple this with the high cost of living and large percentage of the population that lives in urban centers.

We must address public transportation standards and ensure that our infrastructure is secure and safe for the millions of people that rely on it every day. We should also slow the rate

The NJCDD 2016 Election Questionnaire

of increasing cost that has affected New Jersey's public transportation options and ensure that those with developmental disabilities receive a discounted fare.

Finally, we should encourage the creation of more public-private partnerships with the business community. As we have seen with the rise of several ridesharing startups, traditional transportation needs are no longer sufficiently filling consumers' needs. We should work with private businesses to determine more efficient ways for those with developmental disabilities to traverse New Jersey's busy streets.

QUESTION 6—VISION FOR THE FUTURE: As stated above, we should ensure that the social safety net programs that these individuals rely on remain financially solvent. We also need to recruit and train and additional support professionals, as the need for their services is about to increase dramatically. One key to accomplishing this is to make sure they are paid a more competitive wage.

We should also make sure that the developmentally disabled are treated with care respect and that they are not harmed with outdated and harmful practices like the use of physical and chemical restraints and seclusion in schools. Finally, we should work to create community job opportunities where the developmentally disabled can earn a living wage and be a productive member of society, and ensure these individuals are able to travel to and from these jobs in a safe and affordable way.

(Democrat) US Congressman Frank Pallone

As of press time, no responses have been submitted by the candidate

DISTRICT 7

(Republican) US Congressman Leonard Lance

As of press time, no responses have been submitted by the candidate

(Democrat) Peter Jacob



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT:

In general, funding for SSI, SSDI, and Medicaid need to be restored, and in many cases expanded. These programs are critical for not only I/DD individuals, but countless members of our communities. Beyond that, we believe that the federal government should explore opportunities to provide grants to states that wish to employ pilot programs that experiment with new and creative ways in which we can provide better support and empower I/DD individuals to lead meaningful and productive lives. The proper formulas for COLA must be implemented into SSI and SSDI to ensure continued purchasing power and adequate way of life for those with disabilities.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES:

The most direct way to address these issues is to increase the federal minimum wage and reform our health care system such that it is either easier for (a) those who have part time work to secure full time health care benefits or (b) set regulatory standards that preclude employers from cutting full time hours to avoid paying for benefits. These material benefits will go along way towards reducing the high turnover rate.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS:

We support the KASSA, and believe restraints and seclusions must be a last resort for only the most extreme emergency situations. Furthermore, consistent with our views on law enforcement reform in light of the Black Lives Matter movement, we believe that we need to provide our public servants with more training to specifically deal with scenarios they may be unfamiliar with (such as when a child in school acts out) in a non-violent manner and such that they are able to deescalate the tension of the situation.

The NJCDD 2016 Election Questionnaire

QUESTION 4—EMPLOYMENT FIRST: With respect to persons with disabilities—the United States has some of the strongest disability protections in the world and more must be done to enforce those protections when it comes to the work place. Beyond that, it is vital that we make every effort to reach full employment and ensure that everyone that wants a good paying job has a good paying job. We would support the creation of tax credits to incentivize employers to hire people with disabilities

QUESTION 5—TRANSPORTATION: We strongly support the *Rebuild America Act*, which specifically deals with updating and expanding the infrastructure (including transportation) in the US. We support the expansion of public transportation across the state, in addition to the RAA's efforts to create more jobs for the disabled community in addition to benefiting them through updated public transportation.

QUESTION 6—VISION FOR THE FUTURE: Every American has the right to the pursuit of happiness, and it is the government's obligation to ensure that everyone has the opportunity to reach their full potential in life. These are the ideals that inspired the New Deal and Great Society; and it is these ideals that I hope to work towards while in office. People with developmental disabilities must enjoy these same rights and our government must work to provide them with these same opportunities. While the ADA is a global standard in disabilities protections, we must always strive to do more; to learn more about what such individuals need and to experiment with better means by which we can provide them with the support they need.

DISTRICT 8

(Republican) Agha Khan

As of press time, no responses have been submitted by the candidate

(Democrat) US Congressman Albio Sires

As of press time, no responses have been submitted by the candidate

DISTRICT 9

(Republican) Hector Castillo

As of press time, no responses have been submitted by the candidate

(Democrat) US Congressman Bill Pascrell

As of press time, no responses have been submitted by the candidate

DISTRICT 10

(Republican) David Pinckney

As of press time, no responses have been submitted by the candidate

(Democrat) US Congressman Donald Payne, Jr.

