



NJCDD | The New Jersey Council on  
Developmental Disabilities

# 2015 ANNUAL REPORT

be the VOICE

Advocating  
across a  
Lifespan







## Table of Contents



NJCDD Vision .....	3
What are Developmental Disabilities? .....	3
Message from the Council Chair .....	4
Message from the Executive Director .....	5
About the NJCDD .....	6
Part 1: Be The Voice...For Change	
People First New Jersey .....	7
Regional Family Support Planning Councils .....	8
Partners in Policymaking .....	9
Youth Leadership .....	10
Trainings & Presentations .....	10
NJCDD Grants .....	11
Part 2: Be the Voice...For Community	
Community Building Awards .....	12
Developmental Disabilities Awareness Day .....	12
Collaborations and Partnerships .....	13
Part 3: Be the Voice...For Starting Dialog	
Conferences and Events .....	14
At the Statehouse .....	14
Publications & Online .....	14
Fiscal Report .....	15
Council Members and Staff .....	16

# Vision

That all individuals with developmental disabilities are contributing members other neighborhoods and communities; 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; are in a position to affect policy and process decisions that affect their lives; and have the same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident.

## What is a developmental disability?

A developmental disability is a condition that:

- Is attributable to an intellectual or physical impairment or combination of both
- Is manifest before age 22;
- Is likely to continue indefinitely;
- Results in substantial function limitations in three or more of the following areas of major life activity, that is, self-care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living or economic self-sufficiency; and
- Reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services, which are of lifelong or extended duration and are individually planned and coordinated.



# NJCDD

## 2015 ANNUAL REPORT

### The New Jersey Council on Developmental Disabilities



## Message from the Council Chair



It is enlightening when we take pause to look back over the past year. It helps us appreciate, although our work is never done, how much we have accomplished, which is often hard to realize among the daily grind. Looking back over 2015, I am pleased with the progress the Council has made in elevating the voice of those we represent. We have been actively pursuing a seat at the table for those with developmental disabilities at state and local levels. While this is a continual journey, we consistently work at expanding the opportunities to partner with those who are in positions to shape the future of our system.

Along with many of the initiatives you will read about in this annual report, we have worked diligently behind the scenes to keep the Council's expertise at the forefront of policy and planning. In our quest to solidify our relationships with legislators and state agencies, we are making it a priority to regularly meet with those in leadership positions. We recognize the importance of having someone with a developmental disability or a family member be a part of these discussions to share their story. Real life stories intimately reflect areas of challenge and the viability in implementation of current programs and supports. It is what some might refer to as 'where the rubber meets the road.' We see this as a valuable opportunity to educate others with the hope they will gain a better understanding of our daily lives and what is needed to enhance the current systems.

We are equally encouraged by the partnerships we are creating with other organizations who share our vision to achieve equality for those with developmental disabilities in communities all around the state. Through a request for proposals, we are looking to refresh our Partners in Policymaking program to develop and create a training which will teach self-advocates and family members about our policy structures and improve their advocacy abilities. One of our priorities is to attract individuals who wish to channel their passion and strengthen their voice.

We are dedicated to expanding the network of effective advocates. I look forward to working in the coming year to increase our reach throughout the State to balance the vast demand for effective advocacy.

Stephanie A. Pratico





## Message from the Executive Director

This year, 2014, has been a year of changes but also sustainability for the New Jersey Council on Developmental Disabilities. In February, Bob Titus was hired to replace Sue Gottesman as the Council Public Policy Coordinator. Bob brought with him not only a strong background of advocacy on behalf of people with developmental disabilities, but also the perspective of being a family member. Around the same time, Jaymes Brill was hired as the new Coordinator for People First.

People First was approved by the Council membership at their meeting in January, 2014. It took the place of the Monday Morning program. People First is a self-advocacy group made up of people with disabilities who seek to speak for themselves to improve their life and the lives of others. The kick-off event in May was well-attended and introduced staff to many people who are interested in taking leadership in the new organization. Since Jaymes has begun on staff, he has been very active in forming new groups throughout the state.

There were several highlights this year, the most significant one was Developmental Disabilities Awareness Day at Six Flags. This was the fourth year the Council had held this event over the Labor Day weekend. Over 8,000 individuals purchased their tickets through the Council website. It was thrilling to see so many people with disabilities enjoying the park and wearing their DD Council backpacks!

