

ANNUAL REPORT 2021

 **The NJ Council on
Developmental Disabilities**
Advocate · Collaborate · Educate njcdd.org



Advocate



Collaborate



Educate

609-292-3745

njcdd@njcdd.org

PO Box 700, Trenton
New Jersey 08625

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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.

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

Message from the Council Chairperson & Executive Director

The Council continues to ensure that individuals with intellectual and 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 2021 remained a challenging year for families, individual advocates and provider agencies due to the global pandemic and continued transition to a complete redesign of the state's payment for services and new service system. This redesign required a new model transition from a state contracted service system to a fee for service system.

The NJ Council on Developmental Disabilities (NJCDD) responded to individual and family questions, concerns, confusion and often times disruption in the services individuals were receiving for years. The challenges individuals and families faced were mirrored by the provider community as well. NJCDD hosted many forums, town halls on COVID-19 in collaboration with DD Network Partners/System Partners, individual and advocate meetings, and education days. We also disseminated electronic and printed materials to help individuals and families navigate the system and system changes.



Paul A. Blaustein
Chairperson



Mercedes Witowsky
Executive Director

NJCDD spearheaded the launch of the New Jersey Legislative Disability Caucus. The newly-formed Caucus serves as a bipartisan forum within the New Jersey Legislature for lawmakers and their staff to consider the impact on the disability community when shaping all public policies in the Garden State through increased awareness and a greater understanding of the complexities of the disabilities service system and issues affecting individuals with disabilities and their families. People with disabilities, their families, and organizations that serve, support and advocate for people with disabilities in New Jersey serve as a resource to the Caucus, providing education and programming as needed.

NJCDD's FY2021 annual report provides a review of goal activities and targeted objectives. NJCDD's year five of the 2017-2021 Five-Year Plan focused on moving forward toward overall plan accomplishment while balancing the factors related to a global pandemic. NJCDD included the following goals in its current year activities:

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

NJCDD used a variety of strategies to work toward goal accomplishments. NJCDD staff and sub grantees played a vital role in conducting local and statewide meetings to achieve goals. NJCDD partnered with the NJ DD Network, Disability Rights New Jersey and The Boggs Center in carrying out activities that supported our goals.

Significant accomplishments in FY21 also include expanding and strengthening the DD Network collaboration and meeting with the Commissioner and Assistant Commissioner of the NJ Department of Human Services to explore the DD Network issues and recommendations. NJCDD also collaborated with other system partners and state administrators. In particular, NJCDD found it critical to collaborate with the New Jersey Department of Health as testing, vaccine and hospital visitation issues emerged in the wake of COVID-19.

NJCDD families met monthly with the state Division of Developmental Disabilities through the Family Advisory Council (FAC). The FAC is the conduit between statewide family reported issues and the state. NJCDD families met bi-monthly with the NJ Department of Children and Families to discuss issues in service delivery within

the state's children's system of care. In FY21, NJCDD supported the efforts of self-advocates to meet with state leaders to share input on the services and supports they receive. Formal meetings with self-advocates and DDD also took place.

The system redesign in New Jersey and COVID-19 forced all stakeholders to organize around changes that were impacting many aspects of the service system. NJCDD staff and Council members participated in listening sessions, informational meetings, focus groups, read letters and took phone calls from individuals and families being impacted by the state's system redesign. There was a significant increase in the voice of individuals and their families who were being impacted by system issues in general and more specifically as COVID-19 swept across the country.

The NJCDD quickly learned that the best way to remain engaged was to structure more information sessions and remain in steady communication with the state administrators and legislators to report concerns while gaining access to the most current information. However, we needed to do this in new ways. NJCDD staff and Council Members all needed to learn the new technology available to remain connected. NJCDD staff were not able to work in our office for the most of FY2021. Virtual platforms such as Zoom and Zoom Webinar as well as more electronic surveys and scheduling platforms were used.

FY2021 was a productive year, but we have much more to accomplish during the years to come.

Five Year Plan Development

The day-to-day work of the NJCDD is rooted in its Five-Year State Plan. The Five-Year State Plan lays out broad goals and objectives designed to help move the system to where we want to be in five years. Based on that plan, an annual work plan details specific activities and projects that will implement those goals and objectives.



Every five years, NJCDD engages in a robust strategic planning process, inviting the public to help make decisions about priorities, goals, and objectives. The previous Five-Year State Plan ended on September 30, 2021, so a new Five-Year State Plan must be in place. The new plan covers the 2022, 2023, 2024, 2025, and 2026 federal fiscal years, which begin on October 1 and end on September 30.

