

ANNUAL REPORT 2019



**Advocate
Collaborate
Educate**



Paul A. Blaustein
Chairperson



Mercedes Witowsky
Executive Director

Table of Contents

**01 Message from the Council
Chairperson & Executive Director**

Paul Blaustein and Mercedes Witowsky

02 NJCDD Mission and Vision

03 Five Year Plan

04 Advocate
(DDAN) NJ Developmental Disabilities
Advocacy Network

**05 Direct Support
Professional Wages**

**06 Regional Family Support
Planning Councils**

**07 People First New Jersey
Youth Leadership Project**

08 Collaborate
School Safety
Grants

Columbia University, National Center for
Children in Poverty, Bank Street Graduate
School of Education Barriers to Quality
Dental Care

Statewide Parent Advocacy Network:
Special Education Volunteer Advocate
Training

New Jersey Association of Community
Providers: Coalition for a Direct Support
Professional Living Wage

The Arc of New Jersey Training and
Resources Databank

09 Community Innovation Projects

Advancing Opportunities
Hackettstown Elks & Celebrate the
Children School

Partners in Policymaking

10 Educate

Training & Presentations
Education Days: Passing the Torch
to Successor Caregivers

11 Conferences and Events

12 Publications

13 Fiscal Report

**14 NJCDD Council Members,
NJCDD Staff Members**

Message from the Council Chairperson & Executive Director

Welcome to the New Jersey Council on Developmental Disabilities' (NJCDD) annual report for Federal Fiscal Year 2019.

The Council continues to ensure that individuals with intellectual/developmental disabilities (I/DD) and their families have a strong voice while actively participating in the development of meaningful services and supports in New Jersey. The Council's actions continue to reflect that purpose.

Fiscal Year 2019 marked the mid-point of our five-year planning cycle. It was another challenging year for families, individuals, advocates and provider agencies due to the continued transition from a contracted to a fee-for-service payment system.

NJCDD remained focused on our mission of representing individuals with developmental disabilities and their families before government agencies and the state legislature. The Council continued to support advocates in their efforts to promote positive change in the DD services system.

Council members and staff held frequent meetings with government agency leadership, and testified before legislative committees about the state budget and legislative proposals. We also met with state and federal legislators to encourage support for favorable budget allocations and legislation.

Through our national association, NJCDD studied policies and programs in other states and adopted several best practices in New Jersey. NJCDD hosted numerous forums, advocate meetings and education days, while distributing resource materials to assist individuals and families navigate system changes.

Responding to the needs of the individuals and families we serve, the Council had several significant accomplishments.

NJCDD conducted a summit during FY2019 to discuss school safety and emergency evacuation planning for students with I/DD. As a result, a School Safety Report including tangible solutions was issued. Legislation was also introduced requiring schools to consider the needs of all students in emergency planning and to provide the resources needed, including training, to address emergency evacuation planning.

Ensuring competitive wages for direct support professionals (DSPs) remains a top priority. The Council funded the Coalition for a Direct Support Professional Living Wage. The Coalition evaluated DSP wage issues in New Jersey and across the country. Materials were developed to promote these issues and to educate individuals with I/DD, their families, providers, DSPs, state administrators and legislators. As a result of coordinated efforts, the NJ legislature approved increased funding for DSP wages for the third consecutive year.

The New Jersey Developmental Disabilities Advocacy Network (DDAN) held its third summit during FY2019. The group continues to address issues raised within a collective advocacy agenda. DDAN was formed in part to address the transition from a state contracted provider service system to a fee-for-service delivery system. The contracted system had been in existence for more than four decades. The state also transitioned from a state-run case management system to a privatized conflict-free support coordination system.

Additional summits conducted during FY2019 brought thought leaders and subject matter experts together to discuss critical issues impacting individuals with I/DD and their families. Topics included employment, transportation, housing, and dual diagnosis. Each NJCDD summit resulted in system change activities through collaborative efforts among key stakeholders. In response, a competitive bidding process was initiated for system change projects. Contracts were awarded for projects addressing transportation, employment and housing.

