SUSTAINABLE BALANCE

Integration

Independence

Productivity

Self-Direction

2007 Annual Report

New Jersey Council on Developmental Disabilities
To apply its unique resources for culturally competent advocacy, capacity building, and systemic change activity to assure that individuals with developmental disabilities and their families are full participants in the design of and have access to needed community services, individual supports, and other forms of assistance that support self-determination, independence, productivity, integration and inclusion in all facets of community life.

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; and have the same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident.
As the Chair of the NJCDD I am proud of the work the Council has accomplished this past year. We have been quite successful in improving and fine tuning our State Plan so that it reflects the needs of individuals with developmental disabilities in New Jersey. Additionally, the Council has worked hard on allocating funds to Grants to be distributed to the community. Combined with the start up of our Youth Leadership Project, these activities have collectively put us on the right path to support needed systems change within our State.

-- Elaine Buchsbaum, Chair

Members of the Council

CHAIR - Elaine Buchsbaum

CONSUMER REPRESENTATIVES
Gary Rubin
David Tag
Mary Kay Weber

PARENT, FAMILY MEMBER AND GUARDIAN REPRESENTATIVES
Ellie Byra
Jennifer DeMauro
Lorraine D’Sylva-Lee
Carolyn Hayer
Purnima Hernandez
Mercedes Jimenez-Ramirez
Larry Jones
FEDERALLY MANDATED MEMBERS
Celeste Andriot Wood
- Division of Family Health Services
William Ditto
- Division of Disability Services
Roberta Wohle
- Office of Special Education Programs
John Guhl
- Div. of Medical Assistance and Health
Brian Fitzgibbons
- Division of Vocational Rehabilitation
Joseph Young, Esq.
- NJ Protection & Advocacy, Inc.
Kenneth Ritchey
- Division of Developmental Disabilities
Deborah Spitalnik, Ph.D.
- Elizabeth M. Boggs Center, NJUCE

PUBLIC MEMBER
Frank Caragher
- The Arc of Union County

BECOMING A COUNCIL MEMBER
Individuals with developmental disabilities, or parents, family members or guardians of people with developmental disabilities, may apply to become a Council member by contacting the Governor’s Office of Appointments at 609-777-0251 for an application. Further information is available from the Council and can be obtained by calling our offices at 609-292-3745 or at the WEB site, www.njcdd.org.
Letter from the Executive Director

2007 saw a great deal of fresh energy at the Council. We gained the wisdom and knowledge of new members and said goodbye to long-time members who moved on or were replaced by fresh appointments. In a collaboration of staff and members, the Council saw a clear role and purpose for itself in bringing about independence, integration, self-determination and productivity for people with developmental disabilities in New Jersey.

There has been a resurgent effort to focus on realistic and effective activity. We reorganized the grants process, opening greater occasion to invest Council funds in new and innovative projects; applicants welcomed the openness and opportunity for thinking ‘outside of the box’. We inaugurated the Youth Leadership Project, with emphasis on bringing together and supporting individuals with developmental disabilities to become future leaders in the field. We put public relations back into the mix, with a plan for bringing positive and realistic life images of people with developmental disabilities into the public conscience. More than this, we witnessed numerous individuals with developmental disabilities, in diverse settings, take up the mantle of leadership.

As we move into 2008 the Council will further refine its planning and program investment skills, explore additional prospects for pursuing public awareness and public education and build on our growing collaboration with others in New Jersey who share our values. Those values call for people with developmental disabilities to have the “same rights, privileges, responsibilities, and opportunities of citizenship as does any other New Jersey resident.”

In the next year, and into the future, the Council will seek new ideas, innovative concepts, personal thoughts, pragmatic solutions and professional recommendations from a variety of constituents. Working together with others in the developmental disability community the Council will continue to seek progress in services and supports for people with developmental disabilities and their families in New Jersey.

Together, we can *Make it Happen.*

- Alison Lozano, Ph.D., MPA
  Executive Director
OVERALL PHILOSOPHY

◆ Services and needed supports which are generally available to all Individuals must be available to Individuals with developmental disabilities as well.

◆ Services and supports for Individuals with developmental disabilities must be designed and delivered in a manner which shows a sensitivity to the cultural beliefs and practices of the person receiving them.

◆ The relationship between education, work, housing and transportation on the overall independence, productivity and integration of Individuals with developmental disabilities cannot be underplayed, and must be reflected in the overall design of services and supports.

◆ Finally, the role of Individuals with developmental disabilities as self-advocates is a critical element of any overall approach to attaining integration, independence and productivity.
EMPLOYMENT

Individuals with developmental disabilities are employed, have access to career-building activities and advancement, and participate in conventional networking groups and associations.