As of press time, no responses have been submitted by the candidate

DISTRICT 811

(Republican) US Congressman Rodney Frelinghuysen

As of press time, no responses have been submitted by the candidate

(Democrat) Joe Wenzel

As of press time, no responses have been submitted by the candidate

DISTRICT 12

(Republican) Steven Uccio

As of press time, no responses have been submitted by the candidate

(Democrat) US Congresswoman Bonnie Watson Coleman

See Congresswoman Coleman's responses on next page

The NJCDD 2016 Election Questionnaire



QUESTION 1—FEDERAL FUNDING FOR DISABILITY SUPPORT:

The United States lacks a comprehensive, sustainable approach to financing long-term care services. That is why I fully believe that Medicaid, SSI, SSDI must be protected and

kept fully intact to provide the critical safety net for individuals who depend on these programs. These priorities are reflected in my voting records as well as my leadership both when I was a member of the New Jersey General Assembly and now as the 12th Congressional representative on the Federal level. My record reflects the importance I have always placed on fully funding assistance programs, no matter how many times my Republican counterparts have tried to dismantle these critical programs.

QUESTION 2—DIRECT SUPPORT PROFESSIONAL WAGES:

It has been almost a decade since Congress passed a minimum wage increase, and the last increase came at a time when our nation was facing a recession. We need to be supporting DSPs and all working families by supporting livable wages coupled with continual skill trainings. Earning a livable wage with overtime protections and collective bargaining rights will create a healthy economy, better trained DSPs and provide greater safety and well-being for persons with ID/DD.

QUESTION 3—THE USE OF RESTRAINTS AND SECLUSION IN OUR SCHOOLS:

Restraint and seclusion in schools should be reserved for absolute emergency situations, not used as routine punishment for harmless infractions or insubordination. The current patchwork of state laws has proven inadequate to protect students from these abusive practices, which is why federal intervention is necessary. I was proud to support the *Every Student Succeeds Act*, which requires states to develop strategies to reduce their use of restraint or seclusion for children, and I will

continue to support any federal initiatives that further end this practice.

QUESTION 4—EMPLOYMENT FIRST: Our federal dollars should be investing into more job opportunities and job trainings that are accessible for all—including vulnerable populations systematically placed in disadvantageous positions. We must be encouraging the hiring of all populations while incentivizing and rewarding those companies with fair and equitable hiring policies.

We also must prioritize equity for all students so that every person entering the workforce has the same opportunities. Ensuring equal access to jobs starts with equal educational opportunities. Currently, the federal government is not fulfilling its commitment to the Individuals with Disabilities Education Act (IDEA), and I support fully appropriating the funding formula for special needs students.

QUESTION 5—TRANSPORTATION: People with ID/DD continue to face considerable barriers to their full integration and maximum independence in society. Many of these barriers are a result of our public transportation system and the challenges people with DD have in getting from one place to another. Through a federal and state partnership, we have a responsibility to our residents in the creation of an accessible, reliable mass transit infrastructure with affordable service both rail and road.

QUESTION 6—VISION FOR THE FUTURE: People with developmental disabilities should be afforded the opportunities to succeed as contributing members of our society through education and employment. I support appropriations that prioritize federal education funds for critical formula grant programs like IDEA and mandatory funding. I support increased job trainings and opportunities for all people, including those with disabilities. **P&F**



NEW JERSEY
REGIONAL

FAMILY SUPPORT
PLANNING COUNCILS

ARE YOU THE FAMILY MEMBER
OF A PERSON WITH DEVELOPMENTAL DISABILITIES?

Interested in becoming a better advocate for your community?
Join your local Family Support Planning Council!



Learn more about the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) systems and help spread information to other families



Organize public forums and providers fairs to help families learn changes and connect to local resources



Make recommendations to the Division of Developmental Disabilities (DDD) and Department of Children and Families (DCF) about the supports and services families need most



Become a positive force for change in your community

NJCDD.org | Kyoko Coco | 609-341-3112 | kyoko.coco@njcdd.org



www.facebook.com/NJFSPC



Lauren Frizzell at her home in Franklin, NJ
Photo by Rebecca Shavulsky