In July, Elaine Buchsbaum stepped down as the Chair of the Council. She was recognized for her seven years of hard work on behalf of the Council at the Community Building Awards in April. Elaine gave so much of her time and efforts over the past years and the impact of her dedication will be felt for many years to come.

Many more significant activities occurred that can be found in the pages of this report. It can truly be said the New Jersey Council on Developmental Disabilities is making a difference in the lives of people with disabilities in New Jersey.

Kevin Casey



## Advocating across Lifespan



### About the NJ Council of Developmental Disabilities

Established in 1971, the New Jersey Council on Developmental Disabilities (NJCDD) is a federally mandated disability rights and advocacy organization that seeks to give individuals with developmental disabilities and their family members a greater voice in the planning and implementation of policies that affect their lives.

The Council also fosters leadership and advocacy skills within such individuals so that they can work on their own behalf to create better communities where all people with disabilities have the ability to pursue full lives of their choosing.

The NJCDD may have up to 30 members at any time. In Federal Fiscal Year (FFY) 2014 there were 26 members. 60% of the Council's membership is comprised of individuals with intellectual and developmental disabilities (I/DD) and family members of people with I/DD. These members are appointed by the governor of New Jersey.

The remaining members represent a number of I/DD advocacy and public policy organizations, and their presence on the Council is mandated by the state and federal government. The executive directors from the NJCDD's two sister agencies, Disability Rights New Jersey and the

Elizabeth M. Boggs Center on Developmental Disabilities sit on the Council, as well as individuals from a number of state organizations and agencies who design and carry out services upon which people with I/DD and their families rely. Finally, a representative from one of New Jersey's private I/DD service organizations also sits on the Council.

This mixture of individuals and families, public and private support agencies, and disability advocacy organizations ensures that a wide variety of viewpoints are represented on the Council, and that individuals and family members have the opportunity to affect real change in how I/DD services are planned and delivered.

The Council operates under a five-year planning structure, which it adjusts annually. Members discuss and define priority areas and focus activities around achieving the goals outlined in the operational plan. The Council meets these goals through the planning and implementation of in-house projects and on-going programs and partnerships, as well as by awarding grants to innovative programs and organizations throughout the state.



**Be the Voice  
of Change**

## People First New Jersey

The international self-advocacy movement known as People First is grounded in the philosophy that all people with disabilities, regardless of the level or extent of their disability, are capable and entitled to pursue their own advocacy efforts, on their own terms, and with leadership that is chosen by them. In that spirit, People First organizations aim to be as independent as possible, setting their own agendas and maintaining their own networks of volunteers and partners.

Since 2014, the NJCDD has been working with self-advocates around New Jersey to establish county-level People First chapters across our state. Each People First New Jersey chapter is made up of an advocacy advisor and leadership team, who are chosen by its members. Chapter members identify and organize the advocacy and fellowship activities on which they focus their efforts.

These activities can include leadership trainings, public outreach, letter-writing campaigns, meetings with legislators, and more. Local members may also join with other chapters in their region, or statewide, to take on large-scale advocacy projects that relate to all people with disabilities in New Jersey.

In FFY-2015, 79 self-advocates across our state have established eight chapters of People First, including a chapter at New Lisbon Developmental Center. Most other chapter meetings are held in public spaces such as county libraries or community centers.

In addition, the Council's People First Coordinator, Jaymes Brill, joined advocates at eight schools and community organizations across our state, speaking to over 450 students and community members to spread awareness about this new self-advocacy movement. People First advocates also participated in a number of presentations and trainings for students and youth relating to the NJCDD's R-Word and Anti-Bullying campaigns.

People First advocates have remained active, and have begun developing outreach activities relating to transportation, employment, and disability awareness. Advocates also participated at several protests at the NJ State House and Princeton University, and joined with disability advocates from organizations throughout New Jersey at the Alliance Center for Independence's annual Disability Pride Parade.





## Regional Family Support Planning Councils



The NJCDD's Regional Family Support Planning Councils (RFSPCs) provide a way for family members caring for someone with developmental disabilities at home to come together to exchange knowledge and provide vital input into the ways that community services are designed and implemented. There are ten regional councils representing all 21 counties in New Jersey, and membership is comprised entirely of family members of individuals with developmental disabilities.

