



Advocate // Collaborate // Participate

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NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES



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Our Vision

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.

BELIEVE IT !

by Maryann B. Hunsberger
photography by Rebecca Shavulsky

excerpted from *People and Families* - 2007

ON March 23 coordinators of the Monday Morning Project coordinator talked to residents at the Woodbridge Developmental Center about voting with a disability and proposed changes to the state constitution removing old language about voting. Myrta Rosa, 49, who attended the talk, is president of the Woodbridge Self-Advocacy Group, president of the New Jersey Self-Advocacy Group and a member of the Monday Morning Middlesex County Network.

Rosa works as a cashier in Woodbridge Developmental Center's gift shop and workshop five days a week. She received a Hero Award in 2004 from the New Jersey Self-Advocacy Project for her work as an advocate.



"The coordinator, told us about the importance of voting," Rosa said. "He told us how we could all make a difference by voting. We learned how the New Jersey state constitution speaks about individuals with disabilities, and how the words 'idiot' and 'insane' are in there. We talked about how the words needed to be removed and we all helped make this happen. It made me very happy.

"He talked about the Monday Morning Project to an organization of clients at Woodbridge who also feel that we should be able to speak out for justice and have equal opportunities in voting and community planning. I feel that his visit was positive and I look forward to continuing to be an advocate and maybe a member of the Council. I vote in every election. A group of us go to the polls together. I love voting. I learn about who to vote for by watching TV and hearing other people speak about voting." Rosa has lived at Woodbridge since 1998.

The Council Newsletter

The newsletter is a monthly publication that focuses on the Council's activities, and local, state and national news about issues important to people with developmental disabilities and their families. It is offered free to interested subscribers.



People and Families Magazine



People and Families is presented free of charge four times a year. It is a magazine focusing on issues and personal stories of interest to people with developmental disabilities and their families. It also presents timely and critical discussions of topics of significance to New Jersey's DD community. Subscriptions are free for single copies in North America. Bulk copies are available upon request. See the enclosed subscription card to add yourself to our list.

Health Access Newsletter is a publication focusing twice a year on health care for women with disabilities in New Jersey. Each issue includes a feature story and information on resources, research and advocacy for women with disabilities in the area of health and wellness.



The NJ Council on Developmental Disabilities

... is a 25-member policy advisory group that was formed under federal law to advise the Governor, the Legislature and the public about issues affecting people with developmental disabilities and their families, and to advocate on behalf of them.

Seventeen of the Council's public members are people with developmental disabilities and family representatives. Other members include representatives of key state agencies and the executive directors of the Council's federally mandated sister agencies—the Elizabeth M. Boggs Center on Developmental Disabilities and New Jersey Protection and Advocacy. One public member represents providers of services. Public members are appointed by the Governor; other members are dictated by federal law.

The Council meets regularly to identify broad policy issues, approve short and long-range plans for influencing those issues, and to target its funding to build collaborative, innovative efforts to effect positive change in the lives of people with developmental disabilities and their families.

This booklet outlines and explains those efforts.

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Background

The New Jersey Council on Developmental Disabilities was created by the Developmental Disabilities Act of 1974. In addition to setting down a broad number of guidelines for public policies, supports, training and legal services for people with developmental disabilities, the law established in all 50 states and some territories: councils; centers for excellence (at that time known as affiliated programs for their connection with universities and colleges); and agencies to protect and advocate on behalf of people's legal rights.

The federal Administration on Developmental Disabilities oversees and funds the agencies and activities related to the DD Act. A complete text of the act can be found at the Council's WEB site.

State Plan

Every five years the Council develops a plan of long-range goals and objectives for carrying out its mission. Within the framework of that five-year plan, the Council develops a State Plan each year that lays out a complete set of objectives and funding for that year. That plan coincides with the federal fiscal year, which runs from October 1 to September 30. A copy of the State plan is placed on the council's WEB Site for public review and comment.

Collaboration

A primary role of the Council is to promote collaboration among various stakeholders to work toward the common goals outlined in its Vision Statement.

