



# NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES 2013 | ANNUAL REPORT





## OUR VISION

That all people with developmental disabilities are participating, equally included members of their neighborhoods and communities; have the ability to 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 to affect policy and decisions that have an impact on their lives; and have the same rights, privileges, responsibilities, and opportunities of citizenship as any other New Jersey resident.



## ABOUT US

**The New Jersey Council on Developmental Disabilities (NJCDD)** is a publicly funded organization which works to ensure that individuals with intellectual and developmental disabilities (I/DD) and their families have opportunities to contact and inform the decision-makers who design and implement the services and public policies that affect their lives.

60% of the Council's membership is made up of individuals with I/DD or their immediate family members or guardians. The remaining members are federally mandated representatives from various agencies throughout the state that design and carry out services upon which individuals with I/DD and their families rely. The NJCDD's sister agencies, the Elizabeth M. Boggs Center and Disability Rights New Jersey (DRNJ), also have representatives on the Council. Finally, a representative from one of New Jersey's private 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 NJCDD also maintains several programs for individuals of all ages, as well as family members, intended to aid them in developing leadership and advocacy skills and to provide opportunities to make real changes in their own lives and the lives of others. Through public outreach initiatives, the NJCDD also spreads awareness of New Jersey's diverse I/DD population, working to increase support for community integration and inclusion.

To learn more about the **NJCDD**, visit us online at [www.njcdd.org](http://www.njcdd.org).





Council Chair  
Elaine Buchsbaum

## LETTER FROM THE CHAIR

As it has been for the past seven years, Fiscal Year 2013 was another in which I had the great honor and pleasure to Chair the New Jersey Council on Developmental Disabilities as it continued working to better the lives of those with developmental disabilities through advocacy, systems change, and capacity building.

This year we have worked to build community through a number of projects. Building upon our successful Partners in Policymaking training program (PIP), we instituted an Advanced Advocacy Leadership Training not only for PIP graduates, but for our Monday Morning and Youth Leadership participants as well, which we held at the NJ State Aquarium on May 18th.

The PIP family grew this year, as 24 new advocates graduated from our 16th training class. Recently we reviewed data on the advocacy activities of many of our over 300 graduates, and were proud to find that a majority have continued their involvement in all facets of advocacy work.

Our Family Support Councils did extensive work this year to keep communication open between DDD/DCF officials and NJ families, making sure DCF understands their unique needs and collecting feedback from families about the services that they rely upon. Added to these efforts were our "NJ is My Home Too" campaign, our DD Awareness Day at Great Adventure, and the activities of our Youth Leadership and Self-Advocacy programs.

As you'll see in this report, we have been very busy indeed!



Executive Director  
Alison Lozano, Ph.D., M.P.A.

## LETTER FROM THE EXECUTIVE DIRECTOR

2013 was a year of challenges and triumphs for the NJCDD. While we, along with many other DD Councils across the country, had to scale back some of our programs due to federal sequestration, we welcomed our state's plans to close of two of New Jersey's seven Developmental Centers, North Jersey and Woodbridge Developmental Centers. In April, we welcomed Kyoko Coco as the Coordinator of the Family Support Councils. However, in December we said goodbye to Sue Gottesman, who retired from her position as the Public Policy Coordinator.

Thinking back on this year, there were a number of Council activities that really stood out. The first was our annual Disability Awareness Day at Six Flags Great Adventure. It was wonderful to see so many people with disabilities come to the park and enjoy themselves. Many others came by the Council's table as well, taking baseball caps and signing pledges to eliminate the use of the R Word - We made a lot of friends that day!

Other examples of outstanding activities were the trainings the Council sponsored at the State Museum and the State Aquarium, where individuals came to learn how to more effectively advocate for themselves and their families.

In this document, you will see more information about the work of the DD Council. However, we are foremost people; and we are, to a person, dedicated to improving the lives of people with developmental disabilities and their families.





## PARTNERS IN POLICYMAKING

The Partners in Policymaking (PIP) training program gives family members and people with disabilities the skills needed to be effective advocates and leaders with the ability to make real changes in how policies

and services that affect them and their loved ones are designed and implemented.

The PIP program successfully graduated its 16th training class on April 7, 2013, which consisted of a diverse group of 24 advocates. Trainees participated in monthly sessions held between September 2012 and April 2013.