FY2019 was a productive year, but we have much more to accomplish during the years to come.

You can read more in this report about how NJCDD is well-positioned to continue to **advocate** for people with I/DD and their families, **collaborate** with our diverse stakeholders and **educate** our many dedicated constituents.



The New Jersey Council
on Developmental Disabilities

MISSION

To assure that individuals with intellectual/developmental disabilities (I/DD) in New Jersey, and their families, participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of life through culturally competent programs.

The mission according to the federal DD Act is to engage in advocacy, capacity building and systemic change activities.

The New Jersey Council
on Developmental Disabilities

VISION

All individuals with I/DD are participating, equally-included members of their communities who:

- make real choices and have control over their own lives
- have the freedom to strive, excel, and make mistakes
- are in a position to achieve personal goals and affect policy and process decisions that affect their lives
- have the same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident



Five Year Plan

In accordance with the Developmental Disabilities Assistance and Bill of Rights Act 2000, through a public input process, the NJ Council on Developmental Disabilities implements the **NJCDD Five-Year State Planning Goals**.

The NJCDD Five-Year State Planning Goals for FY 2017–2021 focus on the following areas of significance to the I/DD community:

The Council addresses these areas through in-house projects, programs and partnerships, and innovative grant-funded contracts. For more information visit www.njcdd.org/about-the-njcdd.

All Council Position Statements were reviewed and updated. They are available at www.njcdd.org/njcdd-position-statements.



- Self-Advocate and Family Training & Information
- Direct Support Staffing Issues
- Special Education Advocacy
- Employment
- Transportation
- Health and Wellness
- Housing



Advocate



People with I/DD face some of the greatest challenges seen in a generation. These challenges range from the availability of affordable and accessible housing options, systems funding, direct support professional salaries, potential cuts to Medicaid and other social services, and more.

In response, more than 57 advocates representing 35 organizations formed the New Jersey Developmental Disabilities Advocacy Network (DDAN). It is comprised of self-advocates, family members, providers and other key stakeholders.

DDAN's goal is to bring advocates together to work toward advancing the rights, opportunities, and service systems for people with I/DD in New Jersey by addressing following key issues:

- **Medicaid**
- **System Funding**
- **Housing**
- **Transportation**
- **Employment**
- **Health, Safety and Quality Assurance**
- **Person-Centered/Self-Direct Services**
- **Communication**

The 3rd Annual DDAN Summit was held with key leaders at the New Jersey Department of Human Services, Division of Developmental Disabilities on April 26, 2019. Attendees included Carole Johnson, NJ Department of Human Services Commissioner; Jonathan Seifried, Assistant Commissioner and; Paul Aronsohn, NJ Ombudsman for Individuals with Disabilities and their Families.

Federal and State Advocacy



ACL Commissioner Julie Hocker (Center), Ophelia McLain, Sara Newell-Perez and Teresa Nguyen met with new DD Executive Directors in Washington, DC

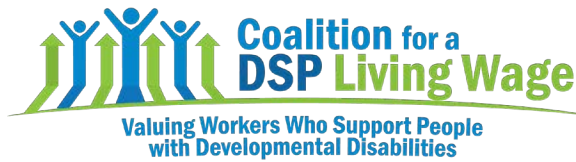


Advocating for fair DSP wages at the NJ Statehouse



Visiting Assemblywoman Downey in her Freehold, NJ office

Advocate



New Jersey experiences a 44 percent turnover rate and 20 percent vacancy rate in the direct support professional (DSP) workforce. NJCDD has taken an active leadership role in working toward solutions to address New Jersey's DSP crisis.

NJCDD contracted with the NJ Association of Community Providers to create a strategic work plan to address the information and advocacy needed to maintain adequate funding to pay workers a wage consistent with DSP's responsibilities. The Coalition for a DSP Living Wage was established to advocate effectively for long-term funding to secure competitive DSP wages.