The Council brings the real life experiences of people with developmental disabilities together with professionals and public officials to effect positive changes in public policies and professional supports. As part of that effort, the Council supports and staffs three standing task forces that regularly discuss the issues of education and health care—one each for women's and men's health.

REGIONAL FAMILY SUPPORT PLANNING COUNCILS

RFSPC #1

PO Box 13
Pompton Plains, NJ 07444
(Sussex, Warren, Morris)

RFSPC #2

(Passaic, Bergen, Hudson)

RFSPC #3

PO Box 174
Bedminster, NJ 07921
(Somerset, Union)

RFSPC #4

PO Box 376
Maplewood, NJ 07040
(Essex)

RFSPC #5

P.O. Box 715
Old Bridge, NJ 08857
(Hunterdon, Mercer, Middlesex)

RFSPC #6

PO Box 76
Lakewood, NJ 08701
RFSPC_NJ6@yahoo.com
(Monmouth, Ocean)

RFSPC #7

PO Box 641
Mt. Laurel, NJ 08020
(800) 216-1199 OPTION #1
RFSPC7@comcast.net
(Burlington, Camden)

RFSPC #8

PO Box 11
Glassboro, NJ 08028
(856) 863-8624
RFSPC8@hotmail.com
(Cumberland, Gloucester, Salem)

RFSPC #9

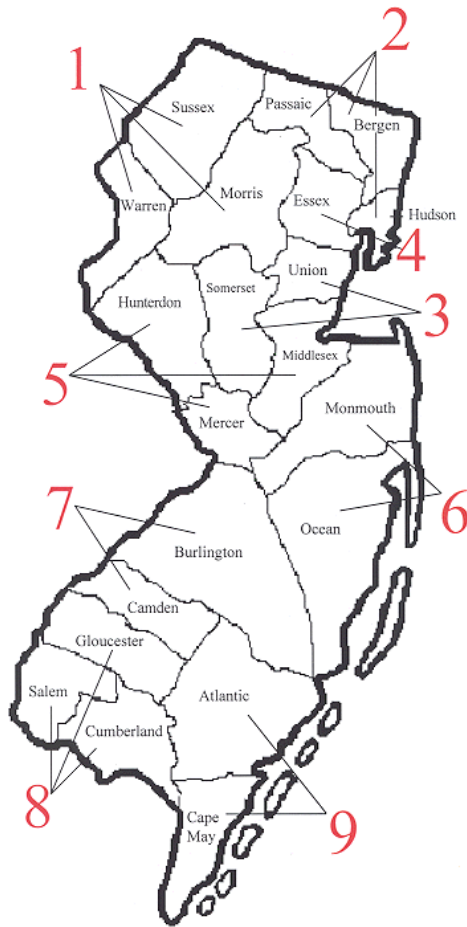
PO Box 84
Somers Point, NJ 08244
(Atlantic, Cape May)

Addresses are current as of the publication of this booklet. Updated addresses may be found on the council WEB Site.

The state's family support coordinator is on staff of the NJ Council on DD. For information on Family support Networks and the Regional family Support Coordinating Councils, call: 800-216-1199 or E-Mail to tasha.jones@njcdd.org .

Family Support

There are nine Regional Family Support Planning Councils throughout the state. These councils, made up of representatives of families that have a family member with a developmental disability, meet regularly and advise the state Division of Developmental Disabilities about supports and services for people with developmental disabilities. A significant portion of that advice comes from meeting with and listening to people in that council's geographic area.



Advocacy and Civic Participation

The Council sponsors the following activities to help people with developmental disabilities get more involved in all aspects of their communities and to help them get the skills they need to make that involvement count.

Partners in Policymaking

Partners in Policymaking is a leadership training program for family members and self-advocates. It provides state-of-the-art knowledge about developmental disabilities issues and builds the competencies necessary to become advocates who can effectively educate public officials. "Partners" learn about current issues and best practices and become familiar with the policymaking and legislative processes at the local, state, and federal levels. The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law. PIP training consists of one weekend session a month for eight consecutive months. Attendance at all eight sessions is mandatory. Overnight accommodations, meals and personal assistance are provided.