In the spring of 2020, NJCDD issued a comprehensive survey for families, self-advocates, providers, and other stakeholders. The survey asked about their experiences with the system, unmet needs, and priorities. More than 1,000 individuals responded. The survey was offered in English, Spanish, Chinese and Portuguese, the four most common languages in New Jersey.

The NJCDD wanted to ensure that a broad range of stakeholders had a chance to participate, and that historically underserved communities would have a voice. Working with leaders from diverse communities, and with input from Council members, NJCDD developed custom outreach lists in an effort to reach community churches, civic centers, and neighborhood providers. In addition, NJCDD hosted five virtual public forums, including one in Spanish, as well as two focus groups in Spanish. More than 230 people registered for these events.

The Federal Developmental Disabilities Act (DD Act), which established the State Councils on Developmental Disabilities, empowers Council members to be the driving force behind the state plan. As such, NJCDD held scores of committee meetings, workgroups, and sub-committee meetings, all with strategies in place to support Council members in providing input and decision-making as it related to developing the state plan.

In addition to quarterly Council meetings, and monthly meetings of the State Plan Committee, topic-focused work groups met for more than 12 hours over the course of several days to review state data and survey results. They discussed important issues around housing, employment, health care, family and individual supports, advocacy and leadership, education, recreation, transportation, and more.

The work culminated in January of 2021 with a strategic planning retreat, at which time each draft goal and objective was carefully considered, word by word.

The Council adopted the plan at its May 2021 meeting. It includes three broad goals in the areas of advocacy, systems change, and capacity-building, with four to six objectives each in the areas of self-advocacy, leadership development, healthcare, housing, employment, transition, special education, formal and informal support, and community capacity-building.

Part 1: ADVOCATE The New Jersey Developmental Disabilities Advocacy Network



The New Jersey Developmental Disabilities Advocacy Network (NJ DDAN) remains a vibrant group of self-advocates, family advocates, providers and other stakeholders to explore areas of importance across DD advocates. This shared approach has helped advance our collective advocacy agenda.

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**
- **Adequacy of System Funding**
- **Housing**
- **Transportation**
- **Employment**

- **Health, Safety and Quality Assurance**
- **Person-Centered/Self-Direct Services**
- **Communication**

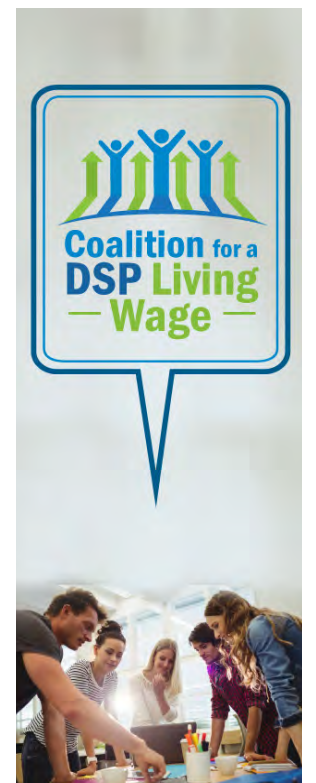
The NJDDAN was organized because of a major system redesign in NJ from a state system that had contracted for services with providers on behalf of individuals with I/DD for over four decades. The contracted system transitioned to a fee-for-service delivery system. The state also transitioned from a state case management system to a privatized using a conflict-free support coordination system. NJ DDAN conducted its third virtual summit with key state leaders in response to the issues raised in a collective advocacy agenda. The state's new acting commissioner of the Department of Human Services attended this event.

Direct Support Professional Wages

New Jersey experiences a 44 percent turnover rate and 25 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 workforce crisis.

NJCDD funded the Coalition for a Direct Support Professional (DSP) Living Wage (Coalition). This funding permitted the Coalition to study the DSP wage issues in New Jersey and across the country. Materials were established to promote the DSP living wage issues and to educate individuals with I/DD and their families, providers, DSPs and the legislature.

As a result of powerful education and messaging on the DSP workforce crisis, the NJ legislature approved increased funding for the fourth and fifth consecutive year in the fee-for-service system with providers and for those self-directing. As a result, most DSPs and their supervisors working within the DD service system received a salary increase or adjustment. In raising awareness of the critical role played by DSPs, the state also provided temporary wage adjustments for certain DSPs during the peak of COVID-19.