In March 2013, participants were asked to prepare testimony pertaining to real developmental disabilities policies or legislation, which they presented to a panel of state legislators at a mock hearing held at the New Jersey Statehouse.

State Senators Stephen Sweeney (Senate President; D-3) and Robert Gordon (D-38); staff members of Senator Linda Greenstein (D-14) and Assemblyman Erik Peterson (D-23); and Senate Majority Chief of Staff Jason Redd volunteered their time to hear testimony from PIP Partners.



## STATEWIDE FAMILY SUPPORT COUNCILS

The ten Regional Family Support Planning Councils in New Jersey represent families in every county, providing assistance in navigating the state's complex DD service system and giving families a voice amongst decision-makers in how such systems are designed and implemented.

The NJCDD assists their efforts by facilitating communication between the councils and the NJ Div. of Developmental Disabilities (DDD) and Dept. of Children & Families (DCF); and by

organizing trainings, information sessions, public forums, and provider fairs equipping families with vital resources and information.

In FY-2013, following the transfer of individuals under 21 years old receiving services from DDD over to DCF, the councils continued to educate families about how this reorganization affects them, and worked to ensure that DCF understands how families with I/DD differ from other populations they serve. The NJCDD's Statewide Family Support Coordinator and Executive Director worked extensively with DCF's Children's Advisory Work Group, ensuring that families were heard as children were transferred from DDD.

Also in FY-13, the NJCDD reached out to families with an online survey evaluating the effectiveness and availability of the services that DDD and DCF provide. Over 1300 families participated, after which a report was delivered to DDD/DCF officials, providing them with valuable insights regarding the services upon which families most rely.





## YOUTH LEADERSHIP

The NJCDD's Youth Leadership Program works with community groups, educators, and parents to provide young people, aged 16 to 25, with training opportunities to develop

leadership skills and effective ways to impact change in their communities.

In FY-2013, the program achieved an impressive list of accomplishments, both in its youth advocacy training classes and its specialized presentations and initiatives.

Two Youth Leadership training groups were held in public schools this year to train young adults in advocacy and leadership skills. Additionally, the Council held its first Leadership Training Institute providing intensive skill building and training for experienced youth leaders. The Youth Leadership Coordinator has also begun collaborating with the National Organization on Disability's *Every Talent, Every Skill, Every Ability* employment initiative, which targets employment issues for urban youth with disabilities.



## SELF ADVOCACY

The Monday Morning Network is a grassroots advocacy project organized for and by New Jersey residents who work to spread awareness to community leaders, educators, and the public about issues of importance to the disabilities community. Advocates speak out for needed changes in the service and support systems that affect them, increased access to public transportation and public

places, and for a greater voice in the design and implementation of community planning and public policy.

In FY-2013, advocates from Monday Morning county chapters continued to increase public awareness and support for NJCDD campaigns including those to close developmental centers in New Jersey, to put an end to bullying in our schools and communities, and to encourage both children and adults to eliminate their use of the "R-word" in everyday speech.

Such promotion was conducted throughout the year at community locations including town festivals, amusement parks, sporting events, and farmers markets.

This year, several members were also successful in scheduling time to visit with legislators on the local and state level to address issues of concern for New Jersey's I/DD community.



# GRANTS & SPONSORSHIPS

## **GRIFFIN-HAMMIS ASSOCIATES, LLC**

Griffin-Hammis Associates is a consulting firm specializing in developing employment opportunities for individuals with I/DD, including entrepreneurship and other self-employment models. In FY-2013, the organization provided intensive Customized Employment/Micro Enterprise training for clients of two DD service organizations in New Jersey. They worked with individuals at various training sites who either gained competitive employment or started small businesses of their own. The training was centered on two components: the rollout of on-site training, and the development of a Community Action team.

## **SAMOST JEWISH FAMILY & CHILDREN'S SERVICES (JFCS): SOUPS & SWEETS PROGRAM**

JFCS provides quality, affordable, and accessible social services to individuals and families in need, helping them meet the challenges of daily life. In FY-2013, JFCS developed their Soups & Sweets program, providing real-world job training for individuals with I/DD through the operation and management of a successful bakery and soup kitchen. A group of eight interns gained 200 hours of culinary training, after which four went on to obtain competitive employment in restaurants, industrial kitchens, and private businesses. The program also began selling products to individuals and organizations, and it is anticipated that the catering business will expand as the community becomes more aware of the program.