For information on Partners in Policymaking, go to the council WEB Site. Programs begin in the Spring of each year.

The Monday Morning Project

Monday Morning is a grass-roots organization of self-advocates concerned with issues affecting people with developmental disabilities. Made up of county-based networks, Monday Morning provides people with a network through which they can learn about public policy issues and participate in public policy discussions. Issues networks have worked on include individual rights, voting rights, public accessibility, affordable-accessible housing and access to transportation. Membership is free and is open to persons with developmental disabilities.



NJ-Youth Leadership

Youth development is the cornerstone of any movement. With a membership that will reflect a wide range of backgrounds and experiences, the Council's new Youth Leadership Initiative will be a key resource for young advocates who want to get involved.



The group is dedicated to educating, empowering and developing leadership skills for young people with range of disabilities, but with a special focus on young people with developmental and intellectual disabilities, as mandated by the federal law governing the Council.

For more information about the Council's Youth Leadership Initiative, contact Frank Latham at 609.292.3453, frank.latham@njcdd.org and visit the Council's website: www.njcdd.org

COMMON GROUND is published 3 times a year by the NJCDD. It presents timely issues of direct concern for individuals with developmental disabilities, their families and professionals within the New Jersey Public Schools. Common Ground offers readers information about the education system in New Jersey, and ideas on acting within their own districts to effect needed change.

The views and opinions expressed do not necessarily reflect those of the editor, members or staff of The New Jersey Council on Developmental Disabilities or members of the volunteer Common Ground editorial advisory board. Single issues of Common Ground are free of charge. Duplicate copies to the same address are available at an annual subscription rate of \$20.00.

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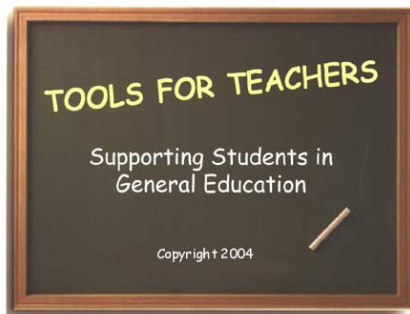
common ground
Increasing the dialogue among stakeholders in New Jersey's special education system

Expanding the Continuum: Partnerships that Support Students with Disabilities

According to the U.S. Department of Education, New Jersey has the highest percentage of IDEA eligible students in the country...
New Jersey's special education system has made significant progress in the past few years...
Partnership between local school districts and providers is critical to the success of these programs...
Changes in the way we think about special education...
When a district needs highly specialized services and supports, instead of a regular setting, some districts have used residential care from a specialized provider...
The type of partnerships often used for students who are coming back into the school after attending a residential program...
Partnerships that support students with disabilities...
Spring 2007

Education

According to the U.S Department of Education, New Jersey has the highest percentage of IDEA-eligible students in separate, 'disability-only' settings — nearly 9%. Many of the state's 603 school districts, recognizing that they lacked expertise, resources and economies of scale, have relied on these providers to serve students with complex special education needs. Now, driven by tighter state monitoring on the issue of least restrictive environment and an effort to contain costs associated with out-of-district placements, local districts are working harder to serve more students with disabilities in neighborhood public schools, and bring back students who have been placed in other programs. Increasingly, they are turning to professionals from out-of-district placements to help them as they seek to serve students closer to home, bringing specialized services into the district, rather than sending their students out for these services.



Available, free, from NJCDD.
Updated regularly.

Contains sections on: Creating Meaningful IEPs, Curriculum Modifications & Adaptations, Collaborative Teaming, Positive Behavioral Supports, Social Relationships and Social Networks, Transitions, Ideas That Have Worked and an Annotated Bibliography of Inclusion Resources.