People First New Jersey

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 about 100 self-advocacy members. Chapters are led by advocates with support as needed by Council staff.

NJCDD's People First Coordinator and advocates gave People First New Jersey presentations at schools and community organizations, throughout the pandemic speaking virtually to more than 500 students and community members. People First New Jersey information and resources were disseminated virtually at statewide resource fairs, conferences, and other community events.

Some sessions began to transition from virtual to in person sessions as the year unfolded. Participation levels increased during remote sessions partially due to the lack of required transportation. As a result, hybrid meetings were offered to help improve advocacy and People First group involvement.



Youth Leadership

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.

The pandemic presented additional challenges while moving from face-to-face interaction to a virtual learning environment. Participants used technology during a challenging year to maintain collaborative programs like Road to Independence Success and Employment (RISE). This opportunity offered the students the chance to increase their computer skills, and made them even more valuable in the job market.

In person meetings returned during this year. Members benefited from more personal interaction during face-to-face sessions.

New Jersey Regional Family Support Planning Councils

The New Jersey 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 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 and regularly meet 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 FY2021, RFSPCs conducted 8 public forums/provider fairs, and 5 statewide meetings with an estimated total of over 1,800 attendees. State leadership explains rapidly changing policies and families share their experiences and ask questions. Paul Aronsohn, Ombudsman for Individuals with Intellectual or Developmental Disabilities and Their Families attended multiple meetings to listen the voice of families. A year after the onset of the global pandemic, the RFSPC hosted a successful peer training session called "how to build an integrated care network to increase your loved one's health and wellness." All four speakers were RFSPC members (parents of individuals with I/DD) who work as a medical, nursing and social work professional. They shared their personal experiences as well as professional expertise to fellow parents and guardians of people with disabilities.

RFSPC remained instrumental in various meaningful changes in the service delivery system. They led the interagency collaborations between DDD and CSOC to create a "DDD short application" for youth who were deemed eligible for the DD services by CSOC. Individuals and families who use self-directed services were able to keep Easter Seals as their fiscal intermediary. They also collaborated with multiple organizations to conduct robust special education advocacy. In September 2020, the Supreme Court of New Jersey ruled to limit the participation of "non-lawyers" (including parent advocates) at IEP meetings or mediations. The RFSPC joined the advocacy action with various organizations, which resulted in rescinding of the aforementioned ruling. The RFSPC played an important role in the statewide advocacy to creating the two important laws for students who were unable to receive appropriate services due to the COVID 19. Thanks to the new laws, students who turn 21 during the 2021 2022 and the 2022 2023 school years are eligible for additional services. Also, the statute of limitations for filing a due process petition seeking compensatory services during the COVID period has been extended.

RFSPC has multiple subcommittees including the Family Advisory Council for adults, Collaboration Committee for children and youth, Public Relations Strategies, Health and Safety, and Community of Practice/Charting the LifeCourse Family Action Group. Statewide Chairs, Vice-Chairs, Family Support Coordinator and Family Liaison became the certified Charting the LifeCourse Ambassadors. Many of members also serve as the Developmental Disabilities Advocacy Network (DDAN) members.



COLLABORATE Partners In Policy Making

On April 17, 2021, in a virtual ceremony, The Boggs Center, New Jersey's federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service celebrated the graduation of its fifth Partners in Policymaking Class. New Jersey Partners in Policymaking is an 8-month leadership development and advocacy education program for adults with developmental disabilities and family members of young children and transition age youth. It is available through a collaboration between the New Jersey Council on Developmental

Disabilities, 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 change in our state.

New Jersey's program is one of twenty-eight Partners in Policymaking programs across the country. This year's class of eleven people with disabilities and fourteen family members, join more than 30,000 graduates across the country ready to collaborate with policymakers to increase the inclusion, self-determination, and well-being of people with disabilities.



New Jersey Legislative Disability Caucus

The newly formed New Jersey Legislative Disability Caucus serves as a bipartisan forum within the New Jersey Legislature. It is a venue for lawmakers and their staff to consider the impact on the disability community when shaping all public policies in the Garden State through increased awareness and a greater understanding of the complexities of the disabilities service system and issues affecting individuals with disabilities and their families. People with disabilities, their families, and organizations that support and advocate for people with disabilities in New Jersey serve as resources for the Caucus.

Legislators who are caucus members serve as champions for individuals with disabilities in New Jersey by meeting with them in their district offices; participating in quarterly education forums; and above all, promoting policies to improve the lives of people with disabilities by considering the impact on the disability community in shaping all public policies in New Jersey.