Council members monitor and evaluate developmental disability service and support programs, inform other families in their area about current family support issues, provide information and feedback to public policymakers, and advocate to local and state officials about their needs. They also work closely with the NJ Division of Developmental Disabilities (DDD) and the Department of Children and Families (DCF) to provide input on policy decision that directly affect individuals with developmental disabilities and their families.

In the spring of 2015, the Family Support Councils co-hosted an online survey with the Family Support Coalition of New Jersey with the goal of identifying service gaps for children and adults with intellectual and developmental disabilities within the DDD and DCF systems. Over 1,300 families responded to the survey, and their valuable feedback was used in advocacy efforts

with DDD/DCF officials.

The Family Support Councils hosted 11 public forums and providers fairs throughout the year, welcoming more than 1,000 families to learn more about a variety of topics including DDD system changes (particularly fee-for-service and support coordination), Medicaid eligibility, housing, and how to access services through DDD, DCF, and The Division of Disability Services (DDS).

In addition, four statewide meetings were held at locations around New Jersey. Guest speakers at these meetings included Peg McDonald, the director of Special Education Programs at the NJ Department of Education, (former) NJ Department of Human Services Deputy Commissioner Lowell Arye, Children's System of Care Director Elizabeth Manley, Joseph Amoroso, the director of the NJ Division of Disability Services, and Christine James, the director of Quality Improvement and System Reform for DDD.

Family Support Council members also met regularly throughout the year with DDD Assistant Commissioner Elizabeth Shea and DCF Director of Children's System of Care (CSOC) Elizabeth Manley. Topics discussed include the State's fee-for-service timeline, tiers, and acuity; the supports program manual; the Home and Community-Based Services Statewide Transition Plan; and the FY-2016 budget.





## Partners in Policymaking

Partners in Policymaking (PIP) is a nationally known leadership and advocacy training program for adults with developmental disabilities and their family members. Participants (Partners) gain knowledge and skills that allow them to make a real impact in influencing public policy.

During this eight-month program, Partners have access to the most up-to-date information on disability issues and best practices in the field of advocacy. They become familiar with policymaking and legislative processes at the local, state, and national levels.

In 2015, Partners met once per month, with each training session devoted to specific topics, such as: the history of the independent living, parent, and self-advocacy movements; community organizing; how government works; and family support. Partners are tasked with completing assignments between sessions and committing to one major project, such as completing an internship, organizing a letter-writing campaign, or hosting a community outreach event.

Near the end of this training program, Partners are asked to research and prepare testimony pertaining to real developmental disabilities

policies or legislation, which they present to a panel of representatives from the NJ State Legislature at a mock hearing held at the NJ State House.

On April 11, at this year's mock hearing, Partners were tasked with providing testimony either for or against a number of proposed bills under consideration by the NJ State Legislature in 2015. Jason Redd, former Senate Majority Chief of Staff, joined NJCDD staff to serve as a mock legislative committee before which the Partners testified. Bills examined by this year's Partners class were Senate Bill No. 2688, establishing an "MVP Emergency Alert System" for missing persons with mental, intellectual, or developmental disabilities; and Senate Bill No. 301, the Innovative Services for Persons with Developmental Disabilities Act.

On May 17, 2015, ten new graduates joined our roster of nearly 400 advocates who have successfully completed the program.

For more information about the NJCDD's Partners in Policymaking program, visit us online at [www.njcdd.org](http://www.njcdd.org).



## Youth Leadership Project



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

Over the course of 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. The program encourages its participants to carry the variety of skills and knowledge that they gain into the world of self-advocacy.

In FFY-2015, the Council's Youth Leadership Project worked with 65 youth advocates in schools and community groups across our state. As these young people with disabilities move on from the program, the NJCDD will continue to encourage their advocacy with the hope that they will continue speaking up for themselves and all people with disabilities as adults.

Youth Leadership Project Coordinator Frank Latham also carried the NJCDD's advocacy message to young people on the state and national level, speaking at a number of conferences and training events including the Dare to Dream Conference and the NJ Department of Children and Families' Children's System of Care Annual Conference.

### Trainings & Presentations

In addition to its on-going programs and public awareness campaigns, the NJCDD carries out specialized trainings and presentations within the community to help develop the advocacy skills of its program participants and to raise the level of awareness and sensitivity to disability issues for individuals and organizations throughout our state.

