

The New Jersey Council of Developmental Disabilities
Annual Report 2010



Grow
ustain
Seeding Systems Change
for the
Future



Make
it Happen
ADVOCATE // COLLABORATE PARTICIPATE

New Jersey Council On Developmental Disabilities



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Annual Report 2010





From the Chair

Welcome to our report on the activities of the New Jersey Council on Developmental Disabilities. Our hope is that these and future activities will promote the growth of positive systems changes for people with developmental disabilities and their families.

I am Elaine Buchsbaum, Chair of the Council and parent of Matt, a young man with developmental disabilities.

Last year was an exciting one for our Council. We funded a number of innovative projects through our grants process. We saw the Youth Leadership and Monday Morning self-advocacy projects expand and gain new focus. We continued to be involved with our community partners in carrying on efforts we had launched previously, such as our emergency preparedness training, the R Word Campaign, and advocacy efforts highlighting the numerous advantages community living has for people with developmental disabilities and their communities. Also, two of our nationally renowned activities—the Partners in Policymaking advocacy training sessions and our magazine People & Families—reached new levels of excellence.

This report also serves to introduce us to those who may not be familiar with who we are and what we're about.

Simply put, we're about helping people with developmental disabilities live the lives they deserve to live—taking part in their communities and making their unique contributions to those communities. We do that through seeding community-based ideas; communicating with our constituents—people with developmental disabilities, their families, their public officials and their neighbors—running our ongoing advocacy endeavors; and working with our partners.

*Elaine Buchsbaum, Chair
New Jersey Council on Developmental Disabilities*





From the Executive Director

***T**his past year we laid much of the important groundwork for our next five-year plan.*

Councils on Developmental Disabilities operate on a five-year planning cycle. This gives us the chance to build a framework to guide the council's goals and objectives; and to give our constituents and partners a clear roadmap of our vision for the near future.

We contracted with Kean University to assess the status of people with developmental disabilities across the state. We met with national and state experts to learn more about best practices in developing strategic plans and in core areas of importance—such as self-advocacy, employment, housing, community living, education, transportation and health care as well as best practices in how to develop effective strategic plans.

All that good work is helping us develop a plan based on real data and real information. Over the coming year we will be sharing details of those efforts and details of our 2011-2016 plan.

As part of our public outreach the council will hold three public hearings on the five-year plan on: June 29th from 10am to 12pm at the Mary Roebling Building in Trenton; July 6th from 1pm to 3pm at the Arc of Morris County in Morris Plains; and July 7th from 1pm to 3pm at the Cumberland County College Conference and Events Center in Vineland. In addition, information about other ways you can offer comments on the five-year plan will be posted on the Council's web site at www.njcdd.org

We look forward to hearing from you.

Alison Lozano, MPA, Ph.D.





Who we are

The New Jersey Council on Developmental Disabilities is a federally mandated and funded New Jersey state agency. New Jersey's Council—as well as the other councils throughout the 50 states and in five territories—was established in 1974 by the federal Developmental Disabilities Act.

The Council's charge is to advocate for people with developmental disabilities and their families, to promote positive systems change on their behalf and to help build the capacity of the broader community to fully include individuals with developmental disabilities.

The Council collaborates with various partners to monitor the state's various formal and informal systems of supports for people with developmental disabilities. The group then makes recommendations to public officials, government agencies, private provider and community representatives, and stakeholders in the developmental disabilities community about ways to improve those systems.

The Council encourages people to participate by working with individuals with developmental disabilities and their family members to help them obtain the tools they need to be better advocates for themselves and others.

Councils bring people with developmental disabilities and their families together with the heads of public agencies that control the supports and services people with developmental disabilities sometimes rely on. Other professionals with influence over public and private systems of support for people with developmental disabilities are also at the table. This is an exciting mix of perspectives that promotes the kinds of dialogue necessary to help build a truly responsive and representative organization.

The Council:

- Monitors public and private services systems for people with developmental disabilities;
- Advises leaders with influence over those systems; and
- Advocates for those systems to progress in ways that are positive for people with developmental disabilities and their families.