New Jersey Legislative Disability Caucus Chair, Senate President Steve Sweeney, honorable legislative caucus members and

advocates from the disability community met virtually on January 26, 2021 for the inaugural meeting of the Caucus. Caucus members discussed the impact of COVID-19 on people with disabilities. With the COVID-19 pandemic taking a disproportionate toll on people with disabilities, the topic led to a robust discussion among policymakers and advocates for this first briefing session of 2021.

Disability advocates shared their experiences with policy makers regarding limited access to vaccines, testing, personal protective equipment, and critical care resources amid the pandemic. They also discussed the loss of educational services, therapy and behavioral supports due to the public health crisis and how it has affected the transition to adult life and compensatory services. The goal of the briefing session was to raise awareness and share ideas, so policymakers can make informed decisions on how to best address the inequities.

Roundtable discussions continued during the fiscal year. Sessions were also held on April 27 and July 27, 2021. Topics included the impact of employment for people with disabilities and housing.

GRANTS

NJCDD offers grants each fiscal year to organizations that provide innovative services for people with I/DD. The following grants were active during FY2021:

Best Buddies Summer Interns

Best Buddies was awarded a contract to deliver a paid summer intern program for students in a cross section of positions within a wide variety of businesses. Twenty-five students completed the program. Students participated in pre-employment skill development focused on transportation, problem solving, job interviews, or workplace communication.

Community Options (Autobility)

Community Options, Inc. received a grant to study the feasibility of using rideshare services for people with I/DD. The study focused on Northern New Jersey while collaborating primarily with Uber. The study determined that it was cost prohibitive for ridesharing organizations like Uber to effectively serve people with I/DD due to low anticipated ridership and the costs associated with accessibility requirements.

Housing Navigation

The Supportive Housing Association received a grant to enhance the housing-related knowledge of support coordinators, support brokers, and other professionals who assist people with I/DD and their families. Support professionals were selected to participate in an education series on the elements of housing to assist in the creation of service/home plans to support people with I/DD.

The Arc of New Jersey Training and Resource Databank

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

SPAN-SEVA Special Education Volunteer Advocates

The SPAN Parent Advocacy Network received grant funding to develop Special Education Volunteer Advocates (SEVAs). The program provided trained volunteers to support families during IEP and related meetings, advocacy coaching, and resources for families.

Community Innovation Projects

NJCDD awards up to \$10,000 in funding for Community Integration Projects (CIPs) to encourage innovative activities designed to bring meaningful change. The following CIPs were active during FY2021:

NJ Self Direction Conference

The Collaborative for Citizen Directed Supports-New Jersey received funds to facilitate a day and a half Self-Direction Conference that aligns people, values, vision and actions to improve self-direction in New Jersey.

Interactive Map Enabling Personalized Connections for Healthy Communities

The Collaborative for Citizen Directed Supports-New Jersey received funds to develop an interactive map. The interactive map connects self-advocates and families with qualified staff. It allows people seeking support, and those qualified and willing to provide the support with a tool to connect and consider collaborating.

EDUCATE

Conferences

NJCDD staff hosted information tables during conferences and events in order to increase awareness about NJCDD programs and resources. The following is a list of some of the conferences attended during FY2021:

- **Autism NJ Conference**
- **Black Issues Conference**
- **NJ School Board Conference**
- **NJ Education Association Conference**
- **NJ Association of Community Providers**
- **NJ League of Municipalities**
- **NJ Self Advocacy Conference**
- **NJ Youth Transition Conference**
- **Governor's Housing Conference**

Publications

People & Families Magazine

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

A wide range of topics were featured during FY2021 including congregate care, the family support act, special education and Medicaid.

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. Featured topics included mental health issues among children, special education by the numbers, and employment. For more information, visit NJCommonGround.org.