## **THE ARC OF NEW JERSEY: CRIMINAL JUSTICE ADVOCACY PROGRAM (CJAP)**

The only program of its kind in New Jersey, CJAP provides alternatives to incarceration for individuals with I/DD within the criminal justice system. The program acts as a liaison between the criminal justice and human services systems, monitoring the quality of care and service provided to those with I/DD as they move through each system. This year, CJAP worked with the Arc of Atlantic County to develop a pilot program supporting individuals with developmental disabilities who have criminal histories and building links between public and private organizations in an effort to expand their services. The program also

created curriculum for service, housing, and mental health providers; law enforcement; and the judiciary, in hopes of educating all stakeholders and forming a more coordinated response system.

## **ARC OF MONMOUTH: "ACHIEVEMENT ZONE" PUBLIC SERVICE ANNOUNCEMENT**

For this grant project, participants worked to create an informative public service announcement showing people with developmental disabilities working in a variety of settings, seeking to raise expectations among people with I/DD and their families about future goals for employment and independence. The short video also showcased the many ways in which those with disabilities have realized their goals of finding fulfilling employment in the community.

## **DEVELOPMENTAL DISABILITIES HEALTH SERVICES (DDHS)**

DDHS works to expand accessible and community-based healthcare options for individuals with I/DD from all backgrounds and in a variety of different communities. In FY-2013, the program worked to establish health home locations in Bergen and Passaic Counties, conducting workforce development trainings for DD service providers in order for them to achieve certifications as Person Centered Medical Homes (PCMHs). Additionally, this grant project conducted evaluations of clinical and financial outcomes concerning mental health services and the use of emergency and inpatient hospital care.

## **NJCDD MINI-GRANTS**

The NJCDD provides mini-grant opportunities to encourage new and innovative local activity that will result in meaningful benefits for people with developmental disabilities and their families. In FY-2013, mini-grant funds were distributed to the Supportive Housing Association of NJ for the establishment of a Family Workgroup; to the Arc of NJ for the implementation of a conference focusing on Dementia in individuals with I/DD; and to the NJ Fetal Alcohol Syndrome Disorders Taskforce to conduct its 40th anniversary summit in Atlantic City, NJ.



# OUT IN THE COMMUNITY

## 2013 DEVELOPMENTAL DISABILITIES AWARENESS DAY

Our annual Developmental Disabilities Awareness Day at Six Flags Great Adventure in Jackson was another great success. This year's celebration, held on Saturday, August 31, 2013, was attended by over 3,000 supporters, who purchased discounted tickets to the park online, through our DD Awareness Day event page.

Volunteers from a number of DD organizations joined the NJCDD for this event, helping to promote awareness and appreciation for New Jersey's developmental disabilities community with information tables throughout the park.

Additionally, nearly 1500 visitors stopped at the Council's information table at the park's entrance to learn more about our R-Word and Anti-Bullying campaigns, which call on the public to help end hurtful language, bullying, and discrimination in our schools and communities. Guests were invited to sign the NJCDD's R-Word Pledge, and to take complimentary materials including baseball caps, bracelets, and stickers to wear as they enjoyed the park; helping to spread awareness of the Council's programs to other Six Flags guests.

## OUTREACH TO LEGISLATORS

The NJCDD worked to maintain steady dialogue with public officials and legislators at all levels of government this past year in an effort to keep representatives informed of the needs and concerns of citizens with developmental disabilities.

Throughout the year, Council members, staff, and program participants reached out to legislators and other leaders on issues relating both to the I/DD population and the public at large, including accessibility and safety concerns, city planning, voting rights, and community inclusion. Several of the Council's members were also able to meet with legislators at the NJ Statehouse and on Capitol Hill to discuss important issues including the closure of institutions, community support programs, housing, and employment,



to name a few.

The Council also submitted testimony to various state and federal legislative committees on issues impacting housing, jobs, education and human services, as well as to the Governor's Taskforce on Developmental Centers and the NJ Division of Developmental Disabilities.