Who We Are

The Council is allowed by law to have up to 30 members. Currently there are 23.

The majority—60 percent—are people with developmental disabilities and immediate family members of people with developmental disabilities. Those “public members” are appointed by the Governor.

The executive directors of the Council’s two sister agencies—The Elizabeth M. Boggs Center for Excellence at the University of Medicine and Dentistry (UMDNJ) and Disability Rights New Jersey (also created by the DD Act)—also are members.

Other members include representatives from key state agencies, to ensure that those representatives interact directly with people with developmental disabilities and family members to discuss public policies.

Also, to have input from the private service delivery sector, the director of a service provider agency is part of the Council membership.

The Council meets four times a year. Through its Planning Committee and guided by federal requirements, the Council develops and operates under a five-year planning structure that is adjusted annually. Members discuss and define priority areas. The group targets its activities towards accomplishing the goals and objectives identified through the planning process. Those goals and objectives are accomplished through the Council’s grants, its in-house projects, and on-going collaborations with many partners.

For a complete list of Council Members, meeting schedules and other background information about the Councils on developmental disabilities visit our web site at www.njcdd.org





The Council's Vision

A All individuals with developmental disabilities...

- are participating, equally included members of their 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 are developmental disabilities?

Developmental Disability means a significant, chronic disability of an individual that...

- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments,
- (B) is manifested before the individual attains age 22,
- (C) is likely to continue indefinitely,
- (D) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) self-care;
 - (ii) receptive and expressive language;
 - (iii) learning;
 - (iv) mobility;
 - (v) self-direction;
 - (vi) capacity for independent living;
 - (vii) economic self-sufficiency; and
- (E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 9, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Some examples of developmental disabilities are: intellectual disabilities; cerebral palsy; chronic seizure disorders; autism; spina bifida; and early onset brain traumas.





Grants

***E**ach year the Council funds a number of projects through grants. Proposals are evaluated and single or multi-year projects (up to three years) are selected based on which proposals best promote the goals and objectives outlined in the Council's State Plan. Creativity, innovation and sustainability beyond the grant period are also important criteria.*

GRANTS THE COUNCIL FUNDED IN 2010 INCLUDED:

Supportive Housing Association of NJ

- Locating Housing Resources

The project established a user-friendly webpage with information about independent living, apartment locations, moving strategies, and discussion tools for living as a good neighbor. Also, the project goes deeper into the specific needs of each person with an exploration of wider generic services, life-sharing/home-sharing, as well as home ownership possibilities. Additionally, the website will have an interactive process using Facebook, YouTube and other social networking opportunities to bring people together share common needs, interests and opportunities, enhancing their independence

Family Resource Network - Get FIT

Get FIT will expand on the existing partnership between The Family Resource Network (FRN) and Rowan University (RU) to increase the capacity of the health & fitness field to serve persons with developmental disabilities (PWDD). Get FIT will be put into operation in different environments including an urban YMCA, a high tech gym, and in collaboration with a private trainer.

The project will produce a curriculum for university programs in health and wellness, linking the university curriculum with developmental disabilities and generic providers.

Mini Grants

The Council also offers mini-grants for smaller community-based ideas, such as: an anger management library; teaching social skills through creative arts; and a student poster contest to promote inclusive education.





Partners in Policymaking

Year End Partners in Policymaking Report 2010

Partners in Policymaking (PIP) is a leadership training program for individuals with developmental disabilities and individuals who have an immediate family member with a developmental disability. PIP provides state-of-the-art knowledge about developmental disabilities issues and builds the competencies necessary to become advocates who can effectively influence systems change.

Last year the schedule was revamped and the additional outreach time was used to more thoroughly spread the word about the trainings throughout the state. The new session began in September of 2010 and runs through April 2011.

Participants meet for one weekend a month for those eight months. They learn about a wide range of topics designed to help them build their advocacy skills. Sessions include lectures and activities that cover the history of developmental disabilities; how government works; how to be an effective advocate; and other related information. The sessions reach their peak with groups of participants working together to identify issues important to people with developmental disabilities, writing testimony about those issues, and presenting that testimony to legislators and professionals who donate their time for a mock legislative hearing at the State Capitol in Trenton.