Investments and Grants

Annually, the Council offers grants to promote innovative ideas, and to support individual and groups advocacy efforts throughout the state. These include major investments with creative partners to help the Council progress toward the goals and objectives of the State Plan, mini-grants to promote local ideas, and leadership training support funds to help individuals attend conferences and seminars they might not otherwise get to attend. Grants are announced in several venues at least once per year.

Annual Grant Investments

- ◆ announced in January of each year
- ◆ require full proposal and long-range plan
- ◆ have specific and measurable outcomes
- ◆ are from one to three years

Mini-Grants

- ◆ accepted at any time during the year
- ◆ limited to \$5,000 per applicant per two-year period
- ◆ reviewed by Council bi-monthly
- ◆ limited availability

Leadership Grants

- ◆ accepted at any time during the year
- ◆ reviewed within 30 days of receipt
- ◆ should be submitted 60 days prior to any event
- ◆ limited availability

The Council WEB Site has a section on grants and contracts which goes into depth on this topic.

from PEOPLE AND FAMILIES, JANUARY 2007

Dealing first hand with a

Birth Defect

EXPERIENCING LIFE



I'm sure Spina Bifida is not a phrase that's a part of most high school students' every-day vocabulary.

It's a birth defect that affects the spine. An estimated 70,000 people in the U.S are currently living with Spina Bifida, and I am one of those people. I have the most severe type of Spina Bifida, myelomeningocele, in which a portion of the spinal cord itself protrudes through the back. Generally people use the terms "Spina Bifida" and "myelomeningocele" interchangeably.

The effects of myelomeningocele may include muscle weakness or paralysis below the area of the spine where the incomplete

closure (or cleft) occurs. I have had many surgeries on my legs and head. I had my first surgery shortly after birth to place a shunt on the left and right ventricles in my brain. The other end of the tube is threaded under my skin into my stomach, preventing fluid from accumulating on my brain, called hydrocephalus. This surgery, called shunting, is needed to relieve fluid buildup in the brain. Until recently most children born with myelomeningocele died shortly after birth. Now that surgery can be performed to drain the spinal fluid, children have a better chance and are more likely to live.

In some cases, children with the disease who also have hydrocephalus, like me, experience learning problems. We may have difficulty with

NJ Department of Education

Office of Special Education Programs

Designee: Carol Kaufman, *Director*

NJ Department of Labor

Div. of Vocational Rehabilitation Services

Thomas Jennings, *Director*

Designee: Brian Fitzibbons

Protection and Advocacy System

New Jersey Protection & Advocacy, Inc.

Joseph Young, Esq., *Acting 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*

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

If you, or someone you know might be interested in being appointed to the Council on Developmental Disabilities, please visit our WEB Site for information on that process. Members joining after this publication was printed can be found at the Council WEB site.

COUNCIL MEMBERS

CHAIR

Elaine Buchsbaum

VICE-CHAIR

Lorraine D'Sylva-Lee

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David Tag, *Voorhees*

Gary Rubin, *Plainfield*

PARENT OR GUARDIAN REPRESENTATIVES

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Elaine Buchsbaum, *Stockton*

Ellie Byra, *Flemington*

Jennifer DeMauro, *Allentown*

Lorraine D'Sylva-Lee, *Changewater*

Carolyn Hayer, *Hackensack*

Purnima Hernandez, *Glen Rock*

Larry Jones, *Toms River*

Mercedes Jimenez-Ramirez, *Teaneck*

PUBLIC MEMBER

Frank Caragher, *The Arc of Union County*,

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 Lisciotta

NJ Department of Human Services

Division of Disability Services

William Ditto, *Director*

paying attention, expressing and understanding language, and grasping reading and math. We also need to learn mobility skills, and often require the aid of crutches, braces, or wheelchairs. I wear braces on my legs. Having this birth defect and trying to cope with all the obstacles I face and have faced has been very difficult.

Having the surgery doesn't scare me anymore. I am used to it because I have had it done many times. I may need to go into surgery if the shunt stops working, clogs or separates. Every time I go to the hospital I stay between five days to a week, then I'm home for another week in order to recuperate and regain my strength.