Raising New Jersey's minimum wage was

the right thing to do, but DSPs are far from minimum wage workers and cannot be left behind. In order to stay competitive and maintain a stable, quality DSP workforce for individuals with I/DD, New Jersey must index DSP wages to the minimum wage.

Individual advocates, families, DSPs, providers and other stakeholders have been actively engaged in education and advocacy efforts to raise awareness regarding the recruitment and retention issues facing the DSP workforce. In spite of the pouring rain, participants rallied on the steps of the NJ Statehouse on May 13, 2019. As a result of collective advocacy efforts, the NJ legislature approved increased funding for the third consecutive year. For more information visit www.njdspcoalition.org.



Advocate



The Regional Family Support Planning Councils (RFSPCs) provide a venue to exchange knowledge and provide input to state and community leaders. Ten regional councils represent all 21 counties in New Jersey. All RFSPC members have a family member with I/DD.

RFSPCs monitor and evaluate NJ's service delivery system for children and adults with developmental disabilities. They disseminate critical information to other families, and gather their feedback for public policymakers. They also closely collaborate with the Department of Human Services, Division of Developmental

Disabilities (DDD) and the Department of Children and Families, Division of Children's System of Care (CSOC).

In FY2019, RFSPCs conducted 16 public forums/provider fairs, 4 statewide meetings and 2 Education Days. They also participated in various outreach events. More than 2,300 people attended events throughout the state.

RFSPCs also conducted a statewide online survey to identify barriers to completing eligibility applications for children and youth. This survey was conducted in collaboration with CSOC. According to CSOC, 60 percent of applications are submitted incomplete.

Families celebrated the 25th Anniversary of the NJ Family Support Act at the National Caregivers Conference on October 11, 2019.



Advocate



People First is an international advocacy movement for people with disabilities. NJCDD launched it in New Jersey during 2014. People First is grounded in the philosophy that all people with disabilities are capable and entitled to pursue advocacy on their own terms. People First chapters strive to be as independent as possible, setting their own agendas and maintaining their own network of volunteers and partners.

In New Jersey, People First chapters have been established in seven counties with 91 members. Chapters are led by advocates chosen solely by members.

People First New Jersey information and resources were disseminated statewide at resource fairs, conferences, and other community events.



The NJCDD's Youth Leadership Project works with schools and community organizations to provide leadership and advocacy training to young adults with developmental disabilities aged 15 to 25. While attending fun and engaging training sessions, these young people develop valuable skills to become the next generation of disability advocates.

During eight two-hour sessions, participants hone their advocacy and public speaking skills, participate in team-building exercises, and develop a better understanding of how government and public policy works.



Collaborate



NJCDD led statewide efforts to establish a forum to discuss issues, challenges, and best practices related to the needs of students with disabilities. More than 70 stakeholders from the public and private sectors participated in a summit on June 4, 2019. Major stakeholders from New Jersey's special education and emergency response communities explored issues and generated solutions to improve school safety for students with disabilities.

NJCDD released a comprehensive report, *School Safety Issues Affecting Students with Disabilities: A Call to Action*.

The report includes tangible school safety solutions for students with disabilities. For more information visit www.njcdd.org/school-safety-issues.

NJCDD continues to work with NJ political leaders to pass legislation to help improve school safety for individuals with disabilities. It will require individual documentation of needs during school security drills, emergency situations, and in school security plans. It will also require staff training on the needs of students with disabilities in emergency planning.

Grants

Funding opportunities are offered to organizations that provide innovative services aligned with NJCDD's 5-Year Plan. The following grants were awarded during FY2019:

Columbia University, National Center for Children in Poverty, Bank Street Graduate School of Education Barriers to Quality Dental Care

The goal of this project is to assess barriers to quality dental care for people with I/DD, and provide recommendations to address those barriers.