The NJCDD's Youth Leadership Coordinator, Frank Latham presented to 40 different schools and organizations, reaching more than 1,700 students, family members, and other New Jersey residents to spread the word about the Council's campaigns to end bullying and use of the R-word in our schools and communities.

Emergency Preparedness Trainings were held at a number of locations around the state, educating 165 individuals with developmental disabilities on what to do and who to turn to in the event of a flood, hurricane, fire, or other emergency situation.

The Council also held a large number of Crisis Intervention Trainings for law enforcement, first responders, and service providers in Burlington, Hudson, Atlantic, and Cumberland counties, as well as law enforcement officers on the state and federal level.





## Council Grants

### Arc of New Jersey / Rutgers University Transportation Research Project

For this project, The Arc of New Jersey and the Rutgers University Center for Advanced Infrastructure and Transportation/ Alan M. Voorhees Transportation Center have teamed up to conduct an extensive study on the issue of transportation for people with I/DD. The research team is using a vast network of self-advocacy groups, as well as a large number of other community connections, to interview and record the experiences of individuals with I/DD from every region of our state, and across all socio-economic backgrounds. The study will examine both current and anticipated transportation needs for our disabilities community in relation to employment, community involvement, recreation, independent living, etc.

After compiling these interviews (in both written and audio format), the research team will analyze their findings and develop a summary report identifying trends and themes, and formulating recommendations. The final product will include real-life examples and personal stories from people with disabilities, putting a "face" on the many transportation issues that exist within our state. Once completed, this comprehensive report will be a highly valuable advocacy tool in improving the transportation resources that New Jersey residents with I/DD rely upon.

### Mini-Grants

In addition to our large-scale grant projects, the NJCDD also provides a number of mini-grants throughout the year in an effort to encourage innovative new programs and activities that benefit New Jersey residents with developmental

disabilities and their families.

In FFY-2015, the council provided funding for a number of projects, including:

- Values into Action, who conducted first responder disability awareness trainings with the help of trainers from the Niagara University First Responders Disability Awareness Program
- Special Parent Advocacy Group, who opened their Special Needs Community Resource Center at PJ Hill Elementary School in Trenton
- Jewish Family and Children's Services, who produced a video of the Soups & Sweets culinary training program, which they used as an education and outreach tool to promote the program and highlight the skills and abilities that Soups & Sweets trainees can bring to potential employers
- SAMBULANCE Safety Squad, which provides complimentary safety education to schools and community groups (basic first aid, 911 scenarios, etc.) This was grant allowed the program to provide presentations/trainings in the summer months to schools, group homes, camps, clubs, and organizations.

### On-Going Grants

Most of the NJCDD's grant projects are eligible to receive funding for up to three years. In FFY-2015, the Council continued its support of a number of programs throughout New Jersey, including: Community Access Unlimited's CAU Community Players program, the Get FIT @ Home 2.0 program, production of the Supportive Housing Association of New Jersey's Community-Based Housing Guide, the Statewide Parent Advocacy Network's Health Advocacy Toolkit for Families of People with Developmental Disabilities, and Griffin Hammis Associates' NJ Customized Employment Initiative.



## Be the Voice for Community



### The 2015 Community Building Awards

Each year, the NJCDD looks to the public to help us identify visionary public policymakers, innovative media outlets, dedicated advocates, and inclusive educators from all across the state. The Council believes such individuals or organizations should be given the acknowledgment they deserve.

The Community Building Awards are intended to show encouragement, support, and recognition to those who have exhibited an exceptional commitment to promoting community inclusion for people with developmental disabilities in New Jersey. Eight award categories were created to honor the hard work and dedication of these community leaders.

The 2015 Community Building Awards Luncheon was held on April 22 at the Wyndham Garden Hotel in Trenton. In addition to honoring six award recipients, the Council was pleased to have our new Executive Director, Kevin Casey, as keynote speaker for the event.

### The 2015 Community Building Award Winners

- The Colleen Fraser Self-Advocate Award Annie Sims
- The Elizabeth Boggs Family Member Advocate Award Bonnie Brien
- The Exceptional Policymaker Award Edward McDonnell, Camden County Freeholder
- The Distinguished DD Systems Change Award Joseph B. Young, Disability Rights New Jersey
- The Inclusive Education Award Community Access Unlimited

- The Multi Media Award Fred Tchang, Assistive Technology Services

### Developmental Disabilities Awareness Day

For the fifth year in a row, the NJCDD closed out the summer with our annual Developmental Disabilities Awareness Day (DD Awareness Day) celebration at Six Flags Great Adventure in Jackson.