A major issue I also have to deal with are the people who stare at me. I know I'm not being made fun of, but it's awkward because instead of asking about my condition, most people just stare. It aggravates me, because it seems as if you think I'm weird.

I don't want you to be afraid of saying anything; I won't take it personally and I'll answer your question the best I can. I'd rather you talk to me and tell me what's on your mind than be afraid to say something wrong. When you don't say something to me I think you just don't want to talk to me.

Kids with Spina Bifida in school require change in the school equipment and the school curriculum. In adapting to the school setting, a lot of structural and location changes should be considered. Section 504 of the Rehabilitation Act of 1973 requires that programs receiving federal funds make their facilities accessible. The structural changes may include adding elevators or ramps, or making schedule or location changes, such as offering a course on the ground floor for example.

I remember being in Paramus in eighth grade and having some people ask me about my legs. They'd ask me what's wrong with my legs, and it would bother me because they'd stare at me and then come talk to me. It's funny, because back then I didn't want to talk about my birth defect when people asked. Now, no one asks me and I want them to. To have friends and to be nice to people is something I want. If you ask me about my birth defect now, I'll tell you about it.

I have a few friends, but most of them are in college now. When they were here I only saw them at lunch, because I didn't have any classes

with them. I also didn't see them outside of school, because they were either busy or we didn't communicate on the phone. I don't do a lot outside of school anyway.

A lot of things are hard for me to do like walking for a long period of time, because my legs start to hurt. Some people in school come and talk to me a bit about something, but the next time I see them, they just say hi. It bothers me when that happens, because I want to have a conversation, not just a hello.

They're mostly girls, because we can come up with something to talk about. With guys it's different because we don't talk to one another and probably won't be able to come up with something to talk about. I've also never had a boy who I could really call my friend, nor have I ever had a boyfriend.

Of course I could start the conversation, but I'm really shy. When I'm in the hallways walking to class people bump into me as if they don't see me and I'm a ghost. I'm also alone walking by myself without any friends so that doesn't really help either. I feel like the way I walk is the reason people bump into me and ignore me. Writing this was very important to me because I want people to understand how someone like me feels and the things that I go through everyday. I am a senior this year and I want to go to college. I want to become a writer to write books about myself. Being shy, I don't say a lot and I want to say something about myself. I want people to not only understand me, but also other people who are "different," because you never know someone unless you try.

Writing this was very important to me because I want people to understand how someone like me feels and the things that I go through everyday.

BY DANIELLE WRIGHT

(EDITOR'S NOTE: Danielle Wright wrote this article for her school newspaper. She submitted it to *People & Families* as a sample of her writing. We asked her if we could use it for the inaugural issue and she agreed. Needless to say, we hope we'll be hearing from her again.)



Buyer Beware

By Marianne Valls

I used to wish my mother would practice what she preached. Now I think the problem's genetic because I immediately know what others should do, but I sometimes fall into the same traps I warn others against.

My first visit with my new primary care physician was pleasant enough. However, when he prescribed a drug called Elidel, I questioned it. I later learned through TV advertisements that Elidel is used for eczema. I had heard of eczema, but never had it. Further investigation on WebMD revealed information that would have made me a more knowledgeable patient. The web site describes eczema as skin that becomes "scratchy, itchy, red, and dry, even cracked, blistery, and leathery."

...when I arrived home after having had my prescriptions filled, I had four instead of the usual three. I called my pharmacist to ask what Nexium was for. He said, "for heartburn." I can't recall ever having so much heartburn that I needed to be medicated for it. Certainly, I never complained about it to my doctor. In fact, he did not even examine me that day.

Remember, doctors are human and can make mistakes. The onus is on us, as consumers, to become knowledgeable about our medical treatment.

Questioning your physician should be an important part of your office visit. However, it is sometimes difficult to question people you perceive to be authority figures. We must start to see health care providers for who they really are: ordinary people who aid us in making decisions about our health.