Advocacy In Action Newsletter

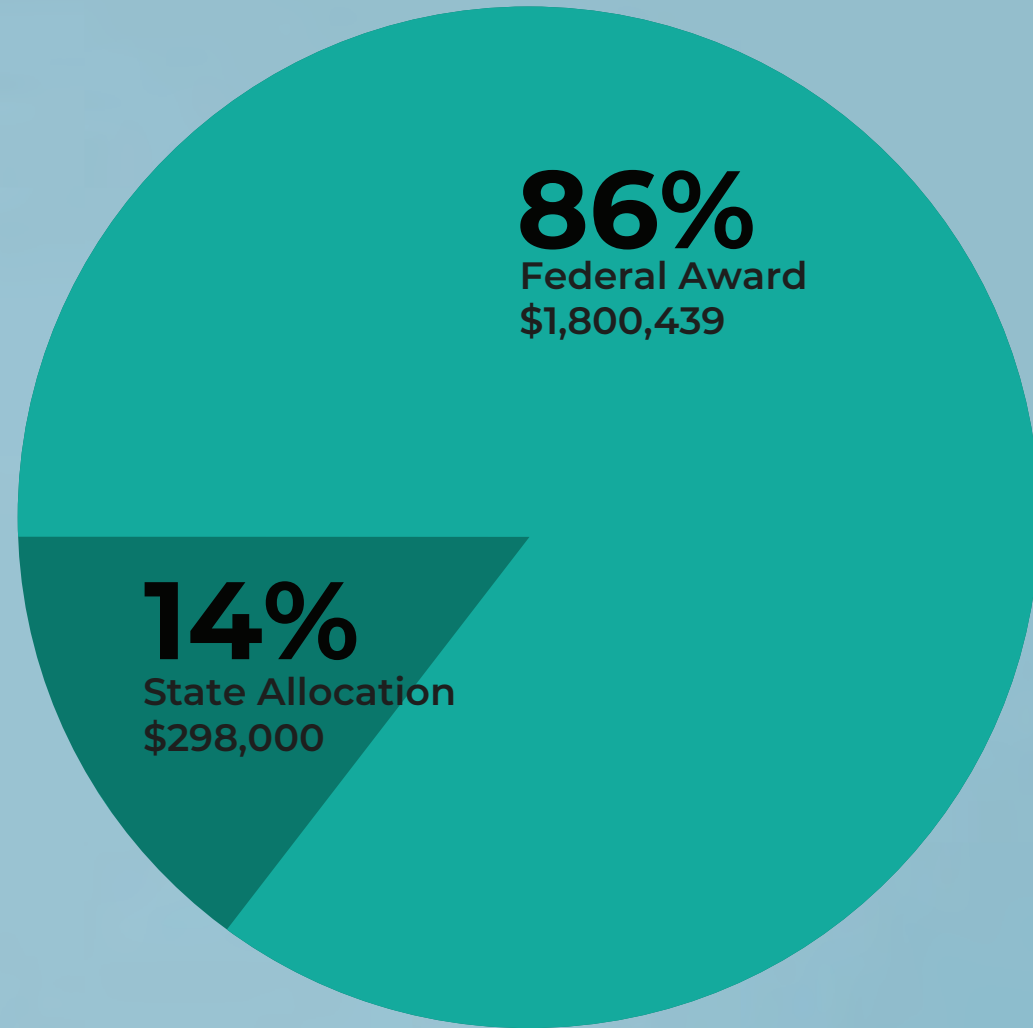
This monthly e-newsletter provides important announcements about NJCDD's programs, grants and initiatives. It also includes key information about public policy, and other news about the developmental disability community.

Issues highlighted a broad range of timely and relevant information during FY 2021 including available grants, national news, and a variety of webinars and events.

Disability In Focus Blog

This blog provides valuable first-hand insight on key issues impacting people with development disabilities and their families. Blog writer Jeremy Einbinder and guest authors examined in depth topics ranging from the disability workforce to community support and the issue of autonomy.

In addition to the above publications, NJCDD produces a number of brochures, fact sheets, and pamphlets highlighting key programs, initiatives and available resources. NJCDD 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.