In November 2009, 26 participants graduated from the previous PIP class—the last one held before a reorganization of the schedule— and 23 participants graduated in April 2011 from the most recent session.

For more information about the PIP visit the Council's web site www.njcdd.org (link to Partners in PolicyMaking).







Monday Morning

Y

ear End Monday Morning Report 2010

Monday Morning is a grassroots advocacy movement for people with developmental disabilities, with networks throughout New Jersey.

In 2010 the project continued to gain strength and recruit new members. The local networks emerged as a major force in the self-advocacy community.

Self-advocates are people with developmental disabilities who are speaking out in their communities about issues important to them and others.

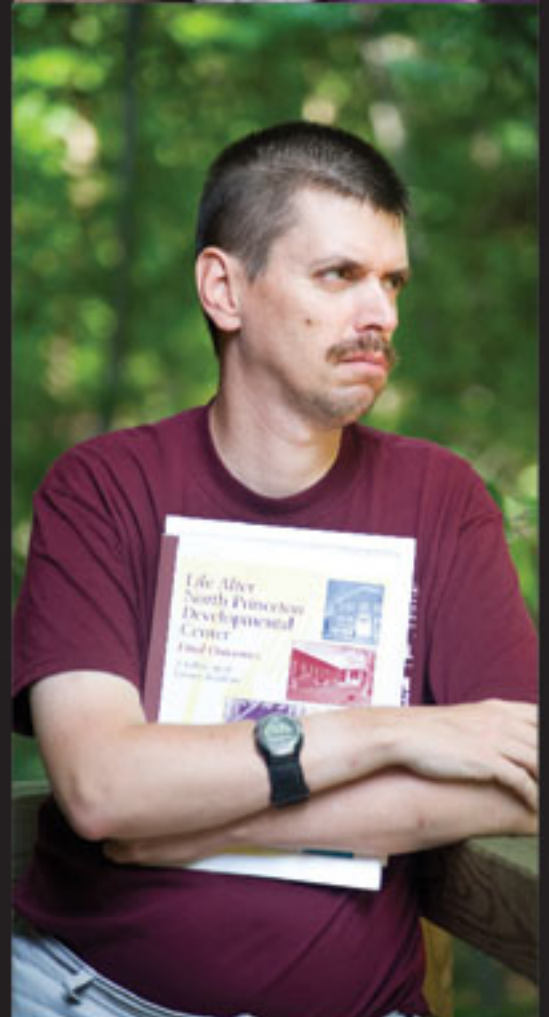
The Bergen County Monday Morning Network worked with officials of the Meadowlands to ensure that the New Meadowlands Stadium, which began hosting games last year, is fully accessible for people with developmental and other disabilities.

This is one example of the many successful local and regional advocacy efforts of the project's statewide networks. With their strong advocacy legislation was introduced, passed and signed into law that will replace the words "mental retardation" with "intellectual and developmental disability" in state laws, regulations, resolutions and other written documents.

Over the mid-term election cycle Monday Morning networks continued to work with local and state officials to increase voter participation among people with disabilities and to ensure their polling places are accessible.

This year the networks have taken on the issue of reducing New Jersey's reliance on developmental centers and promoting community living options for the people who live there.

For more information about the Monday Morning Project visit our web site www.njcdd.org (follow the link to Monday Morning).





Youth Leadership

Year End Youth Leadership Report 2010

The Council's Youth Leadership Program is in its second full year. The program works with local groups and community-based organizations to provide leadership training for young people with developmental disabilities.

Youth that completed the trainings and continued on as groups—putting that knowledge into practice—took part in presentations and rallies around the R Word Campaign. Some of those individuals also served as speakers about that and other issues.

Youth Leadership Program participants have been part of 5 presentations to college students in the past year, organized by the Council.

The program is continuing to expand. To date, about 30 individuals have taken part in education sessions.

New sessions have been written for the trainings based on feedback from those youth who have participated.

One of the new topics available this year is building social network with other young people with and without disabilities.