EDUCATION

Children and youth with developmental disabilities access educational supports, programs and services that promote inclusion and independence throughout the life span.

HOUSING

Individuals with developmental disabilities are active participants in choosing from and arranging for adequate affordable, appropriate and accessible housing.

HEALTH

Individuals with developmental disabilities receive appropriate, accessible health care and dental services throughout the life span.

TRANSPORTATION

Transportation in NJ is fully accessible and adequate.
QUALITY ASSURANCE

A. Individuals with developmental disabilities are active self-advocates, engage in leadership and civic activities.

B. Individuals with developmental disabilities and/or their families make decisions and exercise choice about services and supports.

COMMUNITY SUPPORTS

Individuals with developmental disabilities and their families receive supports and services as needed throughout their life span.

CROSS-CUTTING

There is heightened public awareness that Individuals with developmental disabilities are living as integral and contributing members of our communities.
Employment remains the most logical and effective route to real independence for people with developmental disabilities. Even for individuals with such significant challenges that real-time or traditional employment is not immediately viable, work and productive activity are still critical elements of life and social inclusion.

Supported Employment is the principle methodology available for many individuals leaving school, moving into the community, or deciding to seek employment at a later age. However, unemployment rates remain unacceptably high among people with developmental disabilities, particularly those between 21 and 30 seeking employment.

Professional literature and program brochures continue to state an unemployment rate between 75% and 85%. New research suggests that a more likely figure for the United States (based on census data) is between 30% and 40% officially unemployed. The remaining 45% of this population are not employed, and are not seeking employment. This last statement points to a critical new direction for self-advocates and professionals assisting people with developmental disabilities to choose, get and keep employment.
In 2005, the Council initiated and funded a project which came to be called, the success-of-Savings (SOS) Club. An asset-building effort based on the federal Individual Development Account resource for TANF recipients, this was the first effort to bring this type of service to people with developmental disabilities. The SOS Club provides participants with instruction in basic money-management principles using a combination of classroom sessions, guest speakers, and field trips. Concurrent to this instruction, and extending beyond it, the SOS Club encourages participants to save money by setting up bank accounts, creating a budget, and developing a plan for making regular deposits. As an incentive to saving, the program provides a matching contribution to participant deposits, much in the manner of the federal IDA program.

“I had so much fun at the classes and I learned a lot too. I know how to keep a check register now because all of my questions were answered.” – Sara

“I bought a laptop with the money I saved through the SOS Program with Allies!” – Kim

The Council has collaborated with Allies, Inc. to create a new program—“Project American Dream” (PAD). PAD is an IDA program that allows SOS graduates to continue saving for an additional four years. PAD has been extremely successful in drawing in federal matching dollars which are focused on people with developmental disabilities through the NJ Department of Community Affairs. Fifty-eight SOS graduates are eligible to participate.

“Because of the SOS Program, I am depositing money in the bank regularly now and going to McDonald’s less.” – Kelly

“Through the SOS Program, I learned that record keeping is key to having a checking account.” – Jeffrey
Constitution Change

Council-supported Monday Morning Network self-advocates worked with State Senator Richard Cody’s staff, members of NJ Office of Legislative Services, staff at the Senate State Government Committee in addition to the NJ Department of the Public Advocate and the Brazelon Center for Mental Health Law to come up with the wording of legislation to remove the words ‘idiot’ and ‘insane’ from the NJ Constitution.

NETWORK FACILITATORS

Atlantic County/Jersey Shore
Jo Hudson: 609.266.5005

Bergen County
Tom Bengaff: 201.722.9537

Burlington County
Kerry Walker: 856.786.9032

Camden County
Barbara Coppens
barbaracoppens@aol.com

Cumberland County
Call: 609.292.3745

Essex County
Frances Grant: 973.470.8090

Gloucester County
Nan Ivins: 856.845.4034
nan.ivins@comcast.net

Hudson County
Marianne Valls: 201.659.5347

Lucyanne Miller: 908.006.2861

Mercer County
Nicole Davis: 609.530.0006

Middlesex County
Anita Clavering: 732.727.7791

Monmouth County
Stanley Soden: 732.571.4884

Morris County
Sonya Burroughs: 973.316.0341

Ocean County
Colleen O’Dell-Multer: 732.477.1414

Passaic County
Ellen Brockman: 973.595.7824

Salem County
Call: 609.292.3745

Somerset County
Jackie Jackson: 732.422.8998
Jackiejackson@aol.com

Sussex County
Jackie Engel: 973.300.5536

Union County
Bruce Bentz: 732.346.0424

Warren County
Ed Swahn: 908.689.1648
The New Jersey Council on Developmental Disabilities is collaborating with other disability resource organizations in New Jersey, including our partners funded through the Administration on Developmental Disabilities (the Elizabeth M. Boggs Center on Developmental Disabilities and New Jersey Protection and Advocacy, Inc.) in the development and sponsorship of a series of cultural awareness days. The cultural awareness days are training events for disability service providers to enhance their awareness of specific cultural communities in New Jersey.