On Saturday, August 29, 2015, the Council was joined by volunteers from across the state, including those representing Community Options, Inc., Easter Seals NJ, The Family Resource Network, Community Access Unlimited, and the Statewide Parent Advocacy Network, Inc. (SPAN), to meet and greet Six Flags guests and promote awareness and respect for our state's population of individuals with intellectual and developmental disabilities (I/DD) and their families.

Hundreds of people took advantage of our special partnership with the theme park to obtain deeply discounted tickets to join us for this celebration. Park-goers stopped by our DD Awareness Day tables in droves to receive information about our developmental disabilities community and the services offered to those with I/DD and their families. While visiting us, they were also able to receive a variety of fun prizes and giveaways including bracelets, knapsacks, bandannas, buttons and more, and to sign the NJCDD's R-Word Pledge.





## Collaborations & Partnerships

As is often a gratifying sight to see at each year's DD Awareness Day, Six Flags guests could be spotted throughout the park all day wearing their disability awareness materials, helping us to further our message about respect, awareness, and inclusion for our state's thriving and diverse disabilities community.

To view photos from the 2015 Developmental Disabilities Awareness Day, visit us online at [www.njcdd.org](http://www.njcdd.org)

### Collaborations & Partnerships

The NJCDD collaborates extensively with advocacy groups, public and private agencies, educators, community groups, and volunteer organizations, believing that only by working together toward reaching common goals can we all hope to create positive change and significant progress for our developmental disabilities community.

In FFY-2015, the NJCDD had the honor to work with talented individuals from a variety of organizations on issues important to people with disabilities throughout New Jersey and across the nation. Below is a list of some of the organizations with which the NJCDD collaborated this past year:

- The NJ Olmstead Advisory Committee
- The NJ Commission of Traumatic Brain Injury Research (NJCTBIR)
- The NJ Transit ADA Taskforce & Citizens Advisory Committee
- The NJ Protection and Advocacy DD Advisory Board
- The NJ Self-Advocacy Advisory Board
- The Get Fit Statewide Coalition
- The NJ Gained Taskforce for Disaster Response Planning
- Easter Seals NJ - Emergency Preparedness Training
- The Family Support Coalition
- The Children's Interagency Coordinating Committee (CIACC)
- The Supportive Housing Association of New Jersey Membership And Developers Committees
- Southern Region Children's Coordinating Council
- The Fetal Alcohol Syndrome Disorders Taskforce
- The Arc CARES/Atlantic County Taskforce
- The Children's System of Care Advisory Workgroup
- The NACDD National Strategic Planning Committee
- The NJ State Association of Jewish Federations – Special Needs Working Group
- The DDD Quality Focus Group
- The Arc of New Jersey Partners in Justice Team
- The NJ Dept. of Education Statewide Special Education Advisory Council.



## Publication, Web and Social Media



### People & Families Magazine

The NJCDD's quarterly magazine, *People & Families*, focuses on key issues of importance to New Jersey residents with developmental disabilities and their families. In addition, the magazine highlights programs, individuals, and family members within our state who are working to make our communities more inclusive and accepting of people with developmental disabilities.

In 2015, the magazine covered a wide range of topics, from the 25th anniversary of the Americans with Disabilities Act, inclusive sports programs, transitioning into adult life, community-based housing, sheltered workshops, the passage of the ABLE Act, transportation, and more.

Subscription to *People & Families Magazine* is free, and can be obtained at [www.njcdd.org](http://www.njcdd.org). Web visitors may also view our archive of past issues and request additional hardcopies (while supplies last).