Work done last year with individuals is bearing fruit. Graduates of the trainings and participants in follow-up activities are moving on to serve on boards and committees—such as the National Youth Leadership Network (NYLN), an organization led by and for young people with disabilities; and the advisory board of SABE (Self Advocates Becoming Empowered), currently the only national self-advocacy organization for people with intellectual and developmental disabilities.

For more information visit the Council's Web site at www.njcdd.org (follow the link to Youth Leadership Program).





Family Support

Y

ear end Regional Family Support Planning Council's Report 2010

There are nine Regional Family Support Planning Councils (RFSPCs) in New Jersey. The councils gather and provide information about family support services to families like theirs, advocate for families and individuals with developmental disabilities at the local and state level on issues that directly impact their lives, and partner with the state Division of Developmental Disabilities (DDD) about how to better serve individuals and their families.

Members, through their regional councils, monitor and evaluate family support programs, inform families about current family support issues, provide information to policy makers, partner with DDD, and advocate to local officials and state legislators about helping to meet the need to support a family member with developmental disabilities at home.

Family members of people with developmental disabilities living at home and people with developmental disabilities serve as volunteers on the RFSPCs. The Statewide Family Support Coordinator is on staff at the Council and we provide administrative support.

These events help to keep their communities informed on current topics under discussion at the state and national levels and provide guidance in advocacy efforts. The RFSPCs participate in meetings with DDD and bring valuable input from families and from personal experience on how to shape policy, direct Family Support funding and services.

Last year RFSPC members with DDD began work on developing a new Home and Community Based Waiver to qualify for federal Medicaid reimbursement for family support services.

Sign up to keep informed about family support issues. Find out about becoming a member of your local council. Visit our web site: www.njcdd.org. (follow the link to Family Support).





Campaigns and Partnerships



One of the Council's most successful campaigns, the campaign to stop the use of the "R" Word, carried into its third year with the passage of a law changing references of "mental retardation" to "intellectual and developmental disabilities" in all state laws and regulations.

Materials developed in the Council's R Word Campaign—buttons, bumper stickers, lapel pins, mousepads, T-shirts, etc.—were used by self advocates and their partners throughout New Jersey to build support for the effort.

In addition, requests for 5,360 of those items were mailed throughout New Jersey, and to advocates and supporters in Kentucky, Minnesota and Georgia.

Nearly 900 students in eight state school districts participated in R Word presentations conducted by Council, staff and volunteer partners, as well as exhibitions at 16 conferences where 26,000 R Word items were distributed.

Council members, staff and volunteers also worked with its sister agencies—the Boggs Center for Excellence and Disability Rights New Jersey—and other partners to promote full inclusion in the community for all people with developmental disabilities.

These partnerships continue to focus on highlighting a number of pressing policy issues facing New Jersey and the nation, such as:

- the benefits of community living;
- the need to reduce New Jersey's over-reliance on institutions;
- the need to better support families caring for members with developmental disabilities at home;
- reducing, and eventually eliminating the use of restraints and seclusion;
- increasing employment opportunities for people with developmental disabilities; and,
- improving transition services for students with developmental disabilities leaving school and joining the adult world.

Finally, Emergency Preparedness training for people with developmental disabilities, which the Council piloted over the past two years, is being carried on by other agencies through grants from the Council. Council staff developed the trainings and the materials, and instructed the grantees on how to conduct the sessions.

From October 2009 through September 2010, 625 people completed training covering 10 counties: Ocean, Hunterdon, Camden, Burlington, Gloucester, Salem, Morris, Monmouth, Somerset and Union.





Awards and Communications

Community Building Awards

Each year the Council honors individuals and organizations making significant contributions toward building strong, inclusive communities. These prestigious Community Building Awards are given in a ceremony in April.

