

# ***NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES***

*Advocate // Collaborate // Participate*



*Advocate*

*Collaborate*



*Participate*



## From the Chair

Welcome to our report on the activities and aspirations of the New Jersey Council on Developmental Disabilities.

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

The following report speaks for itself, outlining who we are, what we do and why those efforts are important for people with developmental disabilities and their families.

What I would like to add are some comments on where we plan to go from here.

Recently the Council held its annual retreat. We began the discussions on our next five-year plan.

It is clear from these early discussions that the systems that support people with developmental disabilities in New Jersey need serious attention and change.

Over the next year as we develop our five-year plan we will be looking at ways that our Council can aid the process of restructuring those systems so they better support people with developmental disabilities and their families by streamlining some services, expanding others and ensuring the resources we have are used more efficiently.

These are difficult times.

Our state—like most others and the country as a whole—has serious financial challenges. At the same time thousands are waiting for help they need now or will soon need.

It is imperative that we talk frankly about these issues, develop reasonable solutions based on honest facts and act on those solutions as quickly as possible.

To assist in that process is the goal of this Council and we welcome your input as we work towards that end.

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

## WE MAKE IT HAPPEN

Welcome to the New Jersey Council on Developmental Disabilities (NJCDD)— A federally mandated and funded New Jersey state agency.

### **We Make it Happen, Here's How**

- By Advocating for People with Developmental Disabilities and their Families.
- By Promoting Positive Systems Change.
- By Building Community Capacity.

*Grants* - Each year the Council offers grants for innovative ideas and projects. We're looking for your creative ideas. Work with us to Make Things Happen for People with Developmental Disabilities. For more information read on and visit the web site at: [www.njodd.org](http://www.njodd.org)



*Projects - Want to join one of our ongoing projects?*

**Partners in Policymaking** - *An exclusive Leadership Training for People with Developmental Disabilities and their Families. It's Informative. It's Fun. And it's Essential. Ask about getting in on this Rewarding Opportunity.*

**Monday Morning Project** - *A Grassroots Advocacy Movement for People with Developmental Disabilities and Colleagues. County-based networks meet regularly to learn about and influence local, state and national issues. Get on Board.*

**Youth Leadership Training** - *Our newest project is helping the leaders of the future get the skills they need. It's about understanding Who You Are and How You Can Make A Difference. Coming to your area soon.*

**Family Support** - *There are nine Regional Family Support Planning Councils (RFSPCs) in New Jersey. The groups gather information about services, talk to other families like theirs, and make recommendations to the state Division of Developmental Disabilities about how to better serve individuals and their families.*

*Partnerships and Publications* - Council members and staff monitor what's going on in the state so we can work directly with public officials, professionals in the field, and alongside other agencies and organizations to make sure the network of public and private support services is meeting the needs of people with developmental disabilities and their families. We publish a nationally acclaimed magazine called *People & Families*, published quarterly, that informs and entertains its readership with news, features, columns and reviews about topics related to people with developmental disabilities, but of interest to everybody. Try it; it's free. [www.njedd.org/publications](http://www.njedd.org/publications)



## WHO WE ARE

*The Council* - Is a unique state advisory body created at the federal level. There are councils like ours in every state and some U.S. territories.

Councils bring people with developmental disabilities and their families together with the heads of public agencies that control many of 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 and it promotes the kinds of dialogue necessary to help build a truly responsive and effective Council. Come see us in action sometime.

Find out when and where at: [www.njcdd.org](http://www.njcdd.org).

The Council is allowed by law to have up to 30 members. Currently there are 25. The majority—60 per cent—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 our two sister agencies—The Elizabeth M. Boggs Center for Excellence at the University of Medicine and Dentistry (UMDNJ) and Disability Rights New Jersey—are members.





*NJ Council on Developmental Disabilities, March 2010*

## The Council's Vision

*All individuals with developmental disabilities...*

- Are contributing 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;
- Have the same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident.

The Council meets four to six times a year. Through its Planning

***Sixty percent of the Council's membership are people with developmental disabilities and immediate family members of people with developmental disabilities.***

Committee and guided by federal requirements, the Council develops, and operates under a five-year plan that is adjusted every year. Council members decide on what they want to accomplish over the five years. They decide on activities to accomplish

those goals. The Council's

goals and objectives are accomplished through the Council's grants, its in-house projects, and on-going collaborations with our many partners.

