



Annual Report FY 2016

Introduction: 2017- 2021 Five-Year Plan

The past two years have been a transformative period for advocates both in New Jersey and across the country. 2016 saw a highly polarizing and consequential election cycle, and while developments in Washington D.C. since then have given many disabilities advocates cause for concern – from threats to Medicaid and other social services, to renewed debates around public school vouchers and special education, and more – this period also produced a considerable swell in civic and political engagement among citizens with disabilities.

From the national *#CripTheVote* and *RevUp!* campaigns to generate disability voter turnout at the polls, to the laudable efforts of national disability advocacy groups like ADAPT to protect Medicaid and the Affordable Care Act, people with disabilities have risen to the challenges we face.

In 2016 much of the Council's efforts as a planning and advocacy body focused on forming our Five-Year Plan for Fiscal Years 2017 through 2021. In accordance with our by-laws, the Council operates under a five-year planning structure, which it adjusts annually. Members define priority areas and focus activities around achieving the goals outlined in the plan. These goals are achieved through the 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.

Determined to address the greatest challenges and deficits in community supports and services for individuals with I/DD and their family members, Council members and staff researched and carefully gathered direct input from disability advocates, individuals with disabilities, parents and guardians, provider agencies, educators, and other community stakeholders.

After extensive deliberation, Council members identified seven priority areas to focus their advocacy efforts over the next several years. Since the plan was approved and adopted, the NJCDD has set about achieving our advocacy goals. Examples of our progress are included in this report.

2017 Five-Year Plan Overview

Self-Advocate and Family Training and Information

Goal: Assess statewide training and information available for self-advocates and families and address gaps which support individuals to exercise their rights in the various DD systems

Direct Support Staffing issues

Goal: Develop and implement an advocacy strategy and plan to address staffing issues

Special Education Advocacy

Goal: Enable students and families to exercise their rights within the Special Education system

Employment

Goal: Advance New Jersey's practices/performance as an Employment First state considering all individuals with developmental disabilities

Transportation

Goal: Advocate statewide for clear policies based on the principle that transportation should be available to accommodate the lives of people with disabilities

Health & Wellness

Goal: Advocate for individuals with developmental disabilities to have the same access to quality healthcare as their non-disabled peers

Housing

Goal: Advance New Jersey's practices/performance regarding housing for all individuals with developmental disabilities

About the NJCDD

Established in 1971, the New Jersey Council on Developmental Disabilities (NJCDD) is a federally mandated disability 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 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. Currently, there are 24 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 New Jersey Governor.

The remaining members represent a number of I/DD advocacy and public policy organizations, and their presence on the Council is mandated by state and federal government. The executive directors from the NJCDD's two sister organizations, 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 by the Council, and that individuals and family members have the opportunity to affect real change in how I/DD services are planned and delivered.

Council Projects

People First New Jersey

People First is an international advocacy movement for people with disabilities that was brought to New Jersey by the NJCDD in 2014. People First is grounded in the philosophy that all people with disabilities are capable and entitled to pursue advocacy on their own terms and with leadership that is chosen exclusively by them. People First chapters aim 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 a number of counties across the state. Chapters are assisted by the NJCDD's People First Coordinator, Jaymes Brill, and are lead by advocates chosen solely by chapter members. Members work together to identify and organize the advocacy and fellowship activities on which they focus their efforts.

Advocacy activities carried out by People First New Jersey chapters in FY-16 have included disability voter registration drives, empowering people with disabilities to speak out about abuse and exploitation, working to increase choice and quality of supports for people with disabilities, and working overall to fight against discrimination, exclusion, and bullying.

Over the same period, the NJCDD's People First Coordinator and advocates gave People First New Jersey presentations at 17 schools and community organizations, speaking to nearly 1500 students and community members. People First New Jersey information and resources were also disseminated at resource fairs, conferences, DD awareness events, and other community events across the state, reaching over 4300 individuals with I/DD and stakeholders.

For more information about People First New Jersey, and to find out how to get involved, visit us at www.njcdd.org.

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 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 FY 2016, the NJCDD held Youth Leadership programs at six schools and community locations, training 85 new youth advocates. 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.

Youth Leadership Conference – 200 Students

Dare To Dream Conference Series – 5 locations, 750 Students

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 18) and family members available through 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.

Family Support

Twelve monthly statewide teleconferences – approx. 144 total participants

Four (quarterly) statewide meetings – 117 total participants; featured 10 guest speakers, including 4 state officials

Eleven meetings with DDD officials with committee of 7 family advocates present.

Five meetings with Children's System of Care officials with committee of 11 family advocates present at meetings

Fifteen Public Forums/Providers Fairs with approx. 1200 family members attending

Established Family Advisory Council

Started “Words of Wisdom” Social Media Campaign

Council Initiatives

Health & Wellness

Council funds the “Get Fit” program through the Family Resource Network. In FY16 there were 2000 individuals with I/DD, including some with chronic illness, who were included in the program. “Get Fit” is dedicated to promoting an inclusive culture of Health & Wellness for people with I/DD, Chronic Health Conditions and their caregivers. Get Fit’s partnership with Rowan University has resulted in a total of 804 university students aiming to enter into the health and allied health fields, being trained and equipped to promote health & wellness for people with I/DD.

Outreach to hospitals: 85 Healthcare facilities throughout all 21 counties. These include private, minute clinics, urgent care, medical clinics, hospitals, Community health centers, family medical centers, and dental facilities.