Statewide Parent Advocacy Network: Special Education Volunteer Advocate Training

The Special Education Volunteer Advocate Training (SEVA) program provides trained volunteers to help families improve their advocacy skills. Volunteers support family members during meetings, and provide valuable information.

New Jersey Association of Community Providers: Coalition for a Direct Support Professional Living Wage

This project develops a strategic coalition to create urgency around wages for direct support professionals (DSPs). The project's goal is to achieve a more competitive DSP living wage. For more information visit www.njdspcoalition.org.

The Arc of New Jersey Training and Resources Databank

Training resources for individuals, families and advocates were researched and compiled in an online databank. For more information, visit: www.ddtrainingresources.org.

Collaborate

Community Innovation Projects

NJCDD awards up to \$10,000 in funding for Community Innovation Projects (CIPs) to encourage innovative activities designed to bring meaningful change. The following organizations were awarded CIPs during FY2019:

Advancing Opportunities

Advancing Opportunities received funds to implement new assistive technology tools in group homes. Individuals, families, and direct service professionals will be trained how to use these tools to achieve greater independence and improved communication among stakeholders.

Hackettstown Elks & Celebrate the Children School

The Hackettstown Elks Lodge #2331 purchased communication outreach kits to help first responders communicate more effectively with individuals with I/DD during traumatic events. Special education students at Celebrate the Children School in Denville, NJ assembled the toolkits and provided training to first responders.



Partners in Policymaking

New Jersey Partners in Policymaking is an 8-month leadership development and advocacy education program for adults with developmental disabilities (over age 21) and family members. It is available through a collaboration between NJCDD, The Boggs Center on Developmental Disabilities, and Disability Rights New Jersey.

The goal of this program is to prepare the next generation of disability advocates to work toward meaningful statewide change. Participants (Partners) gain knowledge and skills that improve their ability to influence public policy.

Twenty-five Partners graduated on April 13, 2019. They joined other graduates who continue to advocate for themselves, their families, and people with I/DD.



Educate

Training & Presentations

Anti-Bullying Presentations

The Council's Anti-Bullying presentation educates students about the harmful impact of bullying behavior. Through this interactive presentation attendees learn about the different types of bullying and what they can do to prevent it.

R-word/Respectful Language Presentations

The R-word campaign was started to stop the use of the word "retarded" from being used in everyday language. Through interactive presentations, attendees learn how certain words or phrases can be stigmatizing and hurtful.

Education Days: Passing the Torch to Successor Caregivers

NJCDD sponsored semi-annual education days. Families wanted to learn more about the new fee-for-service system and create meaningful service plans for their loved ones.

In response, My Life, My Plan: How Can the Transition to Fee-For-Service have a Positive Impact on the Supports and Services for Me and/or My Loved One was held on October 27, 2018. Panelists shared creative person-centered ways to achieve lives their loved ones envisioned.

In June 1, 2019, another education day was held focusing on Caregiver Succession Planning: How to Pass the Torch Effectively. Parents were encouraged to attend with their prospective successors. Professionals, individuals, parents and siblings shared their experiences with succession planning.



Caregiver Succession Planning How To Pass The Torch Effectively



Educate

Conferences and Events

NJCDD conducted a series of summits with community stakeholders and subject matter experts during FY2019 to gather input regarding critical issues impacting individuals with I/DD:

- **Housing Summits**
- **Transportation Summit**
- **Employment Summit**
- **Dual Diagnosis Summit**



Council staff host information tables during conferences and events in order to increase awareness about NJCDD's programs. The following is a list of some of the conferences and events attended during FY2019:

- ***Dare to Dream Conference***
- ***NJ League of Municipalities***
- ***NJ Education Association Convention***
- ***The Abilities Expo***
- ***Library Association Conference***
- ***Children's System of Care Conference***
- ***The Arc of Monmouth Self Advocacy Conference***
- ***The Arc of NJ Spring into Action Luncheon***
- ***Facing the Future Employment Conference***
- ***SHA Housing Conference***
- ***NASW-NJ Conference***
- ***Black Issues Convention***
- ***Association of Student Professionals***
- ***NJ Association of Community Providers***
- ***Governor's Housing Conference***

Publications

People & Families Magazine

NJCDD's nationally-recognized quarterly magazine, focusing on issues of importance to New Jersey residents with developmental disabilities. Issues highlight individuals, programs and organizations who make positive contributions to the I/DD community.