## CONFERENCES

The NJCDD was present at a number of conferences and conventions this past year, disseminating information about our organization and the population we serve to a variety of public groups and organizations. Below is a list of some of the events at which the NJCDD was present:

- The NJ Fetal Alcohol Syndrome Disorders Conference
- The Mercer County Career Planning and Readiness Conference
- NJ Arc's Self Advocacy Spring into Action Luncheon
- NJ Arc's Equal Justice Conference
- The NJ Association of Community Providers
- The Association of People Supporting Employment
- The NJ Supportive Housing Association's Developer's Conference
- The NJ National Association of Social Workers Conference
- The NJ League of Municipalities Conference Summit in Atlantic City, NJ.





## COLLABORATIONS & PARTNERSHIPS

The NJ Council on Developmental Disabilities 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 improvement for our I/DD community.

In FY-2013, the NJCDD had the honor to work with talented individuals from a variety of organizations on issues important to people with disabilities within New Jersey and across the nation. Below is a list of some of the organizations with which the Council collaborated:

- NJ SHA Membership and Developers Group
- NJ Fetal Alcohol Syndrome Disorders Task Force
- The Elizabeth M. Boggs Center at UMDNJ
- NJ Coalition on Inclusive Education
- NJ Division of Developmental Disabilities (DDD)
- NJ Department of Children and Families (DCF)
- NJ DD Coalition
- Disability Rights New Jersey
- NJ Family Support Coalition
- NJ Transit ADA Taskforce
- NJ Office of Emergency Management
- NJ Office of Homeland Security
- The Arc of New Jersey
- Burlington County Children's Inter-Agency Coordinating Committee
- Southern Region Children Coordinating Council



## COMMUNITY BUILDING AWARDS

Each year, the NJCDD recognizes individuals and organizations within the community who have demonstrated a commitment to fostering greater inclusion and full participation of individuals with developmental disabilities in New Jersey communities. Such community members are honored by the Council at our annual Community Building Awards Luncheon.

Last year's Community Building Awards were held on April 24, 2013 at the Lafayette Yard Marriott Conference Center in Trenton New Jersey.

### THE 2013 COMMUNITY BUILDING AWARD WINNERS:

- Colleen Faser Self Advocate Award  
*Myrta Rosa*
- Elizabeth Boggs Family Member Advocate Award  
*Walter Bender & Gail Frizzell*
- Lifetime Achievement Advocacy Award  
*Kate Blisard*
- Distinguished DD Systems Change Award  
*The Military 360 Project*
- Access Above and Beyond Award  
*Spring Oaks Assisted Living*
- Exceptional Policymaker Award  
*US Senator Frank Lautenberg*
- Inclusive Education Award  
*The Newell Elementary School First Grade Classroom Team*
- Multi-Media Award  
*The New Jersey Reel Abilities Film Festival*





## NJCDD MEETINGS & TRAININGS

In addition to its variety of programs, the NJCDD also organizes specialized workshops and training events to keep its members and program participants up to date on current issues and new methods of outreach and advocacy.

On May 18, 2013, at the NJ State Aquarium in Camden, participants from the Councils Monday Morning Network, PIP Program, and Youth Leadership Project combined to take part in our first ever Advanced Advocacy Leadership Training. On June 15, at the New Jersey State Museum, the Council held training on community organizing modeled after the Asset Based Community Development technique pioneered by Northwestern University's John McKnight and Jody Kretzmann. The NJCDD was back at the State Museum on July 13, for its "Working as a Team" workshop for Youth Leaders.

The Council also continued to provide free community presentations in FY-2013. Anti-Bullying and R-Word presentations were given at dozens of schools and community outlets all across the state, with many schools requesting Council staff to come back again. Additionally, several Emergency Preparedness trainings were conducted at Easter Seals of New Brunswick, involving nearly 150 youth participants.



## IN THE MEDIA

The NJCDD embraces multiple methods of communication in order to reach the public and our community leaders. In 2013, the Council collaborated with a number of news and media outlets to inform New Jersey residents about issues important to individuals with I/DD and their families.

In online and print news outlets such as *NJ.com*, *NJSpotlight.com*, and *The NJ Star-Ledger*, the Council provided commentary on issues including healthcare, education, and the closure of developmental centers. Council members and staff were also featured on the cable television program *Comcast Newsmakers*.