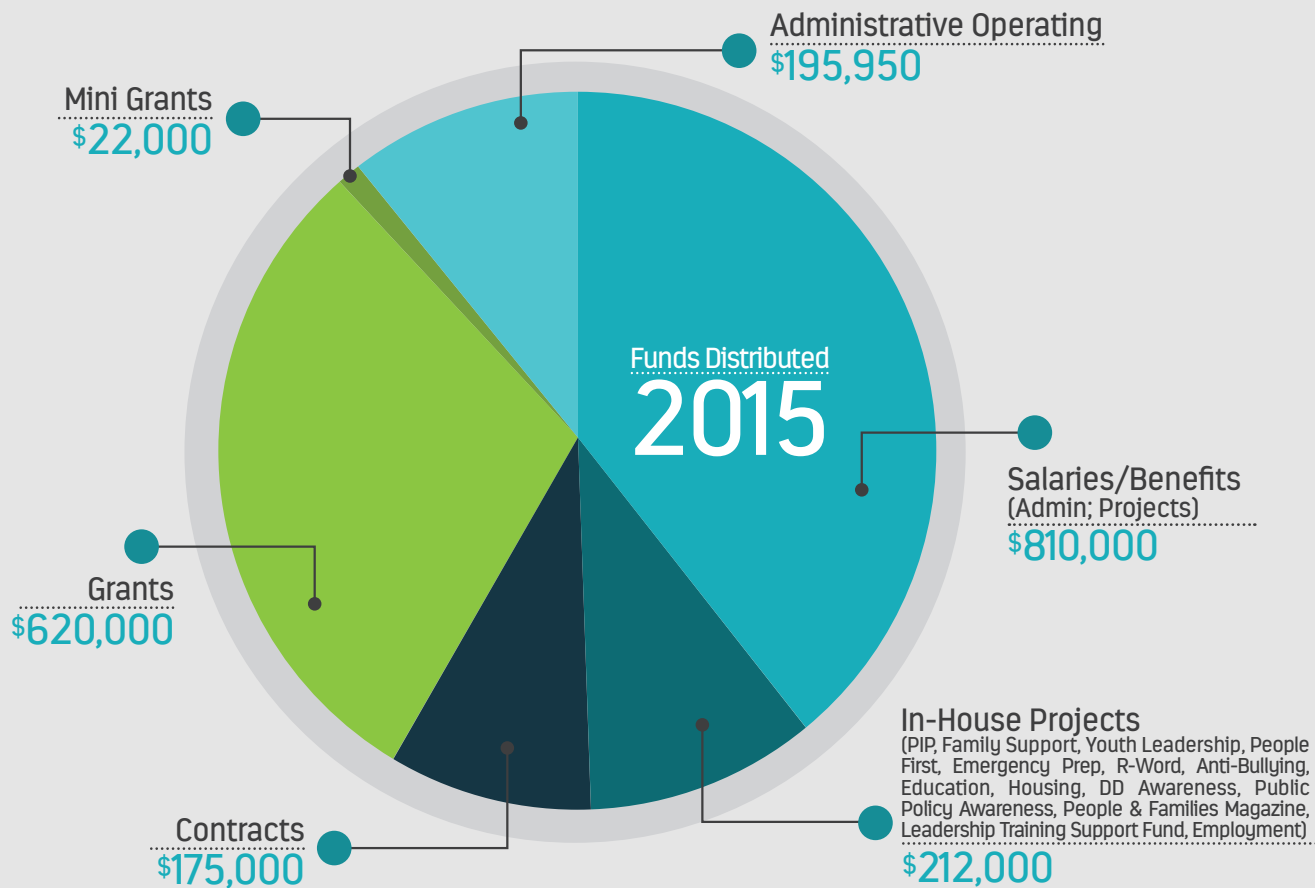
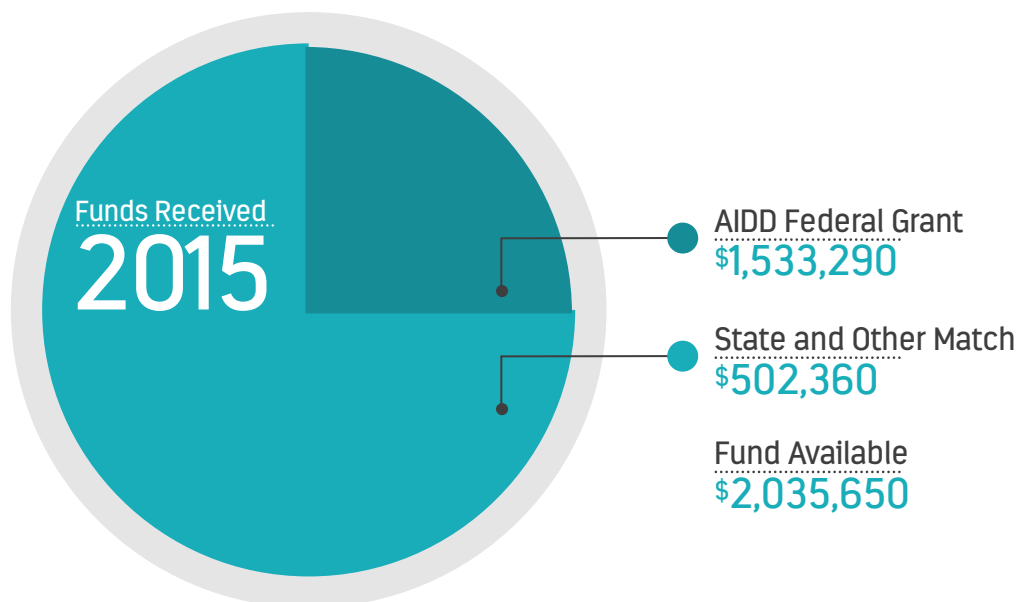
### Common Ground