Common Ground

Published, three times a year Common Ground features articles about special education, legal and legislative developments that shape the education system. This online publication provides valuable information for families,

educators and professionals. For more information, visit www.NJCommonGround.org.

Advocacy In Action Newsletter

This monthly e-newsletter provides important announcements about the Council's programs, grants and initiatives. It also includes key information about public policy, and other news about the developmental disability community.

Disability In Focus Blog

This blog provides valuable first-hand insight on key issues impacting people with development disabilities and their families.



Additional Publications

- Revised Family Crisis Handbook
- Accessing Development Disability Services in New Jersey
- Support Program Policies and Procedure Manual: A Quick Guide for Families
- In Their Own Words: Transportation Issues and Obstacles Facing People with Developmental Disabilities

In addition to the above publications, the Council produces a number of brochures, fact sheets, and pamphlets highlighting key programs, initiatives and available resources. The Council also uses broadcast emails and social media tools to share information and gather valuable feedback. Visit www.njcdd.org to find more information, and to subscribe to our publications.

FISCAL REPORT

Federal Award \$1,676,634

Funding

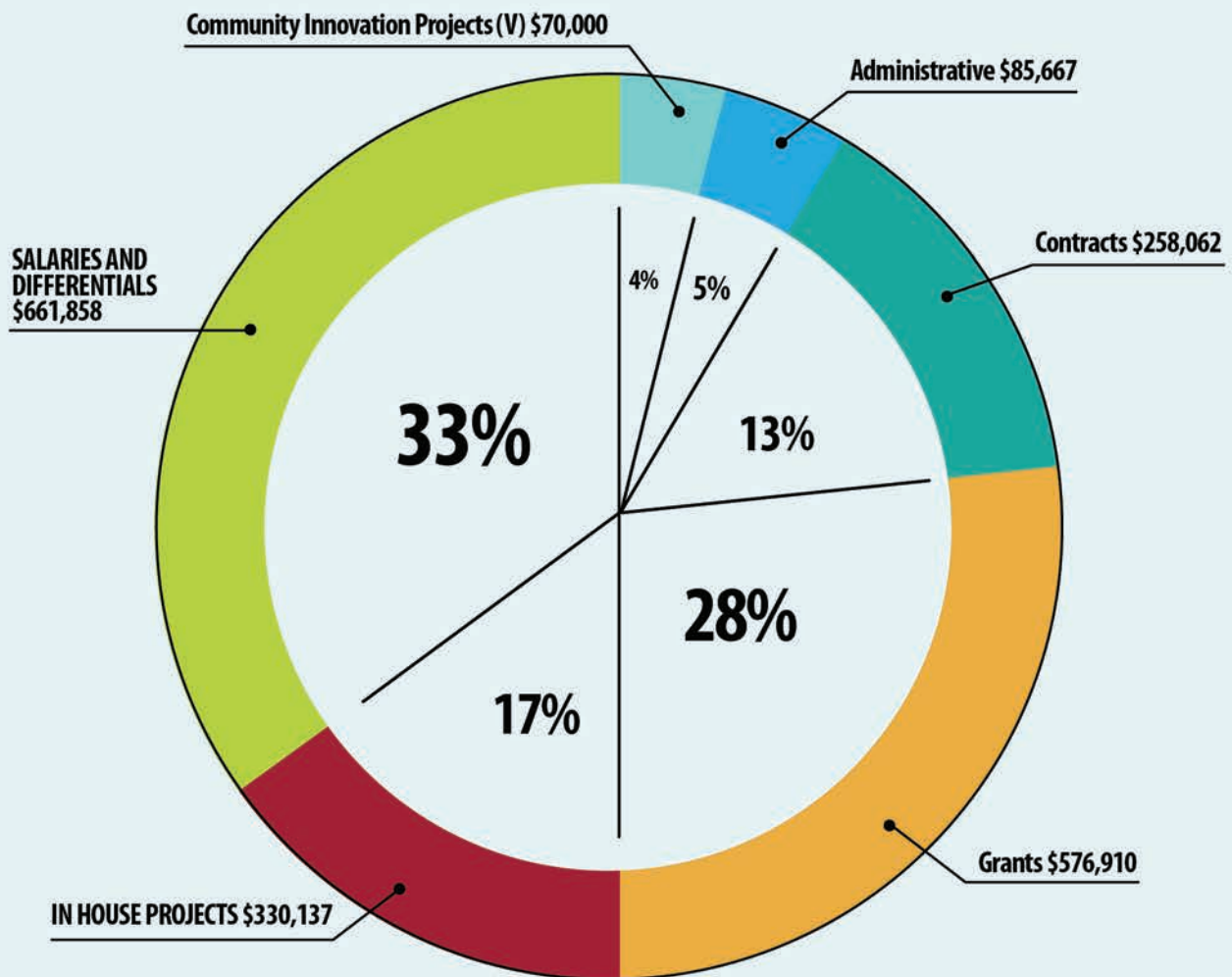
State Allocation \$306,000

85%

Total: \$1,982,634

15%

Funding Distribution



Council Members

Paul A. Blaustein, Chairperson
Myrta Rosa, Vice Chair

Self-Advocates Members

Todd Emmons
Andrew McGeady
Kevin Nunez
Gary Rubin

Parent, Family Member and Guardian Members