2010 Award winners:

Colleen Fraser Self Advocate Award - Bill Byrne
Elizabeth Boggs Family Member Advocate Award - Jane Horowitz
Lifetime Achievement Award - Beverly Roberts
Distinguished DD Systems Award - Rose Williams
Access Above and Beyond Award - Bagel Street Grill
Exceptional Policymaker Award - Assemblyman Joseph Cryan
Multi-Media Award - MyCentralJersey.com

Fellowships Awardees in Inclusive Education

Karen O' Brien	Katherine Siso
Christine Gilbert	Gia Calabreses
Diane Mueller	Megan Earl
Tim Cotov	Donna Eckman
David Gross	Maryann Bate

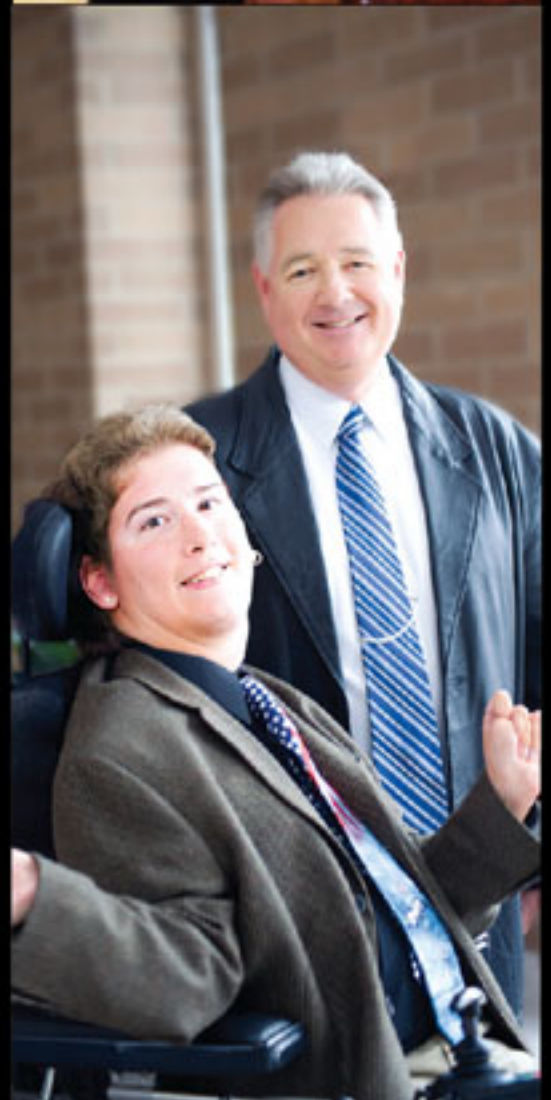
Communication and Publications:

The Council continues its nationally known magazine *People & Families*. The magazine is published four times a year and offers in-depth coverage of important issues affecting people with disabilities and their families, as well as feature stories about their life experiences.

A comprehensive brochure on *Restraints and Seclusion* was published last year, with the assistance of the Council's Education Subcommittee, as well as three issues of *Common Ground*, a professional-based newsletter on education directed at professionals and families.

Visit the web site to see all the latest publications, news and information, a comprehensive resource page for policy makers, more detailed information about the Council and its projects, and a link to the Council blog www.justsaysomething.org

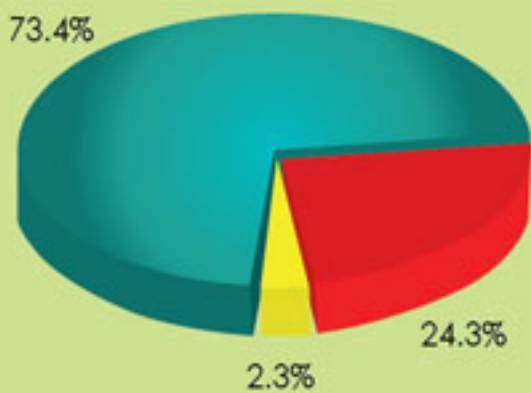
The Council's web address is www.njcdd.org