The Council's newsletter for parents, educators, and special education stakeholders completed its transition into a fully on-line news source for key issues in New Jersey's special education system. In addition to publishing new editions of the e-newsletter three times this year, a website was established to allow readers to track legislative updates and to provide further information to parents, educators, and advocates. To sign up for the Common Ground newsletter, and to learn more, visit [www.NJCommonGround.org](http://www.NJCommonGround.org).

### Web and Social Media

The NJCDD's blog, *Disability in Focus*, had over 40,000 web visitors in 2015, covering such topics as New Jersey's housing waiting list, parents with developmental disabilities, and the importance of sex education for people with disabilities in relation to the criminal justice system. Through communication efforts via eblasts, web, Facebook, and Twitter, important NJCDD announcements and updates were seen by over 80,000 web visitors and email recipients.





### COUNCIL MEMBERS

Chair: Stephanie A. Pratico  
Vice-Chair: Christopher Miller

### SELF ADVOCATE MEMBERS

Todd Emmons  
Russell Fried  
Andrew McGeady  
Christopher Miller  
Myrta Rosa  
Gary Rubin

### FAMILY OR GUARDIAN MEMBERS

Ellie Byra  
Walter Fernandez  
Tara Montague  
Safiyah Muhammad  
Christine Pietrow  
Leah Ziskin, M.D.  
Paul A. Blaustein

### FEDERALLY MANDATED MEMBERS

#### Aid Funded Agencies

Protection And Advocacy System  
Disability Rights New Jersey  
Joseph Young, Executive Director

University Center For Excellence  
In Developmental Disabilities Education, Research,  
and Service; The Elizabeth M. Boggs Center on  
Developmental Disabilities  
Deborah Spitalnik, Ph.D., Executive Director

#### State Agency Representatives

NJ Department Of Health and Senior Services;  
Division of Family Health Services  
Gloria Rodriguez, Assistant Commissioner

NJ Department of Education; Office of Special  
Education Programs  
Peg McDonald

NJ Department of Labor; Division of Vocational  
Rehabilitation Services  
Alice Hunnicutt, Director

NJ Department of Human Services; Division of  
Medical Assistance and Health Services  
Valerie Harr, Director

#### State Statute Mandated Members

NJ Department of Human Services;  
Division of Developmental Disabilities  
Elizabeth M. Shea; Assistant Commissioner

NJ Department of Human Services;  
Division of Disability Services  
Joseph Amoroso, Director

#### Public Agency Member

The Arc/Morris Chapter  
William Testa, Executive Director

#### Council Staff

Executive Director  
Kevin T. Casey

Fiscal Officer/Office Manager  
Gail Furrer

Disabilities Service Specialist  
Dennie Todd

Youth Leadership Project Coordinator  
Frank Latham

People First NJ Coordinator  
Jaymes Brill

Statewide Coordinator of Regional  
Family Support Planning Councils  
Kyoko Coco

Public Policy Coordinator  
Robert Titus

Communications Manager  
Jonathan Waller

Administrative Assistant  
Jacinta Williams

Graphic Designer/Web Admin  
Maria Ali

Clerk/Receptionist  
Gail Hodges