In the spring of 2013, the NJCDD funded an episode of the public television program *Healthbeat with Sara Lee Kessler*, which focused on healthcare issues for people with I/DD. The half-hour episode profiled a training program developed by the Robert Wood Johnson Medical School and the Elizabeth Boggs Center, which educates medical students and family doctors on how to treat patients with I/DD with compassion and dignity. The episode also featured a panel discussion with healthcare experts and DD advocates. The program aired on WHYY Public Television in Philadelphia and NJTV in New Jersey.





## NEW JERSEY IS MY HOME TOO

With the slogan "New Jersey is My Home Too", the NJCDD's newest public outreach campaign seeks to highlight the roles that people with disabilities play in our communities, and to raise awareness of our state's need to down-size its outdated and segregated institutional system in favor of real community-based housing options.

Kicking off the campaign in March of 2013, the NJCDD produced a four-part web video

series taking viewers on a day in the life of several New Jersey residents with I/DD from various backgrounds as they go to work, learn at school, participate in community activities, or play alongside teammates.

To accompany these videos, the Council launched a new page on its website, which contains information, resources, and downloadable materials for advocates to use in generating public support and reaching out to community leaders about closing institutions in New Jersey.

To view "New Jersey is My Home Too" videos and advocacy resources, visit [www.njcdd.org](http://www.njcdd.org).



## PUBLICATIONS, BLOGS & WEB CONTENT

The NJCDD's quarterly publication, *People & Families Magazine*, continued to present valuable information, insightful articles, and meaningful stories of individuals with I/DD and their loved ones in New Jersey. In 2013, the magazine covered issues including

mental health, emergency preparedness, the intersections of poverty and disability, and much more.

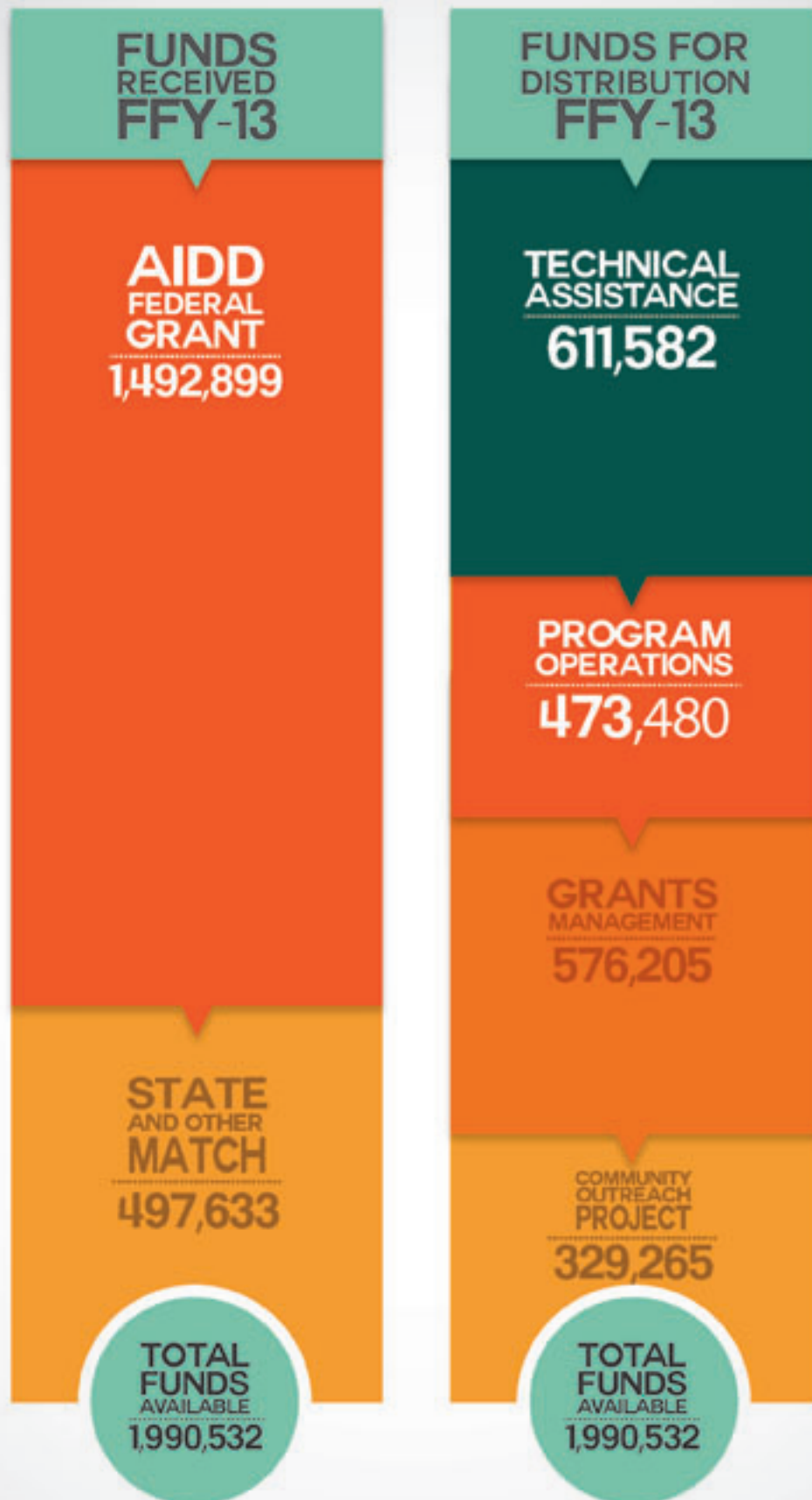
The Council's special education newsletter, *Common Ground*, began its transition into a fully online publication. This new format has allowed for increased availability to educators, parents, and experts; and the addition of online archives, legislative updates, and other tools allows for a more in-depth and comprehensive reader experience.