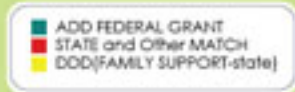


Federal Grant End Of Year Report

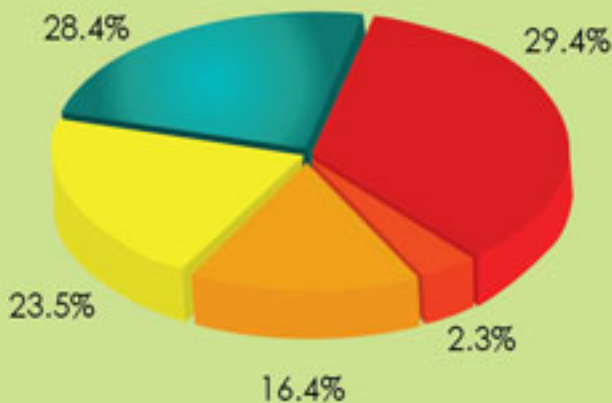
Funds Received FFY-10



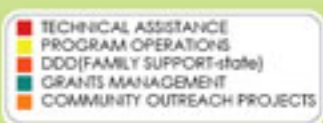
ADD FEDERAL GRANT	1,589,824	% 73.4
STATE and Other MATCH	527,009	% 24.3
DDD(FAMILY SUPPORT-state)	50,000	% 2.3
TOTAL FUNDS AVAILABLE	2,166,833	



Funds Distribution for FFY-10



TECHNICAL ASSISTANCE	636,577	% 29.4
PROGRAM OPERATIONS	510,008	% 23.5
DDD(FAMILY SUPPORT)	50,000	% 2.3
GRANTS MANAGEMENT	615,777	% 28.4
COMMUNITY OUTREACH PROJECTS	354,471	% 16.4
TOTAL FUNDS AVAILABLE	2,166,833	





Members List

Council Members

Chair: Elaine Buchsbaum
Vice-Chair: Christopher Miller

Self-Advocate Members

Todd Emmons, Voorhees
Russell Fried, Laurel Springs
Andrew McGeady, Jackson
Christopher Miller, Neptune City
Myrta Rosa, Plainfield
Gary Rubin, Elizabeth
Betsy Smith, Montclair
David Tag, Lindenwold

Parent or Guardian Representatives

Elaine Buchsbaum, Stockton
Ellie Byra, Flemington
Walter Fernandez, Barnegat
Purnima Hernandez, D.D.S., Glen Rock
Leah Ziskin, M.D., Cherry Hill
Hazeline C. Pilgrim, Montclair
Robin Sims, Bloomfield

The New Jersey Council on Developmental Disabilities

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Federally Mandated Members

Federally mandated members of the Council serve in accordance with the federal Developmental Disabilities Bill of Rights and Assistance Act.

NJ Department of Health and Senior Services

Division of Family Health Services
Assistant Commissioner: Celeste Andriot Wood
Designee: Pauline Lisciotto

NJ Department of Human Services

Division of Disability Services
Director: Joseph M. Amoroso

NJ Department of Education

Office of Special Education Programs

NJ Department of Labor

Div. of Vocational Rehabilitation Services
Director: Alice Hunnicutt

Protection and Advocacy System

Disability Rights New Jersey (DRNJ)
Executive Director: Joseph Young, Esq.

NJ Department of Human Services

Div. of Medical Assistance & Health Services
Director: Valerie Harr

NJ Department of Human Services

Div. of Developmental Disabilities
Deputy Commissioner: Dawn Apgar, Ph.D.

University Center for Excellence in Developmental Disabilities Education, Research and Service

The Boggs Center on Developmental Disabilities
Director: Deborah Spitalnik, Ph.D.
Designee: Michael Knox, Ph.D.

Public Member

Frank Caragher, The Arc of Union County,

Council Staff

Executive Director

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

Deputy Director

Douglas McGruther

Coordinator of Regional Family Support

Planning Councils

Bonnie Brien

Project Manager/Diversity Coordinator

Jane Dunham

Fiscal Officer / Office Manager

Gail Furrer

Public Policy

Sue Gottesman

Clerk/Receptionist

Gail Hodges

Youth Coordinator

Frank Latham

Monday Morning Project Coordinator

Barbara Lee

Database Manager / Secretary

Sharian Mackins-Gist

Communications Director

Norman Reim

State Plan Coordinator / Contracts Manager

Dolores Roselli

Advocacy Training Coordinator (Partners in Policymaking)

Dennie Todd

Administrative Assistant

Jacinta Williams

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