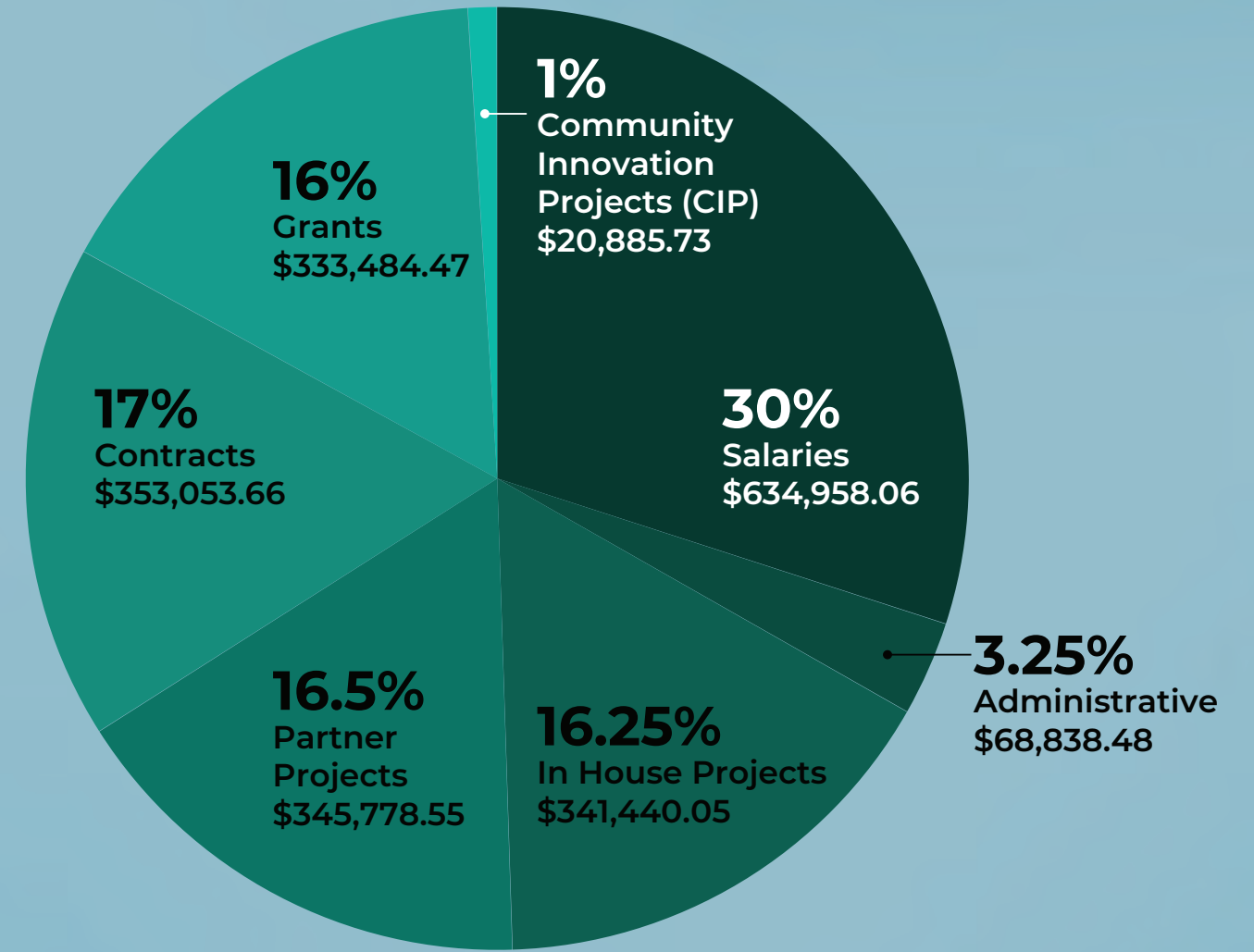


Allocated Funds

Federal Award \$1,800,439

State Allocation \$298,000

Total: \$2,098,439



Expenditures

Salaries \$634,958.06

Administrative \$68,838.48

In House Projects \$341,440.05

Partner Projects \$345,778.55

Contracts \$353,053.66

Grants \$333,484.47

**Community Innovation
Projects (CIP)** \$20,885.73

Total: \$2,098,439.00



NJCDD Members

Council Members

Paul A. Blaustein, Chairperson
Kevin Nunez, Vice Chair

Self-Advocates Members

Todd Emmons
Andrew McGeady
Myrta Rosa
Ryan Roy
Gary Rubin

Parent, Family Member and Guardian Members

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

Council Staff

Mercedes Witowsky, Executive Director
Maria Ali, Graphic Designer/Web Administrator
Gary Brown, Communication Officer
Kyoko Coco, Regional Family Support Planning Council Coordinator
Jodi Fox, Chief Fiscal Officer
Frank Latham, Youth Leadership Coordinator
Maria Leary, Special Project Consultant
Jade Pollock, Diversity, Equity and Inclusion Liaison
Jesse Schwartzman, Advocacy and Outreach Assistant
Robert Titus, Public Policy Coordinator
Jacinta Williams, Administrative Assistant

Public Member

TBA

Federally-Mandated Members

Gwen Orłowski, Executive Director
Disability Rights New Jersey

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 of Medical Assistance and Health Services
Phyllis Napier Melendez (Designee)

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





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