The NJCDD's blog, *Disability In Focus*, continues to pose important questions and tackle subjects that raise awareness (and maybe a few eyebrows). The blog consistently attracts thousands of visitors with each new post.

In FY-2013, the Council launched several new webpages that provide resources and empower advocates in voting rights, emergency preparedness, community inclusion, and more. Visit [www.njcdd.org](http://www.njcdd.org) for more details.



# FEDERAL GRANT END OF YEAR REPORT 2013





## Council Members

### CHAIR

Elaine Buchsbaum

### VICE-CHAIR

Christopher Miller

### SELF ADVOCATE MEMBERS

Todd Emmons

Voorhees, NJ

Russell Fried

Laurel Springs, NJ

Andrew McGeady

Jackson, NJ

Christopher Miller

Neptune City, NJ

Myrta Rosa

Plainfield, NJ

Gary Rubin

Elizabeth, NJ

Betsy Smith

Montclair, NJ

David Tag

Lindenwold, NJ

### FAMILY OR GUARDIAN MEMBERS

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Ellie Byra

Flemington, NJ

Geoffrey Dubrowsky

Brick, NJ

Walter Fernandez

Barnegat, NJ

Purnima Hernandez, D.D.S.

Glen Rock, NJ

Tara Montague

Burlington, NJ

Safiyah Muhammad

East Orange, NJ

Christine Pietrow

Maple Shade, NJ

Regina Tegeler

Bridgewater, NJ

Leah Ziskin, M.D.

Cherry Hill, NJ

## Federally Mandated Members

### STATE AGENCY REPRESENTATIVES

NJ DEPARTMENT OF HEALTH AND  
SENIOR SERVICES;

Division of Family Health Services

Gloria Rodriguez,

Assistant Commissioner

Designee: Felicia Walton

NJ DEPARTMENT OF EDUCATION;

Office of Special Education Programs

Barbara Gantwerk, Assistant

Commissioner

Designee: Kimberly Murray

NJ DEPARTMENT OF LABOR;

Division of Vocational

Rehabilitation Services

Alice Hunnicutt, Director

Designee: David Free

NJ DEPARTMENT OF HUMAN SERVICES;

Division of Medical Assistance

and Health Services

Valerie Harr, Director

Designee: Phyllis Napier Melendez

### AIDD 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

Designee: Michael Knox, Ph.D.

### 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

Designee: Harry Pizutelli

### PUBLIC AGENCY MEMBER

THE ARC/MORRIS CHAPTER

William Testa, Executive Director

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PH.D., M.P.A.

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### Diversity Coordinator

Jane Dunham

### Advocacy Training

### Coordinator

### (Partners In Policymaking)

Dennie Todd

### Youth Leadership Project

### Coordinator

Frank Latham

### Statewide Coordinator Of

### Regional Family Support

### Planning Councils

Kyoko Coco

### Public Policy Coordinator

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### State Plan Coordinator

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### Graphic Designer

### Web Administrator

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