*A complete list of Council Members, meeting schedules and other background information can be found at: [www.njidd.org](http://www.njidd.org)*



## WHAT WE DO

Our activities are guided by our State Plan. The 2008 and 2009 state plans focused on seven main areas—Employment; Health; Housing; Education and Early Intervention; Transportation; Quality of Life; and Community Supports.



*Goals and objectives in those areas were targeted:*

- To promote the idea that people with developmental disabilities can and should work; and provide real opportunities for people with developmental disabilities to earn real wages.
- To support efforts to provide quality educational opportunities for students with developmental disabilities in the least restrictive setting possible.
- To provide access to comprehensive, accessible health care services for children and adults with developmental disabilities.
- To increase integrated, community-based living options for people with developmental disabilities.
- To expand responsive transportation options for people with developmental disabilities.
- To include people with developmental disabilities in policymaking discussions and decisions that affect their lives.
- To support a broad range of community-based support systems, including career development for direct support professionals; promoting principles of self-direction and personal choice; quality data collection and analysis, public awareness and life-span planning.

## GRANTS

Each 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 and innovation are also important criteria. Some recent grant recipients include:



### *Arts Unbound*

A project providing opportunities for artists and crafts-people to create and sell their works.

### *College of Direct Support*

Through the Boggs Center UMDNJ a career path college curriculum was offered to direct support professionals as part of an ongoing effort to strengthen the professionalism and voice of these key participants in the system of supports for people with developmental disabilities.



### *School Design Guidelines for Inclusion*

The NJ Institute of Technology, working with the NJ Schools Financing Authority, drafted guidelines and plans for designing schools that are accessible to, and inclusive of, students with developmental disabilities.



## PROJECTS

The Council Sponsors and Supports its Own Innovative In-House Projects.

### *Partners in Policymaking (PIP)*



The Council's version of the nationally syndicated Partners in Policymaking program is an innovative leadership training program for adults with developmental disabilities and for parents of young children with developmental disabilities.

Participants meet for one weekend a month for eight months to learn about a wide range of topics and build their advocacy skills.

Sessions include lectures and activities on:

- The history of developmental disabilities;
- How government works;
- How to become better advocates; and much more.

The sessions reach their peak when participants form groups and pick an issue to advocate for. The teams write testimony and present it at a "Mock Legislative Hearing" at the State House in Trenton. Legislators and professionals donate their time to serve as Committee Members for the Hearing.

For more info about this exciting opportunity contact PIP Coordinator Dennie Todd at 609. 984.4516 and visit the web site: [www.njodd.org](http://www.njodd.org)



## *Monday Morning*

Grassroots advocacy at its best, the Council's Monday Morning Project—for people with developmental disabilities and their colleagues—has local networks throughout New Jersey. The project went through a rebuilding process over the past two years and is now re-emerging as a major force in the State's Self-Advocacy Community.

Self-advocates are people with developmental disabilities who are speaking out in their communities for themselves and for others.

Local Monday Morning networks continue to work on transportation, accessibility and voting. And now advocates have expanded their focus to:

- Influencing public language so it is more respectful of people with developmental disabilities;
- Speaking out for people still living in institutions who want to live more independently in the community; and,
- Working with the broader community to help promote true participation and representation by people with intellectual disabilities.

To Find Out More, contact project coordinator Barbara Lee at 609.777.3293 and visit our web site: [www.njodd.org](http://www.njodd.org)





The Council's newest project—Youth Leadership—is training young advocates to help them become future leaders.

Over the course of eight sessions, young advocates are introduced to:

- What it means to be an advocate;
- How to build confidence;
- Working with groups and team building
- Public speaking and the whys and hows of stepping into the adult world of advocacy.

The project kicked off in March 2009. To date more than 100 young advocates have participated and continue to work with the project. Key partners include schools, townships, and local community groups and organizations.

Youth Leaders, the Future is You!