Ellie Byra
Elizabeth C. Dalzell
Walter Fernandez
Margaret Kinsell
Kara Kushnir
Tara Montague
Safiyah Muhammad
Helen I. Steinberg

Public Member

William Testa, Executive Director
The Arc of Morris County

Council Staff

Mercedes Witowsky, Executive Director
Maria Ali, Graphic Designer/Web Administrator
Jaymes Brill, People First NJ Coordinator
Gary Brown, Communication Officer
Kyoko Coco, Regional Family Support Planning
Council Coordinator
Jodi Fox, Chief Fiscal Officer
Gail Hodges, Receptionist
Frank Latham, Youth Leadership Coordinator
Rebekah Novemsky, Family Support Liaison
Robert Titus, Public Policy Coordinator
Dennie Todd, Health & Transportation
Coordinator
Jacinta Williams, Administrative Assistant

Federally Mandated Members

Gwen Orłowski, Executive Director
Disability Rights New Jersey
Jill Hoegel (Designee)

Joyce Jelley, Training & Consultation Specialist
**The Boggs Center on Developmental
Disabilities at Rutgers University**

Lisa Asare, Assistant Commissioner
**NJ Department of Health, Division of Family
Health Services**
Dawn Mergen (Designee)

Peri L. Nearon, MPA, Executive Director
**Department of Human Services, Division of
Disability Services**
Jacqueline Moskowitz (Designee)

Susan Martz, Assistant Commissioner
**NJ Department of Education, Office of
Special Education Policy and Dispute
Resolution**
Kimberly Murray (Designee)

Karen Carroll, Director
**NJ Department of Labor, Division of
Vocational Rehabilitation Services**
David Free (Designee)

Meghan Davey, Director
**NJ Department of Human Services, Division
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Phyllis Napier Melendez (Designee)

Jonathan Seifried, Assistant Commissioner
**NJ Department of Human Services, Division
of Developmental Disabilities**