Met with seven out of eleven CILs in New Jersey to review their H.W. programs for people with I/DD.

In a goal to expand the development and training of healthcare providers, the H&W committee met with experts from Methany School and Seton Hall University to develop a white paper to be considered by the Deans of the school of health and medical sciences at Seton Hall University. The paper serves as an instructional guide for their curriculum. This white paper includes: Justification for training, prevalence of disability, training for healthcare providers, the medical home approach, desired outcomes of training healthcare professionals in knowledge, skills, and attitudes, that family members and caretakers are important resources in planning medical care. The goal of this white paper is to assist in educating healthcare students on the needs of persons with I/DD and to have this healthcare curriculum in all medical colleges and universities in New Jersey.

SPAN Grant – Health Advocacy toolkit

Conducted workshops, webinars, etc. 5335 people accessed the toolkit in English and 2065 accessed them in Spanish. SPAN’s Family to Family health information center staff assisted 7660 families, using the toolkit to advocate for their child or youth with special healthcare needs. The toolkit was also shared at the Parent to Parent Annual Fathers Conference, the NJ Special Needs Expo, the NJ Children’s System of Care Youth Conference, and numerous health fairs in underserved communities across the state.

DD Awareness

Cape May DD Awareness Day – 75 Advocates/Professionals

Cumberland County Disability Awareness Day – 50 Advocates/Professionals

No DD Awareness Day event at great adventure; series of advocacy conferences scheduled for FY 2017

DSP Coalition/Advocacy

In FY2016, the NJCDD joined with the Arc of New Jersey, Autism NJ, ABCD, Family Support Coalition of NJ, NJ Statewide Self-Advocacy Network, Statewide Family Support Planning Councils, NJ Association of Community Providers to form the New Jersey Coalition for a DSP Living Wage. The Coalition's mission is to advocate for increased wages and benefits for Direct Support Professionals.

#SaveMedicaidNJ

Legislators in both the US Senate and US House of Representatives are working on legislation that includes severe cuts to Medicaid. It is the largest insurance provider in the country and the single most important funding source for the support services that Americans with developmental disabilities and their families rely upon to lead healthy, dignified, and meaningful lives in our communities. These cuts could potentially reach \$834 billion or more over 10 years. In addition, the President's Budget Proposal includes an added \$610 billion in cuts. That's over \$1.4 trillion in Medicaid **Cuts over 10 years**, which would be catastrophic to our support system.

As a community, we need to be sure that our federal legislators hear us, see us, and understand just how important the continued full funding of Medicaid is to us, our families, and our friends. We need to call on members of the general public, those with disabilities and without them, to join us in this effort.

Publications

People & Families Magazine

Common Ground

Disability In Focus Blog

Advocacy in Action E-newsletter

Social Media

Facebook

Twitter

In the Community

Conferences and Events

In an ongoing effort to spread awareness of the NJCDD's work in the community, the Council often presents information tables and displays at conferences and events geared toward audiences with developmental disabilities and the public at large.

The following is a list of some of the conferences and events at which the council was present in FYs-2016 & 2017:

FY 2016

Disability Pride Parade (2015) – 200 Participants

Disability Pride Parade (2016) – 300 Participants

Canadian People First Annual Meeting (2015) – 200 Self Advocates

ABCD Annual Conference (2015) – 100 Advocates

Arc Advocacy Luncheon – 2 locations, 400 advocates

Transition Conference – 200 Advocates/professionals

Housing Conference – 500 Attendees

NJ League of Municipalities Conference – 3 days, 1000 Attendees

Guardianship Conference – 200 attendees

Facing the Futures Employment conference – 250 attendees

Youth Leadership Conference – 200 Students

Family Support Network Beach Bash – 2000 attendees

NJ Equal Justice Conference

NJ Black Issues Convention

NAACP Convention

NJ Latino Psychological Association

NJ Association of Community Providers

Approx. 6,000 advocates, professionals, and members of public reached

Trainings and Presentations

“Transition Matters” Lecture – 60 Advocates/professionals

R-Word Presentations/Trainings – 8 Schools/Orgs.; 585 Students/Advocates

Anti-Bullying Presentations/Trainings – 22 schools/Orgs.; 1,569 Students/Advocates

Collaborations and Partnerships

Family Support Coalition of New Jersey

At the State House

During FY 2016, the NJCDD Collaborated with several organizations to address issues within the I/DD community:

S-2940 raised the penalty for the endangerment of people with developmental disabilities

S-3117 prohibited the Division of Developmental Disabilities from compelling transfers of individuals with developmental disabilities from out-of-state to in-state facilities unless certain exceptions applied

S-2668 established "MVP Emergency Alert System" for missing persons with mental, intellectual, or developmental disabilities

S-475 required certain information regarding Down syndrome be provided to certain parents and families

NJ Senate and Assembly Majority committees repeatedly reached out to the NJCDD for input on issues that affect the I/DD community. Among those issues include housing, Medicaid, DSP training and compensation, special education, employment and transportation.

FY 2016 Fiscal Report

Allocated Funds

Federal Award	\$1,586,384
State Money	\$306,000
Total:	\$1,892,384

Expenditures

Salaries:	\$575,580
Admin:	\$102,775
In House Project:	\$323,967
Contract:	\$212,161
Grants:	\$663,295
Community Innovation Projects:	\$14,606
Total:	\$1,892,384