For more information or to schedule trainings for your area, contact Frank Latham at 609.292.3453 and visit the Council's web site at: [www.njodd.org](http://www.njodd.org)



## Family Support



Nine Regional Family Support Planning Councils (RFSPCs), located throughout the state, advise the state Division of Developmental Disabilities about funding families need to support a family member with developmental disabilities at home.

Family members of 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.

The RFSPCs hold forums every year (23 in 2008 and 2009) and distribute helpful information to families throughout their regions.

The forums introduce families to new changes in state services—such as a new single point of entry through the state Division of Disability Services; a new Community Care Waiver; new state/county partnerships; and a self-directed fee-for-service funding approach. Forums also allow families to meet provider agencies and discuss the services and supports they offer.

Sign up to keep informed about family support issues and find out about becoming a member of your local council. Contact Bonnie Brien at [bonnie.brien@njodd.org](mailto:bonnie.brien@njodd.org) and visiting our web site: [www.njodd.org](http://www.njodd.org)



# CAMPAIGNS

The council is promoting two important and exciting campaigns.

## *The No R Word Campaign*



The No R Word Campaign seeks to remove the word "retarded" from official use. It also seeks to curb the informal use of the word and its derivatives.

These slang put downs are very hurtful to people with Intellectual Disabilities.

The Council's campaign was part of a first-wave national response to the "over-the-top" use of the word in the movie *Tropic Thunder*, released in the summer of 2008.

We are working with partners to get the word out, and to change laws and official medical terminology—replacing "mental retardation" with "Intellectual Disability."

In addition to the campaign logo and outreach materials—lapel pins, bumper stickers, T-shirts,

mouse pads—we are going into schools and meeting with other local community resources to talk about the issue.

The public and parochial school presentations have been particularly effective, reaching hundreds of children as they form the skills and attitudes they will draw on as they step into leadership roles in their communities.

They and hundreds of others have taken the pledge to stop using the R Word.

Find Out More and Take the Pledge: [www.njodd.org](http://www.njodd.org)

**THE R-WORD CAMPAIGN**

**What You Can Do:**

1. Stop and Think
2. Stop saying "retard" and "retarded"
3. Ask others not to use "retard" and "retarded"
4. Promote tolerance
5. Become part of a community to promote inclusion
6. Take an Action Pledge

The kindest word in all the world is the unkind word omitted.  
— Anonymous

GO TO [www.njodd.org](http://www.njodd.org)

If you would like a presentation on the campaign or if you would like to get materials—buttons, bumper stickers, T-shirts—contact us.

NJ Council on Developmental Disabilities  
609-292-3745 or write to  
PO Box 700  
20 West State Street  
Trenton, NJ 08625-0700

**Don't Use It**  
RETARD is harmful to people with Developmental Disabilities  
[www.njodd.org](http://www.njodd.org)

**T-SHIRTS**  
In 4 color font, one color on back.

**BUTTONS**

**BUMPER STICKERS**

## Just Say Something Campaign



The Council hosted a series of three unique coffeehouse meetings across the state. At those "Community Conversations" people with developmental disabilities, family members and professionals they work with held candid discussions with some key community leaders about public perceptions of people with disabilities.

Out of those conversations we launched the Just Say Something Campaign.

The campaign calls on people throughout the state and beyond to speak up and publicly discuss issues affecting and influencing the lives of people with disabilities whenever and wherever the opportunities arise.

In other words, to just say something when businesses, politicians, celebrities, or others, do something good—or not so good. And to talk about what's important to people with developmental disabilities and the community at large.

The campaign offers a blog site and technical assistance for local community conversations, as well as an e-newsletter, as tools to keep the discussions going. Come Join the Conversations:  
[www.justsaysomething.org](http://www.justsaysomething.org)

**JUST SAY SOMETHING!**

The Most Effective Way To Help Make **POSITIVE CHANGE** Is To **JUST SAY SOMETHING** About What You Think Is **RIGHT** And What You Think Is **WRONG**

Speech Is Not Only **A RIGHT**, It's A **RESPONSIBILITY**

So Just Say Something The Next Time

- 🗨️ You Hear Someone Using Derogatory Language—Like The "R" Word
- 🗨️ You Read About Someone Being Called For Someone with Disabilities at the Local School
- 🗨️ A Neighbor Complains That People With Disabilities and Disabilities Shouldn't Be Living So Close By
- 🗨️ The Governor Announces Support For People with Disabilities With A Question And Other Derogatory Language

And Help Us Keep Tabs On What's Going On And Who's Thinking About It All By Visiting Our New Blog:

**Just Say Something.org**

We Are Looking For People To Be Our Voices From The Community. Make The Blog Happier By Being A Regular Contributor. It's Easy. Can't Become One Of A Selection Of Beautiful Voices From The Community?