The first of this series was held September 17-18, 2004, entitled *La Comunidad Latina y las Incapacidades: Enfrentando las Barreras* (*The Latin Community and Disabilities: Confronting the Barriers*).

The second in the series, was held on June 15, 2007, entitled The South Asian Community and Disabilities: Raising Awareness, Facing Challenges, Accessing Resources.

The organizations who have been collaborating to sponsor these cultural awareness days are exploring similar events focusing on Asian Pacific and Middle-Eastern communities in New Jersey.
**HEALTH**

*Transition to Adulthood*, an educational, interactive tool developed under Council sponsorship and partnership with the Office of Special Child Health Care and several organizations. The product was distributed as a CD as well as posted on the Council’s WEB Site. The interactive tool assists young adults with developmental disabilities and special health care issues to identify needs and resources, covering topics such as how do I stay healthy, where do I want to live, transition planning, and various state resources. -- Though specific to New Jersey, the CD is available to others upon request to the Council.

A second men’s health conference took place toward the end of the year. Fuelled by the success of the first, this conference was planned and coordinated by the Council’s Men’s Health Care Task Force. Another successful day for over 125 men with developmental disabiites.
The chair of the Women’s Task Force was asked to write an article for The 2007 Health & Wellness Guide put out by Garden State Women magazine. The topic was health care parity for women with disabilities. She was later interviewed for NJ Able newspaper. This type of public outreach in non-traditional media is the baseline for Council outreach efforts.

**Women with Disabilities Health Care Task Force** publishes **Health Access**; an issue of the quarterly publication focused on *Celebrating Women* -- A forum about social issues, relationships and sexual health regarding women with disabilities.

additional copies were disseminated at conferences and similar events, such as the 2007 New Jersey Caregivers’ retreat.
Partners in Policymaking [PIP]: November 12, 2006 -
Twenty-three people with developmental disabilities and family members successfully completed an eight (8) month leadership training program. The program provides information and training for participants to help develop and build on their advocacy skills needed to obtain appropriate services for themselves and family members.

Each session is devoted to specific topics with nationally known experts as presenters. Partners’ participants complete assignments between sessions and commit to one major assignment, such as serving an internship, organizing a letter writing campaign, organizing special receptions or town meetings for public officials. The Council has invested in 236 PIP grads since 1998.

Graduates are currently serving on school boards, advisory boards, public committees, the Council, organizing letter writing campaigns and helping organize town meetings for public officials. Dennie Todd (above) a self-advocate and former Council member, currently runs the project as part of the Council staff.
Direct Service Professional (DSP) shortages continue to plague the industry, creating shortages in programs, community opportunity, and employment support.

The NJCDD has collaborated and provided program support for NJUCEDD (Boggs Center), which has formed a coalition to address this issue. A large part of this effort focuses on developing and promoting portable skills among DSPs and acceptance of a well-defined DSP skill set by providers/employers/funders.

College of Direct Support implementation and DSP career path certification are the paths being explored in collaboration with several agencies in the state. Council staff have also begun exploring the option of recruiting permanent alien employees through USCIS (immigration) and USDOL (Labor) protocols as a means of bringing on qualified workers to fill gaps. Discussion of DSP as a potential career opportunity for people with developmental disabilities, themselves, has also come to the forefront.
2007 Activities and Projects

United Spinal, Inc.,
Philadelphia, PA
Survey and Assessment of Accessibility and ADA compliance within meeting, conference and hotel vendors under contract with the State of New Jersey. This report covers the essential, and not so well-known, elements of the ADA as they apply to meeting places and conference centers open to the public under state vendorship. It serves as a means for identifying those vendors which will be appropriate for developmental disability related meetings and gatherings. Report available from the Council.

Allies, Inc.
Hamilton, NJ
Success of Savings – Year 3 of a project initiated by the Council to develop and test a model for asset-building for people with developmental disabilities. One hundred and twenty working individuals with developmental disabilities have participated to date and the program is being replicated in other states. Report available Fall, 2008.

Statewide Parent Advocacy Network
Newark, NJ
SPAN has developed and tested a transition curriculum based on Kids As Self Advocates (KASA), a project of National Family Voices. The KASA model is grounded in the belief that individuals with disabilities can and should be civil rights activists as they transition from school to adult life both at an individual (IEP) and policy level. Final Report available Fall, 2008.