Go to [JustSaySomething.org](http://JustSaySomething.org) to find out more and sign up or to let the Council by email at [ncm@nj.gov](mailto:ncm@nj.gov) or call or phone 8

"For too many years, people with developmental disabilities have been discouraged from speaking up. The Just Say Something campaign is aimed at encouraging them to speak up."

Exec

You are Viewing an Archived Copy from the New Jersey State Library

### ***Emergency Preparedness***

The Council has developed a comprehensive training for people with developmental disabilities to help them prepare for, and handle, emergencies caused by natural disasters, terrorist attacks and other catastrophic events.

Participants learn how to prepare for emergencies and how to conduct themselves when disaster strikes. Each receives a "Go Bag" to carry items they may need in an emergency.

Initial rounds were presented for those living in state sponsored group homes and supervised apartments. The trainings have been expanded to include other individuals living in community-based homes.

For more info and to schedule trainings: [www.njcdd.org](http://www.njcdd.org)

### ***Community Building Awards***

Annually the Council honors individuals and organizations that have made significant contributions to their communities through advocacy, policymaking, lifetime achievement, systems change, providing access, media coverage and education.



These prestigious awards highlight individuals and organizations that have made notable contributions towards building communities inclusive and welcoming to all members. Too often these good works go unrecognized and the Council's Community Building Awards aim to change that.

The Inaugural Event was held in 2009. For a list of winners and more info: [www.njcdd.org](http://www.njcdd.org)



## PARTNERSHIPS



In the fall of 2008 the Council formed the DD Coalition, an ongoing budget and policy discussion group made up of a broad representation of the developmental disabilities community. The Coalition includes people with developmental disabilities, their family members, and professionals and partners who work with them. The group has worked on a number of issues such as deinstitutionalization, seclusion and restraints, and the state budget.

In addition, the council works with a coalition of education experts on issues important to providing educational opportunities for students with developmental disabilities in the least restrictive classroom setting. This education subcommittee makes suggestions to the Council's public policy committee based on their expertise of the state's education system, for review by the Council in forming its education positions and activities.

Finally, the Council is working with a number of state and national organizations—most formally the New Jersey Self-Advocacy Project—to promote the elimination of the R Word.