John J. Heldrich Center for Workforce Development, Rutgers University
New Brunswick, NJ
A brief study of the impact of parental and personal expectations on work outcome among people with developmental disabilities who are working. Results led to revised Employment and Education goals and outcomes for the Council’s Annual State Plan.
Early Intervention Center – Montclair State University  
Family Resource Associates, Shrewsbury, NJ  
United Cerebral Palsy, Inc. - Edison, NJ  

Introduction of early intervention skill sets to staff at child care, “Mommy and me” programs, library story hours, and other settings in which infants and toddlers without disabilities spend considerable time. Outcome is to model resources for families of children with developmental disabilities which would assist them in making community connections that are integral to the current and future inclusion of their child and family in their larger community.  

Project Contacts Available from the Council.

Youth Leadership  
Youth development is the cornerstone of any movement. The Council’s Youth Leadership Project serves as a key resource for young advocates who want to get involved and help move that mission forward. Membership reflects a wide range of backgrounds and experiences, with a special focus on young people with developmental and intellectual disabilities, as mandated by the federal law governing the Council.

Regional Family Support Planning Councils  
The nine regional councils work to provide a conduit for families to advise the state developmental disabilities agency on making decisions that best fit their needs. Family members of people with developmental disabilities or individuals with developmental disabilities can serve on their regional planning council. The NJCDD provides staff and technical support to the nine regional councils.

Monday Morning Self-Advocacy Networks  
A grass-roots organization of advocates concerned with the issues affecting people with developmental disabilities, it is made up of county-based networks. Since inception in 1995, Monday Morning has:

- Registered to vote over 16,000 people with disabilities;
- Helped make dozens of polling places more accessible;
- Provided sensitivity training to poll workers and election officials and collaborated with the State Division of Elections;
- Made dozens of businesses accessible through a statewide Accessibility Campaign;
- Fostered identification of and advocacy around local issues in dozens of municipalities across the state.
PUBLICATIONS

Common Ground

The goal of Common Ground is to increase the dialogue between stakeholders in New Jersey’s education and special education system. Under its federal mandate to review education systems, the NJ D.D. Common Ground is published and disseminated 3 times per year (Winter, Spring, Fall) and consists of information on a broad range of topics and each issue is developed around a current theme in special education policy or practice.

Subscription Free in North America - contact the Council

People & Families

People & Families is a professional high-end publication with sophisticated artwork in the style of national news and features magazines such as “People,” “Time” and “Newsweek”, etc. The magazine provides readers with news, features, in-depth policy analysis, and book and movie reviews about people with developmental disabilities and their families, and issues of interest to them and their colleagues.

Subscription Free in North America - contact the Council

The Council

NJCDD’s monthly newsletter has regular features, which include: News From Trenton (Policy / legislative update); Council Update (News from the Council, current initiatives, etc.); Profile (a person involved with the Council or project funded by the Council); Resources (website, book, agency or other resources); Information Alert (information to inform readers of breaking news that may have a more immediate effect on their lives); Community Calendar.

Subscription Free in North America - contact the Council

Tools For Teachers

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.

Up to three copies free - contact the Council
## Funds - Fiscal Year 2007

<table>
<thead>
<tr>
<th>Program</th>
<th>Admin</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fed Allocation</td>
<td>$466,423</td>
<td>$1,554,744</td>
</tr>
<tr>
<td>State Match</td>
<td>$155,475</td>
<td>$518,249</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>$621,898</td>
<td>$2,072,993</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMPLOYMENT</td>
<td>$172,500</td>
</tr>
<tr>
<td>HOUSING</td>
<td>$222,500</td>
</tr>
<tr>
<td>HEALTH</td>
<td>$137,500</td>
</tr>
<tr>
<td>EDUCATION</td>
<td>$82,500</td>
</tr>
<tr>
<td>TRANSPORTATION</td>
<td>$92,500</td>
</tr>
<tr>
<td>QUALITY ASSURANCE</td>
<td>$55,595</td>
</tr>
<tr>
<td>COMMUNITY SUPPORTS</td>
<td>$688,000</td>
</tr>
<tr>
<td>GENERAL OPERATIONS</td>
<td>$591,898</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>$2,072,993</td>
</tr>
</tbody>
</table>

### Distribution of Funds - FY-2007

![Distribution of Funds - FY-2007](image)
The charge to the Developmental Disabilities Council, according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L. 106-402), is to engage in advocacy, capacity building and systemic change that contribute to a coordinated, consumer and family-centered, consumer- and family-directed comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self determination for individuals with developmental disabilities and their families.

We welcome your letters and comments.

Send them to

Comments and Issues
NJCDD, PO Box 700,
Trenton, NJ
08625-0700.

Please include your name and town.