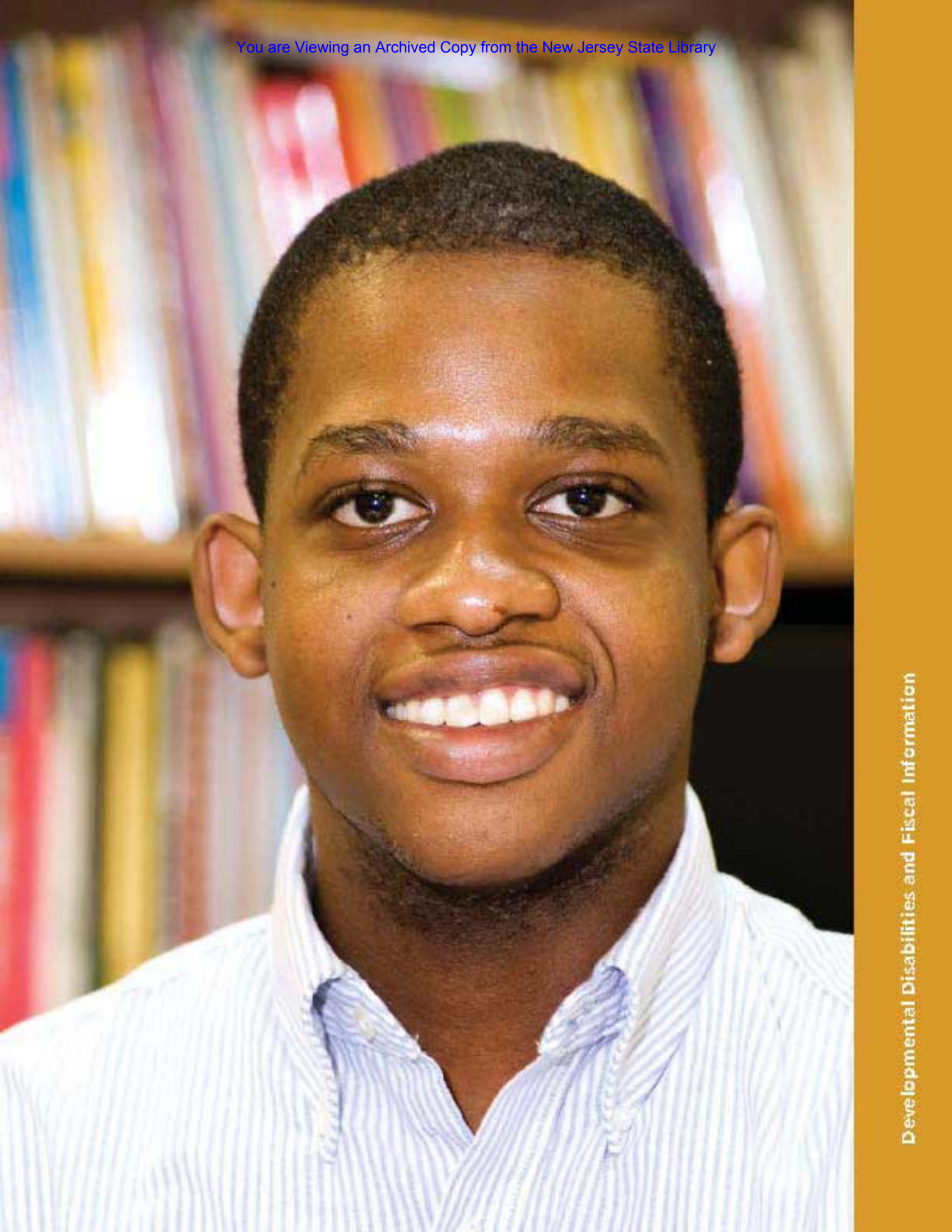
### *Publications*

The Council regularly publishes the nationally recognized magazine *People & Families*. Published four times a year, the magazine is a high-end production offering in-depth coverage of important issues affecting people with disabilities and their families, as well as feature stories about their life experiences.

We also offer other publications—such as this and other reports; periodic newsletters; brochures; etc.—as the need arises.

All our publications are free, while supplies last.

Find out more at the web site [www.njodd.org](http://www.njodd.org)



## DEVELOPMENTAL DISABILITY

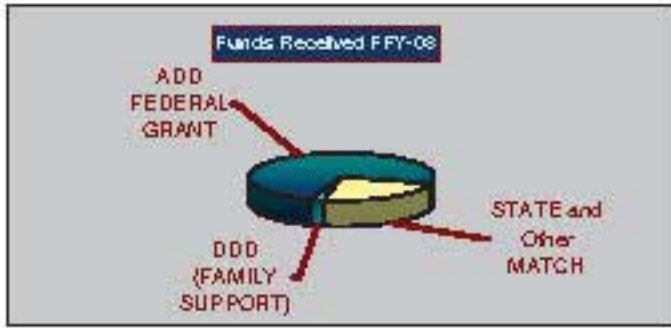
Means a significant, chronic disability of an individual that...

- (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; and
  - (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 bifi da; and early on set brain traumas.



**NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES  
FEDERAL GRANT END OF YEAR REPORT**



**Funds Received FFY - 08**

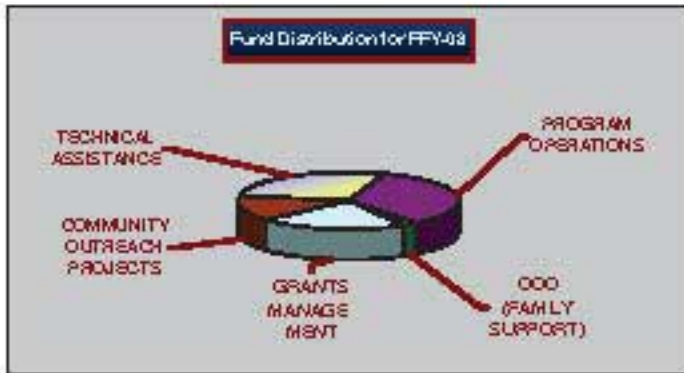
Funds Received for FY	FFY 2008	%
ADD FEDERAL GRANT	1,555,338	73.9
STATE and Other MATCH	498,697	23.7
DDD(FAMILY SUPPORT)	50,000	2.4
<b>Total Funds Available</b>	<b>2,104,035</b>	<b>100.0</b>

**Funds Received FFY - 09**



Funds Received for FY	FFY 2009	%
ADD FEDERAL GRANT	1,592,012	73.6
STATE and Other MATCH	498,424	23.2
DDD(FAMILY SUPPORT)	50,000	2.3
STATE POLICE SUB GRANT	20,000	0.9
<b>Total Funds Available</b>	<b>2,150,436</b>	<b>100.0</b>

**Fund Distribution FFY - 08**



Fund Distribution for FY	FFY 2008	%
TECHNICAL ASSISTANCE	590,393	27.6
PROGRAM OPERATIONS	715,496	34.0
DDD(FAMILY SUPPORT)	50,000	2.4
GRANTS MANAGEMENT	453,397	21.5
COMMUNITY OUTREACH PROJECTS	304,759	14.5
<b>Total Funds Available</b>	<b>2,104,035</b>	<b>100.0</b>

**Funds Distribution FFY - 09**



Fund Distribution for FY	FFY 2009	%
TECHNICAL ASSISTANCE	616,123	29.7
PROGRAM OPERATIONS	769,247	35.8
DDD(FAMILY SUPPORT)	50,000	2.3
STATE POLICE SUB GRANT	20,000	0.9
GRANTS MANAGEMENT	415,920	19.3
COMMUNITY OUTREACH PROJECTS	279,146	13.0
<b>Total Funds Available</b>	<b>2,150,436</b>	<b>100.0</b>

## COUNCIL MEMBERS

Chair  
Elaine Buchsbaum

Vice-Chair  
Mary Kay Weber

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Todd Emmons, Voorhees  
Christopher Miller, Neptune City  
Betsy Smith, Montclair

### Self-Advocate Members

Russell Fried, Laurel Springs  
Myrta Rosa, Woodbridge  
David Tag, Lindenwold

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Andrew McGeady, Jackson  
Gary Rubin, Plainfield,  
Mary Kay Weber, Eatontown

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Elaine Buchsbaum, Stockton  
Purnima Hernandez, D.D.S., Glen Rock  
Hazeline C. Pilgrim, Montclair

### Parent Or Guardian Representatives

Ellie Byra, Flemington  
Mercedes Jimenez-Ramirez, Teaneck  
Robin Sims, Bloomfield

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Walter Fernandez, Barnegat  
Leah Ziskin, M.D., Cherry Hill

### 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  
Celeste Andriot Wood, Assistant Commissioner  
Designee: Pauline Lisciotto

NJ Department of Human Services  
Division of Disability Services  
William Ditto, Director

NJ Department of Education  
Office of Special Education Programs  
Roberta Wojcik, Director  
Designee: Carol Kaufman

NJ Department of Labor  
Div. of Vocational Rehabilitation Services  
Director: Brian Fitzgibbons

Protection and Advocacy System  
Disability Rights New Jersey (DRNJ)  
Joseph Young, Esq., Executive Director

NJ Department of Human Services  
Div. of Medical Assistance & Health Services  
John R. Guhl, Director  
Designee: Valerie Harr

NJ Department of Human Services  
Div. of Developmental Disabilities  
Kenneth W. Ritchey, Assistant Commissioner  
Designee: Frank Kirkland

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

The Boggs Center on Developmental Disabilities  
Deborah Spitalnik, Ph.D., Director  
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

Cultural Diversity and Outreach  
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  
Dennis Rizzo

Advocacy Training Coordinator (Partners in Policymaking)  
Denise Todd

Administrative Assistant  
Jacinta Williams



## NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES

*Advocate // Collaborate // Participate*

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